

“A Place To Call Home: Intellectual Disabilities And Residential Services In Nova
Scotia”

by

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Table Of Contents

Abstract.....	vii
List of Abbreviations Used.....	viii
Acknowledgements.....	ix
Chapter One: Introduction.....	1
Rationale For Research Questions.....	5
A Note On Language.....	6
Chapter Two: The Socio-Historical Context Of Institutionalization And Deinstitutionalization.....	8
Community Living Today: Rights And Citizenship.....	8
Institutions In Nova Scotia.....	9
History of Institutionalization.....	11
Deinstitutionalization And Cultural Change.....	16
Deinstitutionalization And Economic Change.....	19
Community Support And Care.....	21
Deinstitutionalization In Nova Scotia.....	24
Chapter Three: Methods.....	26
Institutional Ethnography.....	26
Participant Observation.....	28
Document Analysis.....	30
Interviews.....	32
Interview Participants.....	34
Ethical Considerations.....	38
Use Of Pseudonyms.....	39

Research Gaps.....	40
Chapter Four: Social, Economic And Political Factors Contributing To Institutionalization.....	42
Increasing Institutionalization And A Shortage Of Community Services.....	42
Institutions In The Community.....	48
Explanations For Expanded Institutions And The Shortage Of Community Services	52
Challenges In Community Planning.....	52
Concerns About Unemployment.....	53
Lack Of Awareness.....	54
Decline In Advocacy.....	56
Efficiency In Neoliberal Societies.....	58
Chapter Five: Conflicting Beliefs About Institutionalization.....	65
Rehabilitation As Justification For Institutionalization.....	67
Long-Term Care As A Justification For Institutionalization.....	69
Arguments Against Rehabilitation.....	73
Flaws In The ‘Continuum Model’	75
Arguments Against Long-Term Care.....	76
Institutionalization As An Infringement Of Human Rights And Citizenship.....	78
Lack Of Collaboration To Create A Common Vision.....	81
Chapter Six: Conclusion.....	86
References.....	94
Appendix I: Interview Guide.....	100

Appendix II: Recruitment Letter.....	103
Appendix III: Consent Form.....	105

Abstract

Despite broader trends toward the deinstitutionalization of people with intellectual disabilities and evidence that they have a higher quality of life in the community, many in Nova Scotia remain segregated in institutional settings. In response, this thesis examines the reasons why people with intellectual disabilities are institutionalized in the province, and the barriers that exist to embracing policies of deinstitutionalization. Through participant observation, document analysis, and qualitative interview research, several themes emerged regarding the social, economic, and political factors, as well as the conflicting beliefs among implicated community members, contributing to the continued existence of institutions. Drawing on an institutional ethnography approach, this thesis examines how these factors and beliefs are related to neo-liberal philosophies and broader ideological beliefs about disability.

List Of Abbreviations Used

ARC	Adult Residential Centre
CBO	Community Based Option
DCS	Department of Community Services
LRE	Least Restrictive Environment
RN	Registered Nurse
RRC	Regional Rehabilitation Centre

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Chapter One: Introduction

According to the 2008 Report of Residential Services, over seven hundred Nova Scotians with disabilities are currently segregated in institutional settings known as Adult Residential or Regional Rehabilitation Centres.¹ These institutions house people with a combination of physical and intellectual disabilities and mental illnesses. In this thesis, I focus specifically on the institutionalization of people with intellectual disabilities.² The institutionalization of people with intellectual disabilities in Nova Scotia stands in contrast to the deinstitutionalization that has occurred in other parts of Canada and around the world. The World Health Organization, the United Nations, and disability advocacy organizations also support deinstitutionalization (Nova Scotia Department of Community Services (DCS), 2008). These groups advocate for people with intellectual disabilities to be supported in integrated community settings.

Divergent social, political, and economic explanations exist for processes of institutionalization and deinstitutionalization. On the one hand, the DCS (2008) claims that rehabilitation — or “the development of interpersonal, community oriented skills, and activities of daily living” (11) — is the goal of the province’s Adult Residential and Rehabilitation Centres. Socio-cultural literature, however, suggests other imperatives for institutionalization. These include beliefs that people with intellectual disabilities are

¹ I understand an ‘institutional setting’ as it is defined by Goffman (1961) as “a place of residence where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life” (xi).

² I use the term ‘intellectual disability’ in reference to “limitations resulting from dysfunction in individual . . . minds . . . in contrast to an ideal of normal capacity (Whyte & Ingstad, 1995, 3). Various terms have been used in relation to such conditions in different places and time periods including mental retardation, mental deficiency, and developmental disability.

objects of pity requiring protection, are threatening to other people, or are burdens on society (Wolfensberger, 1975; Oliver, 1990; Shakespeare, 1994; Hughes, 2009).

Likewise, some see deinstitutionalization as the result of changing attitudes toward people with disabilities and the efforts of disability rights movements (Simmons, 1982; Zola, 1994), while others argue that it has more to do with economic reforms (Scull, 1984, Finch, 1984).

In this thesis, I engage these theories in order to understand how the current models of care for people with intellectual disabilities in Nova Scotia have arisen and what their implications are. More specifically, my project focuses on the following two questions:

- 1) Why are people with intellectual disabilities still institutionalized in Nova Scotia?
- 2) Why has Nova Scotia not fully embraced policies of deinstitutionalization?

In addressing these questions I draw on institutional ethnography, a method of sociological inquiry designed by Dorothy Smith. The purpose of institutional ethnography is to “tease out the linkages among local settings of everyday life, organizations, and translocal processes of administration and governance” (DeVault & McCoy, 2006, 751). The term ‘institution,’ in this sense, does not refer to a specific organization or structure, but rather to “a complex of relations forming part of the ruling apparatus, organized around a distinctive function” such as education, health care, or social services (Smith, 1987, 160). The aim of institutional ethnography is to make sense of the ways these relations — referred to as ‘relations of ruling’ — shape people’s everyday activities and experiences. In other words, it attempts to show “how power is exercised in local settings to accomplish extra-local interests . . . [and] takes place when

the interests of those who rule dominate the actions of those in local settings” (Campbell & Gregor, 2002, 36). By beginning from the standpoint of individuals working in local settings, institutional ethnography aims to problematize institutional structures and ideological beliefs that are often taken for granted by showing how people experience them in their everyday lives.

In Chapter Two, I explore the institutional structures, including social, political, and economic factors, as well as beliefs about disability that have historically contributed to institutionalization and deinstitutionalization. These factors have shaped residential services in Nova Scotia, including those provided in institutions and in the community. A knowledge of them is therefore necessary in order to contextualize the specific social, economic, and political factors, and beliefs about intellectual disability that contribute to the continued existence of institutions in the province today.

In Chapter Three, I describe the methods I used to explore the issues relevant to the deinstitutionalization debate in Nova Scotia. I conducted an analysis of key policy documents, participant observation with community groups, and qualitative interview research with implicated community members including government policymakers, disability service providers or workers, and advocates for community living. Through this research, several key themes emerged regarding the reasons why institutions still exist in Nova Scotia today and the barriers that exist to embracing policies of deinstitutionalization.

As I will explain in Chapter Four, several social, economic, and political factors contribute to the continued existence of institutions. These include the relative ease of institutionalization given that institutions have existed for so many years and are

considered the normal model of support, a lack of community planning to realize deinstitutionalization, concerns about unemployment among institutional workers, a decline in disability advocacy movements, and a lack of public and political awareness about disability. Given that institutional ethnography theory and method guide the researcher to trace the institutional processes that shape people's everyday experiences, I show how the factors contributing to institutionalization in Nova Scotia are related to the neo-liberal framework that currently drives Canadian policies and strategies of governance (Teghtsoonian, 2009; Guberman, 2004). These neo-liberal philosophies aim to reduce spending as a means of increasing the state's overall economic efficiency. In doing so, they may not prioritize services for people who are considered dependent, including those with disabilities (McCluskey, 2002).

While conducting this research, however, it became clear that it is not simply a lack of resources that serves as a barrier to deinstitutionalization, but also conflicting beliefs about the purpose and necessity of institutions. On the one hand, policymakers and an institutional worker who I interviewed believe that institutions are necessary in order to provide rehabilitation or care for people with intellectual disabilities. On the other hand, many community service providers and advocates for community living express that people with intellectual disabilities do not require rehabilitation or care, or express that rehabilitation is not occurring in institutions. They also feel that high levels of standardization in group homes – implemented as a means of ensuring the safety of residents – lead to the creation of 'mini-institutions' in the community. As I will explain in Chapter Five, these conflicting beliefs show the disjuncture that exists between the

attitudes and values embedded in policies regarding disability, and the experiences of those who encounter disability in their daily lives.

Rationale For Research Questions

According to the Nova Scotia Residential Agencies Association (2007), a community-based service organization, institutional life “erodes the human spirit, diminishes well-being and self-worth, and decreases people’s value in the wider community.” In addition, evidence-based research has shown that people with intellectual disabilities typically experience a higher quality of life — including increased physical and emotional well-being, an increased sense of safety, and more meaningful social relationships — when they live with support in the community (see for example, O’Brien, Thesing, Tuck, & Capie, 2001; Young, 2006; Johnson & Traustadóttir, 2005).

Instances of abuse serve as specific examples of the problematic nature of institutions as they currently exist in Nova Scotia. One example is the Riverview Residential Centre, where 19 cases of physical, sexual, and emotional abuse were reported in 2008 and 2009. This institution is located in Riverton and houses one hundred people with intellectual disabilities and long-term mental illnesses (Canadian Press, September 9, 2009). Another example of the problematic nature of institutions is the neglect of an autistic man at Braemore Homes Corporation, an institution in Sydney where about 134 people live. This man was locked in his room and neglected for fifteen days in September 2010. During this time, there was a light shining in the room for 24 hours a day and a video monitoring him from a nursing station (Canadian Press, February 1, 2011). These instances of abuse highlight the urgency of examining and improving Nova Scotia’s residential services.

In recognition of the problematic nature of institutions, the fact that many people with disabilities have stated a preference for community living, and the broader move toward deinstitutionalization, the DCS (2008) recommended the formation of partnerships with the academic community in order to improve upon the current system. Disability advocates have also expressed the need for independent research that critically examines the residential services available for people with intellectual disabilities. Given that very little research in this area exists,³ I hope that this project will be useful to the government and community as they attempt to ameliorate the services available for people with intellectual disabilities.

A Note On Language

In her discussion of the ways academics depict disability, R. Smith (2001) notes that researchers must be conscious of the underlying symbolic meaning and the cultural values associated with the terminology they use and the way they depict disability in their writing. The use of the term ‘people with disabilities’ in contrast to ‘disabled people’ is particularly contentious. On the one hand, many scholars who adhere to the social model of disability, including Oliver (1990), use the term ‘disabled people’ to emphasize that people, no matter what their physical or intellectual capacities, are in fact *disabled* by the contexts in which they live. While I am sympathetic to this argument, I choose to use the term ‘people with disabilities.’ Traustadóttir & Johnson (2005) suggest that the majority of people with intellectual disabilities prefer this term; emphasizing that they are ‘people

³ An exception is Weeks’ book *The first 100 years: The role of Sunset ARC in the evolution of mental health care in Nova Scotia* (1996). This book traces the history of a specific institution, but it does not critically assess the continued existence of this institution in light of the broader deinstitutionalization movement.

first.’ In addition, almost all research participants used the term ‘people with disabilities,’ and so it seemed logical for me to do so as well for the sake of consistency.

Chapter Two: The Socio-Historical Context Of Institutionalization And Deinstitutionalization

Community Living Today: Rights And Citizenship

Today, community living is recognized a human right by the United Nations, the World Health Organization, and disability advocacy organizations. The United Nations' Convention on the Rights of Persons with Disabilities (2006), ratified by Canada in March 2010, for instance, states that:

- a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in particular living arrangements;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs (Article 19).

The disability rights movement arose following the civil rights and women's rights movements occurring in the latter half of the twentieth century, when disability rights activists began advocating for increased choice and control among people with intellectual disabilities regarding their living arrangements and everyday activities. In Canada, organizations such as the Canadian Association for Community Living and People First of Canada play an integral role in asserting the rights of people with intellectual disabilities to live in their communities. They have also recognized that simply closing institutions and attempting to provide community supports may not necessarily ensure the equality and integration of people with disabilities (Bigby & Fyffe, 2006). For these groups, community living extends beyond the right to live in a group home setting rather than in an institution and includes initiatives such as user-directed or

self-managed care. In particular, The People First of Canada - Canadian Association for Community Living Joint Task Force on Deinstitutionalization draws on rights-based arguments in *The Right Way* (2010). This document is a guide for helping community members and government stakeholders realize deinstitutionalization. It states that “the institutionalization of persons with intellectual disabilities is a denial of their basic right of citizenship and participation in the community,” (2) and that people with intellectual disabilities should have the right to access “the necessary disability related supports needed to fully participate in the community” (8).

Institutions In Nova Scotia

Despite the widespread recognition of the rights of people with intellectual disabilities to live in community settings, the Nova Scotia Department of Community Services currently provides a ‘continuum’ model of residential services which encompasses *both* institutional and community models of support. These residential services range from Small Options Homes where three or fewer residents live; to Group Homes and Developmental Residences housing four to twelve people; to Adult Residential and Regional Rehabilitation Centers which house between 32 and 115 individuals who require higher levels of support and who are thought to exhibit behaviour that is challenging in mainstream environments (DCS, 2008).⁴

In order to make sense of the continued existence of institutions in Nova Scotia despite broader trends toward deinstitutionalization, this chapter examines the socio-historical factors contributing to institutionalization and deinstitutionalization. Institutions

⁴ The DCS also provides non-residential services including Direct and Alternative Family Support Programs for families with children with disabilities, and Independent Living Support, which is up to 21 hours a week of support for adults who are semi-independent (DCS, 2008).

became the dominant model of care for people with intellectual disabilities between the eighteenth century and the middle of the twentieth in Canada and other parts of the world, until movements toward deinstitutionalization and the provision of community services developed throughout the latter part of the twentieth century. Both the institutionalization and deinstitutionalization movements have been influenced by attitudes toward people with intellectual disabilities and beliefs regarding their proper treatment by the broader community and by the state. In the case of institutionalization, these attitudes and beliefs include the idea that they are objects of pity deserving charity, protection, and care; that they are societal burdens because they are not able to act independently and work productively in accordance with ideologies of individualism; or that they are deviant, menacing people who constitute a threat to the non-disabled majority.

As previously mentioned, the belief that people with intellectual disabilities are equal citizens deserving the same rights as other people has become more prominent throughout the deinstitutionalization movement. This argument has arisen in response to the harms that were committed against people with disabilities throughout the eugenics movements and during the Second World War, as well as the critiques of institutions published by writers and academic theorists in the 1960s and 1970s.

The deinstitutionalization movement has also been influenced by the political philosophies that determine the aim and scope of residential services through decisions about resource allocation. On the one hand, neo-liberal policies aim to reduce government spending by minimizing the state's role in providing services for people with disabilities. This increases responsibility within the private sector and among individuals and families for providing this support in community settings. On the other hand, welfare

forms of governance aim to ensure that all citizens, including people with disabilities, have equal access to services provided by the state. As such welfare governments play a more prominent role in providing disability services in the community.

The above-mentioned factors have shaped residential services in Nova Scotia, including those provided in institutions and in the community. A knowledge of the broader societal attitudes, values and political structures that shape institutionalization and deinstitutionalization is necessary in order to contextualize the specific social, economic, and political factors, as well as the attitudes toward people with intellectual disabilities, contributing to the continued existence of institutions in Nova Scotia today.

History Of Institutionalization

Beginning in 1759 poorhouses and workhouses were established in Nova Scotia. These institutions housed a variety of people, including those with intellectual disabilities, who could not care for themselves or receive adequate care from their families (DCS, 1995). In 1886, the province established county asylums built specifically for people diagnosed with intellectual disabilities and mental illnesses. Proponents of these asylums believed that they were more benevolent and progressive than the earlier segregation of ‘lunatics’ with criminals, poor people, and other socially deviant groups in poorhouses and workhouses. As Wolfensberger (1975) was one of the first to recognize, and other have since reiterated, the rhetoric of protection, care, and rehabilitation, based on a view of people with intellectual disabilities as objects of pity who deserve charity, largely underpinned asylums at this time (see also Simmons, 1982; Weeks; 1996; Walmsley, 2005). Following the philosophy of Philippe Pinel, most asylums aspired to provide ‘moral treatment,’ which is the belief that the mentally ill and defective will

exhibit the type of behaviour that is expected of them and that if they are treated as rational and capable adults they will act as such. Pinel and his followers believed that a “strictly controlled environment” such as an asylum was the best place for moral treatment to occur (Weeks, 1996, 4-5). In her historical analysis of institutionalization in the United Kingdom, for instance, Walmsley (2005) finds that policymakers in the early twentieth century stressed “that institutions were viewed not as a home for life but as a means of restoring people to the community” (57).

It is questionable whether the rehabilitative aims associated with these institutions were entirely benevolent or whether they were actually motivated by lessening the economic burden posed by people with disabilities. McCallum (1997) explains how the distinction between people with mental illnesses and intellectual disabilities in early twentieth century England began with the separate grouping of patients who were potentially capable of working productively from those for whom rehabilitation was not considered a possibility. People classified as mentally ill constituted the former group and were considered more economically valuable because they could “perform work in the asylum” (65). Those in the latter group, who were often more severely intellectually disabled, were classified as ‘deficient or defective’.

Economic priorities also influenced the shift from provincial institutions to county asylums in Nova Scotia. The province believed that it would be more cost-effective to house people in smaller asylums that were run by municipalities (Weeks, 1996). These county asylums then reflected the work model described by McCallum. They were typically situated in rural areas and operated as county farms (Weeks, 1996). Insofar as residents were expected to work on the farm to support the asylum and reduce the

funding provided by the government and taxpayers (Weeks, 1996; Simmons, 1982), they encouraged residents to be self-reliant and economically productive. Again, residents with less severe disabilities, who were capable of working independently, could make greater contributions to the farm. In many cases, superintendents were hired according to their ability to manage a farm rather than their capacity to support people with intellectual disabilities and mental illnesses. While some legislators argued that farm work was an important form of vocational therapy that benefitted patients, critics felt it was simply a form of free labour (Weeks, 1996).

Given the poor conditions and the emphasis on work in Nova Scotia's asylums throughout the nineteenth and early twentieth centuries, it is likely that 'moral treatment' was perverted as institutions became an economically efficient way to warehouse people who were seen as burdens on society (Simmons, 1982). Oliver (1990) suggests that this occurred throughout the rise of capitalism in Western societies, as it became increasingly important for each individual to possess the cognitive and physical skills necessary to carry out various forms of labour, such as factory work, that predominated during this period. People who did not possess the skills to work independently were increasingly viewed as a social problem and an economic burden. In addition to not being able to work themselves, the high value placed on work outside the home meant that people with disabilities who may have formerly lived with their families in the community could no longer do so. Rather than engaging in care work, other family members needed to spend more time working in order to meet the demands of capitalism. As this occurred, Oliver (1990) suggests that the ideology of individualism became prominent:

The requirements of the capitalist economy were for individuals to sell their labour in the free market and this necessitated a break from collectivist

notions of work as the product of family and group involvement. It demanded nothing less than the ideological construction of the individual (44).

Oliver explains that people who could not fulfill ‘the ideological construction of the individual’ were cast as ‘Other’ in relation to able-bodied and able-minded individuals. One of the ways that capitalist societies ‘dealt with’ with these people was by placing them in institutions. While Oliver notes that it is too simplistic to assume that “some kind of idealized community existed and that disabled people . . . were treated more benignly” (28) prior to the rise of capitalism, he does point out that the predominance of the group collective over the individual as well as the co-operative nature of pre-industrial societies was more likely to enable and support, rather than restrict, the participation of people with disabilities. In contrast, the ideology of individualism arose throughout the rise of capitalism and serves to exclude people with disabilities (Oliver, 1990). This reinforces the point that “disability is not a transhistorical, ubiquitous, social phenomenon, but is bound up with social relationships at specific historical junctures” (Thomas, 2002, 47).

Kittay (2001) and Young (1990) similarly associate the belief that people with intellectual disabilities are a burden, and the resulting rationale for institutionalization, to the value placed on autonomy and rationality in western societies. These values became predominant during the nineteenth century, in part through the influence of Enlightenment philosophers like John Locke, and his understanding of personhood as it applies to the white, bourgeois man, who could act autonomously and rationally (Kittay, 2001). As such these values privilege “physical health, moral soundness, and mental balance” and conceives of those with limited mental or physical capacities as “ugly, dirty,

defiled, impure, contaminated, or sick” (Young, 1990, 123). Accordingly, it could be postulated that people with intellectual disabilities are devalued because they do not fulfill the ideal of each person as an independent, productive, and rational agent who is able to mutually reciprocate in economic relationships. While Young (1990) acknowledges that people with disabilities may have also been devalued prior to the Enlightenment, she argues that the emphasis on independence and productivity during this period served to further the devaluation of anyone who was regarded as dependent.

Wolfensberger (1975), Shakespeare (1994), and Hughes (2009) offer an alternate explanation for institutionalization, as a way for non-disabled people to distance themselves from that which they see as threatening or dangerous. Hughes (2009) and Shakespeare (1994), for example, suggest that people with disabilities are often oppressed and excluded from mainstream society because they embody people’s fears about being frail, vulnerable, or incapable of independence and are thus seen as threatening “to the ‘civilized’ human condition” and to the control and order associated with it (Hughes, 2009, 405). Wolfensberger further suggests that people with intellectual disabilities might be viewed as a menace to the non-disabled because of the individual risk they are thought to pose to others through “alleged crimes against persons and property” as well as the collective risk they are thought to contribute “to social disorganization and genetic decline” (1975, 13). The idea that people with disabilities are a genetic threat became especially prevalent in North America during the eugenics movement in the late nineteenth and early twentieth centuries. During this time it was widely believed that housing people who had ‘less desirable’ cognitive and physical capacities was an effective means of keeping them from having children and ensuring that only those who

fit the prototype of the strong, fit, and rational human being reproduced (Wolfensberger, 1975; Simmons, 1982).

Deinstitutionalization And Cultural Change

Since the middle of the twentieth century, there has been a shift in Canada and internationally toward deinstitutionalization and the provision of community services for people with intellectual disabilities. Critiques of institutions among the general public and by journalists and academic theorists, the rise of disability rights movements, and the political philosophies shaping a state's disability service policies have influenced the deinstitutionalization movement.

Zola (1994) and Simmons (1982) attribute changing attitudes toward people with disabilities and values regarding the ways they should be treated by the state and by the broader society to an increased questioning of authority and of taken for granted practices after the Second World War. In recognition of the corruption that had occurred as the Nazis rose to power, many members of the Canadian public began to critically assess eugenic practices, including the sterilization and segregation of people with intellectual disabilities, when they learned that the Nazis had used eugenic arguments to justify the mass genocide of Jews, homosexuals, people with disabilities, people involved in political and social movements, and others during the Holocaust (Simmons, 1982).

In following years, evidence also emerged exposing the poor conditions and low levels of care in many institutions. For example, a column published in 1960 in the Toronto Star by author and journalist Pierre Berton detailed the poor conditions and extensive overcrowding he witnessed during his visit to the Huronia Regional Centre, an institution in Orillia, Ontario:

It is distressing to visit these older buildings . . . The roofs leak, the floors are pitted with holes and patched with plywood . . . The beds are crowded together head to head, sometimes less than a foot apart . . . There are beds on the veranda. There are beds in the classroom. . . . The stench is appalling even in winter (Berton, 1960, as cited in Simmons, 1982, xv).

During the 1960s and 1970s, an increased questioning of institutions also arose from academic theorists such as Goffman (1961) and Wolfensberger (1975). By critiquing institutional models, these theorists influenced beliefs about the value of institutions among the general public and among many people working in the field. Most famously, Goffman's ethnographic study *Asylums* (1961), which documents the dehumanizing and isolating characteristics of a large American psychiatric hospital, challenged the belief that institutionalizing people who were regarded as deviant or defective would ameliorate their condition (Davis, 2006). According to Goffman, institutional residents learn certain behavioural traits he calls 'adjustments' in order to adapt to the setting. For example, residents may become overly protective of personal items because they are often unable to possess their own things when living in an institution. Having learned to act this way in order to protect their belongings, former institutional residents might have difficulty letting go of their own items or sharing them with others in mainstream society for fear of losing them. When other people regard this behaviour as strange, it perpetuates the stigmatization of people who have been institutionalized.

Goffman's analysis pertained to institutions in general, including mental hospitals, nursing homes, prisons, concentration camps, boarding schools, army barracks, monasteries, and other such facilities. Wolfensberger (1975), however, provided a historical tracing of institutions specifically for people with intellectual disabilities. In

The origin and nature of institutional models (1975), Wolfensberger denounced all institutions for people with intellectual disabilities by claiming that they are “unworkable” given the extent to which they have failed to provide proper support in many parts of the world (69). As an alternative, Wolfensberger advocated for disability services to be based on the concept of normalization, which he defined as the “utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviours which are as culturally normative as possible” (1972, 28). According to the principle of normalization, people with intellectual disabilities should live in the community rather than in an institution and in a home that reflects most people’s ideal of a normal home as closely as possible. Today, deinstitutionalization movements are typically premised on understandings of human rights and citizenship rather than the principle of normalization (Bigby & Fyffe, 2006). Nevertheless, Wolfensberger’s research is important to consider given its influence on Canadian human service providers and disability advocates throughout early phases of deinstitutionalization. Some of the service providers and advocates who participated in my research, for instance, noted that they first became aware of deinstitutionalization and community living when they attended workshops at the National Institute on Mental Retardation in the 1970s and 1980s.

Berton’s, Goffman’s, and Wolfensberger’s work are some examples of the critiques of institutions that arose in the latter half of the twentieth century. These critiques, as well as a growing discomfort with the eugenic arguments which had been used to justify institutionalization, contributed to the deinstitutionalization movement. During this period many people working in the field of intellectual disability, as well as

members of the general public, realized that segregating people with disabilities served “to put their very existence in danger” as it constituted a direct threat to their safety, well-being, and livelihoods (Simmons, 1982, 158).

Deinstitutionalization And Economic Change

Following these critiques, early proponents of deinstitutionalization, including disability advocates, family members of people with intellectual disabilities, and community service providers, often argued that deinstitutionalization would provide an opportunity for people with intellectual disabilities to have a better quality of life in community. However, many early attempts at deinstitutionalization were unsuccessful in ensuring their well-being. In many cases community supports, such as those premised in normalization as advocated by Wolfensberger (1972), were not developed to replace institutions. As Bigby & Fyffe (2006) point out, “the absence of attention to community-based services meant that some previously institutionalized residents were left homeless, isolated, or without support in community settings” (568) during the early phases of deinstitutionalization. An example of this is in Ontario, where the province began deinstitutionalization and implemented the Homes for Special Care Program in the 1960s.⁵ Although the aim of the Homes for Special Care Program was to provide community-based housing for former residents of psychiatric hospitals, it often prioritized bureaucratic and cost-saving interests over the well-being of residents. In some cases residents were more likely to be selected to move into community homes if

⁵ Very little research on deinstitutionalization in Canadian provinces exists. However, Simmons (1982) provides a very comprehensive analysis of the policy developments contributing to institutionalization and deinstitutionalization in Ontario. As such, I use Ontario as an example to show how deinstitutionalization has occurred in other parts of the country.

they did not have family or friends who would protest the move. In other cases, the families of residents who left an institution were not notified because prior to the move because staff were trying to move residents as quickly as possible in order to use money and time efficiently (Simmons, 1982). Simmons notes that “it quickly became apparent . . . that transferring patients to the community had little to do with providing a more homelike atmosphere, or returning patients to the community, and had a great deal to do with saving the government money” (187). Given that the Ontario government provided very little funding for support services in these homes, and given that they were typically located in rural areas or were isolated from the wider community, even in urban areas, Simmons “[characterizes] them as the new back wards of the 1970s.” (187-88).

In reaction to the neglect of some people who moved out of institutions, critics such as Scull (1984) argue that deinstitutionalization has nothing to do with ensuring the well-being of people with intellectual disabilities. Instead, he suggests that deinstitutionalization is primarily motivated by the economic criteria that characterized the shift from welfare to neo-liberal forms of governance in North America. Neo-liberal philosophy emphasizes “the role of economics and of the market in informing governance; the diminishing role of the state in the provision of health and welfare services; and a growing reliance upon self-responsibility for health and well-being” (Henderson, 2005, 243). Accordingly, critics argue that early attempts at deinstitutionalization provided a means for Western governments, who were facing a financial crisis in the 1970s, to decrease public expenditures by closing institutions that were costly to maintain (Scull, 1984; Davis, 2006). Legislators were able to draw on the arguments of Goffman, Wolfensberger, and others to justify community care as more

benevolent and moral than institutionalization. In reality, however, policies of deinstitutionalization actually served to decrease public responsibility and make individuals and the private sector responsible for providing care for people with long-term mental illnesses and disabilities. Feminist scholars in particular often critique these policies because they lead to an increased burden on family members, namely women, to provide unpaid labour as their ‘informal’ care work is rendered invisible in the public sphere and in political discussion (Hankivsky, 2004; Finch, 1984).

Again, neo-liberal reforms were evident throughout the early phases of deinstitutionalization in Ontario, where the provincial government implemented cost-sharing arrangements with “mentally retarded people, their families, and local associations” in order to fund community services (Simmons, 1982, 189). One of the rationale for this arrangement was that it would reduce responsibility for services that the government considered a risky investment: “With local associations contributing to the funding of community services . . . they would have to bear some of the criticism that might be directed against community services” (Simmons, 1982, 190).

Community Support And Care

In response to the neglect of some former institutional residents resulting from early institutional closures, some deinstitutionalization movements since the 1970s have “included the development of community-based vocational, recreational, and day support services systems to provide alternative forms of support as people moved from institutions to the community” (Bigby & Fyffe, 2006, 568). In Ontario, the implementation of such initiatives resulted in large part from a report by Water Williston, a Toronto lawyer, entitled *Present Arrangements for the Care and Supervision of*

Mentally Retarded Persons in Ontario (1971). In this report Williston “recommended an array of home visiting and counseling services, day nurseries and day care centres, the provision of short-term crisis relief programs in residential settings, homemaker and babysitting services . . . and guardianship services” to support people with intellectual disabilities in their communities (Simmons, 1982, 194). Despite Williston’s report, Simmons writes that the predominance of a residual model in the Ontario government in the 1970s, in which social policies “come into play only after the family or private structures have broken down or failed to operate” (226) lead to “insufficient funds to establish and maintain group homes, residences, or sheltered workshops” (231). In other neo-liberal states like Australia, policy reforms have led to similar outcomes for deinstitutionalization. Given that Canada and Australia have both implemented policies of deinstitutionalization while undergoing similar policy reforms in the late twentieth century (Bigby & Fyffe, 2006; Guberman; 2004), Australian research on deinstitutionalization is a relevant point of comparison. Bigby & Fyffe’s (2006) comparative analysis shows how community group home services in Australia are developed and implemented differently depending on whether government authorities remain directly involved in providing them or whether they are tendered out to non-governmental organizations on a competitive basis. They conclude that there are a number of problems with the application of the “managerialist or business principles” (570) characterizing neo-liberal reforms to community services. These problems include a failure to make the services that are available to the mainstream community more accessible for people with disabilities and a lack of continuity in the lives of residents. In

some cases, for instance, residents may be forced to move from one group home to another in order to suit the convenience of the service organization.

The community support and services models adopted in Canada and Australia can be contrasted with welfare states like Sweden, where widespread deinstitutionalization and the provision of community supports for people with disabilities has been embedded within “the growth and development of the welfare state” that began in the 1960s (Tideman, 2005, 214; Ericsson, 2002). Welfare governance is premised on the notion that all citizens are equally entitled to the state’s wealth and resources and that the state should directly ensure the well-being of its citizens (Ilcan & Basok, 2004). Over the last 40 years all institutions were closed in Sweden; children with disabilities now attend mainstream schools and live at home with their parents, and adults with disabilities are supported in their homes in the community. The circumstances in Sweden are not perfect; people with intellectual disabilities are still sometimes socially excluded despite being physically included.⁶ Nevertheless, the Swedish example still demonstrates how sufficient funding, human resources, and government involvement are important aspects of successful deinstitutionalization (Tideman, 2005; Bigby & Fyffe, 2006).

⁶ For example, Tideman (2005) describes how many people with intellectual disabilities living in mainstream communities in Sweden rarely interact with their neighbours. Tideman suggests that this sense of isolation may be characteristic of modern social life, where there is an increased focus on the individual. According to Tideman, the fact that “most social situations (except the family) are based on choice” in modern society increases the risk that “those who are perceived as different will be excluded and treated differently” despite being physically integrated (215).

Deinstitutionalization In Nova Scotia

In response to the deinstitutionalization movement, Nova Scotia closed Mountain View Home, an institution located outside Kentville, in the early 1980s. According to a research participant who worked as liaison between the DCS and community services organizations at this time, one of the driving forces behind the decision to close Mountain View Home was that the building was condemned by the fire marshall. Community advocates, service providers, and government workers saw this as an opportunity to replace the institution with community group homes services. While some former residents of Mountain View Home moved into other large institutions, forty to fifty people with intellectual disabilities moved into community group homes housing fewer residents.

In subsequent years Nova Scotia closed several other institutions. For instance, the province's four children's training centres, which housed about 150 children in total with severe intellectual disabilities whose parents did not feel they could care for them at home, were closed in the early 1990s. In many cases the DCS replaced these institutions with community group homes or provided families individualized funding to pay for support workers and respite care (DCS, 1995).

Despite these past instances of deinstitutionalization, institutions still form a part of Nova Scotia's 'continuum model' of residential services as previously explained. The social, economic, and political factors described in this chapter have shaped these services. These include societal attitudes toward people with disabilities and values regarding the ways they should be treated, as well the political philosophies and forms of

governance shaping the nature of residential services. A knowledge of these factors is necessary in order to make sense of the specific social, economic, and political factors, as well as the beliefs about disability, that are relevant to the deinstitutionalization debate in Nova Scotia today. This is an important question to pursue given that very little research on institutionalization and deinstitutionalization in Nova Scotia exists. In the next chapter, I explore the methods I employed to examine why institutionalization is still occurring in the province, and why the government has not pursued policies of deinstitutionalization more aggressively.

Chapter Three: Methods

I employed qualitative methods to interpret and analyze the social, political, and economic factors, as well as the attitudes and beliefs regarding disability contributing to the continued institutionalization of Nova Scotians with intellectual disabilities. These included participant observation with a local disability advocacy organization; an analysis of the DCS' disability services policies; and semi-structured interviews with government policymakers, disability service providers or workers, and advocates for community living. Institutional ethnography informed my use of these methods. It was particularly helpful for connecting the data I collected to the broader political philosophies and ideological beliefs driving institutionalization and deinstitutionalization.

Institutional Ethnography

As a research framework and method of analysis, institutional ethnography recognizes that people's encounters and interactions in administrative or bureaucratic settings constitute a key aspect of social organization. In order to make sense of this social organization, institutional ethnography aims to explain the connections between people's everyday practices and the relations of ruling embedded in administrative or bureaucratic settings. While collecting and describing the perspectives and knowledge of research participants is an essential component of institutional ethnography, it is distinct from conventional forms of ethnography because its "ultimate purpose . . . is *not* to produce an account *of* or *from* those insiders' perspectives" (Campbell & Gregor, 2002, 89-90). Instead, it attempts to show the relations between individual participants and the broader context by conducting "research into those elements of social organization that connect the local setting and local experiences to sites outside the experiential setting"

(Campbell & Gregor, 2002, 90). My research therefore aims to explain how large-scale bureaucratic or organizational processes regarding disability come into being, how these processes contribute to the continued existence of institutions, and how they then shape the everyday experiences of implicated community members.

By adopting the standpoint of people's lived experiences, institutional ethnography problematizes "the ruling relations themselves, including the social organization of knowledge" in order to show how these ruling relations shape occurrences, understandings, and explanations at the local level (Smith, 2005, 76). In doing so, it "does not substitute the expert's 'reality' for what people know in the doing" (Smith, 2001, 161). By beginning from the standpoint of community members involved in developing, implementing or challenging residential service policies, the particular ruling relations I aim to problematize include the neo-liberal framework underlying residential service policies, as I will explain in Chapter Four, and dominant beliefs and ideologies regarding disability, as I will explain in Chapter Five.

I understand ideologies as "those ideas and images through which the class that rules the society . . . orders, organizes, and sanctions the social relations that sustain its domination" (Smith, 1987, 54). Ideologies, which are a key part of the ruling relations, significantly shape people's lives and ways of thinking because they "dominate and penetrate the social consciousness of the society in general" (Smith, 1987, 54). When individuals adopt ruling ideologies and play a role in dispersing them throughout society, they "actively participate in discursive activity" (Campbell & Gregor, 2002, 41). Discourse, in this sense, is understood as "a field of relations that includes not only texts .

. . . but the activities of people in actual sites who produce them and use them and take up the conceptual frames they circulate” (DeVault & McCoy, 2002, 772).

Participant Observation

The institutional ethnography approach aims to tease out the knowledge, perspectives, and practices of community members regarding institutionalization and deinstitutionalization, and participant observation was an essential component of doing this. Allen (2010) broadly defines participant observation as “the process of generating data by observing and participating in the daily life of a group or social setting,” in order to provide a contextualized account of people’s activities (352). This is a valuable form of research, according to Prus (2005) because it “offers researchers more sustained contact with people in a setting and generally provides valuable opportunities for researchers to learn about and inquire into the viewpoints, practices, and adjustments of others in the setting” (17). As such, it enables them to notice things and to gather data that might be missed throughout other forms of research such as interviews.

In order to gain an accurate sense of the experiences of my research participants, I attended the monthly meetings of a local disability advocacy organization. Members of this organization included paid advocates, community service providers, and people with intellectual disabilities or their family members. The discussion at these meetings often focused on ways to move toward deinstitutionalization and to develop alternative community supports. Participant observation thus provided a more complete understanding of the positions of these community members regarding institutionalization and deinstitutionalization. In this way it was essential for fulfilling the aims of institutional ethnography because it enabled me to gain a better understanding of

the ways policies and bureaucratic structures directly influence the experiences of research participants as they provide disability services or as they advocate on behalf of others who are using them.

Allen (2010) suggests that participant observation “encapsulates a complex field” of practices; with participant observers taking on roles ranging from ‘detached observer,’ with the aim of providing an impartial description of a social situation; to “full participation with the objective of achieving an embodied understanding by ‘standing in someone else’s shoes’ ” (354). In my case, I oscillated between participating and observing when I attended these meetings. In some ways, I acted more as an observer because I focused on listening, rather than speaking, in order to better understand other people’s positions regarding institutionalization and deinstitutionalization. I would, however, participate and offer input when I felt that my opinion or knowledge could make a valuable contribution to the discussion at hand. I also acted as a participant because I adopted the same roles and responsibilities as other attendees. For example, I would take notes at some meetings and bring snacks to others, as these were duties that rotated between group members on a monthly basis.

When conducting participant observation, I clearly stated my role as a researcher whose intention was to examine the reasons why people with intellectual disabilities are institutionalized in the province, and the barriers that exist to embracing policies of deinstitutionalization. Given that the members of this organization believed very strongly in the value of deinstitutionalization and the provision of community supports for people with intellectual disabilities, I was very warmly received at these meetings. Members treated me in the same way as other attendees and expressed that my research could

contribute to their efforts to move toward deinstitutionalization.

It is important to note that I did *not* conduct participant observation among all research participants. I did not conduct participant observation among policymakers or institutional service providers. While further participant observation would have been valuable, it was not feasible to establish the contacts required for lengthy participant observation among policymakers or in an institution within the time constraints of an MA programme. In contrast, advocates very quickly gave me permission to participate in their meetings on a regular basis. Participant observation has thus only enriched my research regarding the viewpoints and experiences of participants who challenge policies of deinstitutionalization.

Document Analysis

In addition to conducting participant observation with a disability community group, I also reviewed and analyzed textual documents relevant to the deinstitutionalization debate. Smith (2001) defines texts as “definite forms of words, numbers, or images that exist in a materially replicable form;” transcending local sites of knowledge (164). In institutional ethnography, textual analyses are particularly important because texts are “key devices in hooking people’s activities in particular settings and at particular times into the transcending organization of the ruling relations” (Smith, 2001, 164). Texts are a significant aspect of the ‘relations of ruling’ because they exemplify the dominant structures and ideologies that “coordinate and concert” people’s everyday experiences as develop, implement, and challenge residential services (Campbell & Gregor, 2002, 32; Smith, 1999, 2001).

I analyzed two main documents for my study: The DCS ’ Report of Residential

Services (2008), and the Homes for Special Care Act (2009). The Report of Residential Services describes the housing and support options currently available for Nova Scotians with intellectual disabilities. Analyzing it was important to this research project because it outlines the ‘continuum of services’ that the DCS provides for people with intellectual disabilities, the guidelines the DCS follows to determine an individual’s eligibility for these services, the official policy of the DCS concerning institutionalization and deinstitutionalization, and the DCS’ goals for the future. The Homes for Special Care Act outlines the province’s regulations for its care facilities. These regulations apply to nursing homes, homes for the aged or disabled, and residential care facilities. They include rules regarding a home’s fire and safety codes, the minimum amount of physical space required for residents, and governmental rights to conduct inspections of homes. These rules are important to consider because they shape the nature of residential facilities, and thus the everyday experiences of service providers, workers, and residents.

By discussing these documents with research participants, I attempt to show how they coordinate the everyday experiences of implicated community members. Although individuals may react differently to texts, the texts themselves do play a role in shaping (although not dictating) people’s responses in local settings, and in ensuring that bureaucratic processes are replicated across multiple sites (Smith, 2001, 178). Even though these individuals may not meet in person, they must adhere to the same textually-mediated regulations in their work. The ‘ruling relations’ become evident as these texts show how ideological beliefs regarding disability are described by the province, and then translated into action as the regulations in these texts shape the nature of residential services in practice.

Interviews

In order to understand the linkages between texts and individuals and the ways in which texts shape individual experiences, institutional ethnographers often conduct interviews with informants who have knowledge and experience regarding a given institutional structure. Accordingly, I conducted twelve semi-structured interviews with government policymakers, residential service providers or workers, and disability advocates. In institutional ethnography, “frontline professionals” such as these individuals are often key interview participants because they enable the researcher to connect peoples’ experiences working within a given structure to “ruling discourses” such as government policies and regimes (DeVault & McCoy, 760). In addition to interviewing ‘frontline professionals, institutional ethnographers might also carry out research among people who use a system rather than those who organize it. While I was unable to conduct interviews with people with intellectual disabilities living in residential service facilities, I did interview two advocates who have experience using disability services because they have children with intellectual disabilities.

I conducted open-ended and varied interviews. These are key components of institutional ethnography, where interviewing could otherwise be understood as “talking with people” and each interview, rather than being standardized, “provides an opportunity for the researcher to learn about a particular piece of the extended relational chain, to check the developing picture of the coordinative process, and to become aware of additional questions that need attention” (DeVault & McCoy, 2006, 757). While I prepared an interview guide (see Appendix I), the questions I asked during interviews varied according to the position of each participant and the knowledge and experiences

they could share with me. The information I gathered from policymakers, for instance, helped me to understand a different part of the system, and from a different perspective, than the information I gained from mothers who advocate on behalf of their children with intellectual disabilities.

In addition to these interviews, “talking with people” also occurred when I would informally ask community members questions about the residential services system during participant observation or through e-mail communication. While this method of inquiry did not constitute a formal interview, it was often essential for ensuring the accuracy of the information included in this thesis.

I began conducting interviews using a snowball method of sampling; starting with some of the people I had met through participant observation. These individuals held knowledge and perspectives that I believed would be valuable for my research. Some of these participants then gave me the contact information, or suggested that I contact, other community members who were knowledgeable about the residential services system. I also gained access to participants through contact information provided on the websites of the DCS and various disability organizations. I contacted each participant via e-mail or telephone, and sent them each a recruitment letter outlining the purpose of my research prior to the interview (see Appendix II).

In the following section, I provide a description of interview participants. I state their position as a policymaker, service provider, or advocate, and describe their experience and background regarding residential services for people with disabilities.

Interview Participants

I interviewed two policymakers currently working for the DCS. Sandy and Doris are involved in implementing and reviewing the services provided for people with intellectual disabilities. Sandy is the director of the Services for Persons with Disabilities Program for the Nova Scotia DCS. In this role, she is responsible for developing policy, legislation, standards, procedures, and budget pertaining to disability services, and also provides support to service providers and staff. She began her career in disability services in 1978, working in a residential program for youth. She has been involved in the deinstitutionalization process in Nova Scotia; including the closure of the Children's Training Centres in the early 1990s. Doris is the DCS' senior policy analyst. In this role she is responsible for developing and drafting new disability service policies. Doris has also worked in disability services since 1978. She spent the first half of her career supporting adults with intellectual disabilities and mental illnesses in nursing homes and other residential care facilities. Doris has worked for the DCS for the past fifteen years.

I originally intended to interview two current and two past policymakers. However, I experienced difficulty accessing past policymakers because their contact information was not publicly available. While I asked other research participants if they knew any past policymakers who might be willing to participate in an interview, none of them were able to provide me with information. As an alternative I interviewed past and current service providers. One of them, Theresa, had been involved with the DCS, working as a liaison between the government and communities as they attempted to develop and implement community group homes in the 1970s. She continued working in this position until her recent retirement. June, the other past services provider, was the

executive director of a community residential services organization from 1979 until 2006. In this position she was involved in developing and implementing residential services. Although she is now retired, June continues to do some consulting work pertaining to community living.

In addition to Theresa and June, I interviewed five current service providers or workers. Four of them, Louise, Dave, Simon, and Marion, work in community settings. Louise has worked to develop services and supports for people with intellectual disabilities for the past 26 years. She is currently the executive director of the same community residential services organization that June had previously worked for. Simon has worked to develop group homes and provide supports for people with intellectual disabilities in Nova Scotia since the late 1970s. He is also involved with local disability advocacy organizations. Dave has held various administrative positions regarding disability services in Nova Scotia throughout his career. He currently runs a residential care facility, and has also worked as a consultant, helping people move from larger residences to small options homes in the community. Marion spent thirty-two years working as a nursing attendant in long-term care institutions in Nova Scotia and Ontario. She has also worked in community group home settings. Marion is currently employed by her daughter Erin, an advocate for community living, to help care for her grandson, Noah, in Erin's home. Brian, the other service worker I interviewed, has worked as clinical social worker at a Regional Rehabilitation Centre for the past two years. He has also worked for People First of Nova Scotia and been involved in advocacy movements.

Although I attempted to contact service providers working in institutions by e-mail numerous times, I was only unable to arrange an interview with one of them. While

I might have been more successful in contacting service providers working in institutions by telephone, their phone numbers were not publicly available. Again, none of my participants were able to provide me with this information. Although these five service providers and workers shared useful insight, the perspectives and knowledge of more institutional service providers would have given me a better grasp of the reasons why people continue to be institutionalized in the province.

Finally, I conducted interviews with four disability advocates. Two of these advocates, Ellen and Doug, held paid positions for disability organizations. Ellen, who passed away shortly before the completion of this project, had been involved with disability advocacy and community living associations in Ontario and Ottawa for 49 years. She was the executive director of the Nova Scotia Association for Community Living. In this role, which she assumed in 1988, Ellen met with national counterparts and was very active in pressuring Nova Scotia to move toward deinstitutionalization. Doug, who has an intellectual disability, has worked as an advocate with People First of Canada for the past 25 years. As the development co-ordinator for People First of Nova Scotia, he promotes the rights of people with intellectual disabilities to the government and to the broader community. He also helps other members of People First who have intellectual disabilities to advocate for themselves and to understand issues regarding their rights.

The other two advocates, Gloria and Erin, are mothers who became involved in advocacy when they had children with disabilities. Gloria has an adult daughter, Caroline, with severe and multiple disabilities. She became involved in disability advocacy after her family moved to Nova Scotia in the late 1980s, and has advocated heavily to receive the necessary support for Caroline to live at home rather than in an institution. She has

been involved with local advocacy organization and with the Canadian Association for Community Living. Erin has a thirteen year-old son, Noah, with severe and multiple disabilities. Like Gloria, she has advocated to receive the supports necessary to support her son at home, and has been involved with local disability advocacy organizations.

In total, I conducted twelve interviews. In determining an appropriate number of participants, I drew on Kelley (2010), who writes that “the determination of sample size in qualitative interview research does not strive for statistical accuracy but rather ties adequacy to the interview technique, the quality of information collected, the population from which samples are drawn and the intended uses of data” (317). Accordingly, I attempted to choose participants who had a high degree of expertise and knowledge pertaining to the provision of residential services for people with intellectual disabilities. In this case the *quality* of data that I garnered from a small number of participants was more important to my study than the overall quantity of participants. When I decided to stop interviews, I once again drew on Kelley (2010), who writes that qualitative interviews should be considered complete based on having achieved “informational redundancy or theoretical saturation, balanced against the amount of information generated and the analytic task it poses” (Kelley, 2010, 317). After having conducted twelve interviews, many of the themes and ideas discussed in interviews became repetitive, and I was not gathering any new data that could help to answer my research questions. As noted above, however, more interviews with participants who hold different views — such as those working in institutions — would have been valuable, but were not possible in this case.

Interview research took place during the summer of 2010. Each interview lasted

between 30 minutes and an hour, with one being slightly longer. For most interviews, I travelled to meet participants in a location that was convenient for them. Eight interviews took place in participants' offices, and one occurred in a participant's home. One occurred over the telephone because the participant was unable to meet in person. Finally, I conducted two interviews in a private room on the Dalhousie University campus because neither of these participants had offices where we could meet.

I recorded and transcribed all interviews. I then analyzed them in order to identify how different participants reflected upon and explained the continued existence of institutions in Nova Scotia and the reasons why policies of deinstitutionalization have not been pursued more aggressively. Since my interview participants were divided into different groups according to their roles as policymakers, service providers or workers, or advocates, I conducted a multi-level analysis by identifying and noting the frequency of key themes that emerged in each interview, in each group of interviews, and in all of the interviews.

Ethical Considerations

In order to carry out research with human participants, I obtained approval from the Dalhousie University Social Sciences and Humanities Human Research Ethics Board prior to commencing my project. Obtaining ethics approval entailed submitting a detailed report explaining the purpose of my research, the research methods I intended to use, and the potential harms that my research could pose to participants. The most significant harm I could foresee was that participants might speak critically of governmental policy or divulge internal information that is considered confidential during interviews. In doing so participants might risk making themselves or others look or feel badly, or might risk

unintentionally acting as whistle blowers. In order to mitigate these risks, I made participants aware of them in an informed consent letter, and assured them that their identity would be hidden in my thesis if they so desired. I also assured them that they were able to terminate the interview at any time if they felt uncomfortable, and that they could withdraw their data after having completed the interview if they did not want me to use any of the information they had shared.

Prior to commencing their interview, each participant signed a consent form where they were informed of the purpose of my research, what was involved in participating, and the potential risks it posed to them (see Appendix III). When signing the form they indicated whether or not they agreed to be digitally recorded and to have their actual names used in my thesis. All participants agreed to being recorded, and most gave me permission to reveal their identity. Some, however, did not want me to use direct quotes in association with their names. After having completed the interview I asked each participant to initial the consent form once again to confirm that I could use the information they had shared with me in my thesis. All participants signed the consent form willingly, and no significant ethical dilemmas occurred throughout my research. In the case of the interview that occurred over the telephone, I e-mailed the participant a consent form, which she was then able to sign and return to me.

Use Of Pseudonyms

Although most research participants gave me permission to reveal their identity, some participants were critical of others during interviews. I therefore thought it more appropriate to use pseudonyms and reduce the risk of the information in my thesis reflecting poorly on any particular participant. By using pseudonyms I was also able to

quote participants who did not want to be directly quoted in association with their names. Even though I did not reveal the names of my participants, it is still possible that some readers will be able to identify them given the small size of Nova Scotia's disability community. I also chose to use the actual names of implicated disability organizations: the Canadian/Nova Scotia Association for Community Living and People First of Canada/Nova Scotia. It seemed senseless to assign these organizations pseudonyms because the majority of people involved in the community know them well.

Research Gaps

The majority of my interviews, as well as participant observation, occurred with people involved in disability advocacy or community service provision, and who are working toward deinstitutionalization. As such it is likely that my research depicts their perspectives and positions more accurately than it depicts the perspectives of people who work in or develop institutional services. In order to fully examine the debates regarding institutionalization, it would be beneficial to conduct further research among more institutional workers and policy-makers. This would provide further insight into the dominant beliefs and practices contributing to institutionalization. In addition, it would be beneficial to conduct research among more people with intellectual disabilities directly, as opposed to research with their family members or advocates. This would help to ensure that the perspectives and interests of people using residential services are accurately represented. Interviews with more institutional workers and people with disabilities are thus important avenues of investigation for future research.

Although any study could be extended to examine additional perspectives, notable themes did emerge through interview, document analysis, and participant observation

research regarding the purpose and necessity of institutions and the social, political and economic factors contributing to their continued existence. In the following two chapters, I will explore these themes more fully in order to examine why Nova Scotians with intellectual disabilities are institutionalized, and why the province has not pursued policies of deinstitutionalization more aggressively.

Chapter Four: Social, Political, And Economic Factors Contributing To Institutionalization

This chapter examines the social, political, and economic factors contributing to the continued existence of institutions in Nova Scotia. These include the relative ease of institutionalization given that institutions have existed for so many years and are considered the normal model of support, a lack of community planning to realize deinstitutionalization, concerns about unemployment among institutional workers, a decline in disability advocacy movements, and a lack of public and political awareness about disability. Comparisons with related studies on deinstitutionalization (Tabatabainia, 2003; Parish, 2005; Bigby & Fyffe, 2006) show that these factors are not unique to Nova Scotia, but are relevant to deinstitutionalization in other places as well. Institutional ethnography suggests that social, political, and economic events occurring in a local context, such as Nova Scotia, are related to extra-local elements of social organization. As such, I relate the factors contributing to the continued existence of institutions in Nova Scotia to the neo-liberal philosophies that drive Canadian government policies.

Increasing Institutionalization And A Shortage Of Community Services

As mentioned in Chapter One, the 2008 Report of Residential Services indicates that over seven hundred Nova Scotians with disabilities currently live in institutional facilities known as Adult Residential and Regional Rehabilitation Centres (ARCs and RRCs). In many cases, these facilities are being constructed, renovated, and enlarged in order to meet the needs of people with disabilities who require support, but are currently not receiving any from the DCS because there is a shortage of services. For example, one of the initiatives in the Report for increasing residential services capacity was to renovate the Cobequid Multi-Service Centre, an RRC in Lower Sackville, so that thirteen more

people could live there (DCS, 2008, 39). In another case, twenty people who had formerly lived in the community moved into the King's County Rehabilitation Centre in Waterville in the fall of 2009 (communication between the Nova Scotia Association for Community Living and the DCS, 2009). By increasing the capacity of ARCs and RRCs, the DCS upholds the belief that large institutions are a viable model of support for people with intellectual disabilities.

As previously mentioned, ARCs and RRCs house people with a variety of intellectual and physical disabilities and mental illnesses. Complete data on the number of people with a given diagnosis living in these facilities is not available. However, a 2010 study commissioned by the Nova Scotia Association for Community Living shows that 79% of the residents at the Annapolis County Adult Residential Centre have a primary diagnosis of an intellectual disability (Wicks, 2010). This study attempted to gather more precise information on the number, age, and sex of Nova Scotians with intellectual disabilities currently residing in ARCs and RRCs, the amount of time they had lived in there, and the number of people who had recently been discharged or admitted to a given facility. The study was unable to provide conclusive evidence because only two of the province's eleven ARCs and RRCs agreed to participate. The other centre that participated in the study was the Metro Community Housing Centre. Although technically classified as an RRC, this residence has a capacity of 5 people; none of whom were reported as having a primary diagnosis of an intellectual disability. Nevertheless, the results from the Annapolis County ARC exemplify the extent to which Nova Scotians with intellectual disabilities continue to be institutionalized. Theresa, a past community services provider, sees this as a step in the wrong direction:

Today I see that things are regressing. I think that if something doesn't happen, [the Department of Community Services] will regress right back to where they were prior to the mid 1970s when institutions were being built and people were being placed in them.

Three advocates and three community service providers who participated in my research further expressed that the expansion of ARCs and RRCs directly results in a shortage of alternative community supports, such as smaller residences or the provision of individualized support workers, due to the challenges inherent in running dual systems. Since Nova Scotia continuously uses its resources to maintain ARCs and RRCs, policymakers and service providers spend less time, money, and energy on improving community-based options. When these alternative forms of support are not easily available, some people who could otherwise live in the community end up living in large institutions and remain there for long periods of time. This makes it appear as though institutions are the only possible option, or might make them a more appealing option to residents when an institution feels like a safer or more comfortable environment than the outside community

In Parish's qualitative analysis of deinstitutionalization in Michigan and Illinois (2005), she similarly finds that that the renovation of existing psychiatric hospitals in Illinois served to increase institutionalization. In this case, people requiring support were placed in these hospitals rather than in alternative community residences. Her study examines the historical and political factors contributing to the development of community residential services between 1970 and 1990 in these two states (Parish, 2005). While there are certainly many social, economic, and political differences between Nova Scotia today and Michigan and Illinois during these two decades, her study was still

useful because it addresses many of the same issues that my research participants noted as relevant to deinstitutionalization. While “poor institutional conditions frequently stimulated deinstitutionalization” in other states, poor conditions actually served to increase institutionalization in Illinois because of policy decisions to increase the capacity of psychiatric hospitals (Parish, 2005, 227). A comparable situation is occurring in Nova Scotia. As Gloria, an advocate for community living, pointed out, “if there are ‘beds to fill’ then we will continue filling them.” Likewise, Parish finds that one barrier to deinstitutionalization in Michigan was the construction of nursing homes specifically for people with intellectual disabilities: “although respondents did not indicate that nursing homes barred community development, documents indicated that these facilities diverted state resources away from community homes” (226). Insufficient community homes can then serve as a justification for maintaining institutions. In her study of families’ views of institutionalization and deinstitutionalization in Australia, Tabatabainia (2003) similarly finds that many family members of people with intellectual disabilities who opposed deinstitutionalization did so “due to the inadequacy of community-based residential settings,” including a lack of qualified staff and of financial resources (247). Given that “many families . . . changed their views positively after the relocation and subsequent adjustment of their relatives to . . . the community” (252), she finds that an adequate community support system can help decrease opposition to deinstitutionalization.

The experiences of Gloria and Erin, two mothers and advocates for community living, illustrate the challenges in accessing alternative community supports in Nova Scotia given the existence of institutions. Both Gloria and Erin have children with severe intellectual disabilities and have advocated to receive individualized funding in order to

support their children at home. During interviews, they recounted the struggles they had encountered throughout their attempts to secure individualized funding. They both felt that deinstitutionalization could place pressure on the government to increase individualized funding. As Erin stated,

It's a double-edged sword for me because not only do I not want [an ARC or RRC] to be the place where he [Noah] ends up should something happen to me, but also so long as institutions exist, I can't get the funding I need to properly care for my son in the place that I feel he should be, which is at home . . . They say, 'you're going to get x amount of dollars to care for your son, if you need more than that, too bad there's a place.' *If they omit the place, then they have to fund him at home* (emphasis added).

Erin explained that the funding she does receive from the government is only sufficient because she employs her mother, Marion, a former institutional nursing attendant who also participated in my research, as a full-time support worker for thirteen year-old Noah. Erin pays her mother far less than a non-family care worker would expect to be paid. Similarly Gloria, whose twenty-five year old daughter has severe and multiple disabilities, discussed how a lack of easily available support services means that people who wish to support a family member with disabilities at home must proactively navigate a complex system. When families are unsuccessful in doing so, they may reach a 'crisis point' resulting in an institutional placement:

I think that if you haven't figured it out by the time your kids reach early teens, that's when parents start running into crises because they realize that there's such a lack of social support. So if you haven't started planning for that and being pro-active, I find that parents seem to run into trouble, and that's when they start looking for possible placement options.

Gloria and Erin have successfully manipulated a complex service system by drawing on the alternative resources that are available to them, such as help from other family members and friends, in order to care for their children at home. As Panitch

(2004) points out in her discussion of mothers who become disability activists, “the child of an inactive mother will get what is available, which is not always what the child needs. In order to ensure that the needs of the child will be addressed, mothers must learn to confront and manipulate the system” (265). In this case, many people with intellectual disabilities who do not have family members or friends who advocate as strongly as Gloria and Erin have may live in an institutional setting due to the lack of easily available alternatives in the community. Gloria further explained that, in many cases, parents might be unwilling to challenge dominant models of care and advocate on behalf of their children because they have never envisioned alternative models of support, and because they are afraid of losing the services they do receive:

I think there’s a lack of knowledge about what is possible . . . We seem to be very complacent, don’t want to rock the boat. I’ve heard “god if I do anything I might lose what I’ve got” coming from parents before.

While the advocates community service providers quoted above argue that deinstitutionalization can create pressure to improve and expand alternative community supports, Sandy and Doris, two policymakers working for the DCS, express concern that if ARCs or RRCs were closed, some of the people with intellectual disabilities who currently live in them would end up living in nursing homes. They suggest, in other words, that these institutions are necessary due to a shortage in alternative options, in order to ensure that people with intellectual disabilities do not live in nursing homes. Similarly Brian, a clinical social worker who works in an RRC, feels that an ARC or RRC is a much better option than a nursing home because it provides people with intellectual disabilities more appropriate forms of support, including rehabilitation services:

While it's great to say that deinstitutionalization has occurred so there's nobody in RRCs, they're just in another institution. And at that point they're vegetating. They're no potential for recovery or rehabilitation. They're getting basic treatment, but there's no individual programming, there's no supports, they're not working towards discharge. That model is much worse in my opinion.

While nursing home placement is a problem recognized by many of the policymakers, service providers, and advocates who participated in interviews, very little evidence-based research has been carried out on this issue. A community living researcher I contacted via e-mail explained that this is because departments of health typically control nursing homes in Canadian provinces, whereas services for people with intellectual disabilities fall under the purview of community services departments. Therefore no single department keeps track of who is placed in a given facility and under what circumstances.

Institutions In The Community

As explained earlier in this chapter, it is clear that many Nova Scotians with intellectual disabilities are currently institutionalized in ARCs and RRCs. The original purpose of this study was to provide insight into why people with intellectual disabilities continue to live in these large facilities. However, an unforeseen finding in my research is that some community service providers and advocates feel that institutionalization is *also* occurring in many of the group homes currently being created under the auspices of the DCS due to the high level of standardization in these homes. Although funding is being used to construct community group homes, these research participants feel that attempts to mitigate and manage risk in these homes lead to creation of community homes that reflect an institutional model, and thereby do not lead to successful community inclusion.

This was expressed by three community service providers and two advocates during interviews, and was also a key topic of discussion throughout my participant observation with a local disability organization.

The DCS is currently attempting to make sure that all of its homes across the province are licensed in accordance with the Homes for Special Care Act. In order to be licensed, service providers must ensure that their group homes adhere to specific fire and safety codes, must ensure a minimum amount of physical space for each resident, and must allow government officials to conduct inspections of the home (Homes for Special Care Act, 2009). As a means of upholding the Homes for Special Care Act, the DCS has placed a moratorium on Small Options Homes, which are homes for three or fewer residents who require support. Small Options Homes were created by municipalities prior to the shift from municipally to provincially administered group home services in 1996, and some of them still exist. They are not subject to the Homes for Special Care Act because they do not house more than three residents. As an alternative to Small Options Homes, the province is directing resources toward the development of ‘community homes’ that house between four and eight people and are subject to the Act.

Sandy and Doris explained that this moratorium is necessary because Small Options Homes can potentially be unsafe. In these homes a lack of regulations increases the risk of residents being mistreated or neglected. Similarly the Report of Residential Services (2008) refers to a policy analysis conducted in Ontario by Sossin (2003), who states that, “articulating standards and criteria for quality of care remains the most important building block of quality assurance and accountability in the delivery of social services” (53).

While Sandy and Doris identify regulations as a key element of providing good support to residents, three community service providers and one advocate feel that ‘community homes’ merely reflect the institutions they aim to replace, albeit with fewer residents. June pointed out that “you can be institutionalized and only living with 4 or 5 people. It’s all about the kind of rules or the absence of rules. If you take the same rules [that apply] in an institution of 100 and put them in place in a small facility [institutionalization] can happen anywhere.” When the staff spends so much time and energy following rules developed at a bureaucratic level, they are often unable to prioritize the needs and interests of the people living in a group home, and ensure that they are well integrated in their communities. As Louise further explained,

people can be isolated and institutionalized in a small home in a community neighbourhood. If we’re not engaging with our neighbours, if there’s no collaboration or co-operation and sharing of things, then people might as well be living out in the country in an institution somewhere.

In relation to the legislation guiding community housing policies in Australia, Gardner & Glanville (2005) similarly suggest that for some people with an intellectual disability the process of deinstitutionalization had led to new forms of care and management that are institutional in nature. A group home resident thus “experiences a subtle form of neglect which leads to her experience of a new form of institutionalization, at once both insidious and perhaps less open to scrutiny as it is overtly accepted as appropriate and integrated community living” (Gardner & Glanville, 2009, 229). Simon, a community services provider, explains that such ‘subtle neglect’ can actually result from regulations that are intended to protect residents. For example, rules against physical contact between staff and residents, implemented as a means of decreasing the

likelihood of physical or sexual abuse, can stand in the way of fostering relationships between residents and staff:

We've had to go full circle in terms of how we interact with clients. So many [residents] have so few people in their lives who they can interact with by giving them a hug, who can hold them. Today [staff] can't do that because it would be interpreted by what that would mean. So they've gone to the other extreme where people don't touch [residents] at all, and that becomes difficult.

Due to the ways many group homes are constructed, they contradict “one important, but usually taken for granted, aspect of housing: The residence as private territory . . . a place where we are supposed to be in control” (Tossebro, 2005, 191). By constituting an invasion of one's private territory (Goffman, 1961), residents of many Community-Based Options (CBOs), according to Kendrick (2001), do not live in real homes even if they are located in the community:

Many CBO residents have little say in where their homes are located, in the type of accommodation, in the key rules of the home, in those that they live with, in those who are selected as staff. They are then not living in a real home . . . but in a facility, a quasi-public place invaded by bureaucracy . . . in a mini-institution under the control of others (60-65).

In this way, physical integration in the community may not necessarily lead to greater social inclusion. In her study of people's lives a year after they had moved from large institutions to small group homes in Australia, Bigby (2005) finds that, while people reported an overall improved quality of life, very few of them were involved in community organizations or had made social connections outside of their families, advocates, and paid workers. Bigby relates this lack of change to the tendering-out of services to the private sector that occurred as deinstitutionalization was accompanied by the restructuring of the welfare state. In this climate divergences between economic and

social interests as well as the failure to involve the entire community — rather than simply the contracted organization — in creating a more inclusive society negatively affected the lives of people with disabilities.

The belief that institutionalization is occurring in community group homes illustrates the different understandings of institutional and community living that emerge among government policymakers, community service providers, and advocates for community living. It is clear that deinstitutionalization as government policymakers define it may not necessarily match the understanding of deinstitutionalization that community service providers or advocates hold. As I will explain further in the next chapter, conflicting beliefs among these community members can stand in the way of creating and implementing agreed-upon policies of deinstitutionalization.

Explanations For Expanded Institutions And The Shortage Of Community Services

Challenges In Community Planning

Three community service providers and two advocates for community living stated that institutions still exist, and community group reflect institutional models, because it might seem easier for policymakers and service providers to follow institutional models rather than undertake individualized community planning. Louise, a community service provider, explained that this planning involves making sure that each person with an intellectual disability receives the forms of support she or he might need to work, volunteer, or participate in social activities in the community. Doug, an advocate for community living, explained that it can be especially difficult to develop the ‘people supports,’ that people with intellectual disabilities require. While technical supports, such as a Braille Reader, can enable the inclusion of people with physical disabilities, ‘people

supports' such as personal companions, are more complex because they entail fostering a long-term supportive relationship based on people's abilities, needs, and interests. In contrast, it can be much easier and more cost-efficient to simply 'fill beds,' in a large facility and provide uniform services to all residents. As Ellen, another advocate for community living, stated,

I think it's a lot easier to put people in a place — and it is — rather than really do individualized planning and person-centered planning. Particularly for someone who has severe behavioural concerns or multiple disabilities or who can become violent at times, those kinds of things. It's a lot easier to put them somewhere where we have what we call 'therapeutic quiet rooms', which used to be called time-out rooms, which used to be called all sorts of things . . .

Similarly, it is often more efficient and cost-effective for community group homes to follow standardized rules than to respond to the individual needs and interests of residents. In their research on deinstitutionalization in Australia, Bigby & Fyffe (2006) find that decisions about where people would live in the community prioritized the effective management and use of resources, but in doing so "compromised the potential to create individualized supports" (572). For instance, some institutional residents had become friends and would have liked to live together in a community group home. However, they were unable to do so if such an arrangement was inconvenient for the service organization.

Concerns About Unemployment

In addition to being 'easier,' an additional justification for maintaining large institutions is that they require many staff to function and therefore create jobs ranging from administrative to nursing to custodial positions. According to Dave, a service provider, job loss is an especially significant concern in rural areas of Nova Scotia where

institutional facilities serve as a main source of employment. Bigby & Fyffe (2006) reiterate this argument when they discuss how ‘Westlands’, an institution in rural Australia, was “a significant employer in the region of professional, direct care, trades, and artisan staff. Its existence had influenced the career direction of many local people who had long work histories within the institution” (574). Although community services also create opportunities for employment, those who have long been employed by an institution may still lose jobs throughout the deinstitutionalization process. Bigby & Fyffe (2006) do note that government planning and involvement can enable many former institutional employees to take up new positions providing support in community settings.

Lack Of Awareness

While some institutional service providers and staff in Nova Scotia may express direct opposition to deinstitutionalization due to concerns about unemployment, two community service providers and four advocates who participated in my research feel that a lack of public awareness about disability means that there is little pressure for issues regarding residential services to take precedence on the public agenda and within the government. As Ellen pointed out, “Most Nova Scotians don’t know that we have 700 people living in institutions. It’s a lack of awareness that these places even exist.” Given that most members of the general public do not think about these residential services unless they are close to someone with a disability, they are less likely think about ways that policies could be changed or implemented differently. Instead, they are more likely to accept policies as they currently exist.

This issue became clear when an advocate for community living⁷ recounted an anecdote at the meeting of a local advocacy group that I attended. She had participated in a government forum where the public was invited to share their opinions on provincial spending priorities. At a small round-table discussion, she suggested that funding should be put toward deinstitutionalization and the development of alternative community support services. No one else at the table had an opinion about this topic or expressed an interest in discussing it further. During the later plenary session, one of the most often-raised topics was the cost of fishing and hunting licenses in the province. This example illustrates the apathy and lack of public attention toward disability issues among the general public.

In my research, three community service providers and four advocates similarly express that there is a lack of awareness among powerful members of bureaucracy regarding the values and interests of people with intellectual disabilities, their families, service providers, and advocacy groups. Rather than listening to the voices of those who use or who are most directly involved with disability services and developing an awareness of their interests and needs, policymakers and bureaucrats focus instead on reducing overall risks as a means of ensuring the physical safety of residents. This lack of awareness then serves as a barrier to effective collaboration in developing residential services. Parish (2005) similarly notes that effective government leadership, in collaboration with community members, enabled deinstitutionalization in Michigan

⁷ This advocate did not participate in an interview because she was primarily engaged in advocacy for people with physical disabilities. Nevertheless, she supported deinstitutionalization and the further development of community services to meet the needs of people with intellectual disabilities.

between 1970 and 1990. In contrast, one of the barriers to deinstitutionalization in Illinois was a lack of commitment to developing community services among politicians.

Like members of the mainstream community who do not conceive of disability services as a critical social issue, these three community service providers and four advocates express that politicians may not understand why institutionalization is problematic unless they have personal experience with disability. As Erin stated,

Although it's not a necessary prerequisite, it would be good if someone in the House [government] has been there, so to speak. Been there meaning that they have spent some time as a disabled person, or they have cared for somebody on that level who has a disability. So that they have cared for somebody and felt love and value for a person, to really be able to see.

Erin felt that it could be beneficial for the politicians who are responsible for creating residential services legislation to spend time with people with disabilities or with disability community groups. She felt that this would help politicians to truly value the perspectives and interests of people with intellectual disabilities, and would help them to understand why deinstitutionalization is necessary. In a similar vein, Theresa explained how Mountain View Home was closed when the Minister of Community Services had a son with an intellectual disability. From his personal experience he believed strongly in the value of community living, and this influenced his decision to close the institution.

Decline In Advocacy

Four community service providers and one advocate express concern that this disregard for disability issues and acceptance of policies as they currently exist is related to a lack of effective advocacy in the province. These research participants feel that advocacy is especially important because, in the past, strong advocacy organizations played a key role in realizing deinstitutionalization by raising awareness about the

problematic nature of institutions and by ensuring that these facilities were replaced by strong community support services. As Dave explained, “I don’t think most of our services would have been implemented [without] advocacy. Advocacy can be the public servant’s best ally if they can convince policymakers that this is the direction in which we should go.”

Parish (2005) similarly discusses how fragmented leadership among members of the Arc (an American advocacy organization previously known as the Association for Retarded Citizens) served as a barrier to deinstitutionalization in Illinois. She writes that conflicting opinions about deinstitutionalization among members of the Arc “were often divisive and led to the Arc’s inability to speak with one voice to policymakers” (227). In contrast, branches of the Arc in other states had often helped realize deinstitutionalization by advocating to government and by raising lawsuits against states for unjust placement in institutions.

Some research participants feel that advocacy movements are also currently declining in Nova Scotia. As Dave further explained,

I don’t know where the [advocacy] organizations are now. Maybe they’ve fought the battle, they’ve seen their good work achieved ...and they’ve become tired. And maybe some of the really strong advocates have worn themselves out and there doesn’t seem to be anyone to pick up the mantle of office and to continue their strong advocacy.

The lack of advocacy that Dave identifies is especially relevant given the small size and limited resources available in Nova Scotia’s disability community. Simon explained that many people who consider themselves advocates also work as service providers or as paid or unpaid support workers and are involved in multiple disability-related associations. Holding these multiple roles, either as a support worker or as a

service provider, can result in advocacy fatigue, as many people have neither the time nor energy to engage effectively in policy debates. Again, this idea seemed to be reinforced during my observations of the meetings of a local advocacy organization. Members of this organization — many of whom also acted as service providers, or who supported family members with intellectual disabilities — frequently expressed concern that they were not advocating as successfully as they could be and discussed strategies for improving their efforts. In all cases, such improvements would require the members of the organization to take on increased responsibilities. However, none of them felt that they had the time or energy to do so. Many of them felt that simply participating in a two-hour meeting each month was the most time they were able to commit to the organization.

In order to more fully understand the barriers to realizing effective advocacy in the province, it would be necessary to examine in more detail the extent to which constraints for time, such as other work and family responsibilities, inhibit the work of advocates. It would also be helpful to reflect upon the extent to which the roles of advocates have changed over the past several decades, and the factors that have contributed to these changes. These are key questions for future research.

Efficiency In Neoliberal Societies

Institutional ethnography suggests that the factors outlined above, that contribute to the continued existence of large institutions and to the construction of institutional facilities in the community in Nova Scotia, do not occur in a vacuum, but rather are related to extra-local occurrences and broader forms of governance. This becomes especially clear given that similar social, political, and economic factors have arisen

regarding deinstitutionalization in the United States, in Australia, and elsewhere. In many ways, these factors are characteristic of the neo-liberal framework that has driven policy decisions in much of the industrialized world, including Canada, the United States, and Australia, since the late twentieth century (Teghtsoonian, 2009; Guberman, 2004; Ilcan & Basok, 2004).

In the Canadian context, Guberman (2004) describes how the Ontario and Quebec governments have adopted policies of deinstitutionalization for people requiring long-term in order to “reduce the cost of its services, deinstitutionalize its ways of assuring care and transfer and share its responsibilities with other stakeholders, including the private sector” (76). Teghtsoonian (2009) similarly discusses how neoliberal reforms have resulted in individual responsibility and market-oriented solutions for people suffering from depression. Although neo-liberal reforms have not resulted in deinstitutionalization across-the-board in Nova Scotia, they do shape institutional and community-based services in the province. While the Department of Community Services plays a role in regulating these services, a mixture of for-profit and non-profit stand alone service agencies are responsible for providing services and support directly (DCS, 2008).

One of underlying premises of neo-liberal philosophies is that the state acts as a “partner, animator, and facilitator for a variety of independent agents and powers” and is not solely responsible for providing services (Rose, 2000, 323). In order to ‘govern at distance’ in this way, government policies encourage the development of private and market-oriented organizations that are controlled through “techniques of accountability such as centrally set but locally managed budgets, and the practices of evaluation and auditing” (Rose, 2000, 324). This emphasizes “an alignment between the self-interested

choices of individuals and the goals of those who govern” rather than direct control (Teghtsoonian, 2009, 29).

In relation to disability services more specifically, Bigby & Fyffe’s research on deinstitutionalization in Australia (2006) finds that “the neo-liberal approach . . . together with managerialism that demanded measurable outcomes, saw a shift away from programmes such as community development and advocacy that had [a] more collective approach” (570). Instead, community service policies adhered to a business model as means of ensuring efficiency and reducing government spending. In this case, residential services were tendered out to non-governmental, for profit organizations on a competitive basis. Similarly, the DCS ‘governs at a distance’ because it structures the continuum and dictates the nature of services, while various agencies compete to provide them. This context shapes the relations between policymakers, service providers, and people living in residential services or advocating on behalf of residents.

Rose (2000) writes that the strategies of control implicated in governing at a distance “can be broadly divided into two families: those that seek to regulate conduct by enmeshing individuals within circuits of inclusion and those that seek to act upon pathologies through . . . circuits of exclusion” (324). On the one hand, circuits of inclusion are premised in “the ethos of individual autonomy characteristic of advanced forms of liberalism: choice, personal responsibility, control over one’s fate, self-promotion and self-government” (329). Circuits of inclusion, which ensure citizenship and access to aspects of mainstream work, recreational, and social spaces, are thus reserved for people who are able to responsibly care for themselves and their families. By

limiting access to circuits of inclusion, the state is able to reduce spending because ‘responsible’ citizens require less support and can actively contribute to the economy.

On the other, hand, marginalized people who “have either refused the bonds of civility and self responsibility or . . . aspire to them but have not been given the skills, capacities, and means” to fulfill them are relegated to circuits of exclusion (Rose, 2000, 331). People with intellectual disabilities may fall into these circuits of exclusion when they are unable to fulfill the liberal ideals of personhood or the ideologies of individualism that are necessary for accessing circuits of inclusion. In this way they appear ‘intractably risky’ because they “either cannot or do not wish to exercise the self-control upon conduct necessary in a culture of freedom” (Rose, 2000, 333). The control of these ‘intractably risky’ individuals often occurs through segregation, such as placement in institutional facilities.

Given that neo-liberal governments aim to reduce spending and increase efficiency, they may not prioritize the needs and interests of people who are dependent and who are not contributing to the economy. From a cost-saving perspective, it is more efficient to relegate these individuals to circuits of exclusion. McCluskey (2002) argues that

the ostensibly neutral ideal of efficiency always incorporates assumptions about *whose* particular interests are taken as the standard for determining society’s well being . . . the current neoliberal view rests on the biased assumption that certain *capital and corporate* interests are necessarily in the *public* interest- because these interests are the standard by which economic growth is measured (120-121).

The neo-liberal framework, and in particular the drive to increase efficiency and reduce spending, shapes that ways residential service policies are created and

implemented in Nova Scotia. Large institutions may still exist because it is more efficient and requires less resources to house people in them than in smaller community residences. Likewise, it is more efficient and requires fewer resources to standardize community group homes, in accordance with the Homes for Special Care Act, than to undertake individualized planning and ensure that these homes meet the needs of each resident.

The challenges faced by advocates explained above — as many advocates also act as paid or unpaid support workers or service providers — arise in part due to the fact that “the task of government today is no longer engaged in traditional planning but is more involved in enabling, inspiring, and assisting citizens to take responsibility for social problems in their communities” (Ilcan & Basok, 2004, 132). In their study of the roles of voluntary organizations in Windsor, Ontario, Ilcan & Basok (2004) suggest that the decline in publicly funded services that has occurred throughout the shift to neo-liberal forms of governance may result in advocates feeling as though they have no choice but to respond to the immediate problems people are facing because there are few publicly funded service agencies available to deal with these problems. Furthermore, they may experience fatigue as they try to engage in multiple forms of advocacy, or when they hold multiple roles as advocates and service providers or paid/unpaid support workers. In other words, many advocates might aim to combat the structural origins of problems regarding disability services by advocating to the government to implement policies of deinstitutionalization and provide community services. However, many of them might instead spend much of their time helping to find immediate solutions to the crises people are facing such as a lack of housing or support services. By focusing on immediate,

individual problems at the micro-level, advocates may have less time and energy to work towards structural change serving a large number of people at the macro-level. In summary, neo-liberal reforms coupled with the small size and limited resources available within Nova Scotia's disability community diminishes advocates' ability to effectively mobilize for political change.

Based upon the findings provided in this chapter, it appears that institutions, as well as community residences reflecting institutional models, still exist in Nova Scotia due to several political, economic, and social factors. These include the challenges inherent in undertaking community planning, concerns about unemployment, a lack of political and public awareness about disability, and a decline in advocacy movements. These factors are each related to extra-local forms of governance such as neo-liberal policy reforms, which aim to ensure the government's overall economic efficiency by cutting back government services and tendering them out to private organizations. Neo-liberal philosophies constitute ruling relations that coordinate people's activities and actions at the local level. These ruling relations then shape the perspectives and practices of community members involved in developing, implementing, and challenging residential service policies. In particular, policies prioritizing economic efficiency and the interests of those who fall into 'circuits of inclusion,' are often less attentive to the needs and interests of people who may not be economically productive and require support throughout their lives — those who fall into 'circuits of exclusion' (Rose, 2000). The experiences of those who fall into circuits of exclusion are particularly shaped by dominant relations organized around risk management. This focus on risk management — rather than individualized supports — poses a challenge for advocates and people with

disabilities as their interests and needs are rarely taken into consideration in the public or political sphere.

In this chapter I have examined how several social, economic, and political factors contribute to the continued existence of institutions in Nova Scotia. However, my research finds that it is not *only* a lack of resources that serves as a barrier to deinstitutionalization. In the following chapter, I will examine how conflicting beliefs among implicated community members about the purpose and necessity of institutions serve as a barrier to creating and implementing policies of deinstitutionalization.

Chapter Five: Conflicting Beliefs About Institutionalization

This chapter examines how conflicting beliefs among research participants about the necessity and purpose of institutions stand in the way of embracing policies of deinstitutionalization. On the one hand, two policymakers and a participant working in an institution believe that institutions are necessary because they provide the opportunity for people with intellectual disabilities to be either rehabilitated or cared for. These beliefs are also demonstrated in the Nova Scotia Report of Residential Services (2008). In contrast, many of the community service providers and advocates who participated in my research feel that institutions are either incapable of providing rehabilitation, or feel that people with intellectual disabilities do not *require* rehabilitation. These research participants also challenge the view that some people with intellectual disabilities need to be institutionalized because their care needs are so high; stating that this care could potentially be provided in an integrated community setting. In addition, many advocates and community service providers further believe that institutionalization is wrong because it is a human rights infringement. They assert that all people with intellectual disabilities should have the right to live, and be provided support, in integrated community settings.

An institutional ethnography approach suggests that ideologies produced by the ruling class pervasively shape people's discursive activity at the local level (Smith, 1987). This approach is useful for showing how dominant beliefs about disability, as well as the ideologies that inform these beliefs, shape the everyday practices — or the discursive activity — of research participants who argue that institutions are necessary for people with intellectual disabilities. Socio-cultural literature suggests that the rhetoric

of rehabilitation and care have typically been embedded in institutional models (Wolfensberger, 1975; Oliver, 1990), and Oliver further associates this rhetoric with the ideology of individualism that predominates in capitalist societies.

An institutional ethnography approach is equally useful for showing how rights-based arguments, which have predominated throughout the deinstitutionalization movement, affect the thinking and actions of advocates. While rights-based movements may also be premised in ideologies of individualism (Kittay, 2001), my research finds that local advocates and disability organizations conceive of rights in a way that challenges this ideology. These advocates, who have direct experience with disability, recognize the importance of on-going support and social relationships for people with intellectual disabilities. In doing so, their perspectives reflect a relational understanding of personhood (Ells, 2001).

Difficulties in reconciling the conflicting beliefs expressed by these research participant arise from a lack of clear and open communication between advocates and community service providers on the one hand, and policymakers and people working in institutions on the other. While the two policymakers participating in my research stated that they welcomed communication and collaboration with community members and felt as though they had a positive relationship with these groups, many community service providers and advocates for community living felt as though policymakers often ignored their opinions, interests, and needs. In this way, a lack of communication and collaboration serves as barrier to challenging policies of institutionalization.

Rehabilitation As Justification For Institutionalization

During interviews, Sandy, Doris, and Brian all explained that large institutional facilities are necessary because they provide the opportunity for people with intellectual disabilities to be rehabilitated. As Sandy stated, an institution “need not be a lifelong home,” but is a transitional step that could lead to independent community living. The DCS affirms this position in the Report of Residential Services (2008). This policy document claims that the aim of ARCs and RRCs is to teach residents with “with complex behavioral and skill development needs” community-oriented, interpersonal, and life skills (11).

The following quote from Brian also exemplifies the belief that can people can be rehabilitated in institutional facilities. When discussing the RRC where he works, he stated that:

Our program is about rehabilitation; it’s never long-term care. We focus on getting people back into the community. Anyone that comes to us has basically failed everywhere else in the system. They come to us, we do huge amount of assessments, get programs in place, and they’re able to discharge back into the community. . . . While we’re a physical building of an institution, our focus and goal is to get people back into the community.

Brian explained that institutionalization is an especially necessary means of rehabilitation for people who may have learned to behave inappropriately while living in the community. For example, he referred to some young adults with autism living in the RRC where he works. The parents of these residents had often placated them while they were living at home. Given that these residents had always been placated, they were unable to appropriately control their anger and often reacted aggressively when they did not get their own way. According to

Brian, these individuals constituted a threat to other people and to their property. He believes that living in an institution, where there are higher levels of control, can provide the opportunity for these individuals to learn better communication skills so that they can control their anger. They can then leave the RRC and live with housemates in a community group home setting, where they can use their communication skills, rather than aggression, to convey their needs.

In order to rehabilitate residents who exhibit this type of behaviour, Brian stated that the continuum of services for people with intellectual disabilities should reflect the medical model of care. The medical model emphasizes acute treatment and recovery and is often used to rehabilitate people with short-term illnesses or physical disabilities. His belief that institutions are necessary as a first, or 'acute,' step in the rehabilitative process seems to echo government policy. In particular, the Report of Residential Services states that ARCs and RRCs are well suited to provide acute treatment because residents living in them "have access to a number of professional services including medical services, nursing, psychological and psychiatry services, social work, speech language therapy, physiotherapy and occupational therapy" (DCS, 2008, 12).

One of the underlying premises of disability service programs and policies that emphasize rehabilitation, such as the continuum of services in Nova Scotia, is the 'least restrictive environment' (LRE) principle that became popular in the United States in the 1960s and 1970s. The LRE principle consists of a continuum of services ranging from the least restrictive to the most restrictive setting. In this continuum, the most restrictive settings are typically more segregated and offer more intensive services, whereas the least

restrictive settings are more integrated and offer less intensive services. Taylor (2001) explains that the goal of the LRE principle is to rehabilitate residents so that they can “move progressively to less and less restrictive settings and ideally to independent living” (18). Similarly, the ‘continuum’ policy of services in Nova Scotia emphasizes that people will move through services as they develop the capacity to live independently.

Long-Term Care As A Justification For Institutionalization

Although Sandy, Doris, and Brian feel that the primary goal of ARCs and RRCs is to rehabilitate residents, each of them also believes that rehabilitation is not possible for some residents due to the severity of their disabilities. They all expressed that institutions are necessary because people with especially complex or severe disabilities could not be well cared for in the community. As an alternative they believe that an institution might in fact “be a lifelong home,” as Sandy put it, for individuals who require intensive care and medical services. This might include the regular support of doctors and nurses and access to medical technologies. Sandy, Doris, and Brian thus justify institutionalization because they feel that these facilities can effectively provide high levels of care. Again, Brian’s insights exemplify this belief:

There will always be people who need to live in a large facility because their care needs are so high. You can’t staff a small option home with three people and have twelve RNs [registered nurses] there all the time, because some of these people need RN care, and have a physician that is always on call and ready to come . . . We [the RRC] offer equivalent physical care to a nursing home. There will always be people who need that level of care.

Likewise, Doris discussed how institutions “are required in the continuum” for people with the most complex care needs, stating that “we do need all levels of support” in Nova Scotia. The Report of Residential Services (2008) also provides evidence to support this claim and to justify the continued existence of ARCs and RRCs. The Report

cites Dr. Brian Hennen, a local psychiatrist, who states that a “small number of individuals . . . may require continuous, specialized, experienced, collaborative, and integrated management which is unlikely to be found in most domains” (DCS, 2008,19). According to Hennen institutions are necessary for these individuals because the community is unprepared to support them and thus presents a risk to their safety and well-being.

In my research, Sandy and Doris also used arguments of care and safety to justify the implementation of regulations in community group homes. Sandy stated that regulations are an important means of protecting vulnerable residents from service providers who might mistreat them or provide an inadequate level of support:

The most important thing is the safety of individuals, the safety and well-being. Through licensing and standards it's very clear that service providers are providing the services to individuals, but our staff have a monitoring role to go in and make sure that the standards, the regulations, the Homes for Special Care Act, are all being met. Otherwise you could have a service provider with the most vulnerable population who could be providing food, shelter, and clothing, but at standards so poor that it puts somebody at risk.

The beliefs that institutions are necessary in order to rehabilitate or care for people with intellectual disabilities are not unique to the research participants quoted above, or to Nova Scotia policies. According to Wolfensberger (1975), these beliefs are embedded in institutional models across North America and Europe. In the case of rehabilitation, Wolfensberger finds that many institutions have been designed in accordance with the view that residents are capable of “growth, development, and learning” (15). Following Phillippe Pinel’s philosophy of moral treatment, these institutions have emphasized interactions between residents, staff, and the surrounding environment (Wolfensberger, 1975). ARCs and RRCs today may be very different from institutions that were initially

developed in accordance with moral treatment. However Brian, as an institutional worker, expressed beliefs similar to the philosophies of Pinel regarding the best way to rehabilitate people with intellectual disabilities. For instance, Pinel believed that people should live in a “strictly controlled environment,” rather than in the mainstream community, in order to be rehabilitated (Weeks, 1996, 4-5). This statement is similar to Brian’s explanation that some individuals need rehabilitative treatment in an institution in order to learn to live in the community. While Brian’s perspective itself may not be representative of all people working in institutions, the findings of this study nevertheless suggest that rehabilitation is still a common ideal among those who work with people with intellectual disabilities in institutions today.

In the case of long-term care, the belief that that people with intellectual disabilities need to be cared for, and that this care is best provided in an institutional facility, may reflect a paternalistic model which views an individual with an intellectual disability as an “ ‘eternal child’ who ‘never grows old.’ ” (Wolfensberger, 1975, 13). As eternal children, people with intellectual disabilities require care and protection “against injury and risk” (Wolfensberger, 13). While Wolfensberger’s analysis may be dated, other studies have similarly suggested that paternalistic models, and the resulting rationale for institutionalization according to arguments of care and safety, are still relevant. In her research on the continued existence of institutions in Manitoba, for example, Schwartz (2010) finds that various community members, including advocates, family members, and policymakers, drew on arguments of care and safety in order to argue that these facilities should be kept open. She writes that policymakers in particular

were concerned that some people with intellectual disabilities did not have the necessary competence to live in the community and needed to be kept safe in institutional facilities.

Another dominant belief embedded in institutional models is the view that people with intellectual disabilities require specialized medical and professional services in order to be rehabilitated or cared for. According to Oliver (1990), this belief is associated with the ‘personal tragedy theory’ that locates disability as a tragedy occurring within each individual regardless of the wider social environment. He suggests that that this ‘tragedy’ understanding of disability further leads to treatments that attempt to identify and treat the cause of the disability through medical means. If experts do not believe that a person with a disability is ‘curable,’ as may be the case for those who are institutionalized in order to receive long-term care, institutional living nevertheless often emphasizes one’s medical needs, such as the administration of medication and visits with doctors, over other aspects of one’s life, such as participation in social interactions. This is especially the case in institutions where medical professionals hold positions of authority and where the daily routines of the facility are structured around routines similar to those in hospitals (Wolfensberger, 1975). An example of the medicalized nature of institutions in Nova Scotia is that the ‘capacity’ of these facilities is referred to in terms of ‘the number of beds’ available (DCS, 2008, 40). This language reflects the logic of hospitalization and promotes an image of residents as sick or passive.

According to Oliver (1990), the beliefs about disability explained above that serve to justify institutionalization may be related to the ideology of individualism that predominates in capitalist societies. This ideology attributes value to people based on their ability to work independently and productively for economic gains. In cases where

institutions emphasize rehabilitation, the underlying goal may be to enable residents to live and work independently and productively, so that they can fulfill their potential as autonomous individuals. In cases where residents are institutionalized in order to receive long-term care, their segregation may be justified on the basis that they are sick, or are eternal children, and are thus unable to live up to the ideology of individualism.

Arguments Against Rehabilitation

The views of Sandy, Doris, and Brian are closely aligned with the justification for institutionalization provided in the Report of Residential Services (2008). They all explain that institutions are necessary to provide people with disabilities the opportunity to be rehabilitated or cared for so that they can live independently in the community. In contrast, all four advocates and four of the community service providers who participated in my research expressed that institutional environments are incapable of rehabilitation.

As Doug pointed out:

We visited the Cobequid center, and there's a doctor's office [program] where people can learn how to go to the doctor's office. I just shake my head. When I learned to go to the doctor's office, I learned by going to the doctor's office. There doesn't need to be a program to do that. I believe there's very little rehabilitation going on. There's nothing on the other end. A lot of people are there for lifetime and the meals and stuff . . . When I was in a group home, they taught me how to cook meals, so I can do that better at home than they can where they're cooking for one hundred people.

The fact that the skills learned in an institution are not transferable to other environments, combined with the shortage of community supports, means that many people with intellectual disabilities spend long periods of time in institutions rather than moving into the community, even as they supposedly in the process of rehabilitation (Griffiths & Brown, 2006; Taylor 2001). As Erin wryly stated, the province's RRCs are "the Hotel California, truth be told. You can check in but you can't check out."

Community service providers and advocates are concerned that institutionalization does not prepare residents to live independently, even in cases where they do leave an institution. Instead, they believe that institutionalization fosters behaviour that prohibits former residents from successfully integrating into their communities. Ellen discussed how she had observed this when spending time with former institutional residents:

I remember two ladies from two different institutions and one of them, when it came lunchtime and people would go to the cafeteria to have their lunch, would eat everything really really quickly, just shove it in her face as fast as she could and kind of hide it, obviously used to people stealing it off her plate. And the other person would sit there until someone said she could eat her lunch . . . It's institutional behaviour.

Goffman (1961) describes how these 'adjustments' to institutional life lead to the further stigmatization of people who have been institutionalized. This stigmatization occurs because the behaviour people learn in institutions is regarded as strange in mainstream society. In the example given above, the institutional residents had learned to eat in a way that many others might consider rude. Many people might attribute this behaviour to an individual's disability, rather than an outcome of being institutionalized.

In addition to arguing against institutionalization on the basis that these facilities are not appropriate environments for rehabilitation, all four advocates and three community service providers further express that people with intellectual disabilities do not *require* rehabilitation. These research participants stated that people with intellectual disabilities are capable of learning and growing throughout their lives, but are not sick and therefore do not need rehabilitation to get better. Simon pointed out that people do not 'graduate' through support services in a linear way. Instead they require ongoing support and exposure to a variety of mainstream environments throughout their lives.

Likewise, Erin expressed that people with intellectual disabilities need acceptance for their differences rather than rehabilitation, stating that “people with disabilities can’t all be ‘rehabed.’ They’re disabled forever. They’re the best they can be now.” As Gloria, another parent advocate, similarly explained:

[Caroline] has health-related problems . . . but she’s not sick. She’s been healthier than her ‘normal’ brother. When they were growing up he’s the one who had the most colds and flus and things like that. She’s not a sickly person. She just has different needs . . .

Flaws In The ‘Continuum Model’

Simon, Erin, and Gloria are critical of medical understandings of disability for perpetuating the belief that people with intellectual disabilities are sick, and that, following the logic of the medical model, they can be rehabilitated or cured. During interviews, four other participants similarly critiqued the concept of rehabilitation. Many of the questions that advocates and community service providers raise regarding deinstitutionalization and community living are similar to Taylor’s critique of the LRE principle and continuum of care policies. As he points out, the LRE principle assumes that more intensive services can only be provided in a segregated environment, although these services could be made available in integrated settings. In his words, “any health related, educational, or habilitative services that can theoretically be provided in a segregated setting can be provided in an integrated one” (Taylor, 2001, 19).

Policies justifying institutionalization in accordance with the LRE principle also contradict evidence-based research on best practices in residential services, which demonstrates that institutions are unsuccessful at providing good support and that people with intellectual disabilities typically have a much higher quality of life in the community

(see for example, O'Brien, Thesing, Tuck, & Capie, 2001; Young, 2006; Johnson & Traustadóttir, 2005). This is even the case in some contexts—like the United States—where proponents of institutions have attempted to ameliorate these facilities by increasing funding and by hiring more professionals to work in them (Taylor, 2001). Despite these reforms, federal audits have found “serious quality of life and medical deficiencies in institutions” (US General Accounting Office, 1996, as cited in Taylor, 2001, 19). There may be many social, economic, and political differences between Nova Scotia today and the United States in the late twentieth century. However, the similarities in institutional models in across Canada and the United States, as they are developed according the rhetoric of rehabilitation or care (Wolfensberger, 1975), make findings from this audit a relevant point of comparison.

Arguments Against Long-Term Care

Two of the advocates and four of the community service providers further express the view that people should not be institutionalized simply because they need high levels of care. They assert that high levels of care and support, including medical services when they are necessary, could potentially be provided in integrated community settings. As Simon explained, “[The belief is that] you have to be cared for, and therefore you have to be able to access a doctor at the ready, as opposed to as other people do within the community.” He and four other research participants feel that many people with intellectual disabilities should be able to access the same social and medical services that other people use in mainstream community settings. They express that this would be possible if more members of the mainstream population were knowledgeable about the differing needs of people with intellectual disabilities. If this were the case, people with

disabilities would not require ‘specialists,’ including doctors, social workers, and therapists, who work solely in institutional facilities.

The perspectives of these research participants reflect broader theoretical critiques of institutionalization, such as Oliver’s argument that medical and rehabilitative understandings of disability serve as a mechanism of social control through which professionals exert power over people who are considered abnormal in relation to the able-bodied individual (1990). This form of social control is especially evident in institutions, where people with disabilities are cast as the “deviant object of dread that requires taming by professional practices” (Schwartz, 2010, 7). Doctors and allied health professionals, who exert social control when they assess and chart the progress of residents, constitute these ‘professional practices.’ As Illich famously argued, these “disabling professions” (1977, 11) lead to the social construction of dependency, calling for specialized services to treat disability. These specialized services are upheld by “theories, practitioners, institutions and social policies” (Robertson, 1997, 428). When they are considered necessities, they reinforce the belief that people with intellectual disabilities need to live in facilities where they have access to them. Schwartz (2010) argues that such professional control has shaped the way disability policies and services are developed and implemented in Manitoba. In her research, she finds that “people with intellectual disabilities are referred to in the context of abnormal people who require environments and activities that are deemed to be appropriate in the views of the professionals responsible for their care” (8).

Institutionalization As An Infringement Of Human Rights And Citizenship

In addition to challenging the beliefs that institutions are a necessary means of care or rehabilitation, all four advocates who participated in interviews draw on rights-based arguments to explain why people with intellectual disabilities should live in the community. Similar arguments frequently arose when I conducted participant observation with a local advocacy organization. According to these advocates all people with intellectual disabilities should be considered equal citizens, and should have the right to live in and be provided the support they need in a mainstream community setting. As Ellen stated, “if we’re going to talk about human rights and we’re going to talk about full citizenship to people, to *all* Canadians, then we have to support people to be citizens in their community.” Ellen further likened institutionalization to other widely recognized human rights injustices, such as the placement of native children in residential schools. As Gloria similarly stated, institutionalization “is a human rights issue. And we need to do a better job of talking about human rights.”

These research participants express that people with intellectual disabilities should have the right to decide where and with whom they live, and to control the activities they undertake on a daily basis as much as possible. This might include the freedom to decide what food they eat, who they interact with, and where they go to work, volunteer, run errands, or socialize. These four advocates and two other service providers argue that the ability to make these decisions autonomously is especially restricted in larger facilities because regulations and routines are set in place in with the end goal of ensuring the safety and providing supports for large numbers of residents. June explained how this planning for the ‘worst case scenario’ restricts the autonomy of each resident: “If you’re

going to have 100 people under one roof you've got to have an awful lot of rules and policies and conditions that tend to be designed for the worst-case scenario." These research participants further argue that the rights of people with intellectual disabilities to make autonomous choices and live freely is limited in community group homes that adhere to the Homes for Special Care Act as well as large institutions. They feel that the rights of people living in these group homes are being denied because residents are not able to make the kinds of autonomous decisions, such as those mentioned above, that most people do in their own homes.

The perspectives of some research participants regarding human rights can be associated with the rights-based activism that has predominated throughout the deinstitutionalization movement and other social movements since the late twentieth century. In Chapter Two, I explained how disability organizations such as the Canadian Association for Community Living and People First of Canada are particularly involved in rights-based activism. Given that all four advocates were involved with these associations, it is not surprising that they held similar views of the rights of people with intellectual disabilities.

In some cases, disability rights movements might also reflect the ideology of individualism. Kittay (2001), for instance, points out that the disability rights movement "has followed a blueprint developed by persons of colour, women, gays, and lesbians;" all of whom demanded equality and freedom according to a liberal conception of each person as independent, rational, and self-sufficient (558). The central premise of these movements is that people will fulfill these liberal tenets of personhood given structural changes in society. Kittay, however, is concerned that the liberal underpinnings of the

disability rights movement serves to exclude those who may never be able to realize full independence and will require ongoing support despite structural changes. As such, she suggests that the disability rights movement will be unsuccessful in ensuring that some people with severe intellectual disabilities are attributed due value and respect in our society. She notes that these individuals might remain excluded even as disability rights movements progress (Kittay, 2001, 559).

Kittay points to the limits of rights-based activism in ensuring the inclusion and well-being of people with intellectual disabilities. However, it is important to note that the advocates who participated in my research and the organizations with which they are affiliated conceive of human rights in a way that challenges ideologies of individualism and liberal understandings of personhood. In many cases they recognize that people with intellectual disabilities require ongoing support throughout their lives. As such, their conception of rights encompasses the right to receive support. In this way, their perspectives may reflect a relational, rather liberal understanding of personhood. A relational understanding of personhood “features interconnections with, and interdependencies upon, the body, others, and the structures of the world,” and recognizes that *all* people, regardless of conditions of ability or disability require the on-going support of others throughout their lives (Ells, 2001, 600-602).

The fact that these advocates challenge dominant understandings of rights and personhood may be related to their lived experiences providing support and care for people with intellectual disabilities. An institutional ethnography approach suggests that knowledge that is considered objective and is embedded in dominant ideologies generally differs from people’s subjective experiences (Allan, 2011, 357). While these differences

exist for all people, Smith suggests that they are particularly relevant for oppressed groups of people. Given that members of the ruling class generally produce objective knowledge, it will reflect their perspectives and interests more closely than those of people who are oppressed. More specifically, ideologies of individualism, which are generally produced by people who are able-bodied and who are able to live up to liberal ideals of personhood, may not accurately reflect the values and interests of people who are exposed to higher levels of dependency, including people with intellectual disabilities or those who provide care and support for them. People's direct experiences with disability may lead them to critically reflect on the value of human life in its various forms and reject ruling ideologies of individualism and liberalism. Accordingly, advocates who have personal experience with disability may hold different views than policymakers or service providers who adopt ruling ideas in their work.

Lack Of Collaboration To Create A Common Vision

The data gathered for this research project illustrates the conflicting beliefs that emerge between policymakers, service providers or workers, and advocates about the purpose and necessity of institutions. Despite these conflicting beliefs, all of them state that their goal is to ensure the well-being of people with intellectual disabilities, and all of them recognize the importance of collaboration among implicated community members to ameliorate residential services. Theresa feels that such collaboration was an essential aspect of successful deinstitutionalization in the past:

Perhaps it's simplistic but I think back to the time when there was a lot of community development happening there was a lot more connection. We [government] met at least once a month or very frequently with those community groups. And they held us accountable. They were very forthright, they weren't antagonistic. Not everything got resolved right away in a meeting room, it had to be hammered out.

Research participants hold different understandings of the extent to which collaboration is currently occurring. On the one hand policymakers state that they welcome interaction with advocates. As Doris stated, “Our Minister [of Community Services] has very openly said that she wants to meet with advocacy groups, she wants staff to meet with them, we’re open to new ideas . . . I would always say we want to be on the table with advocacy rather than on opposite sides of the table.” However, advocates for community living and community service providers do not necessarily feel that they had been included in decision making processes at the governmental level. As Gloria stated:

What we want is government to include us as stakeholders because we know the community that we are talking about and we feel that we and other community organizations are really vital players in this. I think the lack of willingness of governments to include us at the table is what’s really frustrating and what seems to be holding things up . . . If they would sit down and talk with us they would have a better understanding of what we’re asking for.

Brian also felt that open communication among people who work in larger facilities, community services providers, and advocates for community living could help the latter two groups to see that people working in institutions also want to support people with intellectual disabilities to be successfully integrated in their communities:

There’s a divide between service providers and advocacy groups sometimes. For example, us [the RRC], we’re really hated. They don’t understand what we do and that our goal is the same as them. As long as we’re divided we don’t have as much power to get things done and change. That’s why I keep trying to work toward bringing us together, other service providers, advocacy groups, other health care providers and professionals.

Due to these tensions and conflicting opinions, the only discussion community service providers and advocates will have with institutional workers and service providers is to tell them that these facilities should be replaced by alternative community supports.

The policymakers and institutional worker who participated in my research, however, do not feel that closing institutions will ensure the well-being of people with intellectual disabilities. These research participants are therefore unable to collaboratively achieve a common vision for residential services. Advocates and policymakers recognize this lack of vision as a problem. As June, a past community service provider who has also worked closely with advocacy groups, pointed out,

I think that first of all there needs to be a shared set of beliefs. Hopefully between advocacy organizations, government, and others. That would be a really good start at this point. A shared statement of values about what community living should look like, or what community services in general for people with disabilities should look like.

In the Report of Residential Services (2008), the DCS acknowledged that it has been operating without a clear philosophical vision and provided some recommendations for creating one. While these recommendations emphasize the importance of community living and collaboration with community members, as noted by the advocate above, they also state the importance of a continuum of residential services, including institutions, for people with intellectual disabilities. As such, their vision for community services does not match the vision held by advocates for deinstitutionalization.

Other research on deinstitutionalization similarly demonstrates the importance of a common vision in order to realize deinstitutionalization. For instance, Parish (2005) notes that a common vision enabled deinstitutionalization in Michigan. In contrast, one of the barriers to deinstitutionalization in Illinois was “no evidence of any sort of central vision guiding developmental disabilities policy or services” (229). In order to arrive at this vision, she emphasizes “the critical importance of collaborators drawn from the breadth of organizations across a state that share common goals” (Parish, 2005, 220).

This was also one Kendrick's (2001) recommendations in his report on Nova Scotia's community services, where he emphasizes the importance of collaboration and partnerships between 'key catalysts,' including "professionals, advocates, governments, service providers, and others associated with community living" in order to ensure that good supports are provided for people with intellectual disabilities (7-9).

This chapter has examined how research participants draw on conflicting beliefs concerning rehabilitation, care, and human rights to either justify the continued existence of institutions, or to argue that deinstitutionalization is necessary. An institutional ethnography approach suggests that dominant beliefs about disability shape the discursive activity of people working at the local level. Accordingly, I have shown how dominant beliefs about rehabilitation and care, which disability 'experts' — including doctors and health professionals — produce, are associated with the ideology of individualism. These ruling ideas then shape local policies as well as the perspectives and practices of research participants who feel that institutions are necessary for some people with intellectual disabilities. Many of the advocates and community service providers who participated in my research, however, challenge these dominant beliefs about rehabilitation and care. In doing so, their perspectives closely reflect critiques of institutions provided by academic theorists such as Goffman (1961), Wolfensberger (1975), and others. All advocates further argue that community living is human right that should be extended to all people with intellectual disabilities. This finding suggests that rights-based arguments, which have been predominant in the deinstitutionalization movement since the late twentieth century, pervasively shape the perspective, knowledge, and practices of advocates in Nova Scotia. However it is important to note that these advocates, who have personal

experiences with disability, may challenge the ideologies of individualism that typically form a part of rights-based arguments.

Although research participants hold different beliefs about the purpose and necessity of institutions, they all share the goal of ensuring the well-being of people with intellectual disabilities. In addition, they all believe that community members can best achieve this goal if they work collaboratively to realize a common vision for residential services. However, a lack of clear and open communication among community members stands in the way of reconciling conflicting opinions and realizing a common vision.

Chapter Six: Conclusion

Despite broader trends toward deinstitutionalization, instances of abuse in institutions, and evidence that people with disabilities have a higher quality of life in the community (O'Brien, Thesing, Tuck, & Capie, 2001; Young, 2006; Johnson & Traustadóttir, 2005), a significant number of Nova Scotians with intellectual disabilities continue to live in large institutional facilities (DCS, 2008). In response, this thesis has examined why people with intellectual disabilities are institutionalized in Nova Scotia and why the province has not pursued policies of deinstitutionalization more aggressively.

In conducting an institutional analysis, several key themes have emerged regarding the relations of ruling – including both structural factors and dominant ideological beliefs about disability – that shape the current residential system and contribute to the continued existence of institutions. First, structural factors that serve as barriers to deinstitutionalization, as outlined in Chapter Four, arise in part due to a sharp focus on the efficient and productive use of economic resources among policymakers and the broader community in Nova Scotia. Insofar as people with intellectual disabilities are typically considered dependent or non-productive, issues regarding disability, and institutionalization and deinstitutionalization rarely take precedence on the public or political agenda. This means that there is little pressure for the government to create or implement policies of deinstitutionalization.

An emphasis on productivity and efficiency also means that large institutions, as well as community group homes reflecting institutional models, are typically constructed according to a 'one size fits all' approach where all residents are provided similar

supports and services regardless of their different interests and needs. In many cases, adopting a ‘one size fits all’ approach might seem easier and more efficient than developing alternative community supports. The latter involves a high degree of planning, flexibility, and creativity to ensure that people are provided appropriate supports in an integrated environment.

Economic interests may also take precedence when employees of institutions resist deinstitutionalization because it constitutes a threat to their livelihoods. It is important for policymakers to consider the concerns of institutional staff, especially in rural communities where there are few other job prospects. Nevertheless, this issue exemplifies the extent to which the interests of able-bodied employees, who are considered productive and contributing members of society, are privileged over the interests of residents with disabilities.

In attempting to combat this emphasis on economic productivity that contributes to the continued existence of institutions, advocates can play an instrumental role in raising awareness about disability issues among government policymakers and members of the public. In doing so, they have played a key role in realizing deinstitutionalization in the past and in ensuring that institutions were replaced by community supports. Today, however, many advocates hold multiple and overlapping positions as advocates, support persons, or service providers. These heavy workloads compromise the time and energy these individuals are able to devote to advocacy activities.

Institutional ethnography suggests that local institutional processes — including the social, economic, and political factors contributing to the continued existence of institutions — are related to broader forms of governance. In particular, the barriers to

deinstitutionalization that I have just summarized are related to the neo-liberal reforms that aim to reduce spending as a means of ensuring the state's overall economic efficiency. In doing so, neo-liberal policies do not prioritize the interests and needs of people who may not be economically productive, including some people with intellectual disabilities. The challenges faced by advocates may similarly be related to neo-liberal reforms that have reduced funding and support for advocacy and voluntary organizations. In doing so, these reforms have made individuals increasingly responsible for combating social problems in their own communities. The key point of this explanation is to demonstrate the ways neo-liberal philosophies shape the experiences of research participants as they develop, implement, and challenge residential services policies. An important question for future research would be to examine the perspectives of people with intellectual disabilities using these services as a means of discerning how neo-liberal reforms shape their experiences.

It would be too simplistic, however, to conclude that institutions still exist simply because of neo-liberal policy reforms and efforts to reduce spending. In many cases, the Nova Scotia government does continue to provide funding for residential services. However, advocates for community living feel that funding is being misused because it is being directed toward the renovation and expansion of existing institutions, or toward the development of community group homes with a high emphasis on standards and regulations. As explained in Chapter Five, my research finds that conflicting beliefs among policymakers, institutional workers, and advocates for community living about the purpose and necessity of institutions, serve as significant barriers to deinstitutionalization.

Findings suggest that medical and rehabilitative understandings of disability – based upon the knowledge disability ‘experts’ including doctors and allied health professionals produce – often take precedence over the knowledge, perspectives, and practices of people who encounter disability in their daily lives, including people with intellectual disabilities, their family members, and advocates. The former group is typically interested in finding ways to rehabilitate or treat people with intellectual disabilities so that they may become independent and functioning members of society. Institutions are often seen as an appropriate environment for this rehabilitation. For people with more severe disabilities, for whom rehabilitation is not considered a possibility, institutions are considered a necessary means of providing care and medical treatment.

Although these research participants do not constitute a representative sample, the justifications for institutionalization they provide are similarly embedded in institutional models throughout North America, Europe and other parts of the world (Wolfensberger 1975; Oliver, 1990; Walmsley, 2005). The rhetoric of rehabilitation and care may further be related to the ideology of individualism that attributes value to people based on their ability to act productively and work independently (Oliver, 1990). As this occurs, people who cannot meet the demands of individualism, including some people with intellectual disabilities, are increasingly seen as burdens, or as objects of pity suffering from a personal tragedy. One of the ways of dealing with this burden is to segregate these people in institutional facilities.

In cases where community group homes have been developed, some research participants express concern that these group homes merely reflect the institutional

models they aim to replace, albeit with fewer residents. This is especially due to a high emphasis on risk management and ensuring the physical safety of residents in accordance with the regulations outlined in the Homes for Special Care Act. Some community service providers and advocates express concern that these regulations limit the ability of service providers and workers to respond to the needs and interests of each resident. This finding suggests that research participants hold different understandings of what it means to be institutionalized, in either large institutions or in community-based facilities with fewer residents. The original purpose of this study was to examine why people with intellectual disabilities are institutionalized in *large* facilities. In light of this finding, a further investigation of these divergent perspectives would provide a more nuanced understanding of the different *ways* in which people can be institutionalized. This is an important question for future research.

When policymakers and others who hold positions of power adopt the ruling ideas of rehabilitation, care, and safety, policies may undermine the perspectives, practices, and knowledge of people who encounter disability in their daily lives, who advocate on behalf of those with intellectual disabilities, or who work in community services. Many of these individuals do not believe that people with intellectual disabilities need to be rehabilitated or kept safe, but rather require on-going support in order to live in the community. Rather than understanding disability as a medical problem or as a personal tragedy, many advocates for community living point to the societal factors, including the creation of a more accepting and accessible community that could enable successful deinstitutionalization. As such, their perspectives are reflective of a structural analysis

that places the barriers to deinstitutionalization within the broader community, and does not focus solely on the limitations of each person with a disability.

This emphasis on risk management, rehabilitation, and care prevails despite the fact that international organizations like the United Nations as well as prominent Canadian disability advocacy and service organizations recognize community living as a human rights issue, and do not solely understand disability as medical problem requiring treatment. Discussions of rights arose frequently in my research. Advocates' overriding argument for deinstitutionalization is that people with intellectual disabilities have the right to live in, and be provided support in integrated community settings.

In many cases rights activists emphasize the potential independence and abilities of people with intellectual disabilities. Kittay (2001) discusses how these movements have often attempted to achieve equality by asserting that people with disabilities can potentially live independently and productively if oppressive social structures are removed. In this way, rights movements may be problematic because they appeal to the same ideologies of individualism and emphasis on economic efficiency that serve to exclude some people with disabilities (Kittay, 2001). Kittay's argument is important for advocates to consider as they draw on rights-based arguments in their efforts to realize deinstitutionalization. However, a significant finding in my research is that many advocates and disability organizations recognize the on-going support needs and the importance of social relationships for people with intellectual disabilities. In doing so, their understanding of rights may reflect a relational, rather than liberal understanding of personhood.

In summary, interviews revealed that research participants draw on different beliefs in order to justify the continued existence of institutions, or to argue that deinstitutionalization is necessary. This finding suggests a disjuncture between the beliefs and values embedded in policies regarding disability, and the experiences of those who encounter disability in their daily lives. Although all research participants agree that they could better meet the needs and interests of people with intellectual disabilities if they developed a guiding philosophy for residential services, conflicting beliefs stand in the way of collaboratively developing one. Many participants are optimistic, however, that community members will realize stronger partnerships in the future; thus allowing them to collaborate and communicate more effectively. A promising step in this direction is that the current Minister of Community Services has stated that the province's Services for Persons with Disabilities Program, in collaboration with advocates, service providers, and other government departments, will assume leadership in creating a new guiding disability strategy for the province. Initiatives like this one could help the province move toward a collective understanding of community living that privileges the voices of those who live and work in residential services in relation to the policymakers who implement them at a bureaucratic level.

Ultimately, it seems likely that a social model of community care is an important starting point for developing a stronger vision of deinstitutionalization (Guberman, 2004). This model presents care and support in the community as a collective responsibility and as a critical social issue. While it ensures that the government provides appropriate supports to all people who need them, it emphasizes partnerships “between all concerned stakeholders: people with disabilities, family caregivers, the public sector, the private

sector, the voluntary sector and the community” (Guberman, 2004, 82). Insofar as this model asserts that people with intellectual disabilities should receive appropriate public services “as an entitlement right of citizenship” (Guberman, 2004, 82), a recognition of the relational aspects of personhood as described by Kittay (2001) and Ells (2001) is an essential aspect of a social model of community care. A relational understanding of personhood recognizes that “being a person has little to do with rationality and everything to do with *relationships* — to our world and to those in it (Kittay, 2001, 566-67). It extends conceptions of citizenship to include people who have higher levels of dependence and who may require increased support from others throughout their lives. In doing so, it calls into question the ideologies of individualism that measure personhood according to the ability to act independently, rationally, and productively. A relational understanding of personhood is especially important to consider given that it corresponds to the perspectives of advocates who encounter disability in their lives. A social model of community care, in conjunction with a recognition of the relational aspects of personhood, could help to make sure that the interests and needs of various community members, including people with intellectual disabilities, “are truly recognized, appreciated, and taken into consideration” as policies are created and implemented (Guberman, 2004, 85).

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Appendix I: Interview Guide

For Advocates

- 1) How did you get involved in disability advocacy concerning residential services? What exactly do you do as a disability advocate?
- 2) How long have you been involved in disability advocacy in Nova Scotia? Have you been involved in advocacy in any other parts of Canada or the world? If so, what are some of the differences you see between Nova Scotia residential services and those in these other places?
- 3) Throughout the time you have been involved in disability advocacy in Nova Scotia, have there been changes in provision of residential services? If so, what are they? How have these changes come about?
- 4) What is your position concerning the continued existence of institutions in Nova Scotia?
- 5) In your work, what prevailing attitudes toward disability do you observe among the general public?
- 6) Why do you think people with intellectual disabilities are placed in institutions in Nova Scotia?
- 7) Why do you think Nova Scotia has not embraced policies of deinstitutionalization more fully? For instance, what imperatives have led to a decreased focus on institutionalization here, in contrast to other places?
- 8) What do you think we are doing well in terms of providing support for people with intellectual disabilities? What do you think we could be doing better?

For Service Providers And Workers

- 1) How did you begin working in residential services? What do you do in your position?
- 2) How long have you been involved in residential service provision/work in Nova Scotia?
Have you held similar positions in any other parts of Canada or the world? If so, what are some of the differences you see between Nova Scotia residential services and those in these other places?
- 3) Throughout the time you have been involved in residential service provision/work in Nova Scotia, have there been changes in these services? If so, what are they? How have these changes come about?
- 4) What is your position concerning the continued existence of institutions in Nova Scotia?
- 5) In your work, what prevailing attitudes toward disability do you observe among the general public?
- 6) Why do you think people with intellectual disabilities are placed in institutions in Nova Scotia?
- 7) Why do you think Nova Scotia has not embraced policies of deinstitutionalization more fully? For instance, what imperatives have led to a decreased focus on institutionalization here, in contrast to other places?
- 8) What do you think we are doing well in terms of providing support for people with intellectual disabilities? What do you think we could be doing better?

For Policymakers

- 1) What is your current position with the Nova Scotia government, or what was your position in the past?
- 2) How long have you been working for the NS government/how long did you work for the NS government?
- 3) Throughout the time you have been working/worked for the NS government, have there been changes in the provision of residential services? If so, what are they? How have these changes come about?
- 4) Have you held similar positions in other provinces or other parts of the world? If so, what are the differences and similarities between the provision of services in NS and these places?
- 5) What is your position concerning the continued existence of institutions in Nova Scotia?
- 6) Why do you think people with intellectual disabilities are placed in institutions?
- 7) In your work, what prevailing attitudes toward disability do you observe among the general public?
- 8) Why do you think Nova Scotia has not embraced policies of deinstitutionalization more fully? For instance, what imperatives have led to a decreased focus on institutionalization here, in contrast to other places?
- 9) What do you think the NS government is doing well in terms of its provision of support for people with intellectual disabilities? What do you think it could be doing better?

Appendix II: Recruitment Letter

Date

Rachel Barken
Department of Sociology and Social Anthropology
Dalhousie University
6135 University Avenue
Halifax, Nova Scotia
B3H 4P9

E-mail address: rachelbarken@dal.ca

Dear xx,

My name is Rachel Barken and I am a Master's student in Sociology at Dalhousie University. I am writing to invite you to participate in an interview for my thesis project entitled "A Place to Call Home: Intellectual Disabilities and Residential Services in Nova Scotia."

The purpose of this study is to examine why some Nova Scotians with intellectual disabilities still live in institutions, such as Adult Residential and Rehabilitation Centers, even though large institutions have been closed in other parts of Canada and the world. In order to address this question, I am conducting interviews with eight to ten disability advocates and governmental policymakers. The interviews will address the following two questions:

- 1) Why are people with intellectual disabilities institutionalized in Nova Scotia?
- 2) Why has Nova Scotia not fully embraced policies of deinstitutionalization?

As disability advocate/service provider/policymaker with knowledge pertaining to Nova Scotia's residential services system, your opinions and knowledge about the current residential services system would be especially valuable. The interview will take approximately one hour of your time and can be conducted in a location that is convenient for you, such as your office. If you prefer to meet elsewhere, I can arrange for us to meet in a room on the Dalhousie campus.

My goal, in conducting this project, is to help Nova Scotia develop better support services for people with intellectual disabilities, and I will be very happy to provide you with an electronic copy of my thesis or of a summary of my findings once my research is complete. If you have any questions or concerns, please contact myself or my supervisor, Dr. Fiona Martin, at f.martin@dal.ca or at (902) 494-6750.

If you are interested in participating in an interview, please contact me as soon as possible to arrange a date and time.

Sincerely,

Rachel Barken

Appendix III: Consent Form

Title of research project: “A Place to Call Home: Intellectual Disabilities and Residential Services in Nova Scotia.”

Principal investigator: Rachel Barken

Contact information:

Department of Sociology and Social Anthropology
Dalhousie University
6135 University Avenue
Halifax, Nova Scotia
B3H 4P9

E-mail address: rachelbarken@dal.ca

Purpose of research:

The purpose of this study is to examine why some Nova Scotians with intellectual disabilities still live in institutions, such as Adult Residential and Rehabilitation Centers, even though large institutions have been closed in other parts of Canada and the world. *As disability advocate/service provider/policymaker* with knowledge pertaining to Nova Scotia’s residential services system, I am especially interested in your views concerning the following two questions:

- 1) Why are people with intellectual disabilities institutionalized in Nova Scotia?
- 2) Why has Nova Scotia not fully embraced policies of deinstitutionalization?

What is involved in participating?

The interview should take about one hour of your time. With your permission, it will be tape-recorded and I will directly quote you in my thesis. If you prefer not to be tape recorded, I will take handwritten notes. Given that the interview will focus on the views and insights you have gained in your professional role as a *disability advocate/service provider/policymaker*, I do not anticipate that we will discuss issues beyond those that you encounter in your everyday work experiences. However, there is a risk that you might make yourself or others look or feel badly if you speak critically of the government or of community organizations.

If you provide consent, I will use your real name, and also refer to your position or the name of the organization with which you work, when I am quoting you or discussing results in my thesis.

If you would prefer that your identity be concealed, then I will use a pseudonym instead of your actual name and I will not refer to your specific position or the name of your organization in my thesis. That being said, it is still possible that readers will be able

guess the identity of participants given the small size this community. In the event that you change your mind based on the information you have provided in the interview, I will ask you to indicate whether or not you would like your identity concealed now and after we have conducted the interview.

Your participation in my research is completely voluntary and you are free to terminate the interview at any time without any repercussions. I will treat all material confidentially by removing any identifying features, if that is your wish. If you divulge any information that you decide to withdraw, you may do so during the interview, or until I submit a draft of my thesis in December 2010.

I will be happy to provide you with a copy of my thesis once it is completed. Upon request, I will also provide you with a transcribed copy of your interview. All interview data will remain confidential and will only be shared with supervisor, Dr. Fiona Martin, or with Dalhousie's Research Ethics Board, with pseudonyms where appropriate, upon request.

If you have any questions or concerns after we have completed the interview, please contact myself or my supervisor, Dr. Fiona Martin, at f.martin@dal.ca or at (902) 494-6750.

Title of research project: "A Place to Call Home: Intellectual Disabilities and Residential Services in Nova Scotia."

You will be provided with a copy of this informed consent form to keep for your records.

1) ___ **"I have read and understood the above information. I consent to participating in an interview and to being tape recorded"**

___ **"I have read and understood the above information. I consent to participating in an interview, but I would prefer to not be tape-recorded. I am aware that the researcher will take handwritten notes throughout the interview"**

2) ___ **I would like my identity hidden. Please do not reveal my name, position, or organizational affiliation in your project.**

Please initial here after the interview: _____

___ **You have permission to use my name, position, and organization affiliation in your thesis.**

Please initial here after the interview: _____

Signature: _____ **Co-signatory:** _____

Name: _____

Date: _____

If you wish, please provide an e-mail address so that I can send you an electronic copy of my thesis and a summary of my findings after my research is complete:

E-mail address: _____