INSTITUTIONALIZED CARE FOR ADULTS WITH SIGNIFICANT DISABILITIES AND MENTAL ILLNESSES IN THE PROVINCE OF NEW BRUNSWICK

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ABSTRACT

In this research I focused on the experiences of people diagnosed with severe disabilities and mental illnesses between nineteen and sixty-four who live in long-term care facilities, their families, front-line workers, and administrators of formal care delivery. By examining historic and current long-term care policies and legislations pertinent to New Brunswick, analyzing care philosophies, and spending considerable time in the facilities collecting data, this dissertation contains a thorough analysis of the matter. There are specific consistencies/inconsistencies between mandated care objectives and care delivery, and supports are not always available in times of crises. A number of factors lead parents to seek out-of-home placement for their children, there are issues with the assessment processes necessary to attain services, extended waiting periods for placements, and parents and residents experience difficulties post-placement. Management has problems finding and retaining employees, dealing with bureaucratic red tape, and spending time negotiating for funding. People do not understand the work front-line workers do, the people they work with, or their rationale for remaining in this undervalued and underpaid work. A critical feature of this research is that it contains residents' interpretations of themselves, their relationships, and engagement in activities.

DEDICATION

I dedicate this research first and foremost to those living in long-term care facilities. It was my deep desire to give them the opportunity to take their turn at to the podium. Too often, others have spoken on their behalf, and their views sometimes have little to do with the experiences of those actually living in long-term care. It is my hope that by hearing what these people have to say, readers of this document will discover how these individuals think about themselves, how they understand their relationships with people in and outside the facilities, and the limited number of areas where they are able to make decisions for themselves. My thanks to them for allowing me into their world and talking to me about matters important to them. In particular, I dedicate this research to my son Johnathan who also lives in a long-term care facility. Though limited in speech, you always have your say and I always enjoy listening.

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My first acknowledgment is directed to Dr. Jacqueline Low, who has spent hours, pouring over draft copies of each chapter, challenging me to make my conceptualizations clearer and my analyses deeper. She always responded quickly to my emails and phone calls, and arranged face-to-face time with me to discuss concerns as needed. It is because of you, that I will continue to hone my writing and analytical skills. I also want to thank Dr. Luc Theriault and Dr. Dale Ballucci for the time they invested in reading the draft copy of this dissertation, and for their valuable insights on how to improve this document. I also want to acknowledge the Department of Sociology who supported this research financially. This monetary investment allowed me to remain focused until this research was completed. Managers gave me access to conduct research in the facilities, which otherwise would have make this research impossible. I trust I have drawn attention to the important services you offer as well as the difficulties you face in care delivery. I also want to thank the front-line workers and have endeavoured to offer readers a better understanding of the work you do, the people you work with, and your rationales for remaining in this work. I am also grateful for those in the Department of Social Development who oversee formal long-term care delivery. Finally, I thank my husband Hugh for his emotional support through this entire process.

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CHAPTER ONE: INTRODUCTION

In this research I focused on the experiences of residents, families, front-line care workers, and administrators involved in long-term care for people diagnosed with severe disabilities and mental illnesses in New Brunswick. According to the Department of Social Development (SD/DS), there are approximately 90 specialized care facilities and community residences in New Brunswick, where care is provided to roughly 701 individuals who require level 3 or level 4 care (SD/DS 2011-2012). While instructive, these numbers do not provide an in-depth understanding of the experiences of people diagnosed with severe disabilities and mental illnesses who live in long-term care facilities in New Brunswick.

Further, while Canadian research on disability and institutional care for people diagnosed with disabilities exists, there is little or no detailed qualitative research on adults with severe disabilities and institutional care in New Brunswick (Fudge Schormans 2005, Kirby 2004, Moran et al. 2002, Prince 2004).[1] Therefore, in my doctoral research I addressed the question: "What are the experiences of residents, family members, front line workers, and administrators in the social world of long-term care in New Brunswick, for adults with significant cognitive and/or physical disabilities and mental illnesses?" A related research question was, "What are the inter-relationships between individuals in these different positions in long-term care?"

In addressing these questions I took a Foucauldian analysis, because his concepts of bio-power, discourse, disciplinary techniques, and the asymmetrical nature of power

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[1] See also Low 1996, Malacrida 2005, Titchkosky 2003, Tremain 2002.

relationships were useful for analyzing the experience of formal long-term care in New Brunswick. With bio-power, once knowledge about a particular area gains acceptance a certain discourse is legitimized, power relations ensue, and disciplinary techniques are employed in order to gain desired results. These concepts were pertinent for understanding why some individuals had the power to classify other individuals, designate them abnormal, determine their level of care needs, apply disciplinary techniques to control their conduct, and to use specific practices to manage their lives. Foucault's (2001:173) concept of culture was also relevant for analyzing the particular ethos behind formal care provision in long-term care facilities. In addition, I made use of Weber's (1925/1977) ideal type of bureaucracy in my analysis because it helped to understand the bureaucratic nature of long-term care facilities. I also used Goffman's (1961) understanding of total institutions because it is the classic sociological study of institutional care.

I used a qualitative research design to address my research questions because it allowed me to analyze participants' first-hand experiences and the meaning they gave to these experiences, through interviews and time spent at the facilities. I conducted field work in all regions of New Brunswick and spent extensive time in long-term care facilities, where I conducted interviews with the people who live and work in long-term care, as well as with relatives of residents living in long-term care facilities. I also analysed pertinent historical, legislative, and social policy documents related to institutional care in the province that provided important context for my findings.

The major contribution of my research was that it addressed the dearth of research on people diagnosed with severe disabilities and mental illnesses in institutional care in New Brunswick. It did so by providing a venue for parents to share what it is like to arrive at the point where they seek the out-of-home placement of their children, and by allowing insight into formal care providers' understandings of their role in providing long-term care services and hands-on care. It also meant that I was able to reveal consistencies and inconsistencies between official and non-official long-term care philosophies, and actual care provision. In addition, I provide five original conceptual models of processes in long-term care. Finally, this research provided a window into what it is like to live in a long-term care facility in residents' own words.

In order to better reflect the experiences of the people who participated in this research, I use person-first language to refer to persons diagnosed with disabilities and mental illnesses in my analysis. This clarifies that I do not see disability or mental illness as their central 'characteristic,' and that these individuals are not their disability (Mitler 2003:27). Person-first language is also consistent with the terminology found in most government policies and documents. Similarly, I use the term 'resident' rather than 'client' throughout the document to further establish their identity as persons first and their diagnoses and living situations as incidental to their identity. In distinguishing between persons diagnosed with disabilities and those with mental illnesses, I use the biomedical designation because that is how they are categorized in long-term care facilities. Finally, my use of 'institutional' care in this study is to distinguish between formal (institutional) and informal care (extra-institutional care).

Dissertation Structure

In Chapter Two, the literature review, I discuss the major areas and issues that emerged from my thematic analysis of research into long-term care for people with disabilities and mental illness. These include issues with assessment processes, difficulties finding placements, struggles post-placement, and the types of problems front-line workers face in the course of their work. Another important area in this literature is the social, emotional, and cultural climates of long-term care facilities. In the theory chapter I discuss the utility of critical Foucauldian theory in framing my analysis which facilitated investigating issues with bio-power, discourses, disciplinary techniques, asymmetrical power-laden relationships, and discerning the cultures in long-term care facilities. In Chapter Four I discuss the logic of a qualitative approach to this research, matters of epistemology, sources of data and fieldwork methods, ethical protocol and reflexivity, and how rigour was achieved in this research.

In Chapter Five I present findings from interviews with parents who talked about the specific factors that led them to have their children placed out-of-home. These included the physical, financial and emotional toll of caregiving, loss of respite care services and school supports, the age and size of their children, the aggressive behaviours their children engaged in, and their concerns that their other children might have to take over caregiving responsibilities. I also analyzed the assessment processes used in determining eligibility and level of care required for formal care services. In addition I discuss issues participants' faced post-placement such as extended waiting time because of limited housing options. I conclude by describing the lack of collaboration between government departments and between the public and private care sectors.

Official and non-official philosophies undergirding current long-term care provision are discussed in Chapter Six. These philosophies include attempting to maintain residents' rights and dignity, working to integrate, normalize and develop them, helping them to become more independent, and ensuring that they abide by established rules and expectations at the facilities. I address management's experiences of care provision in Chapter Seven, and include their recollections of the formal care that was delivered in the large institutions in the province. Managers expressed frustration over training requirements for employees, the lack of government funding, low employee wages and benefits, difficulties finding and retaining employees, and problems with bureaucratic red tape.

The experiences of front-line workers care providers are the focus of Chapter Eight. Front-line workers told that me they became involved in this work for altruistic reasons or out of a desire for change, but predominantly because of previous encounters they had with persons with disabilities. Although their jobs involve extensive responsibilities, they explained that they remain in this line of work because of their relationships with residents. Front-line workers are frustrated because they feel that their work is undervalued, and people have no understanding of the work they do, or the people they work with. Their relationships with residents are typically warm, they feel protective of residents, and some go over and above job requirements in providing care.

In Chapter Nine I analyze the experiences of residents of long-term care. Residents self-identify by comparing themselves with who they used to be, and with other individuals. They also self-identify by diagnosis, family ranking, professional status, or according to their special abilities. Their private bedrooms are spaces where they express their individuality through decorations and personal belongings. Residents experience a variety of relationships with individuals in and outside the facilities, and are able to exercise autonomy in what they wear, with certain activities and, occasionally, through engagement in paid employment. At the same time, their capacity to be self-determining is hindered by limited funding, limited staffing, and on occasion, the severity of their disabilities.

In Chapter 10, the conclusion, I discuss the theoretical implications of my findings and reflect on how the lived experiences of people associated with long-term care in New Brunswick differs from, but still reflects some elements of Goffman's total institution, as well as how Foucault's concept of bio-power is exercised in institutional care. I also provide recommendations for policy reform, discuss the limitations of this study, and make suggestions for future research into long-term care for people with severe disabilities and mental illnesses.

Official Definitions of Long Term Care

Thomas (2007:85, 86) explains that formal care involves paid employees and/or volunteers who provide social and health supports, while informal care (Theriault and Salhani 2001:219) is provided by family members, relatives, neighbours and friends who are not paid to do so. Vaillencourt et al. (2003:5) call this the "domestic sector." Statistics Canada (2005/2006) defines residential care facilities in Canada as those having at least four beds under the jurisdiction of either the Department of Health or

Social Services, targeted for individuals with cognitive, mental, emotional, drug or alcohol related issues, and categorized as private, not-for-profit, or government operated (Statistics Canada 2005/2006). Private facilities for seniors and others with cognitive disabilities, have been around for a long time, and constitute 43.4% of approved beds. Non-profit facilities represent 32.6% of these facilities, and the remaining 24% are government-owned (Statistics Canada 2005/2006).

Formal long-term care in New Brunswick is made up of various services and supports to address the "long term functional limitations" needs of individuals requiring assistance, because of issues with mental and physical health (SD/DS website). Notable in this explanation is the discourse framing residents in terms of dependency. The objective of long-term care services is to assist such individuals within their homes, or in other settings such as long-term care facilities, as necessary (SD/DS 2011-2012). Eligibility for long-term care services requires individuals to undergo functional assessments, after which they may be placed in nursing homes, special care homes, foster homes, community residences or, in some cases, receive support to enable them to remain in their homes of origin.

Currently, New Brunswick uses a level one to four classification system for determining eligibility for residential care (Hollander and Walker 1998:56, 57). Individuals assessed as either level 1 or 2 require a low to moderate level of care, generally require only some supervision and/or assistance with daily living activities, and may have mobility issues (SD/DS 2012). Level 3 requirements for care refer to individuals with mental or physical issues or functional limitations, who require twenty-four hour supervision, but are "medically stable." Individuals designated as level 3 require assistance or prompting with personal care and daily activities, or have other individuals do these things for them (SD/DS 2012). On the other hand, individuals with level 4 require more care, sometimes because of engaging in aggressive behaviour, and/or requiring “maximum assistance” (SD/DS 2012). In level 3 and 4 classifications, a biomedical perspective of disability is reflected in the explicit references to individual’s functional limitations. This perspective of disability is in keeping with that found in the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) and in New Brunswick’s Disability Policies (HRDC 2003:58).

Contextual Moments in the History of Long-Term Care in New Brunswick

Below, I discuss five contextual moments in the history of long-term care in the province of New Brunswick that have particular significance for my findings. These contextual moments include: the institutional era of the late 1800’s and early 1900’s, key legislative and policy changes in the 1960’s and 1970’s, the era of deinstitutionalization that began in the late 1960’s, three key pieces of legislation that were passed in each decade between 1970 and 1990 and finally, the contemporary period, which involves the current move towards re-institutionalization.

The Institutional Era

The late 19th century was known as the institutional era (Cameron and Valentine 2001) or ‘law and order period’ in Canada (Crichton and Jongbloed 1998). This institutional movement was initiated by mental hygienists who followed social pathology theory, which holds that those born bad, including those labelled retarded, cause social problems. This position is consistent with Canadian mental retardation policy at that time which spoke of the ‘menace of the feeble-minded’ (Wight-Felske 1982, Haller 1963). George Matthews and Dr. George Peters lobbied the Government of New Brunswick to create an asylum for the insane on seeing lunatics housed with felons and criminals in inhumane circumstances (Francis 1975, LaJeunesse 2002, Whalen 1963). Though efforts were taken to gather information about treatment approaches from the U.S. and Europe, it was ten years before funds were allotted for construction (Francis 1975, LaJeneusse 2002). The Provincial Lunatic Asylum replaced the Temporary Asylum in 1848 (GNB Archives) and was later renamed the Provincial Hospital for Nervous Diseases in 1904 (LeBlanc and St-Amand 2008:36).

The Restigouche Hospital Center was established in 1954 as a second psychiatric hospital to address the overcrowding at the Saint John facility. Restraints, insulin shock therapies, hydrotherapies, electro-convulsive therapies and lobotomies were used with residents at these facilities, which supports institutions as places to “cure and to control” (LeBlanc and St-Amand 2008:26) abnormal and deviant individuals (Thomas 2007), and is consistent with a biomedical interpretation of residents. The extreme overcrowding and dingy surroundings in the institutions contrasted with aims of curing or restoring individuals, and some residents tried to escape or commit suicide. Residents were under constant supervision in the asylums, supporting Michel Foucault’s (1995) argument of the ‘gaze’ as critical to institutional life (Hughes 2005, Krogh and Johnson 2006). Requests for expansions to deal with overcrowding were denied, although the Government enacted other legislation designed to bring even more people into these facilities (Francis 1975). Requests for funding to hire additional staff were also denied (Francis 1975, St-Amand 1988). The approach to social welfare that was in effect at the time the Temporary Asylum was established was intended to serve a social control function, by socializing residents and their families into what were seen as the accepted norms and values of society, characteristic of Parsonian thinking (Titmuss 1974).

In Chapter Five I point out that similar with the institutional era, residents are still tested to see if they will fit into the normative structure of care facilities, and in Chapter Six I argue that newer, smaller facilities are different from larger long-term care institutions in terms of physical appearance and care objectives. However, the emphasis on rules, meant to ensure a carefully controlled living environment for residents in one particular adult community residence, resonates with the focus on controlling residents, characteristic of the institutional era. Other similarities and differences between care, then and now, and between larger and smaller facilities are revealed through the first-hand accounts of managers (Chapter Seven), front-line workers (Chapter Eight) and a former resident of one of the large institutions now living in an adult community residence (Chapter Nine). Managers describe terrible living conditions in the institutions, the poor state of residents, and of families being discouraged from visiting loved ones. The significance of keys in institutional care is discussed in Chapter Eight, and additional descriptors of the dingy environments of institutions are provided.

Key Legislative and Policy Change 1960-1980

A number of key legislative and policy changes with implications for persons diagnosed with disabilities and mental illnesses in Canada and in New Brunswick, occurred between the 1960s and the 1980s. The *Canadian Human Rights Act* (1985), which recognizes persons with disabilities as having equal rights to other Canadians, came into effect, and the *Obstacles Report* (1981) was developed in response to the UN's initiation of the *International Year of the Disabled* and provided 130 recommendations for improving the lives of Canadians with disabilities. The *Canadian Charter of Rights and Freedoms* (1982) was also enacted during this time period and offers protection from discrimination for persons with disabilities. Challenges were also made to institutional care and the notion of madness itself, at this time. The inability of some participants in this research to find facilities for individuals diagnosed with significant disabilities and/or mental illnesses who required this type of care, contravenes the *Human Rights Act* (1976-77), as well as the *Charter of Rights and Freedoms* (1982), which I discuss in Chapter Five.

Deinstitutionalization in New Brunswick

In 1968, the Government of New Brunswick (GNB 1968) published a *Report* on mental health and introduced legislation to reform psychiatric care, which included possibilities for community care. This legislation went into effect in 1970. A policy shift during Richard Hatfield's stint as premier (1970-1987) led to investigations of alternative care approaches to the large institutions. By 1978, a concentrated focus on deinstitutionalization ensued (Goss 1998:105). The heavy cost of running the institutions in Saint John and Restigouche was also key in deciding for deinstitutionalization, highlighting the role of economic factors in this policy decision (Westhues 2006). Residents began transferring out of Centracare and the Restigouche

Hospital into adult community residences, special care homes, and nursing homes. As of March 2012, 18,744 adults were living in long-term care facilities throughout New Brunswick, 12,182 of them in nursing homes, and 6,562 in adult residential facilities.

Approximately 410 special care homes provided residential services for 5,600 residents requiring level 1 or level 2 care in 2012, and roughly 90 community residences and specialized care bed homes provided residential care to approximately 701 clients with level 3 or level 4 care needs (SD/DS 2011-2012). Centracare and the Hospital Centre in Restigouche were eventually turned into tertiary care sites (Goss 1998), and in 2007, the Government announced plans to replace this facility with a new 140-bed psychiatric hospital in Campbellton (GNB 2012a). Deinstitutionalization increased in the 80s and 90s, and in 2011 an additional adult community residence opened in Moncton to accommodate individuals transitioning out of the facility in Restigouche. Centracare was closed in 1998, relocated to a different area of Saint John, and renamed the South Bay facility with a mandate of tertiary care provision (GNB 2011a). In Chapter Seven I discuss the problems managers experienced with deinstitutionalization, including insufficient funding to implement the process, the fears that employees of large institutions had about the possibility of losing their jobs and that residents would be unable to adjust to life outside the institutions, the anxiety expressed by the public who feared having the formerly institutionalized as neighbours, and the concerns of parents about the possibility of having to take back caregiving responsibilities.

Key Legislative Changes in Treatment and Care Approaches

Legislations and official standards regarding the appropriate treatment of, and formal long-term care provision to persons diagnosed with disabilities and/or mental illness in New Brunswick, include the *Infirm Persons Act* (1973), the *Mental Health Act* (1994), the *Public Trustee Act* (2008), and more recently the *Standards and Procedures for Adult Residential Facilities* (SPARF 2009). Despite these official mandates and standards, there are occasions when those responsible for care delivery find it impossible to meet these criteria. Examples of the gaps between legislated requirements and care delivery include: the typical inability of residents to choose the facilities where they live, which I take up in Chapter Five, the inability to always ensure access to nutritional food, as noted in Chapter Six, and the difficulties finding employees with mandated training requirements (SPARF 2009) as discussed in Chapter Seven. In Chapter Eight I provide analyses of other gaps between legislated requirements and care delivery, which demonstrate the tension between protecting residents and ensuring their rights, which I also analyze in Chapter Eight. The limits placed on residents' autonomy because of limited funding and staffing are a focus of Chapter Nine, and economic policies that make it difficult to meet care requirements are discussed in Chapters Five, Six and Seven.

21st Century: Re-institutionalization

Richard and Smallwood (2011:12) point out that while 117 children and youth with complex needs cost the Government of New Brunswick over $16 million in 2008, they still contend that re-institutionalization is not a good idea. As noted in Chapter Five, one participant was disappointed that re-institutionalizing individuals was under consideration. Nevertheless, the Government is looking for ways to deal with those who engage in aggressive behaviours, to the point that they pose a danger to themselves and others, and to respond to the extensive costs of paying individuals to work one-on-one with difficult clients and funding spaces for individualized care. Both of these issues provide incentives for envisioning alternative ways of reacting to this issue in a fiscally responsible way. Two smaller long-term care institutions were being erected in the province at the time of data collection - one facility with thirty-four beds, and the other with eighteen beds. I discuss the issue of re-institutionalization in Chapter Five where two managers talked about the matter. One manager was frustrated at the possibility of re-institutionalization, while another manager argued re-institutionalizing certain individuals who are aggressive, to be an important policy solution.

CHAPTER TWO: LITERATURE REVIEW

What follows is an inductive thematic analysis of the literature on long-term care for adults diagnosed with severe disabilities and mental illnesses who are between nineteen and sixty-four years of age. The purpose of a thematic literature review is to reveal the main issues and areas within a body of literature about a given topic (Given 2008). In addition, the aim of this analysis is to identify gaps in the literature, which in turn inform the research questions I posed in this research. The major issues and areas that emerged in the literature which I review below include: factors that lead families to seek out-of-home placement for their loved ones, issues surrounding assessment processes, problems of limited placement options, and the post-placement experiences of parents and residents. Other issues and areas examined in this literature include those faced by front-line workers, difficulties residents of long-term care facilities experience, the health status of people diagnosed with disabilities, and the various social, emotional and cultural climates that exist in long-term care facilities. I conclude this literature review with a discussion of how my research questions address the gaps in the long-term care literature I have identified.

Issues Surrounding Out-of-Home Placement

There are a number of major areas and issues in the literature surrounding out-of-home placement. The first of these has to do with the various factors leading parents to conclude there is no other option but to seek out-of-home placement for their children. The second is related to the assessment processes, conducted on a needs-led basis and amidst fixed budgets, to determine if individuals require the type of care offered in long-term care facilities. Another issue raised in this area involves the classification of individuals according to level of care required and the inherent power in certain people being able to categorize others. Other issues to do with out-of-home placements include the lack of available housing options for placements and the post-placement difficulties for parents and residents.

According to the literature, there are a number of factors that lead families to eventually seek out-of-home placement for their loved ones (Black et al. 2010, Bourke-Taylor et al. 2011),[2] despite parents' desire to care for their children in their own home (McConkey et al. 2006, Power 2008).[3] The age (Black et al. 2010, McConkey et al. 2011),[4] size (Mirfin-Veitch et al. 2003, Werner et al. 2009), and behaviours (Grant and Ramcharan 2001, Hastings et al. 2006)[5] of their children lead parents to seek out-of-home placement. For the purposes of this research, behaviours refer to the aggression, physical violence, self-harm, destructive and disruptive behaviours displayed by individuals (Emerson and Bromley 1995, Emerson et al. 2001).[6] Chadwick et al. (2008) and McConkey et al. (2013) find a higher propensity for challenging behaviours among

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[2] See also Anderson et al. 2002, Blacher and Hanneman 1993, Blacher et al. 1992, Bromley and Blacher 1991, Chadwick et al. 2008, Cummins 2001, Essex et al. 1997, Fadden et al. 1987, Grant and Ramcharan 2001, Guberman et al. 2001, 2003, Hastings et al., 2006, Kobe et al. 1991, Lewis and Johnson 2005, Llewellyn et al. 1999, McConkey 2003, McConkey et al. 2008, 2010, 2013, McDermott et al. 1997, Mohide and Streiner 1993, Power 2008, Rousey et al. 1990, Singer and Irvin 1989, Stoneman and Berman 1993, Werner et al. 2009.

[3] See also Bromley and Blacher 1989, Llewellyn et al. 1999, Mirfin-Veitch et al. 2003.

[4] See also Blacher and Hanneman 1993, Mirfin-Veitch et al. 2003, Werner et al. 2009.

[5] See also Blacher et al. 1992, Black et al. 2010, Bromley and Blacher 1991, Essex et al. 1997, Hanneman and Blacher, 1998, Kobe et al. 1991, Llewellyn et al. 1999, McConkey et al. 2008, 2011, 2013, Rousey et al. 1990, Mirfin-Veitch et al. 2003.

[6] See also Breeze and Repper 1998, Lowe et al. 2007.

pre-pubescent children with autism, as well as among males, while Holden and Gitlesen (2006) note that behaviours intensify with severity of disability.[7]

Additional factors leading to out-of-home placement cited in the literature are out of parents' concerns for their other family members. Siblings experience a lack of attention, because of parents' focus on caring for the child with disabilities (Chadwick et al. 2013, Mirfin-Veitch et al 2003). Parents also have concerns for their other children's safety when aggressive behaviours are displayed (McConkey et al. 2006, Power 2008).[8] As a consequence, their other children are typically unable to have friends over (Mirfin-Veitch et al. 2003). For Llewellyn et al. (1999) and Werner et al. (2009), a lack of informal supports such as hands-on assistance with caregiving, or emotional support from relatives and friends, are factors (Essex et al. 1997), while McConkey et al. (2006, 2013) and Rillotta et al. (2012)[9] find inadequate formal supports to be the reason parents seek out-of-home placement. According to McConkey et al. (2010, 2011) and Staley (2008),[10] insufficient respite care resources and training opportunities for behaviour management do not exist (Beresford 2009). Guralnick et al. (2008) claim that, although access to professional advice and assistance in caregiving is shown to reduce stress for mothers, there is a general lack of knowledge about the formal support mechanisms that exist (Sardi et al. 2008, Summers et al. 2007).[11]

There are higher unmet needs among individuals with severe disabilities, according to Allen and Mor (1997). Unmet needs have been noted in school resources

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[7] See also Emerson et al. 2001, McClintock et al. 2003.

[8] See also Llewellyn et al. 1999.

[9] See also Black et al. 2010, Chadwick et al. 2013, Llewellyn et al. 1999, Shearn and Todd 1997, Werner et al. 2009.

[10] See also McNally et al. 1999, Werner et al. 2009.

[11] See also McConkey 2003.

(Forsythe et al. 2010), supports in their communities (McConkey et al. 2006), and general formal service systems provisions (McConkey et al. 2011), particularly as children reach adulthood (Mencap 2010). According to Essex et al. (1997), these constitute predictors to seeking out-of-home placement. The greater financial costs of caring for children with extensive care needs, such as the need to purchase specialized equipment (Fadden et al. 1987, Lewis and Johnson 2005), as Anderson et al. (2002) and Bourke-Taylor et al. (2011)[12] point out, are further exacerbated by the unemployment and underemployment of parents, particularly mothers, and the need for fathers to constantly adjust work schedules to meet care demands.

The literature also shows that mothers, who typically provide the greater bulk of caregiving (Norlin and Broberg 2013, Statistics Canada 2006, 2008),[13] face more restrictions to engaging in leisure activities and social relationships (Power 2008, Werner et al. 2009)[14] and have poorer health (Bourke-Taylor et al. 2011, Norlin and Broberg 2013).[15] According to Mirfin-Veitch et al (2003:103), parents' decisions to seek out-of-home placement for their children is a process rather than a 'spur-of-the-moment' response to a discreet event.[16] Blacher and Hanneman (1993:158) write that while issues such as sudden illnesses, the death of a family member (Grant et al. 2003), the cancellation of existing services, or introduction of sudden funding cuts function are "triggering events," the major factor leading to out-of-home placement is better understood as a "snowball effect." The "snowball effect" occurs when the daily burden

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[12] See also Werner et al., 2009.
[13] See also Guberman et al. 2003, Schofield et al. 1999.
[14] See also Dobson et al. 2001, Fadden et al. 1987, McConkey et al. 2008.
[15] See also Black et al. 2010, McConkey et al. 2008.
[16] See also Blacher and Hanneman 1993, Essex et al. 1997.

(Blacher and Hanneman 1993, Werner et al. 2009),[17] physical and emotional exhaustion (Green 2007),[18] and overall stress of extensive caregiving (Stoneman and Berman 1993, Werner et al. 2009)[19] accumulate over time, sometimes resulting in emotional exhaustion and depression for caregivers (Cummins 2001, Olsson and Hwang 2001).[20]

Assessment for adult residential care in New Brunswick falls under the jurisdiction of the Disability Support Program and the Long-Term Care Program. While the Long-Term Care Program also provides services for seniors in the province, the Disability Support Program is targeted at individuals between nineteen and sixty four years of age. The Disability Support Program promotes a person-centered approach to individuals, as part of their goal of providing individualized and flexible disability supports, both inside and outside residential care facilities. To be considered for long-term care placement, individuals must: live in New Brunswick, have a long-term disability, and have demonstrated unmet needs (GNB 2011b). Assessments take place in three ways: by gathering and applying information from the individual in need of services and/or their family and friends, with the assistance of individuals from the Department of Social Development, Department of Mental Health, or independent facilitators.

The same standardized assessment and uniform eligibility criteria, as well as classification for level of care required (1 - 4), are used for adults between nineteen and sixty-four years of age as well as for seniors (GNB 2008). Brotman (2002) and

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[17] See also McDermott et al. 1997.
[18] See also Shearn and Todd 1997, Werner et al. 2009.
[19] See also Bromley and Blacher 1991, Rousey et al. 1990, Singer and Irvin 1989.
[20] See also Lambrenos et al. 1996, Mohide and Streiner 1993.

Hackstaff et al. (2004)[21] explain that assessments should evaluate clients' functional capacities (physical, cognitive, mental), health statuses, social and physical environments, and whether various types of support (familial and/or financial) are available. According to Xenitidis et al. (2000), various assessment tools exist and include the Functional Independence Measure (FIM), the Assessment of Motor and Process Skills (ASM), the Assessment of Living Skills and Resources (ALSR) (Fricke 2013) and the Camberwell Assessment of Needs for Adults with Developmental and Intellectual Disabilities (CANDID).

In a publication of the Canadian Healthcare Association (2009), the Functional Autonomy Measurement Scale (SMAF) is used in Quebec, while the Resident Assessment Minimum Data Set 2.0 (RAI-MDS 2.0) is used in seven provinces and one territory. The Activities of Daily Living Assessment Tool (ADL) is the chosen standardized assessment instrument used in New Brunswick to determine long-term care needs. James (2008) explains that the ADL device is used to evaluate individual's functional mobility, coping ability, as well as capacity to do their own personal care and carry out instrumental tasks such as shopping, housekeeping, using the telephone, and managing money (Katz 1983). A medical certificate is also necessary for establishing placement needs, as are financial assessments, which are conducted on the individuals in need of placement and their immediate families (GNB 2008).

Research shows that there are a number of problems with the assessment process including the fact that assessment processes are highly subjective (Barnes 1998, Gillman

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[21] See also Aronson and Shiffman 1995, Lloyd and Taylor 1995.

et al. 2000, Valentine 2002). [22] For example, according to Human Resources Development Canada (HRDC) (2003), differing disability criteria are used for programs, and Oliver (1996) explains that the needs of persons can be difficult to define - an issue in needs-led assessments. Although assessments for services are conducted on a needs-led basis (Cameron 2006, Janlov et al. 2006),[23] Parry-Jones and Soulsby (2001) contend that attaining services is another matter, as client's choices are contingent on availability of supports.[24] Corazzini (2000) and Egan and Kadushin (1999) see this as a problem for case managers, whose responsibilities involve trying to meet clients' needs while being fiscally responsible. Others (Drinkwater 2005, Valentine 2002)[25] view assessments as power-laden, because medical and other professionals make determinations about both the level of care needed (Oliver 1996), and how individuals will be eventually classified (Gillman et al. 2000, Valentine 2002). Janlov et al. (2006) conclude that those conducting the assessments, rather than those being assessed possess greater control over the assessment process.[26]

For Richards (2000), the assessment tools themselves affect assessment procedures, such as when attention to the assessment tool distracts attention away from clients' needs and concerns. Corazzini-Gomez (2002) also notes that those being assessed can feel powerless in defining their specific needs.[27] Chernesky and Gutheil

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[22] See also Barnes 1998, Davis and Watson 2002, Drinkwater 2005, Goffman 1961, Griffiths 1988, HRDC 2003, Oliver 1996.

[23] See also Hardy et al. 1999, Lloyd and Taylor, 1995, Parry-Jones and Soulsby 2001.

[24] See also Cameron 2006, Hardy et al. 1999, Janlov et al. 2006.

[25] See also Gillman et al. 2000, Goffman 1961, Griffiths 1988, MacDonald et al. 1993, Oliver 1996.

[26] See also Corazzini 2000, Corazzini-Gomez 2002, Hardy et al 1999, Olaison and Cedersund 2006, Richards 2000, Wilcox and Taber 1990.

[27] See also Hardy et al. 1999, Richards 2000.

(2008) argue that this becomes problematic when client definitions about need differ from those of service providers. While Goffman (1961) observes that practices like record keeping effectively demarcate staff from residents, Drinkwater (2005) argues that keeping files and records on residents suits management purposes. At the same time he acknowledges the inherent power in such practices (Drinkwater 2005). According to Griffiths (1988:1), power is also entrenched in such official philosophical mandates as the dictate that residents live a life “as normal as possible” in smaller facilities while developing skills toward greater independence (MacDonald et al. 1993).

The literature reflects that ‘home’ is a subjective concept and one that is difficult to define. For instance, ‘home’ is theorized by Willcocks et al. (1987) as having metaphysical and psychological dimensions, by Sixsmith (1986) and Smith (1994) as a multi-faceted phenomenon comprised of personal, social, and physical features, and by O’Brien (1994) as a space where residents are able to exercise a measure of control. Further, Despres (1991) conceptualizes ‘home’ as a place where behavioural and physical boundaries identify residents, where psycho-social well-being is possible, and a subconscious expression of the self exists. For Collins (1993), smaller community residences can function much like ‘mini-institutions’ rather than homes, despite caregivers’ concerted attempts to create home-like environments. Atkinson (1998), Higgins (1989) and Goffman (1961) all conclude that the reality of home for residents in formal long-term care settings is questionable given that the needs of the group typically trump individual resident’s wishes.

Bach, cited in Priest (2012), and Mencap (2002), found that once parents decide to have their children placed out-of-home, housing is often unavailable to support this decision.[28] According to Bickenbach (2006) and Fakhoury and Priebe (2007),[29] there is a lack of housing options for individuals who require care which is an ongoing problem since the initiation of deinstitutionalization[30] despite repeated recommendations that it is a problem that needs addressing (Canadian Association of Community Living 2008, Mental Health Commission of Canada 2012a).[31] Others, such as Gallant (2012) and Prince (2009), point to housing as a basic right in keeping with the *Canadian Charter of Rights and Freedoms* 1982,[32] making it predominantly the responsibility of Government (Environics Research Group 2004).

Sandys (1982) and Wight-Felske (1982) note, however, that in the *Canada Health Act* (1985) housing for people with significant disabilities and/or disabilities is contingent on availability as well as the amount of funds the Government is willing to invest in this area. Another issue which further complicates the problem, according to McConkey et al (2011), is that certain individuals are offered placements over others based on the level of care they require and their ability to adjust to others living in a facility. Priest (2012) finds that waiting for a space in an adult residential facility in Canada can last for decades. He provides the example of one individual in Ontario who waited thirty-seven years before finally attaining a placement. Extended wait times and inadequate placement resources have been a problem in New Brunswick as well (Morrisey 2007).

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[28] See also Braddock 2002, Braddock and Hemp 2006, McConkey et al. 2011.

[29] See also the Mental Health Commission of Canada (2012a)

[30] See also Dear and Wolch 1987, Enns and Neufeldt 2003, Krupinski 1995, McColl et al. 2006, Read 2009, Rose 1979, Wharf and McKenzie 2004.

[31] See also Canadian Mental Health Association (2008).

[32] See also Lord and Hutchison 2007, Rioux and Samson 2006, Westhues 2006.

Issues Post-Placement

Research shows that once children are placed out-of-home, parents face a number of difficulties (Baker and Blacher 2002, Marshall Jr. et al. 2012).[33] According to Blacher (2001), most parents regard their decision for out-of-home placement advantageous for all concerned, including for those placed. For instance, Werner et al. (2009) point to parents' greater freedom to engage in social and leisure activities. Marshall Jr. et al. (2012) draw attention however, to the emotional costs associated with passing parental caregiving responsibilities over to others. According to Baker and Blacher (2002), parents experience negative feelings because of their perception that they have failed to fulfill their parental role, while Mirfin-Veitch et al. (2003) write about the persistent guilt parents feel about no longer being their children's care providers. Werner et al. (2009:37, 38) find that when worry over their children's well-being is added to this equation, parent's post-placement experiences are 'bittersweet.' According to Mirfin-Veitch et al. (2003:105), parents describe having their children placed out-of-home as the "most painful decision of their lives."

In research about the effects out-of-home placement of children with disabilities has on family well-being Baker and Blacher (2002:10) find the highest stress and caretaking burden in families where children under the age of fifteen have been placed out-of-home. However, these same parents experience less of a negative impact on their marital relationships compared to parents who placed their children when they were older than fifteen. The literature is inconclusive when it comes to the level of contact

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[33] See also Blacher 2001, Werner et al. 2009.

children receive from family members once placed out-of-home.[34] Seltzer et al. (2001) report that families usually maintain contact with loved ones irrespective of their age while Baker and Blacher (2002) contend that children receive more frequent visits compared to adults. Marshall and Baffour (2011) find this to be particularly true in the case of young adults in care. What is established in the literature is that residents of smaller adult community residences receive more frequent contact from family members (parents and/or siblings and other relatives) compared to when they lived in the larger institutions and this includes individuals with severe and profound disabilities (de Kock et al. 1988, Felce et al. 1980). In addition, individuals cared for initially by parents rather than having been institutionalized from birth experience substantially greater contact with all family members (de Kock 1988:137).

Issues that Affect the Provision and Receiving of Care

According to the literature, some of the issues that formal caregivers face include having to deal with the fall-out of the per diem funding mechanism, the funding shortages because of retrenchment, and shifting funding priorities. Other issues in the literature involve the extensive job responsibilities of these workers which they typically carry out in work environments characterized by high turnover rates, staff shortages, and occasional violent behaviours by residents. Research also shows that front-line workers usually possess little training for the work they do and are poorly compensated for their efforts. These issues, taken together, reportedly have the potential to lead to burnout among these employees. According to the literature, younger adults diagnosed with

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[34] See also de Kock et al. 1988, Felce et al. 1980.

significant disabilities and mental illnesses in long-term care facilities, face a number of difficulties as well. These individuals feel isolated, have difficulty establishing and maintaining meaningful relationships, have typically poor health statuses, and formal caregivers spend limited time engaging in activities with them. Canadians, who work in the developmental sector, experience a greater number of injuries than those in other areas of social services, according to the literature.

Baines (2004) finds that funding cuts, leaner service delivery, and the deskilling of employees, not only increase the danger and probability of violence for this sector, but also result in a Taylorized routinized form of labour (Dominelli and Hoogvelt 1996:56). Taylorized labour is typified by lowered training prerequisites and wages (Doninelli and Hoogvelt 1996:56). For Shaddock et al. (1998), the common challenges faced by front-line workers who work in facilities for adults with intellectual disabilities, that go beyond their extensive job responsibilities, are inadequate wages and benefits, staff turnover and shortages, lack of opportunities for advancement and, at times, aggressive behaviours by residents, all of which can lead to burnout (Mills and Rose 2011, Hewitt and Larson 2007).[35] According to Baines et al. (2002), supportive and positive relationships between staff and residents as well as among coworkers, not only facilitate best practices in long-term care settings but reduce the potential for burnout (Shaddock et al. 1998).

Work related stress in facilities for children and adults with intellectual disabilities also raises concerns about diminished quality of care and the potential for

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[35] See also Baines 2004, Braddock and Mitchell 1992, Cushing 2003, Lakin and Stanfille 2007, Steinhoffsmith 1999, and Ungerson 1999.

abuse of residents (MacDonald et al. 1993, Shaddock et al. 1998).[36] Mansell et al. (2008) write that staff members in community residences for persons with intellectual disabilities who possess enhanced professional training have views about caregiving tasks that align with existing policies and philosophies about caregiving, perceive the majority of their caregiving responsibilities as less difficult than those with lesser training, and have a greater tendency to interpret resident's challenging behaviour as a response to inadequate stimulation. Two additional challenges for front-line workers, according to Levinson (2010), are the dismissal of their first-hand knowledge of residents and their need to constantly engage in risk management, by discerning the right balance between ensuring residents' autonomy and potential risks. At the same time, Levinson (2010) reports that staff members' tacit knowledge or know-how about group home work, not contained in written care mandates and philosophies about care, translates into the ability to exercise a great deal of autonomy in their work.

According to the literature, residents of long-term care facilities with intellectual disabilities also face a number of issues (Cushing 2003, Mansell et al. 2008).[37] For example, some report that residents feel isolated, and they experience little meaningful activity with staff members, who typically provide well under six minutes per hour assisting residents in this way, and less than one minute per hour when it comes to residents with the most severe disabilities (Jones et al. 1999, 2001, Mansell et al. 2008).[38] At the same time, staff care practices with such individuals are the strongest

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[36] See also Rusch et al. 1986.

[37] See also Baines 2004, Emerson et al. 1999, Felce and Perry 1995, Felce et al. 2002, Hatton et al. 1995, Jones et al. 1999.

[38] See also Emerson and Hatton 1996, Emerson et al. 1999, Felce et al. 2002, Felce and Perry 1995, Hatton et al. 1995.

determinant for meaningful activity engagement (Felce et al. 2000a, 2000b, 2002, Mansell et al. 2008).[39]

Reid et al. (1989) cite the following as factors that positively affect the amount of time staff members spend assisting residents with meaningful activities: clear job expectations, and professionally trained employees who possess both knowledge and experience, who are better supervised, and experience support, training, and clear guidance from management. Hundert et al. (2003) also find that staff members pay more attention to residents with intellectual disabilities if they display problem behaviours. Funding cuts that result in lowered staff-to-resident ratios and increased time pressures for staff, are associated with little time available for the relational aspects of care (Baines 2004, Cushing 2003).

The literature shows that younger adults who are diagnosed with significant disabilities and mental illnesses and live in long-term care facilities value their relationships with caregiving staff. However, social interactions between staff members and residents are typically scarce, short-lived, and predominantly instructional in nature (Markova and Jahoda 1992, Schepsi and Reid 1994).[40] Thomas (2007) and Yates (2005) highlight the asymmetrical nature of relationships in long-term care settings,[41] which for Higgins (1989) and McConkey et al. (1999) explain why nurturing and caring relationships between staff members and residents are difficult to maintain and interchanges as equals are impossible.

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[39] See also Felce et al. 1986, Felce and Perry 1995, Hatton et al. 1995, Jones et al. 1999, 2001.

[40] See also Hile and Walbran 1991.

[41] See also Allan 1985, Devlin and Pothier 2006, Drinkwater 2005, Foucault 1977, Higgins 1989, Hughes and Paterson 1997, Tremain 2005.

Marshall and Baffour (2011) report that a lack of regular contact between family members/friends and young adults in long-term care facilities is problematic for, as Allen and Ciambrone (2003) explain, residents then look to front-line staff for instrumental and emotional support. Further, Drinkwater (2005:239) points out that friendship between formal caregivers and persons with disabilities are seen as transgressing boundaries. In those cases where relationships do exist between front-line workers and residents, interactions are characterized as reciprocal because of the mutual affirmative interactions that take place (Pottie and Sumarah 2004) and the everyday give-and-take nature of these relationships (Levinson 2010).

According to the literature, social relationships for people with intellectual disabilities are scarce (Cushing 2003, Lunsky 2002)[42] and few meaningful relationships exist between residents and individuals outside the facilities where they live (Felce et al. 1999, Stalker 1998).[43] The likelihood of such relationships for adults with severe intellectual disabilities is even smaller, according to Johnson et al. (2012) and Kennedy (2001),[44] particularly if these individuals have communication problems (McLean et al. 1996). According to Robertson et al. (2007), neighbours of long-term care community residences seldom know residents by name, or have much contact with these individuals, and particularly among those who display challenging behaviours and have severe intellectual disabilities.

While the literature reflects that friendships often develop between volunteers and residents, especially in situations where volunteers regularly accompany residents to

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[42] See also Brown et al. 1997, Lutfiya 1993.

[43] See also Emerson and Hatton 1996, Northway 1997.

[44] See also Kennedy et al. 1990, Krauss and Erickson 1988, Krauss et al. 1992, Robertson et al. 2001.

sports and leisure outings (de Kock et al. 1988, Kittay 1999), such relationships are disadvantaged, argue O'Brien and O'Brien (1993), because of their difficulty to preserve. It is also reported that people with intellectual disabilities have a greater desire for friendships among those with whom they share common interests and experiences (Cummins and Lau 2003, Gregory et al. 2001),[45] opting to socialize more with each other, according to Johnson et al. (2012),[46] rather than with visitors or staff members, despite the occasional violent behaviors of their fellow residents (Baines 2004).

Gregory et al (2001) find that greater accessibility for younger individuals diagnosed with intellectual disabilities in residential care to structured day-activities, such as day centres, is positively associated with friendships and relationships. Activity centers are located in various areas throughout New Brunswick and function as places where residents of adult community residence facilities, as well as others, can freely engage in meaningful activities, at locations other than the facilities. Residents of adult community residences tend to take advantage of such amenities more often than when they lived in the larger institutions, according to de Kock et al. (1988). According to GNB (2011b), activity centers provide individuals with mental illness "social, vocational, recreational, and advocacy activities," while developing greater independence, and less reliance on formal services. Specific tactics to make individuals more independent include education, providing peer support, and facilitating "mutual self-help" (GNB 2011b). In addition, 1,776 individuals participated in 26 different activity centers in 2009-2010, and of those under 65, approximately 1,100 individuals participated in the day programs offered by thirty-nine Adult Developmental Activities,

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[45] See also Emerson and Pretty 1987, Higgins 1989.

[46] See also Landesman-Dwyer et al. 1979.

Programs and Training (ADAPT) agencies in the province (GNB 2011b). Other than formal programs, the two most commonly reported sites of activity outside of the facilities where residents live are restaurants and cafes (de Kock et al. 1988).

According to the literature, there are concerns about the health of adults with intellectual disabilities in general (Beange and Bauman 1990, Lennox et al. 2001).[47] Visual impairment among these individuals is very high, at least in the adult population (Warburg 2001:434), and osteoporosis, pneumonia, sensory impairments, epilepsy, dental disease and gastrointestinal disorders are also more prevalent (Backer et al. 2009, Jansen et al. 2004).[48] Despite the fact that these individuals experience twice as many health problems (van Schrojenstein et al. 2000) and their health needs are typically greater than the rest of the population, Iacono and Davis (2003) and Scheepers et al. (2005)[49] report that their health needs gain less attention, they encounter unequal health care services, and are less understood than those of children. Others describe shorter life expectancies (Backer et al. 2009) and excessive mortality rates (van Schrojenstein et al. 2000) among these individuals.

The literature shows that the communication problems of some individuals with disabilities make it difficult for them to talk about their health concerns (Powrie 2003, van Schrojenstein et al. 2000), which points to the important insights possible from support workers, informal carers, and health personnel knowledgeable about this population (Backer et al. 2009, Powrie 2003), and the need for standardized pain assessment measures and intuition in clinical decision making for people with profound

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[47] See also Minihan and Dean 1990, van Schrojenstein et al. 2000, Whittaker and McIntosh 2000.

[48] See also Barr et al. 1999, Center et al. 1998, Cooke 1997.

[49] See also Backer et al. 2009, Beange and Bauman 1990, Sutherland et al. 2002.

and multiple disabilities (Davies and Evans 2001:516). For Powrie (2003), it also speaks to the importance of training mechanisms to enhance the quality of communication between adults with profound disabilities whose health needs are often overlooked (Lennox et al. 2001, Whittaker and McIntosh 2000)[50] and their formal caretakers (Dobson et al. 2002, Lacey 1998). Warburg (2001:435) argues that it is unethical that easily diagnosed and treatable conditions are left untreated in this day and age.

The Social, Emotional, and Cultural Climates of Long-Term Care

It is Moos et al.'s (1979:75) contention that the environments of sheltered care settings, or long-term care facilities, have distinctive 'personalities,' and a sense of the social climates of these settings can be gained by paying attention to the particular features of these institutions. Specific features to note, for Moos et al. (1979), are the organizational aspects, level of physical comfort, opportunities for residents to experience personal growth and influence care provision, and the nature of relationships within the facilities, which tend to be either predominantly cohesive or conflictual. The ability to make changes or adjust the operation of long-term care facilities is related to the 'explicitness' of rules, the importance of "order and regularity," and residents' awareness of daily routines (Moos et al. 1979:77). Opportunities for personal growth are commensurate with residents' freedom to come and go, the degree to which residents are encouraged to be self-sufficient in their personal affairs, and the level of responsibility and self-direction residents are encouraged to exercise (Moos et al. 1979:77). de Rivera (1992:197) argues that it is possible to capture the emotional

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[50] See also Minihan and Dean 1990, Powrie 2003.

atmospheres of certain settings (like long-term care facilities) because of the palpable "group phenomenon" that exists. This allows the use of descriptors like joy, freedom, sadness, tension, or fear, to discuss the 'climate' of such settings.

According to Foucault and Geertz it is also possible to detect a sense of the cultural atmospheres in long-term care facilities. Foucault (2001:173, 238) defines culture as an established set of 'values' and argues that examining the routine "techniques and procedures" used in settings, techniques which are driven by a particular "field of knowledge (savoir)," allows one to ascertain something about the culture of that place. Examining philosophical care mandates makes it possible to discern what Foucault considers the core 'logic' (Sewell 1999:44) informing the daily operation of long-term care facilities, including the approaches taken with residents. Geertz (1973:5) conceptualizes culture as "webs of significance" that are based on shared meaning. These 'webs' require "thick description" to explain how it is possible that their 'co-presence' creates certain situations (Geertz 1973:14). For Geertz (1973:19), it is not so much what is said in certain settings that is important, but the "meaning of the speech event," and the contextualization of that 'event' in a way that facilitates its analysis.

Gaps in the Literature

Several gaps in the literature on long-term care for people with severe disabilities and mental illnesses in New Brunswick were revealed in this review. For instance, there is no information on how official care philosophies and legislation are experienced at ground level in long-term care facilities in New Brunswick. In addition, research on factors leading New Brunswick families to eventually seek out-of-home placement for their children is missing. There is also little information about issues with the assessment processes and/or lack of placement options in New Brunswick. Another gap in the literature is how managers and front-line workers of adult community residence agencies in the province define their experiences with care delivery and hands-on-care. Similarly, there is nothing in the literature about how residents of adult community residences or young adults in nursing homes experience living in a long-term care facility in New Brunswick. Moreover, there is no study to date in New Brunswick that contains residents' actual accounts or those of government administrators of long term care in the province.

These gaps in the literature shaped my research questions: "What are the experiences of residents, family members, front line workers, and administrators in the social world of long-term care in New Brunswick for adults with significant cognitive and/or physical disabilities and mental illnesses?" and "What are the inter-relationships between individuals in these different positions in long-term care?" Addressing these research questions allowed me to examine historic and current long-term care policies and legislation pertinent to New Brunswick, analyze official and non-official care philosophies, and spend considerable time in the facilities collecting data, which allowed analysis of formal long-term care for adults between nineteen and sixty-four in New Brunswick. Second, in pointing out the specific consistencies and inconsistencies between philosophical objectives and care delivery, I was able to address issues not documented in the literature.

Third, collecting data from parents as well as individuals providing formal care delivery means I was able to uncover the specific factors leading families in New Brunswick to seek out-of-home placement for their children, and highlight the particular issues with assessment processes, and placement opportunities, in the province. Fourth, managers and front-line workers in long-term care facilities throughout New Brunswick were able to relate their experiences with delivering care, so I was able to draw attention to the predominant issues these individuals face in the course of their work. Fifth, residents of adult community residences, and young adults in nursing homes, were able to talk about their experiences as well, which is, to the best of my knowledge, the first research about long-term care in New Brunswick which actually includes the perspectives of the people living in long-term care facilities. For all of these reasons, this research addresses gaps in our understanding of long term care in the province of New Brunswick.

CHAPTER THREE: THEORY

A critical theoretical approach is a useful analytic framework to interpret my research questions: “What are the experiences of residents, family members, front line workers, and administrators in the social world of long-term care in New Brunswick for adults with significant cognitive and/or physical disabilities and mental illnesses?” and “What are the inter-relationships between individuals in these different positions in long-term care?” It is useful because, with a critical perspective, the researcher pays attention to the context, power, and discourses surrounding long-term care, and disability itself. A key ontological assumption of critical theory is that context matters. Foucault also held it to be impossible to understand an issue without noting the historical context that gave rise to the problem in the first place (Tremain 2002:33). This stance supports the argument that phenomena should not be investigated in isolation (Connerton 1976:12), without first accounting for the historical context of that phenomena (Guba and Lincoln 2005:114) or the “social totality” (Ritzer and Goodman 2004:276) of the matter.

As a historical realist approach (Guba and Lincoln 1994:110), critical theory is useful for contextualizing institutionalized long-term care for people diagnosed with disabilities and the concept of disability itself, in their specific historical, social, and ideological settings (Devlin and Pothier 2006), in this case, New Brunswick. It is also valuable for revealing how ideologies and discourses shape long-term care policies for residents, as well as care delivery practices. Critical theory’s attention to context is also important for offering insight into Rioux and Valentine’s (2006:47, 48) contention that people diagnosed with disabilities, are still fundamentally unequal to other citizens, and fail to enjoy similar "citizenship rights."

The incorporation of a critical lens also allows me to see how systemic issues oppress people with disabilities and create barriers for them (Rioux and Valentine 2006:47, 48). A critical theoretical approach is consistent with a Foucauldian analysis as well, in that notions about madness (Foucault 1965, 1988) and knowledge deemed as legitimate (1989) are interpreted in light of the political, social, and economic contexts in which they arise. By taking into account the contextual factors of participants' experiences, I am able to acknowledge how these factors shape the way participants interpret their experiences. Foucauldian theory is also useful in framing my analysis because this perspective aligns well with critical theory (Morrow and Brown 1994:17) and addresses the role of medical discourse in constructing disease and illness (Foucault 1977, Thomas 2007: 35).

Issues of Power, Bio-power, and Knowledge/Power Analyses

Critical theory is valuable for drawing attention to the implications of neo-liberalist discourse currently prevalent in Canada (Prince 2012, Rice and Prince 2012).[51] Neo-liberalism emphasizes efficiency, market values, and leaner Government, in the belief that government intervention and social programs hinder personal freedom and initiative and, therefore, creates dependent individuals (Prince 2012, Schaeffer and Smith 2005). Policy imperatives of neo-liberalism include retrenchment (McGilly 1998), which involves more regulation (Guest 1997) and surveillance (Puttee 2002), less

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[51] See also Baker and Scott 1997, Orsini and Smith 2007, Touraine 2001.

eligibility for programs (Rioux and Prince 2002), conditional and limited housing options (Wight-Felske 1982, Sandys 1982) and the offloading of program costs and burdens (Rice and Prince 2001).

A neo-liberalist paradigm results in “welfare pluralism,” which refers to less Government and greater personal responsibility (Graham et al. 2003, Wharf and MacKenzie 2004), stronger reliance on voluntarism, non-governmental organizations (Pedlar and Hutchinson 2000) and increasing involvement of the private sector (Guest 1997) which for Pedlar and Hutchinson (2000:638) results in the commodification of disability. Although the result is greater opportunities for innovation and collaboration (Evers and Svetlik 1993), commodification occurs when “monetary value” becomes the focus of providing supports to these persons with disabilities (Pedlar and Hutchinson 2000:638). The consequence is that persons with severe disabilities and mental illnesses are then at a distinct disadvantage, because their need for more intensive care can potentially compromise profit margins (Pedlar and Hutchinson 2000:650).

Critical theory assumes that society is marked by power imbalances, that issues of ‘power (lessness)’ exist (Devlin and Pothier 2006:9), and that some groups of people have more ‘privileges’ than others (Kincheloe and McLaren 2005:304), all of which characterizes the relationships between people in government, health, and social service sectors, and persons diagnosed with disabilities (Davis 2000). Critical theory is a useful paradigm for investigating the power imbalances of these relationships and the historical-structural explanations behind these discrepancies (Kincheloe and McLaren 2005, Ulichny 1997). For example, the power to decide service availability is facilitated by statistical data, which is an important consideration in both critical (Carlson 2005) and Foucauldian (1976) analyses.

For Drinkwater (2005:241), a critical lens helps to reveal and problematize the entrenched power relations between those providing and receiving services, which is consistent with Foucault's (1978, 1979, 1988) analyses of power relations in institutions. The issue of domination resonates with critical theorists (Morrow and Brown 1994:10) and makes language of particular interest, as language can make it possible for some individuals to regulate and dominate others (Kincheloe and McLaren 2005:310), therefore, making language an important point of analysis (Corker and Shakespeare 2002). Language and discourse also change meaning in particular contexts (Kincheloe and McLaren 2005), and are "deeply partial" (Devlin and Pothier 2006:7). Foucault's ideas about language and discourse are particularly valuable to this research with respect to disability and mental illness, as are his notions about bio-power, governance, the power of 'experts' to assess, classify, label, rehabilitate, conduct surveillance on, administrate, and apply disciplinary practices on individuals.

According to Foucault (1978a), bio-power is a form of power that arose out of the eighteenth century when human beings were reconceived as a biological species and reinforced when humans were constituted in dichotomous terms (as either normal or abnormal) through statistical means. This paradigm shift occurred because of the ascendance of professionals, whose claim to scientific knowledge had gained legitimacy, as did the implementation of administrative practices over particular populations. Foucault (1979:27) explains that in bio-power, knowledge and power are inseparable because, once a certain "field of knowledge" is legitimized, it necessarily assumes power relations.

Foucault's (1976) ideas about discourse and power are pertinent for analyzing how discourses about the institutionalized are implicated in the purpose of institutions and in the appropriate responses to be taken with residents. Therefore, Foucault's (1979) bio-power is critical to understanding the experiences of people diagnosed with disabilities and mental illness, as well as long-term care provision. Bio-power is also valuable for comprehending how statistics make it possible to generalize about, and manage individuals (Foucault 1976), and how prenatal diagnoses, assessments (Krogh and Johnson 2006, Tremain 2005), and various normalizing technologies (Price and Shildrick 2002, Tremain 2002), such as rehabilitation (Sullivan 2005), and other interventions (Fairclough 1989, Yates 2005), become legitimized.

Chadwick (1996:38, 39) explains that in power/knowledge analyses, the goal is to explore the 'structures' that make it possible for some individuals to govern the conduct of others. Knowledge/power allows certain individuals - experts - to carry out a number of tasks, that include attaching particular names or labels to individuals (Swain et al. 2003, Thomas 2007).[52] That is, they have "definitional power" to categorize and classify people (Valentine 2002:215). Complications arise, however, when multiple experts – medical, educational, and psychological – have differing approaches to labeling persons with disabilities (Valentine 2002). In addition, assessments do not account for the various coping mechanisms individuals develop or the "social, political and environmental" aspects of disability (Krogh and Johnson 2006:164). The power to

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[52] See also Zola 1993.

make such decisions has implications for the termination of pregnancies where fetal disabilities are diagnosed (Carlson 2005, Hughes 2005).[53]

For persons with disabilities and mental illnesses who require formal long-term care, individuals such as physicians and social workers serve as experts, categorizing and conducting assessments to determine long-term care needs (Thomas 2007). It is well established that bio-power affords certain individuals a lot of power over people's lives (Yates 2005:68), for these experts determine how to think about people, how to treat them, how to manage them and, according to Oliver (1996:36), the type of supports they will receive. Physicians are conceived as 'experts' (Oliver 1996:36), and a "profession of knowers" (Scully 2002:57) because of the power they exercise over people's lives. For Krogh and Johnson (2006:159), physicians have the most power, not just in their ability to make determinations about access to services, but also because of their capacity to influence funding priorities.

In order to attain services, people diagnosed with disabilities are expected to forego their privacy and expect 'interference' (Krogh and Johnson 2006:152).[54] Foucault (1991) acknowledges that power relations are necessary for society to function, which makes his ideas germane to problematizing the lop-sidedness of relationships between formal caregivers and care recipients (Thomas 2007, Yates 2005). Foucault (1991:18) does not view such power relations as 'bad,' but given their existence, the emphasis should be on trying to even the playing the field or affecting a 'reversal' (Foucault 1991:12), at least to some degree. It is in this way that Foucault (1991) has relevance for individual actors. The exercise of power over individuals is taking place

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[53] See also Oliver 1996.
[54] See also Orme 2001.

whenever possibilities for conduct are accomplished through the application of disciplinary techniques and practices (Sullivan 2005). Discipline, explains Foucault (1977:215), is where power is similar to a 'technology,' and entails the implementation of an entire range of tools, methods, and practices, which reinforce each other, and accomplish certain purposes with individuals.

According to Carlson (2005:137), the creation of institutions for people diagnosed with disabilities as well as others, facilitated the legitimation of a field of experts and a new field of knowledge about "idiocy and feeblemindedness." These institutions constituted spaces to supervise the institutionalized, while protecting society from them, writes Carlson (2005:140,141), who compared these facilities to prisons. Prisons, for Foucault (1977:227), are settings where individuals became "useful object(s)" for the application of disciplinary techniques. Deinstitutionalization did not alleviate the situation for residents, in Drinkwater's (2005:232) opinion, but merely constituted a change of locale for the exercise of bio-power. Drinkwater (2005) views "perpetual visibility" and other disciplinary techniques as methods for making residents of long-term care facilities 'docile' (Tremain 2005:19). The continuous visibility of individuals in such institutions is accomplished through, what Foucault (1995) conceived of as, the 'gaze' (Hughes 2005, Krogh and Johnson 2006). The "administrative gaze," for Krogh and Johnson (2006:152), abstracts, measures, classifies and diminishes persons diagnosed with disabilities and mental illnesses to 'impairments,' which renders "worthy or unworthy" individuals.

This gaze finds expression in long-term care facilities in various ways, like maintaining records on residents (Drinkwater 2005, Wilson and Beresford 2002), and using time-out rooms (Malacrida 2005). Although surveillance techniques, combined with other disciplinary mechanisms, degrade and dehumanize residents (Malacrida 2005, Goffman 1961), they reach their optimum effectiveness when residents interiorize them and subsequently engage in self-discipline (Foucault 1980, Price and Shildrick 2002).[55] Family members of residents also face disciplinary techniques, albeit more subtle, which effectively reduce service complaints because of constant fears about the closure of facilities, funding cuts (Oliver 1996:67) and the potential loss of services (Krogh and Johnson 2006).

Foucault and the Body

The human body is crucial to a Foucauldian analysis (Hughes 2005, Hughes and Paterson 1997) and to this research in light of the classification, labeling, assessing and other disciplinary techniques people diagnosed with disabilities and mental illnesses undergo. It is necessary that I account for the objectification (Foucault 1977, 1978b, 1982, Sullivan 2005),[56] administration (Drinkwater 2005, Hughes 2005)[57] and subjectification (Allen 2005, Foucault 1979, 1982)[58] that residents of long-term care facilities endure. Subjectification occurs through the ongoing governance of individual's behaviours, gestures, and bodies (Foucault 1978b:97). Such processes eventually render individuals docile (Carlson 2005, Foucault 1977, Sullivan 2005) and determine their

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[55] See also Sullivan 2005, Thomas 2007.

[56] See also Tremain 2002.

[57] See also Chadwick 1996, Davis 1993, Finkelstein 1980.

[58] See also Drinkwater 2005, Thomas 2007, Tremain 2005, Yates 2005.

"possibilities of conduct" (Tremain 2002:36, Tremain 2005), possibilities which are accomplished through monitoring behaviours (Thomas 2007).

A Foucauldian (1980a:131) historical-critical analysis is also pertinent for examining those "regimes of truth" which make categorization, subjectification, and objectification possible (Allen 2005, Carlson 2005)[59] in the first place. Foucault (1980a:131) argues that in every culture and society, there are certain discourses that gain acceptance and come to constitute a certain 'truth' about the matter. Other theoretical concerns that I discuss below which became relevant to my analysis include various discourses of disability such as dependence, impairment and abnormality, conceptualizations of disability found in the worthy poor, biomedical, social, critical, and biopsychosocial models of disability, theorizations about the emergence of self and self-identity, Weber's (1925/1977) ideal type of bureaucracy, Goffman's understanding of total institutions, and the concept of reverse integration.

Discourses and Conceptualizations of Disability

A dominant discourse of disability and more particularly, severe disabilities, is that of dependency (Thomas 2007, Krogh and Johnson 2006).[60] In social policies and government guidelines, disability discourses involve discourses of efficiency (Chadwick 1996), which raises the potential of a lower quality of care at less cost (Krogh and Johnson 2006:159).[61] Medical and individual disability model discourses are also well established in the welfare state (Chadwick 1996) and impairment is the result of welfare

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[59] See also Corker and Shakespeare 2002, Drinkwater 2005, Tremain 2002.

[60] See also Dalley 1991, Illsley 1981, Michalko 2002, Stone 2003.

[61] See also Browne 2000, Burke 2000.

and medical discourses (Hughes 2005:82). These discourses constitute individuals as abnormal (Thomas 2007, Waldschmidt 2005),[62] which is a problem, according to Foucault, because determinations about abnormality and deviancy lead to prevention and treatment efforts and attempts to correct disability and mental illness (Thomas 2007:37).

Discourses of abnormality are also a problem because a functional perspective of disability informed by biomedical discourse is predominant in New Brunswick (HRDC 2003), which legitimizes efforts to normalize individuals. Normalization theory, as conceived by Nirje (1969, 1993), is about bringing individuals considered abnormal into as normal a state as possible. This process involves specific efforts to assist individuals to gradually incorporate acceptable ways of conducting themselves, to adopt particular patterns of living, and to adapt to their respective communities with the intent of bringing them into as close an alignment as possible to others considered normal (Nirje 1969, 1993).

Programs developed out of normalization theory show how discourses about persons diagnosed with disability become established in government documents and eventually find expression in the field. Wolfensberger (1995) developed social role valorization (SRV) by building on normalization theory (Mann and van Kraayenoord 2011). The idea behind SRV is that by participating in valued social roles, people diagnosed with disabilities can access “the good things in life” (Thomas and Wolfensberger 1999:197). Other discourses surrounding people diagnosed with severe disabilities include a perception of these individuals as worthy poor, that they should be

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[62] See also Canguilhem 1974.

segregated, institutionalized, deinstitutionalized, integrated, included, and their human and citizenship rights ensured.

Integration is about finding ways for people diagnosed with disabilities to fit into society - at least as much as possible. This policy has been criticized by some, however, for assuming these individuals want to be integrated (Northway 1997, Smith and Brown 1992). Inclusion is about accepting and acknowledging that people are different (Mann and van Kraayenoord 2011:205) but also asks people diagnosed with disabilities to adjust. Further, Campbell (2005:113) argues that inclusion only succeeds when these individuals can be ‘assimilated (normalized).’ Campbell (2005:113) wonders what should happen to those individuals (Hindness 2000:11) who are unable to respond to normalization efforts. This matter, of ‘governing’ (Campbell 2005:113) those unable to be assimilated, resonates well with Foucault’s ideas about bio-power.

Cognitive disabilities and mental illnesses are not the same thing. There are multiple forms of mental illness affecting individuals from all cultures, educational backgrounds, socioeconomic statuses, and ages (Canadian Mental Health Association website), which cause serious disturbances in thinking, moods or behaviours, and make it difficult for individuals to cope with everyday life. Conceptualizing cognitive disability is more difficult, because of the many different models in the literature on disability and long-term care (HRDC 2003:6). For instance, the worthy poor, biomedical, social and critical disability theory models of disability, are all part of this literature, which I discuss below. A worthy poor notion of disability views persons diagnosed with disabilities as objects of charity, requiring rehabilitation, protection, segregation, institutionalization, and when reinforced by a biomedical view, necessitates their evaluation and categorization based on functional limitations (Dunn 2006, Rioux and Samson 2006).[63]

A biomedical perception of disability views disability as a deviation from the norm, and a tragedy, which makes it impossible for individuals to experience 'good' lives (Michalko 2002, Prince 2004).[64] Medical and welfare discourses both assume abnormal individuals (Thomas 2007, Waldschmidt 2005).[65] A biomedical paradigm provides the rationale for, either trying to control disability through preventive efforts or, normalizing the tragically afflicted through rehabilitative attempts (Malacrida 2005, Scully 2002).[66] For McColl et al. (2006:27), the problem with a biomedical perspective is that it reinforces the biomedical culture surrounding disability, assumes a "sick role" for people diagnosed with disabilities, and necessarily constitutes them as a "segregated minority group." A biomedical perspective also disallows the heterogeneity of disability (McColl et al. 2006).

A biomedical interpretation of disability does, however, acknowledge impairment, as noted in the International Classification of Diseases (ICD), which frames disability as impairment (HRDC 2003). According to HRDC (2003), the focus of most Canadian disability programs and benefits is medically certified impairments. For instance, the Canada Pension Plan disability program and Disability Tax Credit, require information regarding functional limitations (HRDC 2003). Attention to functional limitations is consistent with a biomedical interpretation (Oliver 1996), and depicts

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[63] See also Bach and Rioux 1996, Rioux 1993, Rioux and Prince 2002.
[64] See also Davis 1995, Kleinman and Kleinman 1997, Linton 1998, Oliver 1996, Thomson 1997.
[65] See also Canguilhem 1974.
[66] See also Oliver 1996, Park and Radford 1998.

disability along ‘quantitative’ lines, where functional capacities are measured “against a standard” (HRDC 2003:7). The two main criticisms of the biomedical model, according to HRDC (2003:6), are that it does not account for social and environmental factors which can be disabling, and it makes it possible to characterize some individuals as inferior and abnormal.

Social science approaches conceptualize disability as a socially created phenomenon informed by historical and cultural contexts (Michalko 2002, Oliver 1983).[67] The fundamental principle setting the social model apart from the biomedical understanding of disability is the distinction drawn between impairment and disability. The social model does not deny the ‘biological’ reality of disability but reinterprets it as impairment arising out of external factors (Michalko 2002:53). Michalko (2002:53) explains that according to the social model, individuals are not disabled by their biological makeup, but by society in the imposition of labels. Inequitable social arrangements are also a problem for people diagnosed with disabilities within a social model perspective.

The way buildings are designed and infrastructure developed makes such areas as work spaces and public transportation inaccessible for persons with disabilities (Silvers et al. 1998). Kirby (2004:232) concludes that society is dominantly organized for people whose “primary mobility” does not entail a wheelchair. Therefore, appropriate responses from a social model interpretation of disability involve concerted efforts to remove physical and societal barriers (Jongbloed 2003).[68] The main criticism of the social model is that it does not account for the limitations imposed by severe

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[67] See also Ingstad and Whyte 1995, Scheer and Groce 1988.

[68] See also Ells 2001, Silvers et al. 1998.

bodily impairment. Numerous theorists argue that the body must be taken into account for both impairment and disability are important to disability research.

One rationale for acknowledging impairment is that it allows investigating the impact of discourse on the management and governance of the bodies of people diagnosed with disabilities (Bury 2000, Frazee et al. 2006).[69] Another rationale, besides the fact that acknowledging the body draws attention to the realities and lived experiences of impaired bodies (Bury 2000, Turner 2001),[70] is that it facilitates examining how particular societies validate certain bodies and their usage (Shilling 1993:145). The argument that the body needs accounting for is further reinforced by the reality that were it possible to remove every existing physical and social barrier, the reality of the chronically impaired body remains (Morris 1991, 1996, Pindar 1996).

Like the social model, critical disability theory acknowledges individual's impairments and disability as the consequence of oppressive laws, language, and social disadvantage (Hosking 2008). In addition, the voices of disabled people are privileged in a critical disability theory stance and the goal is to transform society (Devlin and Pothier 2006, Rioux and Valentine 2006).[71] Where critical disability theory differs from the social model is in acknowledging that the fight for equality for disabled persons sometimes demands attention to the differences that exist among these individuals (Hosking 2008), for the social model does not account for the physical and cognitive limitations of severe disability. After assessing these models, I conclude that the

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[69] See also Frank 1998, Hughes 2005, Hughes and Paterson 1997, Meekosha 2000, Paterson and Hughes 1999, Price and Shildrick 2002, Thomas 1999, Tremain 2005, Turner 1996, 2001.

[70] See also Crow 1992, 1996, French 1993, Williams 1999.

[71] See also Barnes and Mercer 1997, Clear 1999, Vernon 1997.

biopsychosocial model of disability is the best model for this research, for it represents a synthesis of the biomedical and social model (Bickenbach et al. 1999) and offers a more comprehensive view of disability not captured by the social and critical disability models, for these models do not adequately account for the bodily experience of physical impairment.

Another reason I find the biopsychosocial model of disability more useful is because, although the biomedical model is consistent with predominant discourses in New Brunswick’s long-term care policies (HRDC 2003), acknowledges the physical, cognitive, functional, and impairment features of disability, and assumptions about abnormality and normalizing techniques, the biomedical model does not account for the breadth and complexity of the experiences of people with disabilities (Corker and Shakespeare 2002, French 1993). In contrast, the biopsychosocial model acknowledges the biological, individual, and social factors of disability where capacity to function and disability itself are products of the relationships between “diseases, disorders and injuries” (WHO 2002:10). Attention to the biological, individual, and social factors of disability allows for times when responses from a biomedical perspective of disability are necessary to deal with issues of impairment, that the provision of individualized supports and technological devices can mean greater opportunities for participation, and that ongoing effort is required to deal with attitudinal and physical barriers.

Self and Self-Identity

Understanding how individuals with disabilities and mental illness perceive themselves requires investigating how the emergence of self is conceptualized. For

Mead (1967:199), the self emerges through social interaction where individuals internalize the attitudes of others to fit in. According to Schutz (1967, 1970), the 'life-world' is the best way to understand how 'I' is produced through interaction with others. The 'life-world' is where the 'I' emerges, and constitutes those everyday interactions with people. The 'life world' is conceptualized as concentric circles of interaction of varying degrees of influence or relevance, and the closer to the inner circle of relevance, the greater the impact on the self (Schutz 1967, 1970). Cooley (1902:87) uses the "looking glass" analogy to explain how the self emerges, where "the imaginations which people have of each other" constitute reality and individuals develop a self-feeling as the result of imagining others' judgments.

Goffman (1963) elaborates on Cooley's ideas (Scheff 2003) by postulating that one's personal identity is a 'subjective' phenomenon (Goffman 1963:129) and that one's identity can become stigmatized. Goffman (1963) defines the three types of stigma: body (physical), character (personal), and tribal (social). It is Clarke's (2008:10) contention that Goffman and Foucault have something to offer in analyses of the "self and identity" in terms of being socially constructed phenomena, and he views Goffman's work as a harbinger of some of Foucault's (1977, 1984, 1995) writings. For instance, in *Discipline and Punish* (1977), Foucault analyzes the connections between power and knowledge with respect to one's identity (Clarke 2008). According to Foucault (1980b:73, 74), one's 'identity' is the result of the influence and exercise of power by others on individuals. Foucault (1982:781) explains that categorization establishes an identity that individuals come to accept and recognize as true (Foucault 1982:781).

The Bureaucratic Management of Populations

Max Weber's theories about bureaucracies are useful for analyzing the management of populations as well as understanding some of the difficulties formal care providers face negotiating for government funding and supports for residents. According to Weber (1925/1977), bureaucracy is a hierarchical system of administration organized according to official functions, with employees in various offices and positions responsible for specified duties or tasks and accountable to those in higher positions of authority. Bureaucracies are characterized by their efficiency and scope of operations (Weber 1921/1968) and typified by employees with "expert training" (Weber 1958:197, 198), able to carry out tasks and make decisions in an abstract and impersonal manner because of the rules of the organization (Weber 1958). Maintaining written records and files are important to the operation of bureaucracies (Weber 1958). Bureaucracies also have an "iron cage" effect (Weber 1958:181) in that employees are reduced to 'cogs' (Weber 1921/1969:1iii) and individuals face extreme difficulties trying to address real people's issues. This is because of the "red tape" in bureaucratic organizations that involves consistently utilizing a "means and ends" rationale (Weber 1921/1968:1116). In due course, the vigilant attention to "costs and benefits" in bureaucracies facilitates emotionally detached responses to issues (Gabriel 2005:11).

Long-Term Care as a Total Institution

Erving Goffman's research (1961) is vital to analyzing the experiences of care providers, care recipients, and institutionalized care in New Brunswick. Institutionalized care for people with mental illnesses and severe disability has changed since Goffman (1961) conducted his research. For instance, current policies and legislation mandate individualized rather than population care approaches and greater public accountability for care standards. In addition, residents now live in smaller facilities with more pleasant physical surrounding and have greater opportunities for making choices about their daily lives. However, this does not mean that some of Goffman's (1961) concepts are no longer pertinent to this study. For Goffman (1961:17), institutional life is characterized by strictly ordered routines and abiding by the same expectations in the "immediate company" of a great number of other individuals. In addition, all facets of residents' lives are carried out in one place and determined by institutional authorities according to a "rational plan" that suits the objectives of the institution (Goffman 1961:17).

Other ideas of Goffman (1961) relevant to this research are the phases residents experience in entering, remaining and, on occasion, leaving the institutions, the work of developing compliance in residents, and the organizational features of institutions. For Goffman (1961:15, 16), institutions are 'total' because of their impenetrable nature and "encompassing tendencies," the barriers to socializing between residents and individuals outside the facilities, and the approaches taken with residents. Being institutionalized involves three phases: the pre-patient phase, inpatient phase, and ex-patient phase for the more fortunate (Goffman 1961:119). These three phases involve residents in a "moral career" (Goffman 1961:65). Mortification is key to the in-patient phase and requires the implementation of a number of specific techniques that include transferring the legal rights of residents (Goffman 1961:75) to others on entering the facilities and severing all contact between patients and loved ones to affect a "deep initial break" (Goffman

1961:24). Goffman 1961:24) refers to this ‘break’ as the “first curtailment of self.” Such mortification techniques are intentional and designed to strip patients of all indicators of their previous identities (Goffman 1961). Patients are also assessed to see if they will be ‘pliant’ (Goffman 1961:26), which is important since the needs of the institution always take priority over individuals (Goffman 1961).

All institutions have organizational features (Goffman 1961). One organizational feature that Goffman (1961:51, 52) pointed out was the “privilege system,” where a world is built around “minor privileges.” Goffman (1961:51, 52) held this to be potentially the most critical aspect of “inmate culture” as declining privileges had a “terrible significance.” It is the responsibility of those working directly with residents to uphold the expectations of institutions (Goffman 1961:107). Goffman (1961:56) observed that residents occasionally engaged in “secondary adjustments” by not specifically challenging staff members but attaining ‘forbidden’ or ‘permitted’ items in unacceptable ways (Goffman 1961:56). Secondary adjustments allowed residents to assert their individuality and exercise some freedom despite their living situations (Goffman 1961:56) and were tactics to show ‘disaffiliation’ with their environment (Goffman 1961:269).

Perceptions about patients inform the nature of relationships between staff and residents and the type of work required of them and, therefore, a kind of morality (Goffman 1961:83) behind the operation of the institutions. Patients are under constant surveillance (Goffman 1961:18) and the need for constant intervention in their lives means no “back region” (Goffman 1961:106) or place where staff and residents are not under surveillance. Goffman (1961:76) also pointed out that staff members are constantly conflicted between maintaining “human standards” and “institutional efficiency.” Normality for patients is unachievable (Goffman 1961:81, 82) and the ways institutions are organized reveal the clear demarcation between caregivers and care recipients (Goffman 1961:104). Although residents are typically viewed as ‘material’ that require work (Goffman 1961:74), formal caregivers can experience concern and affection for residents, which Goffman (1961:79) refers to as an “involvement cycle.” Finally, Goffman (1961:101) asserted that special events or “institutional ceremonies” organized to create opportunities for solidarity among staff and residents are, in reality, ‘fictitious’ (Goffman 1961:102).

Reverse Integration

Reverse integration is where people without disabilities enter spaces dominated by people diagnosed with disabilities, rather than the typical approach. Reverse integration is an approach currently being practiced in a school in Montreal, Mackay Centre, where children without disabilities are integrated into classrooms and other settings, designed for the children with disabilities, which means they have to learn to adjust to the children with disabilities unlike the usual integration approaches. Boone (Jan. 21, 2008, *Montreal Gazette*) explains that reverse integration is a new idea that is “socially progressive” as all children under Grade one and up to and including Grade Six attend classes with children with various disabilities for an entire school year. According to Gagnon’s (April 12, 2010, *La Presse Montréal*) observations, children at the Mackay Centre School - with and without disabilities - play together, and disability seems natural rather than abnormal to all of the children. L’Arche takes a somewhat similar approach by holding weekly open houses at the facilities so friendships among residents and outsiders can be developed in a safe environment, as staff members are always present. This tactic taken by L'Arche tactic is not reverse integration by definition but is so in practice, where outsiders are required to adjust to residents.

CHAPTER FOUR: METHODOLOGY

I used a qualitative approach in this research because it allowed me to examine institutionalized care in New Brunswick for adults with disabilities and mental illnesses as experienced by service providers, those delivering and receiving hands-on care, and family members. There is a robust background of qualitative research into disability (Racino 1999:19) and institutional care (Malacrida 2005; Mansell, et al. 2008),[72] but my objective was not just to ascertain the perspectives of individuals such as those delivering formal care, but also to discover how residents in long-term care facilities characterize their experiences. A qualitative approach was useful for allowing participants to describe their experiences and me to discern what was said, and how it was said. Taking a qualitative approach also provided the opportunity to focus on the meanings participants gave to their experiences and to acknowledge these experiences as social constructions (Denzin and Lincoln 1994:4). Finally, utilizing a qualitative approach enabled me to reflexively engage with the data throughout the research process (Shah 2006, Vernon 1997)[73] and be aware of the interactive relationship between myself and participants (Denzin and Lincoln 1994, Guba and Lincoln 2005).

Epistemological Assumptions and the Importance of Voice

This section focuses on matters of epistemology and the various assumptions that surround a critical theoretical approach to data with regard to the role of

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[72] See also MacDonald et al. 1993, Taylor and Bogdan 1994, Taylor et al. 1996.

[73] See also Guba and Lincoln 1994.

researchers, the researcher/researched relationship, what constitutes knowledge, and the importance of participants' voices - particularly the disenfranchised. A critical epistemology has implications for what is expected of researchers. Researchers in this paradigm are obligated to engage in transformation (Giroux 1988:213), acknowledge the embeddedness of individuals' accounts, reveal some of the difficulties individuals experience (Giroux 1988:213), and challenge misconceptions about their lived reality (Guba and Lincoln 1994). Clear (1999:439) calls this "resurrecting the monstrous." The researcher is, therefore, both "advocate and activist" (Guba and Lincoln 2005:194), making connections between the 'personal' and 'political' (Oliver 1996:170).

Activism might involve engaging in political struggle (Okely 1997) or providing background support/advice in accessing resources (Davis 2000:202). It follows, therefore, that critical disability research is political (Devlin and Pothier 2006, Rioux and Valentine 2006).[74] Kincheloe and McLaren (2005:305) explain that critical researchers often declare their intention to engage in transformation.[75] Research goals here relate to emancipation and issues of social justice (Guba and Lincoln 1994, Crotty 1998).[76] Yates (2005:75, 76) posits that research into institutionalized long-term care should involve problematizing those actions seen as 'natural' that result in subjectifying residents, and those practices that facilitate exercising power over residents that are less obvious and remain undisputed. While Fawcett and Hearn (2004:207) characterize people diagnosed with disabilities simply as research participants, Davis (2000) describes them as the real experts on their own experiences.

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[74] See also Barnes and Mercer 1997, Clear 1999, Vernon 1997.

[75] See also Kincheloe 2001.

[76] See also Forester 1985.

A critical epistemology also assumes a dialogic/dialectical (Guba and Lincoln 1994, 2005) and interactive (Denzin and Lincoln 1994) relationship between researchers and participants more typical of “conversational partners” (Parker and Lynn 2002:16). A dialogic/dialectical approach for Ritzer and Goodman (2004:276), forces researchers to examine the “real world,” involves the sharing of research agendas (Bamburg and Budwig 1992, Swain and Gillman 1998) and the ongoing interactive analyses of the data (Davis 2000, Priestley 1997).[77] Qualitative methods are also essential to ‘hermeneutical/dialectical’ approaches (Guba and Lincoln 1994:115) to account for the complexity of participants’ experiences (Clark et al. 2007). A further assumption of critical epistemology is that researchers bring personal values (Davis 2000), specific biographies (Denzin and Lincoln 1994) and “epistemological and political baggage” (Kincheloe and McLaren 2005:306) to the research. Researchers are, therefore, obliged to reveal their assumptions going into the research, which for Kincheloe and McLaren (2005:309) is the strength of critical theory.

A critical epistemology has implications for how research outcomes are viewed as well. There is no one interpretation in the critical hermeneutic tradition (Grondin 1994, Gross and Keith 1997)[78] and the findings that emerge from the interactive process between researcher and researched (Guba and Lincoln 1994) render a jointly constructed account (Guba and Lincoln 2005). In addition, because researchers’ values are implicated throughout the research process, findings are ‘value-mediated’ (Guba and Lincoln 2005:193), making value-free descriptions unachievable (Mayers 2001, Smith

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[77] See also Barnes 1992, Stone and Priestley 1996.
[78] See also Rosen 1987, Vattimo 1994.

1999).[79] While researchers' voices are important for transformative, activist, and advocacy ends, research participants' voices are those crucial to research processes and outcomes. Critical theorists are characterized by Guba and Lincoln (2005:187) as 'bricoleurs,' whose task it is to generate practical knowledge with applicable outcomes. Knowledge does not accumulate, explain Guba and Lincoln (1994:114), but increases and is adjusted because of being constantly revised. Therefore, knowledge constitutes "generalization by similarity" (Guba and Lincoln 2005:194).

Ultimately, research from a critical epistemological standpoint is about providing opportunity to those not typically heard (Ball 1994:4), such as those diagnosed with significant disabilities and mental illnesses, to understand their experiences with social and welfare policies targeted to them (Wilson and Beresford 2002:155), for they typically hold little priority in "public policy" (Racino 1999:19, 20). Getting their standpoints is critical (Moore et al 1998l Rioux et al.) to learning about the embodied experience of disability (Devlin and Pothier 2006) and issues with violence and abuse (Rioux et al 1997) they may be facing in formal long-term care settings. Their stories are also valuable for insight into the asymmetrical nature of their relationships with care-providers (Matsuda 1987), their experiences with the various forms of domination they encounter (Parker and Lynn (2002) and, ultimately, allowing researchers to perceive their lived experiences (Delgado 1989:2439).

Opportunities for disenfranchised persons to become involved in the struggle for empowerment (Vernon 1997), including those diagnosed with disabilities and mental illnesses (Devlin and Pothier 2006), are possible within a critical epistemology

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[79] See also Denzin and Lincoln 1994.

(Kincheloe and McLaren 2005, Ritzer and Goodman 2004).[80] A qualitative research approach is also consistent with giving voice to the oppressed and vulnerable (Denzin and Lincoln 1994), as are Foucauldian analyses in hearing from people subjected to power (Allan 2005). Yates (2005:71) listens to care recipients' stories so he can understand the power practices exercised in long-term care facilities, the experience of these practices for residents, the problems that result from these experiences, and residents' perceptions of the situation.

Research Design

I used a qualitative research design that included fieldwork and comparative coding. Data collection took place in 2010 and 2011, and semi-structured interviews and participant observation (PO) in adult community residences served as my primary sources of data. The combination of PO and semi-structured interviews allowed greater detail in the data to emerge (Johansson et al. 2007:367), enabled me to examine, discern, and analyze how participants constructed and experienced "their worlds" (Owens 2007:305), and facilitated my ability to check for inconsistencies in the data (Silverman 1998). This same combination also made it possible to pay individualized attention to each participant, to treat them as experts of their own experiences (Heyman et al. 1998, Swain and Gillman),[81] and to gain insight into the social (Moos et al. 1979), emotional (de Rivera 1992), and cultural environments (Geertz 1973) of adult community

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[80] See also Bauman 1976.

[81] See also Booth and Booth 1994, 1996, Pitcairn 1994.

residences. Historic and current long-term care policies and legislations pertinent to New Brunswick served as secondary sources of data.

Participant Observation

I follow Owens' (2007:305) argument that when it comes to fieldwork, detailed observations are necessary to capture the complexity and "socially constructed" nature of situations. A critical fieldwork approach informed by a Foucauldian analysis was valuable for seeing and problematizing the "power and subjectivity" residents face in long-term care facilities (Yates 2005:75, 76). It was important to conduct fieldwork because, first of all, Foucault (1982:780) argues that if you want to understand how 'madness' is defined by society, you have to examine what is going on "in the field of insanity." Secondly, fieldwork was important because I wanted to envision alternate ways of responding to what I learned about long-term care throughout the province rather than just chronicling apparent 'facts' (Maguire 1987:3).

Further, as Langille et al. (2009:85) reveal, participatory research has been beneficial in providing fresh information, engendering greater sensitivity to the issues at hand, resulting in practical changes to policy, and more involvement in advocacy efforts. Moreover, the time spent in fieldwork made it possible to access "more detailed information" through the conversations that took place during my time at the facilities (Johansson et al. 2007:367), such as how front-line workers view residents and how they conceive their roles as caregivers. Conducting fieldwork enabled me to observe front-line workers and residents in their milieus, which offered an emic perspective and, therefore, greater understanding into participants' perceptions about their social realities

(Field and Morse 1992). Through "behavioural observation" I was also able to see how residents with limited verbal skills interacted with caregivers and responded to various incidents (Sigelman et al. 1983:211).

I spent approximately 160 hours with an average of forty hours per week at four different non-profit adult community residences in the Northern, Eastern, and Western areas of New Brunswick where care was targeted to individuals diagnosed with more severe disabilities and/or mental illnesses between the ages of nineteen and sixty-four and who required level 3 and/or 4 care delivery. I had already conducted research in Southern New Brunswick for my Master's research. There were a total of thirty-seven residents living in the four adult community residences where I did fieldwork, which meant an average of 9.25 residents per facility. Johnson et al. (2006:132) admonishes researchers that they need to think ahead of time regarding their specific role during fieldwork to reduce 'anxieties' related to field research and enhance the quality of the data. I concluded my role to be predominantly that of an observer, for I did not want to interfere with regular routines at the facilities and I wanted residents and front-line staff workers to be as comfortable with my presence as possible during my time there.

I offered to assist front-line workers during fieldwork in whatever ways they chose and, upon their direction, helped with such tasks as washing and drying dishes, baking cookies and muffins, preparing snacks, sweeping, making a resident's bed, feeding another resident unable to feed herself, toileting a resident, and assisting a front-line worker as he changed a bandage on a resident. Still, the greatest amount of my time was spent conducting observation (Owens 2007:305). It is often not possible in field work like this to give precise counts. Therefore, throughout my findings chapters I use the words all, most, several, some, occasionally, and one to indicate the relative occurrence of experiences of the people who took part in this research (Becker 1966). By most, I mean more than three-quarters but less than all, several indicates at least five participants, some means less than five, but more than two participants, and occasionally, refers to one or two participants.

Interviews

Thirty-nine individuals participated in interviews. Interviews were conducted among individuals from the Department of Social Development, social workers, the New Brunswick Association of Community Living, Boards of Directors, managers of adult community residence agencies, executives of nursing homes, front-line workers, family members, and residents who live in long-term care facilities. TABLE I on the following page represents the demographic characteristics of all participants. The board member listed in TABLE I also had a child living in an adult community residence and talked about her experiences as a mother. For that reason, she is only counted once in the data.

TABLE I: DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS

ORGANIZATION OR STATUS	**NUMBER OF PARTICIPANTS**	**M**	**F**	**%**
Dept. of Social Development	2		2	5.1
Social Worker	2		2	5.1
Physician	1		1	2.6
Nursing Home Executives	2		2	5.1
Boards of Directors	1		1	2.6
Operators of Adult Community Residence Agencies	5	4	1	12.8
Middle Management in Adult Community Residences	3	1	2	7.7
Front-Line Workers	6		6	15.4
Residents	11	6	5	28.2
Parents	5	1	4	12.8
Siblings	1	1		2.6
N.B. Association of Community Living	1		1	2.6
TOTALS	**39**	**13**	**26**	**100**

As shown in TABLE I, residents of long-term care facilities had the highest representation of all participants in the data at 28.2%, front-line workers came in second at 15.4%, operators of adult community residences and parents were equally represented at 12.8% while middle management comprised 7.7% of all participants. Residents had the greatest representation in this research which is important because persons with severe disabilities are often excluded from research about their care experiences (Beadle-Brown et al. 2012). This research would have been incomplete without their participation and they had the most to benefit with regards to potential research outcomes.[82] The average age of residents who participated (six men and five women) was fifty-four as noted in TABLE II below. Pseudonyms for all other participants can be found in TABLE III on the following page.

TABLE II: DEMOGRAPHIC CHARACTERISTICS OF RESIDENTS

Resident Pseudonyms	Male	Female	Age
Adam	1		46
Ben	1		40
Blake	1		58
Devin	1		46
Doris (NH)		1	58
Henry	1		64
Isabelle		1	53
Kate		1	54
Mary (NH)		1	51
Theresa (NH)		1	58
Tom	1		63
Total	**6**	**5**	**591**

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[82] See pages 68 - 77 for an extensive discussion of the difficulties in approaching and interviewing residents of long-term care facilities and my role and agency in selecting the sample to study.

TABLE III: PSEUDONYMS

ORGANIZATION/STATUS	PARTICIPANT PSEUDONYMS
Dept. of Social Development	Debbie Rita
Social Worker	Linda Sherri
Physician	Dr. Faulkner
Nursing Home Executives	Olivia Sharon
Board of Directors	Brenda* (listed as both a Board member and Mother)
Operators of Adult Community Residence Agencies	Doug Ed Celeste Bruce Byron
Middle Management in Adult Community Residences	Yvette Rhonda Mark
Front Line Workers	Rachel Amanda Shirley Breanne Simone Margaret
Residents	Adam Ben Blake Tom Devin Henry Kate Isabelle Doris Theresa Mary
Parents	Emilie Cormier Francois Cormier Lorna Brenda* Kim
Siblings	Mike
N.B. Association of Community Living	Norma

According to Mann and Stewart (2004:377), the research question should inform the interview style. I chose a semi-structured interview style because open-ended questions defined the areas I wanted to explore and provided the opportunity to focus more attention on certain topics or issues as they arose (Britten 1995:251). Semi-structured interviews also provided more room for equal participation between researcher and participants, and because this interviewing technique is more typical of a conversation, this approach facilitated my ability to use additional questions and 'probes' for further explanations where necessary (Mann and Stewart 2004:377). Using semi-structured interviews meant that all thirty-nine participants were able to express themselves freely (Holmes et al. 2004, Lloyd et al. 2006)[83] and I was able to clarify questions as needed (Holmes et al. 2004:568). This same interview technique also allowed me to formulate additional questions during the interview (Burgess 1984:102) and to use a probing technique that involved repeating certain 'words' from participants' responses and reformulating them in my attempt to gain further understanding (Owens 2007:303). I also used an "inverted funneling" technique with residents that involved beginning with just a few questions and then focusing on the particular topics they were interested in talking about (Owens 2007:306).

Monitoring residents' body language allowed me to pay close attention to whether residents remained comfortable during interviews (Booth and Booth 1996). More specifically, I watched for relaxed body posture and facial expressions (Dewing 2007) and whether or not residents were able to speak freely, became restless, agitated, or emotionally upset. During interviews, I posed questions in a loose framework by

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[83] See also Swain and Gillman 1998.

saying things like “can you tell me about?,” which allowed residents to frame their responses as they saw fit, to use their own words, and to talk about matters important to them. After all, my goal was that these individuals leave the interviews “feeling positive” about having participated in the research (Charmaz 1991:392). This was particularly true in the case of more vulnerable participants. Any fears I had about doing research among residents with more severe disabilities were not fulfilled, similar to Peel and Wilson’s (2008:407) experience. Therefore, I discovered that it is still possible to give voice to these individuals (Lloyd et al. 2006:1388) and that a “muffled voice” is better than none (Stratton 2002:125).

Research participants from the Department of Social Development, operators of adult community residence agencies, executives of nursing homes, and two supervisors in middle management chose to be interviewed in their offices. Everyone else was interviewed at the facilities, with the exception of three family members, two of whom were interviewed in their homes, and the other in a private room in one of the bed and breakfasts where I stayed during field work. Although Gilbert (2004:304) cautions against interviewing staff members in the facilities where they work, every front-line staff member who participated asked to be interviewed at the facilities. These staff members took careful measures, however, to talk privately during interviews, arranging to be totally alone with me in various areas of the facilities when fellow staff members and residents were preoccupied elsewhere in the buildings. These areas included residents’ bedrooms, kitchen tables, and the basement. Each of these participants also chose the time of day and much of the content of the interviews, more typical of semi-structured interviews. I had to take a different approach with residents.

My intention was to interview residents at locations familiar to them other than the facilities, and with individuals known to them who would stay with them during interviews. This proved impossible, however. First, I had difficulty coming up with locations other than the adult community residences. The only other locations where residents spend significant amounts of time are at vocational centers/workshops or day centers, but these settings do not lend themselves to private interviews. A considerable number of individuals frequent these centers to participate in programs and activities or connect with friends. The more adherents there are at these centers, the less freedom employees have to sit with individual residents during interviews. Their time is taken up with leading and monitoring activities, and mediating relationship issues among attendees.

Secondly, I was mistaken in assuming that interviews could be conducted in residents' homes of origin and with family members acting as third parties during interviews, for I had difficulty establishing contact with family members. I collected data in areas of the province other than where I live, which meant I had no way of knowing the names of family members to contact. Privacy regulations exacerbated this situation. In addition, few relatives maintain contact with their adult family members once placed in care. Staff members explain that this lack of contact is because some parents are elderly and experience health and/or other life issues, some parents are fearful of the aggressive behaviors their adult children display, and others have passed away. A further explanation for the lack of contact is that prior to deinstitutionalization relatives were discouraged from visiting their loved ones, so as not to upset them.

I eventually did find some parents and relatives to interview through inquiries to staff members. These family members were not related to the residents who assented to interviews. I conducted one-on-one interviews with nursing home residents in their bedrooms with doors closed for privacy, and with residents of adult community residences in their bedrooms or at the kitchen table with a staff member present and when others were preoccupied elsewhere in the facility. Consequently, I was able to conduct interviews with residents of adult community residences in settings and among third party individuals familiar to them. The staff members acting as third parties were individuals with whom residents appeared to be most comfortable, probably because of their long-term association with them. By comfortable, I mean that residents freely interacted with the individuals who acted as third parties during my time at the facilities and appeared to enjoy being around these front-line workers. Although it was beneficial to have third parties present during interviews, particularly where I could not conduct interviews with residents otherwise, it also created problems with ensuring anonymity and confidentiality for residents. This was not an issue for interviews among nursing home residents as they did not require the presence of a third party.

Entrée/Access, Gatekeepers, and Establishing Rapport

I was able to gain access into adult community residences to conduct fieldwork because of the trust previously established with a participant in my Master's research, substantiating Campbell and Gregor's (2002:64) contention that establishing trust is crucial to access and Lauder's (2003:192) argument that "Leaving on good terms" makes it more possible to get additional data or confirmation of existing data from the same source if necessary. This participant gave me a list of not-for-profit adult community residence agencies throughout New Brunswick, along with pertinent contact information, thereby facilitating my entrée into the facilities and illustrating the potential of snowball sampling (Neuman 2003:214). Operators of four different adult community residence agencies provided me with access to their facilities to collect data and allowed me to choose the facilities in which to conduct research, except for the agency that only operated one facility.

I interpreted this offer of unhindered access to these facilities as their desire to ensure that my research proceeded unhindered and perhaps, more importantly, to show that the day-to-day happenings in these facilities were completely open to investigation. These operators also expressed happiness that someone was interested in the type of supports they offered, the type of work they did, and the type of people they provided services to, all matters typically garnering little attention. Because I had no prior knowledge of these facilities I told operators that I was willing to conduct fieldwork in the facilities of their choosing, which is a potential source of bias. However, while I could have asked the operators for a description of these facilities as a means of choosing between them, the operators may have described them in such a way that would have led me to choose one over the other, which would have also been a source of potential bias.

I encountered tremendous difficulty, however, in trying to gain entrée into private-for-profit adult community residence facilities. One reason is that the former participant from my MA research had no knowledge if there was a list of private-for-profit agencies available or where one might be found. Another reason is that although the Department of Social Development lists the special care homes operating in the province on their website, they do not have a similar posting of private-for-profit adult community residences. While an extensive Google search provided the names of a number of agencies labeled as private-for-profits in New Brunswick, the operators of these agencies on being contacted told me there was some mistake and that they were not-for-profit organizations, which contradicts the on-line information. Moreover, three of the adult community residences where I conducted research are listed as privately owned companies on public websites but these, along with the fourth agency, are listed as members of the New Brunswick Association of Residential Agencies, Inc., which is only open to not-for-profits. Therefore, I have to accept that all agencies where I conducted research were not-for-profit as reported by participants. I also inquired at each adult community residence during fieldwork if anyone knew of private-for profit adult community residences in their area. No one knew of any but could easily name the local private-for-profit special care and nursing homes.

Still unable to find private-for-profit adult community residences in which to conduct research I contacted one of my PhD research participants from the Department of Social Development to inquire if a list of private-for-profit adult community residence agencies exists similar to the not-for-profit agencies listing posted on their website. I was told that such a list is not available and refused the contact information of operators of private-for-profit adult community residences in the province. Instead, I was asked to forward an additional letter explaining my research which she would pass on to private-for-profit operators to inquire of their interest in participating in the research. I was not surprised when I failed to receive any responses. Although frustrated and disappointed at my inability to gain access to private-for-profit adult community residences, I can still draw substantial comparisons between care delivered by the not-for-profit sector and the private-for-profit sector because of extensive time spent frequenting these facilities to visit my son over the past twenty-five years. He was a resident in private-for-profit adult community residences for sixteen of these years.

My first encounter with the power of gatekeepers who represent those individuals with the power to determine whether I could collect data among people with disabilities (Wadenstein and Ahlstrom 2009), was from an unexpected source, the Office of the Public Trustee in New Brunswick. As a gesture of transparency on my part I sent a letter to their recently established Office to seek advice on the best way of proceeding during interviews with residents in long-term care facilities. I received a written reply denying me permission to interview persons under their jurisdiction. I contacted the Office of the Public Trustee to reaffirm that my request was for advice rather than consent. An individual speaking on behalf of the Office reiterated their denial, stating that they were protecting clients' privacy and that my research would only be of third-party benefit (to myself as the researcher) with no direct benefit to clients, although indirect benefits could ensue at the point of publication if social policies were influenced. I then contacted a lawyer friend who confirmed the power of the Office of the Public Trustee to deny access to individuals under their jurisdiction and that there was little hope of recourse.

To the first argument, using pseudonyms and excluding information that could identify participants should address privacy concerns. Besides, any notion of privacy is lost for residents of long-term care facilities given that many of these individuals face 24-hours-a-day, 7-days-a-week surveillance for all aspects of their lives because of the number of 'experts' overseeing and making determinations about their lives (Krogh and Johnson 2006, Tremain 2005).[84] This then begs the question, protecting their privacy from whom? If it is the general public then we do a disservice to residents of long-term care facilities by keeping them invisible. To the second argument, residents would benefit from being able to talk about the experiences and issues that matter to them and thereby, expressing at least some independence. Independence for Wadenstein and Ahlstrom (2009:760) means not only having the ability to express one's opinions but that others are considerate of these opinions. Allowing residents to participate in research about the care they receive shows the same respect typically granted to persons without disabilities or mental illnesses.

Although the individual speaking on behalf of the Office of the Public Trustee explained that their denial of consent was informed by policies currently under development and the *Infirm Persons Act* (1973), I found little in this document or the *Mental Health Act* (1994), *Family Services Act* (1983), *Human Rights Act* (1985), *Public Trustee Act* (2008) or the *2008-2009 Annual Report* of the Department of Justice and Consumer Affairs to support disallowing residents from sharing their experiences so as to protect their privacy. Perhaps most troubling was that this denial basically dismisses the REB process, and suggests that the rigor of this process and the procedures involved in planning research protocols to meet Tri-Council Policy Statement (CIHR et al. 1998) standards might not be as well known in the larger

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[84] See also Carlson 2005, Foucault 1995, Hughes 2005.

community as they should be. Nevertheless, this denial made it necessary for me to ask the operators if each agency if any of the residents in their facilities were under the jurisdiction of the Office of the Public Trustee to ensure that I did not engage them in interviews.

As a condition of access front-line workers' assistance was required in determining which residents might be interested in being interviewed, which meant I had to rely on their help in recruiting participants (Moore and Savage 2002).[85] Since operators of adult community residences, as primary gatekeepers, had already provided permission to conduct interviews and PO in the facilities, hands-on-caregivers were, in effect, secondary gatekeepers, as I needed their help with recruitment and ensuring that residents understood, (1) why I wanted to interview them, (2) what the interview process would entail and, (3) that they could withdraw at any point during that process. I also needed staff members to sit with residents during interviews. Unlike in other research (Davis et al. 1999), there were no front-line staff members who questioned residents' abilities to participate or understand the process. While front-line workers could not deny me the opportunity to conduct interviews with residents as the operators of the agencies had already given me that authority, they still had the power to deny 'access' (Stalker 1998:8) by not assisting with recruitment or refusing to act as third parties. Either would have effectively prevented me from being able to proceed.

I noted that front-line workers at each facility acted somewhat protectively of residents during the first couple of days of fieldwork, watching carefully as I interacted with these individuals. Once employees observed that I consistently treated residents

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[85] See the section 'Limitations of the Study and Suggestions for Future Research' in Chapter Ten.

with respect and on residents' terms, and my level of comfort in their midst, the protective stances all but disappeared. Their initial protectionism was not offensive but rather encouraging in their attention to residents' best interests. The power of these secondary gatekeepers was also explicit in their ability to determine which residents were eligible to participate (Wadenstein and Ahlstrom 200) but in the final analysis, residents were the ultimate gatekeepers when it came to their willingness to talk about their experiences (Davis et al. 1999, Orb et al. 2001).

Staff members, because of their long-term association with care recipients, were beneficial to ensuring participants understood my explanation of the interview process and that they had complete freedom to withdraw from participating at any point. The freedom to decline from participating was substantiated when one individual stated he was not interested, shrugged, and simply walked away. He later approached me to see if I would tape him singing one of his favorite songs, which I did, for I wanted participants to be in control during interviews (Owens, 2007:303). From all appearances, residents who participated in interviews did so because they wanted to and not because they were pressured or coerced in any way (Moore and Savage 2002:634). This was important to avoid acquiescence, a matter I deal with later in the "Ethical Protocol" section of this chapter.

I encountered a number of interesting situations while attempting to establish rapport with front-line workers at the facilities. For the first couple of days at one adult community residence, there were times when I felt staff members intentionally distanced themselves from me, not unlike Levinson (2010) who was reminded frequently by a certain staff member that he was an outsider when he conducted research in a group home. Language proved to be an effective technique of maintaining distance. Once it was known that I was Anglophone, staff members, despite being bilingual, spoke solely in French to keep me from certain conversations. On one occasion, three female staff members who were seated at the same table as I conversed extensively in French, all stood at once, headed off to a bedroom, and closed the door behind them. The operator of this facility also talked with staff members on one occasion for a period of time in French, after which she turned to me and pleasantly explained that she was not going to translate what was said because it did not concern me. On every other occasion, however, this same operator conducted all conversations in English in her effort to include me in what was going on. Staff members eventually accepted my presence at the facility, speaking in English and translating conversations.

One female front-line worker was particularly stand-offish at the start, which the operator warned me she would be, but this same staff member gave me a warm hug at the end of the week as I was leaving and said that I was welcome to come back and visit anytime I was in the area. A male front-line worker at a different adult community residence made no efforts to conceal his resistance to my presence at the facility. He made numerous comments and asked me one day “Are you still here?” He never made such comments in the presence of other staff members, however. It also seemed that he tried to gross me out one day by asking me to help change a resident’s bandage, because of a deep bed sore that constantly seeped and required the monitoring of extra-mural nurses at various times during fieldwork. I assisted other staff members at this facility with whatever they requested, but this was a task no one else requested assistance with. I struggled with the putrid smell and appearance of the bedsore but gave the front-line worker no indication of this.

Front-line workers and residents at most adult community residences were hospitable from the time I arrived at the facilities, and there were times that I felt staff members went out of their way to ensure that I felt welcome in their midst. For instance, one individual translated all exchanges between staff during a shift change from French to English. Various staff members responded positively to my offer to assist them in whatever ways possible, one thanking me for my help at the end of her shift and adding the next day, “We were lucky to have you here to help us today!” In addition, there were some front-line workers at each facility who shared more openly with me on learning that I had a son in care, perhaps because of my empathy and experiences in this area (Owens 2007:303). Alternatively, their greater willingness to share may also have been out of fears of losing their jobs.

Policy Analysis

Examining historic and current long-term care policies in New Brunswick, which are the same for persons diagnosed with disabilities and mental illnesses, along with pertinent legislations, provided me with the type of information I needed to contextualize my data (Devlin and Pothier 2006, Rioux and Valentine 2006).[86] The Provincial Archives in Fredericton, N.B. proved to be a valuable source of information with regard to the purpose and operation of asylums during the eighteen and nineteen

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[86] See also Connerton 1976, Guba and Lincoln 1994, 2005, Ritzer and Goodman 2004, Tremain 2002.

hundreds, as annual reports and records revealed some of the philosophical frameworks and objectives behind care provision as well as the perceptions that existed about people with significant disabilities and/or mental illnesses at the time.

Another component of this policy analysis entailed an examination of the *Standards and Procedures for Adult Residential Facilities* (2009), which was the document containing the specific guidelines and mandates that operators of the adult community residences were required to adhere to when I was collecting my data. Other government documents and legislations that I examined included the *Family Services Act* (1983), *Human Rights Act* (1985), *Mental Health Act* (1994) and *Public Trustee Act* (2008), to ascertain appropriate care and acceptable treatment requisites for people diagnosed with disabilities and/or mental illnesses. I was also granted access to documents in three adult community residences that contained the specific care provision philosophies and objectives developed by the operators of those agencies.

Ethical Protocols

Research participants needed to have a good understanding of the nature and purposes of the research (Campbell and Gregor 2002). Thus, I provided all participants with a letter explaining the research, inviting their participation, outlining expectations about their role and level of involvement in the research, giving assurance they could withdraw from participating at any point up to the completion of the final research report, confirming the confidentiality of their participation, and eventually gaining their formalized consent (see APPENDIX I). These same letters also contained pertinent information about myself as researcher and the names and contact information of my supervisor, Dr. Jacqueline Low, and Dr. Bernd Kurz, Chair of the Review Ethics Board of UNB should they have questions about the research. I provided operators of adult community residence agencies with letters containing the same information as above, in addition to requests for permission to conduct fieldwork and interviews among employees and care recipients at the facilities. These individuals signed consent forms as well (see APPENDIX II). I provided executives of nursing homes with similar letters to those of the operators of adult community residences except I did not request permission to conduct fieldwork in their facilities. Care recipients, on the other hand, signed assent forms (Appendix III).

Seeking the assent of the people who live in long-term care facilities was consistent with Tri-Council Policy requirements. In Statement Article 2.7, researchers are mandated to discover whether these individuals desire to participate and acknowledge that they can still 'dissent' from participating, even if authorized representatives have consented on their behalf (CIHR et al. 1998). I was also well aware that gaining consent from authorized representatives would not automatically mean care recipients wanted to participate (Stalker 1998). In addition, I knew that proxy consent from care providers might protect me from potential litigation issues (Dewing 2007, Vass et al. 2003) but I was not interested in perpetuating care recipients as "eternal children" (Stalker 1998:9) and did not want to be guilty of reinforcing their disablement (Thompson 2002:96) by not engaging residents in at least some aspect of the informed consent process. Nevertheless, I had to first establish residents' capacity to assent.

I did so first, by focusing on their level of engagement in everyday decision-making (Thompson 2002). This approach was important because residents of long-term care facilities can sometimes take on a “learned helplessness” (Lindsey 1994:161), conceding their choices to those providing formal care or to other individuals (Thompson 2002:102), although less so in smaller community-type residences (Ellis 1992). Attention to residents’ daily actions revealed some level of “competency” (Lloyd et al. 2006:1399) and helped me to discern the ability of residents to assent. The second way of determining residents’ capacity to assent was by watching indicators of their ‘well-being’ which included their facial expressions (Dewing 2007). Fieldwork was particularly beneficial in this matter as I was able to observe their engagement in decision-making and sense their measure of well-being.

I had a general impression of what well-being meant for each resident by the third day at each facility and some insight into whether they took advantage of available opportunities to make decisions, both informative for revealing whether residents had some control over their lives (Thompson 2002). The level of decision-making exercised by the residents I interviewed led me to conclude that these individuals chose to participate in this research of their own free will and their capacity to assent was further established in that they agreed to participate during a state of well-being. In a further attempt to establish that residents participated of their own free will as mandated in Tri-Council Policy Statement (CIHR et al. 1998) Article 2.7, I presented each with a brief assent form purposely devised with their various “level[s] of comprehension” (Stalker 1998:8) in mind and explained these assent forms to them in the presence of staff members.

I asked residents to sign the assent forms only after they had agreed to be interviewed, and staff and I had determined that they understood what they were agreeing to. They signed these form by printing or writing their names or by making a mark. I also stopped at various points during interviews to confirm their desire to continue as I considered their initial agreement to participate ‘insufficient’ (Sigelman et al. 1981:57), for assent is not a one-time event (Dewing 2007, Lloyd et al. 2006).[87] Staff members well known to participants acted as third parties (Dewing 2007:20) and were present at all times during interviews, which was beneficial for recognizing signs of “discomfort or stress” (Lloyd et al. 2006:1398) in residents should they occur. Therefore, I contend that those residents who agreed to be interviewed had the capacity to provide assent of their own volition and did so without coercion (Holmes et al. 2004), which is important when it comes to acquiescence.

While some argue that involving third parties raises concerns about the validity of the data (Boeije 2004) and distorts the voice of the person with the disability who participates in the research (Parsons et al. 2001), it is important to recognize that data from interviews, whether or not a third party is involved, is a joint product resulting from the interaction between interviewee and interviewer (Charmaz 2002) and later, with the person who transcribes the data, if different from the interviewer (Low 2006). It is no different in interviews where a third party is present, it just adds to the construction of the narrative (Low 2006:166). This should not be understood as unreflective of the participant’s experiences, as people who experience communication problems due to disability rely on others to help them with communication throughout their lives (Low 2006). Nonetheless, addressing the issue of acquiescence is an important consideration in research with persons with developmental disabilities (Flynn 1986, Lindsay 1994).

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[87] See also Gilbert 2004, Knox et al. 2000, Orb et al. 2001, Thompson 2002, Tymchuk 1997, Usher and Arthur 1998.

Acquiescence occurs when these people give answers that they believe are expected of them (Sigelman et al. 1983:159) or to ‘please’ researchers (Biklen and Moseley 1988:159). While acquiescing to please the interviewer can be an issue for any informant, including those without disabilities, research has shown a higher incidence of acquiescence among individuals with developmental disabilities, particularly for yes or no type questions (Matikka and Vesala 1997, Sigelman et al. 1981, 1982, 1983). However, high rates of acquiescence are lower for open-ended questions (Sigelman et al. 1981, 1982, 1983). Therefore, the in-depth questioning approach I used was more amenable as it enabled care recipients to discuss their experiences of care and whatever else they wanted to talk about.

Waiting until at least the third day of fieldwork before conducting interviews with care recipients also helped to guard against acquiescence, as I had a sense of those who might be interested in being interviewed because they had already engaged me in numerous conversations by that time. I was also clear with staff that care recipients were not to be coerced in any manner to participate, and was present when each was approached to inquire of their interest in participating to ensure that these participants exercised freedom of choice on the matter. Participants need to be willing to share their experience (Orb et al. 2001:93). I also felt that the credibility of the data would be enhanced if participants freely talked about their experiences without duress. Therefore, although I was keenly interested in getting care recipients’ perspectives, I was not willing to compromise their freedom of choice in the matter or their sense of well-being to do so.

Acquiescence was less an issue for nursing home residents who had bodily, rather than cognitive impairments. Nevertheless, I had to go back to the REB to inform them that I needed to seek consent rather than assent from nursing home residents, as they were fully capable and competent. Nursing home residents ended up signing similar interview consent forms to other non-residents of long-term care facilities (APPENDIX V), and enjoyed greater anonymity and confidentiality than residents of adult community residences because third parties were not required during interviews. As for residents of adult community residences who lacked legal competence, I was obliged to explain how I planned to prevent these individuals from being exposed to more than minimal risk (Tri- Council Policy Statement, CIHR et al. 1998) wherein the potential harm to these individuals would be "no greater than those encountered" in everyday life (Article 2.5(c)).

This mandate provided the rationale for requesting third parties well known to care recipients to be present at all times during interviews, part of whose role involved ensuring a secure and safe environment for informants and monitoring their wellbeing. Having authority figures present at all times was already a normal part of care recipients' experiences. Conducting interviews with care recipients in settings familiar to them, which did not in and of themselves pose risks, were further attempts at reducing the measure of risk to these individuals. The questions asked were topical to their everyday lives and, therefore, posed no greater harm than that of their everyday experiences. Finally, participants did not be receive remuneration for their participation nor was this research part of a clinical trial.

To comply with Tri-Council Policy Statement (CIHR et al. 1998):Article 2.6(a), letters were sent to relevant persons having authority over informants apprising them of the purpose and nature of my research and the manner in which incompetent persons would be treated. These authority figures signed consent forms giving me permission to do fieldwork in the facilities and to conduct interviews with care recipients. I attempted to ensure confidentiality by using pseudonyms, not asking questions that could identify participants, and not including identifiable information about these individuals in publications. My own background of having an adult child with disabilities living in long-term care has resulted in a great deal of empathy regarding my subject matter. Brady (2006) recommends that to really understand participants' stories, qualitative researchers must use both empathy and sympathy, though Stake (2010:47) delineates between the two, empathy having more to do with 'perception' than 'emotion.'

I argue that empathy strengthened the quality of data I was able to retrieve. First, my ongoing engagement with residents at the long-term care facilities where my son has lived provides me with a keen awareness of how to interact with residents in ways that show dignity and respect. Because of this I am very comfortable interacting with these individuals, which in turn makes them feel at ease. Therefore, the residents who participated in this study freely shared their stories during interviews and conversations. Parents who participated also talked openly about their experiences as they knew I understood the type of caregiving demands that are associated with caring for children with severe disabilities, the sense of desperation that sometimes leads to out-of-home placement, and the general emotional difficulties post-placement.

My personal empathy was also beneficial because it meant I had a deep desire to better understand how participants interpreted their experiences with long-term care. At the same time, I acknowledge Maxwell's (2005:31) caution that a researcher's personal empathy about a certain subject matter heightens the possibility of becoming 'over involved' during data collection, thereby compromising ones' stance as researcher. I was able to avoid this problem, however, because of a deep interest in discerning all participants' realities, which facilitated a more complete analysis of long-term care provision. I also worked at avoiding the problem that Maxwell (2005) emphasized by intentionally working at "manufacturing distance" (McCracken 1988:23) during data collection, a matter I explicate later in this Chapter in the discussion of the "insider awareness" (Douglas 1976) I brought to this research.

Anonymity and Confidentiality

I took the following steps in my attempt to keep from revealing specific names and/or locations of adult community residences and nursing homes where I conducted research, for purposes of anonymity and confidentiality. In discussing the physical characteristics of facilities, I excluded all information that might identity facilities, using A, B, C, or D to refer to adult community residences, and I or II to refer to nursing homes. I also used pseudonyms for all interviewees (see Table I) and made no connections between participants and the facilities, with the exception of operators of adult community residences and executives of nursing homes. In addition, all identifiable information about research participants was kept in a locked file cabinet and in a locked office. Nevertheless, using pseudonyms and refraining from asking questions or disclosing identifiable information about participants, were insufficient to ensuring complete anonymity and confidentiality for residents of adult community residences.

I was well aware of concerns that exist about exploiting these individuals (Clear 1999, Fawcett and Hearn 2004)[88] and that despite my best attempts to follow certain codes and optimal research procedures these efforts would be insufficient (Swain and Gillman 1998:21), as absolute confidentiality is impossible (Lunt and Thornton 1997:150). Although involving staff members as third parties enabled residents' inclusion in this research (Goodley 1996), protected their best interests by ensuring the maintenance of their well-being during interviews (Dewing 2007), protected me from potential accusations of inappropriate activity towards residents, and enhanced the validity of my data by the confirmation of residents' responses, their presence also compromised residents' anonymity and confidentiality. This is a problem, given that confidentiality is a key tenet of ethical research. Another problem I encountered was that two staff members tried to influence the interview process, one staff member suggesting that I ask other specific questions about a matter and another staff member trying to persuade a particular resident to reframe his negative description of a particular staff member and adding additional information in an attempt to contextualize this resident's comments. The resident refused to change his interpretation of the matter.

While it was crucial that third parties were a constant presence during interviews, and their presence suited the best interests of both residents of adult community residences and I, it should be duly noted that anonymity and confidentiality

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[88] See also Moore et al. 1998, Shakespeare et al. 1993, Swain and Gillman 1998.

for residents were weakened. The requirement that third parties stay with residents during interviews substantiates Phtiaka's (1994) argument that internal confidentiality is difficult, and in some cases impossible, in research carried out in institutional-type settings (Snyder 2002, Weinberg 2002),[89] obliging I and other researchers to state at the outset our 'limitations' in ensuring absolute anonymity and confidentiality for research participants (Snyder 2002:78). Van den Hoonaard's (2002:179) contention that confidentiality as mandated by review ethics boards "is legally wasted in the social sciences," has particular relevance in this situation.

The Matter of Incomplete Disclosure

I decided not to reveal my personal background of having an adult son with significant disabilities living in an adult community residence unless asked about my personal background. I reasoned that this disclosure might raise questions about the possibility of ulterior motives for the research, such as intentionally looking for problems with care delivery or seeking alternative accommodations for my son. This would have resulted in staff members being less forthcoming in what they shared. As it turned out, various staff members expressed opinions about parents, particularly mothers, that I am certain would have been lost, had they known of my particular background. For instance, one staff member told me that if one looked carefully at care recipients' parents, one would discover that at least one of them has borderline mental issues.

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[89] See also Stratton 2002.

Another reason for incomplete disclosure was that I did not want to be treated differently than another researcher without a similar background. Finally, I chose incomplete disclosure out of a concern that I might be less successful establishing rapport with individuals at the facilities which, in the end, would have implications for the quality of the data elicited. My goal was to observe the daily activities and routines at the facilities, the interactions between staff members and persons in care, and between staff members themselves as they would naturally occur; as much as this would have been possible when someone is conducting fieldwork. Nevertheless, by taking an incomplete disclosure stance I felt uneasy as to whether I was breaching acceptable ethical research practices, or conducting covert research (Clark 1996, Humphreys 1970).[90] I finally resolved that since covert research is that which obscures motives, purposely deceives informants, and involves disguising one's identity (Lugosi 2006:544), this was not pertinent my situation. All participants, with the exception of residents, were made aware from the outset that my purpose of being in the facilities was to conduct interviews and do fieldwork in their midst to get at the experiences of people connected to care provision in long-term care facilities. Therefore, I had fully disclosed my intentions (Patton 1990).

On the first day at each facility, staff members introduced me to residents as one who was there to conduct research. When staff members approached some residents to see if they were interested in being interviewed, the purpose for my presence was relayed yet again. Therefore, no one was deceived as to why I was in their midst nor did I attempt to disguise my role as a researcher. A covert approach would have been

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[90] See also Milgram 1974.

impossible anyway because I had to explain my research intentions to the operators of the agencies to get permission to collect data. By the second or third day of fieldwork, staff members or residents asked specific questions about my personal background to which I was completely honest, sharing that I had a son who lived in a different adult community residence in another area New Brunswick and therein transitioning into complete disclosure. Rather than being a problem, several staff members told me they now understood why I was so comfortable with residents, which they said was not generally the case with other visitors. Consequently, sharing personal background information only when asked turned out to be the right approach for this research because of the rapport I was able to establish with participants and the credibility of the data I was able to elicit.

Risks with Leaving the Field

I took specific precautions to keep from exposing care recipients residents to more than minimal risk. Early in the research, I clarified the ‘boundaries’ of my relationship with residents at the facilities (Thompson 2002:104, 105), being cognizant that withdrawing from the field after spending time among persons with disabilities can be fraught with ethical implications. I was aware that residents of long-term care facilities with developmental disabilities tend to experience less friendships and face more restrictions when it comes to socializing with individuals not living in the facilities (Stalker 1998:10). Therefore, I told residents at the outset that I would be with them only five days after which I would return home to a different area of the province.

This tactic eliminated false expectations about the length of my stay. Consequently, residents knew from the start that an extended friendship with me would be impossible because of my limited time with them and because I lived a significant distance from the facilities. By the fourth day, I reminded residents that the following day would be my last day there to keep them briefed on the matter and to prepare them for my departure. Nevertheless, some expressions of attachment did surface. For instance, one female resident gave me a poem she had written for me and a male resident of a different facility devised some questions to ask me after I had interviewed him, which I answered. Another female resident at a third facility told me she had something she wanted to talk to me about, that she and the other care recipients had been talking and they wondered if I would come work for them full time.

Time spent in the field allowed me to observe that while residents have less friendships and social contacts, particularly those with more significant disabilities, they still enjoy some friendships. The smaller spaces in the adult community residences which are operated much like typical family dwellings, also appeared to facilitate closer and more familial relationships between staff and residents, and between residents themselves, and Activity Centers, coffee shops and malls provide opportunities for friendships between residents and other individuals as well. Therefore, based on this knowledge, residents' accounts, and my personal observations I concluded that leaving the field would have limited detrimental impact on residents because of the friendships they already enjoyed. However, I failed to anticipate my own difficulty withdrawing from the field and I still ponder how the residents are doing. I reveal this matter for two reasons: First, it is important to acknowledge that emotion work is at times a very real issue, particularly for qualitative researchers involved in fieldwork (Gilbert 2001, Holland 2007)[91] and second, sharing this difficulty is consistent with the value of a reflexive, transparent approach to analyses.

Mode of Analysis

I took an inductive approach to thematic data analysis, engaging in constant comparative analysis of the data using NVivo 9 (Ryan and Bernard 2003), and maintaining all hard copies of the data in a filing system (Lofland 1971). These databases were critical to analysing the data (Lofland 1971:119) and helpful for recognizing patterns and major themes as they surfaced in the data. Theorizing throughout the research process facilitated "representativeness and consistency" in my data (Corbin and Strauss 1990:9) and my openness to emergent information and the constant re-evaluation of data made for better theoretical analyses (Glaser and Strauss 1967, Corbin and Strauss 1990).[92] Following Low (2004:448), I used comparative coding to analyze themes as they emerged from the data (Corbin and Strauss 1990). This tactic facilitated attention to points of "consensus and convergence" (Low 2004:448) and the "similarities and differences" (Schwandt 2001:110) in participants' accounts. Although I went into this research with several basic concepts in mind, I had to conceptualize other themes during data collection as they emerged. For example, I had to theorize about the formation of residents' self-identities and self-perceptions, which meant re-examining Cooley's (1902) conception of the "looking glass self," Schutz's

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[91] See also Hubbard et al. 2001.

[92] See also Kirk and Miller 1986.

(1967, 1970) perception of the 'life-world,' and Mead's (1967) theorizing about the emergence of self.

Reflexivity

Critical researchers are mandated to be reflexive and engage in self-reflection (May 1998) throughout the research process (Allan 2005, Fawcett and Hearn 2004).[93] A reflexive approach accounts for our motives as researchers (Davis 2000), helps to explain the actions taken (Campbell and Oliver 1996:24), and the decisions made (Swain and Gillman 1998:21). A reflexive approach is also important for acknowledging how researchers' values and social identities impact data gathering and analyses (Shah 2006, Vernon 1997)[94] and revealing one's power and influence as researcher (Clear 1999, Davis 2000).[95] This influence is observable in the way findings are shaped (Davis 2000, Guba and Lincoln 1994), and who gets to tell their stories (Parker and Lynn 2002). Reflexivity involves self-confession (Foucault 1999:291), which is an illuminating process (Lunt and Thornton 1997) that challenges preconceived assumptions (Kincheloe and McLaren 2005). Although my research did not entail a grounded theory approach, I did include some techniques of analysis from grounded theory. These insights included comparative coding and theoretic sampling (Strauss and Corbin 1990).

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[93] See also Agger 1991, Barnes and Mercer 1997, Campbell and Oliver 1996, Clear 1996, 1999, Corker 1999, Davis 2000, Denzin and Lincoln 1994, Guba and Lincoln 1994, 2005, Kincheloe and McLaren 2005, Lunt and Thornton 1997, May 1998, Oliver 1997, Parker and Lynn 2002, Shah 2006, Swain and Gillman 1998, Vernon 1997.

[94] See also Guba and Lincoln 1994.

[95] See also Agger 1991, Moore et al. 1998, Shakespeare et al. 1993.

According to Creswell (2003:200), it is particularly important in qualitative research that researcher's identify the "values, assumptions and biases" they bring to a study. Vernon (1997:159) further cautions that if the topic of research is similar to a researcher's life experiences, the greater the need to re-evaluate how one's beliefs influence the research process, the questions asked, and interpretation of findings. The focus of my research is of particular interest to me for two reasons. First of all, having a son in the long-term care system now for twenty-five years has meant having the ability to observe care delivery by both the non-profit and private for-profit sectors. Second, I know some adult community residences have closed because of government cutbacks, that facilities have been physically altered to make room for increasing numbers of residents, and that some individuals have been placed out-of-province due to lack of available spaces (Morrisey 2007). On the other hand, I am also very thankful for the care my son receives because of the work ethic and attitudes of front-line staff members and the continual upgrades to the particular facility where my son lives.

Situating my-self as investigator is important, not just for revealing my years of experience observing formal care delivery, but also for elucidating my rationale for wanting to learn as much as possible about the experiences of delivering and receiving care. McCracken (1988:19) is right, however, that while my experiences can be beneficial with regard to insights about the subject matter and the questions I ask participants, they also raise concerns about the potential for researcher bias. Besides, a critical epistemology requires that I confront the specific biography (Denzin and Lincoln 1994) I brought to this research. Therefore, following Maxwell's (2005) mandate regarding the need to explain how these biases were dealt with I provide the following:

First of all, advantages and disadvantages are intrinsic to the personal background I bring to this research. A specific advantage I brought to the research is my "insider awareness" (Douglas 1976), which meant a genuine interest in how other parents experienced out-of-home placement of their children.

Insider awareness also facilitated a measure of intersubjectivity (Prus 1994), linking together (Darlington and Scott 2002:54), and merging (Padgett 1998:60) between family members and I that involved some mutual sharing of information (Boyd 1993, Sorrell and Redmond 1995).[96] Insider awareness typically results in greater willingness by participants to trust their 'thoughts' to researchers like me (Darlington and Scott 2002:54). The "social distance" between mothers and I was minimized even further because of our similar experiences (Oakley 1981:55). For instance, in the course of being interviewed, Kim looked at me and said, "I am sure you have the same concern for your child every day" as she discussed her concerns regarding her daughter's future.

Insider awareness also brings certain disadvantages, however. For instance, I had to confront the matter of whether I was capable of conducting "sound research" (Labaree 2002:116) because of my stance. I responded to this concern by engaging reflexively with the data and critically examining my personal assumptions and tacit knowledge throughout data collection (Hammersley and Atkinson 1989), which helped in dealing with this issue. This required being introspective about everything I encountered during data collection, how I wrote up the data, and whether I over-emphasized particular areas the research or the views of certain participants, which would have compromised representational integrity (Owens 2007:302). Thus, I was able

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[96] Lowenberg 1993.

to distance myself from my tacit knowledge of a parent’s experience of long-term-care placement (Altheide and Johnson 1994).

In addition, this research did not entail engaging in “backyard research” which, according to Glesne and Peshkin (1992) is research that is carried out with people already known to the researcher. The fieldwork and interviews I conducted were with people formerly unknown to myself, save for one informant from my Master’s research, and in facilities where I had never conducted research before. Therefore, I was not hindered from being able to introduce more difficult issues (Creswell 2003:184) with participants, which is often not the case when participants and researchers know each other. I also worked at “manufacturing distance,” which McCracken (1988:23) argues is a requisite when dealing with issues where there is a profound and “blinding familiarity.” I failed to adequately address this matter in previous research (Morrisey 2007) by incorrectly assuming to understand what a participant meant when referring to the concept of ‘happiness’ and mistakenly thinking that the privatization of care rather than increased levels of administration leads to compromised care (Morrisey 2007).

For these reasons, I determined in this research to pay greater attention to the data and to be more sensitive to check my preconceived assumptions in an attempt to overcome my biases. By constantly comparing the data, I also worked at guarding against bias, a technique which facilitates more accuracy and ‘consistency’ (Corbin and Strauss 1990:9) in the data. Although skeptical about the possibility of any researcher being completely self-aware, the intentional efforts I took to deal with insider awareness did help in guarding against bias. Moreover, it is wrong to assume that individuals without first-hand experience with disability would be better suited to do research about disability (Oliver 1990 in Bickenbach et al. 1999:1179).

Rigour, Validity, Reliability, and Generalizability

In the following section, I explain the specific endeavours I undertook to produce valid and reliable data and, ultimately, to conduct rigorous research. Part of my explanation involves a discussion of the nature of validity in qualitative research, my approaches to enhancing the validity of the data, the ways I worked to avoid compromising validity, and the specific measures I took to deal with internal and external validity threats, as well as my influence and impact as researcher. In this section, I also argue my potential to make moderate generalizations from the data I collected and contend for the reliability of this data because of my careful documentation of procedures, the contextualization of the data, and the saturation of emergent themes.

Validity

Since validity is a goal in any research (Maxwell 2005:105), it is necessary to address potential concerns related to validity, as well as reliability, and to work towards a good research design. While validity is conditional on participants' truthful accounts, differing interpretations of similar environments and experiences do not undermine validity in qualitative research (Neuman 2003). To enrich the validity and authenticity of accounts (Neuman 2003), all participants were encouraged to discuss things in their own way (Wearing 1998). The discourses that emerged during interviews and fieldwork revealed the connections between macro and micro levels of care delivery and illustrated how validity can be enhanced through the "dense connectivity" of dissimilar information and linkages (Neuman 2003:185).

A qualitative research approach is advantageous to theoretical validity, according to Kirk and Miller (1986:25), because of the constant reflexive process involved in analyzing the data. I also carefully developed and constantly tested concepts and categories for consistency throughout the research process in an attempt to achieve construct validity (Corbin and Strauss 1990). All concepts emerged from the data and were used in discerning "more general concepts and thematic statements" (Wasserman et al. 2009:356). Oliver (1992) argues that the validity of critical research lies in its potential for praxis, although Fawcett and Hearn (2004:210) contend that this should not be the only measure. The theoretical validity of this research became more apparent as the "tentative conclusions" I initially drew about some matters were eventually invalidated because of being constantly reflexive in my data analyses (Kirk and Miller 1986).

In addition, I met frequently with my supervisor to discuss my analysis, and while she confirmed several of my initial conclusions regarding emergent themes in these discussions, we recognized other themes in the data I had missed, such as how care recipients' self-identities emerge. This type of reflexive interaction pushed me to engage in a deeper analysis of the data. Because fieldwork takes into account participants' meanings, it inherently has 'validities' atypical of 'nonqualitative' approaches (Kirk and Miller 1986:31). The compelling depictions I provide in the following chapters also reveal my personal experiences with the research, thereby constituting a plausible account of the data (Neuman 2003:185).

A semi-structured interviewing technique allowed information to emerge that would inform, rather than verify, theory (Charmaz 1991:392). A semi-structured interview style also avoided some of the problems associated with close-ended questions that might have hindered participants' ability to understand the intentions or meaning of questions, made it impossible to get information on the actual conditions of their lives, opinions or values, which then would have compromised the ecological validity of the data (Cicourel 1982). Moreover, a semi-structured interview style also helped in addressing another validity threat, 'reactivity,' which is the potential effect I could have had on research participants (Maxwell 2005:108, 109). Although it is impossible to completely control researcher influence, Maxwell (2005:109) charges researchers to be vigilant with respect to our influence on what participants say and the 'inferences' drawn. A reflexive approach (Davis 2000, Fawcett and Hearn 2004)[97] was fruitful in helping me recognize my power and influence as researcher and how my values and social identity impacted both data collection and interpretation (Vernon 1997, Shah 2006), an approach consistent with Foucauldian analyses (Allan 2005), and the generation of more credible data.

Semi-structured interviews allowed participants to talk about issues important to them and in their own way (Wearing 1998), as noted earlier. I followed Charmaz's (1991:391) recommendations by framing questions so participants could freely discuss

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[97] See also Agger 1991, Allan 2005, Barnes and Mercer 1997, Campbell and Oliver 1996, Clear 1996, 1999, Davis 2000, Denzin and Lincoln 1994, Lunt and Thornton 1997, Parker and Lynn 2002, Shah 2006.

their feelings and experiences, and by starting questions with ‘What,’ ‘How,’ or “Tell me about” to avoid restricting the type of information they might offer and to try and minimize my influence on their responses. By using a semi-structured questioning style and a reflexive approach to the data, it is my conclusion that I lessened my impact as researcher and was able to get more credible data. My interview approach with residents was also intentional for enhancing validity. I used simple “open-ended questions” (Sigelman et al. 1983:205) with individuals, which enhanced the validity of their responses, and the time I spent in the facilities made residents more aware of who I was, what they were agreeing to, and helped in discerning if their interpretations of their experiences matched my observations (Silverman 1998). Conducting respondent validation exercises with participants (Stalker 1998) so they could provide input on how I presented my findings prior to finalizing my report, further validated the data.

Taking the necessary time to build rapport with participants elicited more credible data, as did member checking, an approach said to engender more credible data among people with significant disabilities (Bigby et al. 2009). According to Kincheloe and McLaren (1994:147), member checking involves providing participants with my interpretation of the data to see if it was accurate. Lincoln and Guba (1985:301) explain member-checking as testing findings with the individuals from whom the data was drawn. Credibility is established when the analysis is ‘plausible’ to participants (Kincheloe and McLaren 1994:147). For Barbour (2001:1117), “respondent validation” is priceless in situations where researchers want to work with participants to bring about ‘change.’ Research has been conducted with ‘integrity’ if researchers hold themselves accountable to those who participated in the research and can be impacted by research results (Ristock and Pennell 1996:116). By providing all participants with a copy of my analysis to ensure I represented them accurately in the research and by following optimum ethical protocols during data collection, it is my contention that I conducted this research with integrity.

I avoided external validity threats by not making wrong inferences or generalizing to groups, other than those studied (Creswell 2003:171). However, I was able to make moderate generalizations or generalizations by similarity, which I discuss more fully in the next section. Internal validity threats can arise from using inadequate procedures or difficulty with applying procedures (Creswell 2003). Conducting interviews and fieldwork helped to bridge the gap between what people said and actually did (Silverman 1998).[98] More specifically, fieldwork allowed me to observe behaviours, while interviews provided participants' accounts of their everyday experiences. This type of information facilitated a deeper understanding of the meanings that these individuals attached to their everyday world with respect to their experiences with the long-term care system. Combining data from fieldwork, interviews, and relevant documents also helped to situate my research historically, culturally, politically, and contextually, and allowed me to theorize about the data (Silverman 1998:110). Recognizing broader structural conditions or accounting for the "conditional matrix" (Corbin and Strauss 1990:11) made for a richer analysis.

Conducting semi-structured interviews and engaging in substantial fieldwork made for rich data and my personal exposure to long-term care and similar background experiences to family members, albeit limited in some ways, may have reinforced the

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[98] See also Gilbert and Mulkay 1983, Webb and Stimson 1976.

validity of the data as well. By engaging in member-checking, providing rich, thick descriptions, clarifying researcher bias, and acknowledging all data, including discrepant information, I took specific approaches that would add to the accuracy of findings (Creswell 2003:196). Including discrepant information is consistent with a reflexive analytical approach. The tactics I used in an attempt to try and overcome researcher bias were dealt with earlier in this chapter. Spending close to 160 hours in the field functioned as a validity check to any misinformation I might have gained through interviews (Kirk and Miller 1986), thereby significantly strengthening the validity and reliability of this research (Kirk and Miller 1986).

Reliability

According to Silverman (1998:111), a main concern for researchers is the 'reliability' of their data. Kirk and Miller (1986:72) explain that documenting research procedure makes it possible to measure reliability. The specific ways I endeavoured to be rigorous in data collection included: using a tape recorder for all interviews on participants' permission, taking extensive field and interview notes, utilizing the NVivo 9 computer program created specifically for qualitative data analyses, and maintaining a filing system for all data. Files are critical 'stimulants' in analyses (Lofland 1971:119) and field notes are useful for addressing the "conditional matrix" (Corbin and Strauss 1990:11), where the detailed contextualization of observations enhances the reliability of data (Kirk and Miller 1986). By carefully documenting all of my research activities, I have provided, in Orb et al.'s (2001:95) words, an "audit trail" (Streubert and Carpenter 1999), which makes it possible to confirm my data.

I was also able to achieve synchronic reliability, or internal reliability, by comparing data (Kirk and Miller 1986:42) from all sources, which generated similar information (Kirk and Miller 1986:80). Synchronic reliability occurs when there is consistency within data that emerges over a specific time period and an internal logic is observable in findings. At the same time, synchronic reliability allows that different findings might emerge from data collected on the same phenomenon at a different point in time. This research is also reliable as theoretical saturation was reached, which happens when there is a prevalent pattern that continue to emerge in the data (Engward 2013:40).[99] Similar to Marquis and Jackson (2000:415), themes were noted as they emerged until saturation was reached. The extensive number of participants in this research, compared to that of Chan et al. (2001) in their research among adults with intellectual disabilities in long-term respite care, further strengthens my data.

Generalizability

Although the breadth of my research is extensive, my conclusions are not a complete revelation of formal long-term care delivery for adults diagnosed with significant disabilities and/or mental illnesses in New Brunswick, nor representative of the entirety of issues related to this topic, but constitute a partial understandings of the phenomenon (Kirk and Miller 1986:46). The "rich description of the field notes" (Bigby et al. 2009:370), however, supports the transferability of my research and I have provided enough 'descriptive' information to generate "similarity judgments" (Lincoln

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[99] See also Bryant and Charmaz 2007, Charmaz 2006, Glaser and Strauss 1967, Wasserman et al. 2009.

and Guba 1985:316). Guba and Lincoln (2005:194) call this “generalization by similarity,” which is possible when the combined “social, political, cultural, economic, ethnic and gender circumstances and values” are analogous in other milieus. Generalizations of this kind are moderate - *moderatum* generalizations – “generalizations of everyday life” (Williams 2000:215). My intent in this research was not to make predictive, self-evident or ‘statistical’ simplifications (Williams 2000:221), but I should be able to make some generalizations or “say something of something” (Geertz 1979:218), about the formal long-term care experience in New Brunswick from the data. So, the *moderatum* generalizations I am making are not less rigorous but of a different kind.

Goal of Research

There are a number of research goals inherent with a critical theoretical perspective. The goal is never simply to increase knowledge (Quantz 1992, Villaverde and Kincheloe 1998)[100] but to bring about social change (Alway 1995, Devlin and Pothier 2006), tangible improvement (Kincheloe and McLaren 2005:308) and the imagining of fresh options (Morrow and Brown 1994:11). Critical research is unequivocally directed toward critiquing relationships marked by power (Morrow and Brown 1994:11) and prevailing forms of power (Kincheloe and McLaren 2005:306), as well as seeking the emancipation (Gitlen et al. 1989) and liberation (Marcuse 1964,

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[100] See also Agger 1991, Horkheimer 1972, Kincheloe 1991, Kincheloe and Steinberg 1993.

Vernon 1997) of humankind by addressing social justice issues (Guba and Lincoln 2005, Kincheloe and McLaren 2005).

The four-fold goal of critical inquiry is that of "critique and transformation, restitution and emancipation" (Guba and Lincoln 2005:194). Empowering individuals and oppressed groups (Kincheloe and McLaren 2005, Smith 2005), including persons with disabilities (Barnes and Mercer 1997, Oliver 1992), is key to critical research. Having a voice is an important step towards empowerment (Vernon 19972) and within a critical disability paradigm, assumptions about disability as misfortune or abnormality are challenged (Devlin and Pothier 2006) and the emancipation of persons with disabilities crucial (Clear 1999, Stone and Priestley 1996).[101] Finally, advocacy and activism are important goals in a critical research paradigm (Guba and Lincoln 1994). Personal goals for this research are discussed in the following paragraph.

Maxwell (2005) mandated that researchers establish their research goals along three lines: personal, practical, and intellectual. It was a personal desire to give voice to people diagnosed with severe disabilities and/or mental illnesses who live in long-term care facilities, a group seldom heard from. I was also interested in others' experiences with care delivery and how the philosophical and structural components of the long-term care system inform care delivery at ground level. In addition, I wanted to raise awareness about issues with long-term care delivery for residents and those responsible for care delivery. The practical potential of this research lies in a drawing attention to the specific gaps between both official and non-official philosophical care objectives and actual care provision.

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[101] See also Oliver 1992, 1996, 1997.

As for intellectual goals, I was intentional in addressing the specific gaps in the literature regarding residents' experiences with care provision in general, and particularly in New Brunswick. Residents' views, those of other participants, and the observations I gleaned in the field, deepen the value of this research. In light of my research goals and the mandate to utilize the most effective strategies to respond to the research questions, I took a qualitative research approach, with fieldwork and interviews as my primary data sources, and analyses of various documents and legislations as secondary data sources. Therefore, a qualitative research design was fruitful for gathering and analyzing the "rich data" I needed to contribute to a better understanding of long-term care for adults with significant disabilities and/or mental illnesses in New Brunswick (Becker 1970, Johnson 2002).

CHAPTER FIVE: THE OUT-OF-HOME PLACEMENT PROCESS

This chapter deals with parents' experiences of having their children with significant disabilities and/or serious mental illnesses placed into long-term care facilities. There are a number of cumulative factors leading parents to conclude they have no alternative but to find other caregiving and living arrangements for their children. Once parents reach this conclusion, they reach out to various persons in an attempt to get the placement process started. Assessments are necessary to determine eligibility for services, the level of care required, and the amount of money families will be able to contribute toward their children's care. A number of factors complicate out-of-home placements once it is determined that formal long-term care services are required: limited housing options, a lack of communication and fragmentation of services between government departments, a lack of communication between care sectors, and the need to ensure that residents are a suitable fit in the facilities. Parents face a number of issues post-placement that include difficulty handing caregiving responsibilities over to others and guilt over having placed their children placed out-of-home. Residents of long-term care facilities have problems adjusting to their new living situations, fellow residents, and not being able to return home to live with their families.

Factors Leading to Out-of-Home Placements

According to the five parents who participated in this research, various factors led them to seek out-of-home placement for their children, although four parents told me they would have preferred to care for their children in their own homes, consistent with

Llewellyn et al.'s (1999) findings. Three factors leading to out-of-home placements were the age, size and behaviours of their children. All parents had reached their caregiving capacity and there were concerns for personal well-being. Three parents were worried over the well-being of their other children, four parents discussed the financial costs of care-giving, and all parents discussed the negative impact that caregiving had in their social lives. Contextual factors that informed out-of-home placement decisions included the loss of supports formerly available in the school system for two parents, and the loss of respite care services for one couple. All parents experienced significant stress with caregiving and one mother had become emotionally exhausted. It was the cumulative effect of the above factors that led the parents to seek out-of-home placement for their children, all parents considering this decision to be their last remaining option.

Toll of Caregiving, Contextual Factors, and Point of Decision

Parents' physical wellbeing was compromised because of the effects of years of caregiving, consistent with other findings (Bourke-Taylor et al. 2011, Norlin and Broberg 2013), influencing their decision to have their children placed out-of-home. For instance, Emilie was unable to lift her right arm when I interviewed her because of the damage done to her shoulder from repeatedly lifting her daughter, Evangeline. Emilie's husband Francois had also come to the point where he had difficulty lifting Evangeline as she grew older. Francois explained: "She was getting so heavy that a couple of times I had an accident where I fell with her and I cut her and I cut myself." The increasing size of Lorna's son Caleb became a real issue for Lorna as well, who told me she knew she had to do something before she incurred a long-term injury from straining to lift him, something found in other research on parents with children with severe disabilities (Mirfin-Veitch et al. 2003, Werner et al. 2009). Lorna described it this way:

> I realized I can't do this. He weighed 100 pounds, and I was still lifting him into the bed, out of the bed, into the bathtub, and I was thinking, 'I'm strong, because I've done it all my life, but all of a sudden I'm getting older and I can't. When you're 50, you can't do what you did when you were 30. (Lorna*)*

According to Fadden et al. (1987) and Lewis and Johnson (2005), there are additional costs associated with caring for children with disabilities. This was the case in this research, and served as an additional factor informing parents' decisions to have their children placed out-of-home placement. Francois discussed his experiences with this matter:

> The Government told me that if I bought a van, that they would put a lift in. So I bought a van, but they never did put it in. So I built two ramps, and we pushed the wheelchair in with our own strength. (Francois)

The need to purchase a van so that a lift could be installed reveals that requirements for specialized equipment can mean greater financial demands on families. In addition, Francois built the ramps himself because the promised government funding did not come through but it meant that he and Emilie had to rely on their physical strength to make the ramps work.

Another financial stress for Francois and Emilie was that Emilie did not have paid employment. Francois explained: "When only one parent is working, it's hard." Emilie gave her perspective on the matter: "I didn't work. I was at home because I wanted to be with Evangeline. Evangeline was important. I spent all of my years at home for Evangeline." The argument that mothers typically provide the bulk of caregiving was reinforced in this research, as all mothers were the primary caregivers prior to out-of-home placement (c.f. Norlin and Broberg 2013, Statistics Canada 2006, 2008). In addition, only Lorna had a paid part-time job at the time, which supports Anderson et al. (2002) and Bourke-Taylor et al.'s (2011) findings about the unemployment and underemployment that mothers in these types of caregiving situations experience.

Kim told me that there were times when her husband had to take time off work to look after both Kim and her daughter before their child was placed in a facility because Kim was emotionally exhausted. Kim explained that she reached the point where she "just could not get out of bed." Kim's account reveals the emotional toll that caring for a child with severe disabilities can present for parents, consistent with Cummins' (2001) and Green's (2007) position on the matter. The contention that father's work lives can be impacted, which Anderson et al. (2002) and Werner et al. (2009) argue, was also relevant in Kim's husband having to take time off work. All parents reported that their social lives were negatively impacted by the intense level of care their children required, in keeping with Fadden et al.'s (1987) and Werner et al.'s (2009) research. For instance, Lorna shared: "We never went very many places together, because one of us always stayed home to take care of Caleb. That got to be tiresome and stressful." Similarly, Kim said: "We used to say our entertainment was the TV because we had no social life."

It was also difficult for parents to take their children on social outings. Francois and Emilie talked about reaching a point where they just stopped taking Evangeline to the annual party Francois' boss held for employees and their families. In Emilie's words, “We didn’t dare. She would get nervous and make a scene a lot of times.” It was also increasingly difficult, nearly impossible, to find people willing to babysit. On the rare occasions when Francois and Emilie were able to find a babysitter, they were often called home because the sitter was having difficulties with Evangeline. Francois concluded his discussion of the matter with, “Really, it is a sad story.” It was also a problem for the parents to entertain friends in their homes because of their children’s behaviours and their physical displays of aggression. According to Kim, “It just got to the point that the friends we had stopped coming because a lot of times there would be a big temper tantrum.”

Behaviours (Grant and Ramcharan 2001, Hastings et al. 2006) combined with the size (Mirfin-Veitch et al. 2003, Werner et al. 2009) of children are noted as exacerbating factors for families of children with disabilities. This was also the case for the families who participated in this research. For instance, William explained that after their father’s death his sister Ethel never recovered and her violent behaviours and increasing size were the deciding factors in having Ethel placed out-of-home:

> Her world collapsed, and she never seemed to recover. Things went from bad to worse. Sometimes, she would get violent, and she had gotten to be quite a size so, for my mother, there was just no way. (William)

There was a period of time when Lorna and her husband had the freedom to go out once a week but this stopped once they lost respite care services. Lorna described the situation prior to losing respite care services:

> We planned every Thursday night to go out. Some weeks, if it was a bad week, we could not wait for Thursday night to come. It was wonderful! It was absolutely wonderful! (Lorna)

Lorna told me she was devastated when she lost respite care services as a result of funding cutbacks because she was then responsible to care for Caleb twenty-four hours a day, without reprieve.

McConkey et al. (2010, 2011) and Staley (2008) contend that there insufficient respite care resources exist for such families. The loss of respite care was an additional factor in Lorna's decision for out-of-home placement. According to Brenda and Lorna, programs once available to their children in the school system were lost when they got older, a perennial problem documented in other research (c.f. Forsythe et al. 2010, Mencap 2010). Lorna found this loss particularly difficult as she was unable to find alternative programs for Caleb because, in her words, "he was multi-handicapped." Blacher and Hanneman (1993:158) argue that losing school services is a trigger for parents to place children in care. So too, it was for Brenda and Lorna, as was the loss of respite care for Lorna. However, these events alone did not lead them to this decision.

Another factor for parents was related to concerns that their children with disabilities would outlive them and their other children would become responsible for caregiving. To avert this scenario, Brenda and her husband made alternate care arrangements for their daughter. Parents' concern about this matter is legitimate for according to Norma, a representative of the New Brunswick Association of Community Living, "This is the first generation in history where people with disabilities are outliving their parents . . . so we have a lot of families that are in crisis." In discussing the arrangements she and her husband made for their daughter, Brenda said, "If we are both killed in a car accident tomorrow our daughter is situated and our other daughter doesn't have to worry." Brenda then pointed to her sister-in-law's failure to make future caregiving arrangements for her son, also diagnosed with disabilities, as irresponsible.

According to Stoneman and Berman (1993), as well as Werner et al. (2009), the accumulated stress and care burden or "snowball effect" (Blacher and Hanneman 1993:158), leads parents to seek out-of home placement for their children. This was also the case in this research. Two couples were counseled by relatives that they needed to consider having their children placed out-of-home because of the accumulating stress relatives were observing in these parents. According to Francois and Emilie, relatives told them to prepare for the point when Evangeline would have to be placed in a long-term care facility because "It's going to come one day. It's going to come." Relatives also talked with Kim and her husband about considering the possibility of having their daughter placed early on but as Kim told me, "I just couldn't picture letting her go and stay with strangers." All parents did eventually conclude, however, that they could no longer meet the care demands their children required.

Lorna, who has another son besides Caleb, told me: "You know, I was primary caregiver, plus I worked part-time, plus I ran the household, and I was kind of doing it all. It was hard." According to Lorna, the final crunch came one day when she was struggling to lift her son: "He was twenty-one and I thought, my God, I just can't do this forever," and that twenty-one seemed like a good age to consider alternative care. Lorna's experience reinforces findings that the age (Black et al. 2010, McConkey et al. 2011) and size (Mirfin-Veitch et al. 2003, Werner et al. 2009) of the person being cared for are key factors in deciding for out-of-home placement. Lorna told me that her husband was unaware she had reached this point but went on to say, "I guess I had never come out and said that before."

Kim gave her rationale for finally deciding to have her daughter placed out-of-home: "The reason she went into the home . . . was basically because I just eventually hit the wall because she was, and she is still, twenty-four hour care." Brenda gave her rationale as well: "I guess I just got to the point that it was either going to be her or me, that was going to go and, I guess I was desperate." Brenda added that having her daughter placed was "a really difficult thing to do but at the time it was all I had to do." Emilie and Francois also talked about reaching the point where they no longer knew what to do. Doug, operator of adult community residence agency A, said that despite one particular mother's love for her son and efforts to care for him, his violent behaviour as well as her own tiredness led her to decide for out-of-home placement:

> The mother was super. She loved this child. She was just overtired. She tried, and she tried, and she tried, but you know, she couldn't. This child used to tip a washer full of water and clothes over. That's how strong he was. And he was violent to his mother. (Doug)

Dr. Faulkner also said that parents get to a point where "they can't cope with it anymore."

All parents characterized their decision for out-of-home placements as their only option rather than a choice, because of the exhaustion of remaining alternatives. Francois was explicit that he and Emilie had no choice in the matter because once Evangeline reached a certain age they lost the government funding that had been available to support them in caring for her at home:

> Up to the age of sixteen we got $300 a month to help with caring for Evangeline but, when she turned eighteen we got nothing. They would take my blue cross to buy medicine, so it cost a lot. You are doing your share, but it's not enough. (Francois)

Francois and Emilie's experience is consistent with the argument that insufficient government funding can be a roadblock to parents' capacities to provide the level of care needed (Werner et al. 2009:36), and the contention that age is a factor in deciding for out-of home placement (Black et al. 2010, McConkey et al. 2011).

While Francois and Emilie were pleased with the care Evangeline received at the adult community residence where she lived and their relationship with the operator of the facility, Francois was frustrated that the Government was spending far more to finance her care at this facility than it would have cost the Government to provide the resources for them to care for Evangeline in their own home, which they preferred to do:

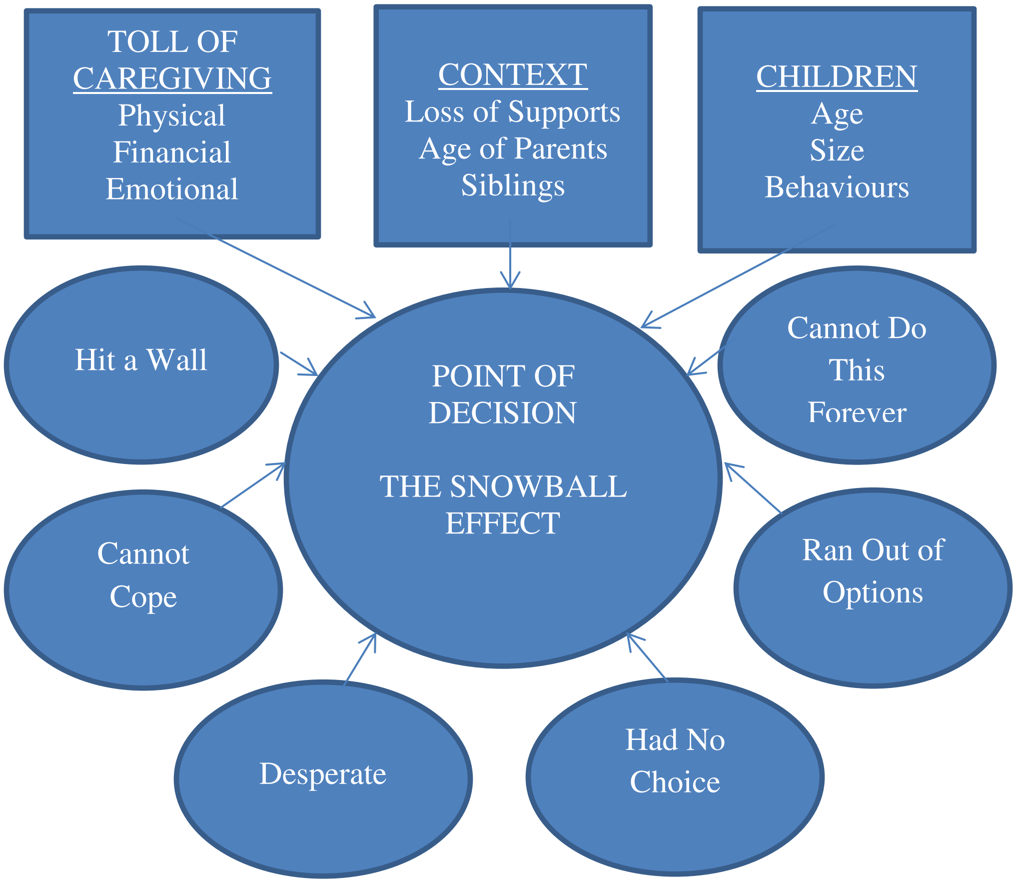
> What they pay here [at the adult community residence] for Evangeline, if the Government would give that to the parents, you know, we would have kept Evangeline but the parents have no choice but to give away their children! It would be a lot cheaper at home. (Francois)

Francois went on to explain that when Evangeline was young he and Emilie had agreed that they would not have her placed in a care facility but that "when she was older we had no choice," despite Evangeline being loved more than her siblings:

> Parents have no choice but to give away their children. It's a hard decision. It is hard how you feel! . . . It's a sad story when you can no longer take care of them. You love them as well, even more than your regular children, so you cannot part with them. (Francois).

Francois' description supports Mirfin-Veitch et al.'s (2003:105) characterization of the decision to have one's child placed out-of-home as the "most painful" one parents make. Francois concluded: "We went through a lot and wish parents could have help but it's a sad story the way it is." A conceptual model of the factors that led parents in this research to have their children placed out-of-home placement can be found below.

FIGURE I: FACTORS LEADING TO OUT-OF-HOME PLACEMENT



Assessment Processes and Hindrances to Out-of-Home Placements

To get the placement process started, parents sometimes contacted their family physicians, individuals from local care provision agencies, their children's case workers, or the Department of Social Development directly. Before placements take place, however, assessments have to be conducted to determine the level of care required and the amount of finances families can contribute towards their child's care. The Daily Activities of Living (ADL) assessment form is the generic tool used to evaluate the instrumental activities of daily living capabilities of clients, their cognitive, mental, and health statuses, and whether they engage in physical displays of aggression, self-harm, or disruptive behaviours, to determine the level of care and supervision individuals will require. The ADL form relies on a functional assessment model of disability (Hollander and Walker 1998) and the information gathered about the functional aspects and medical histories of individuals informs the types of services residents will receive (Danforth 2000). Numerous participants reported extended waiting periods for out-of-home placements that resulted from limited housing options, the fragmentation of services and lack of communication between government departments as well as between care sectors, and the need for residents to be tested for fit in the facilities.

First Steps in the Placement Process - Determining Eligibility

Some families reach out to their physicians for help, according to Dr. Faulkner, who explained that:

> Usually, it's a family that approaches us with numerous incidents of things that they do not like . . . These people don't really need specialized medical care. They just need a glorified babysitter but, you know, to have one for twenty-four hours can be costly. (Dr. Faulkner)

Dr. Faulkner was quick to add, however, that as a physician she does not make the decision to have individuals placed in care: "It's the choice of the family, the social worker, and the team." Dr. Faulkner's assertion that her role does not entail making decisions to have persons placed in long-term care facilities, aligns with Mirfin-Veitch et al.'s (2003:105) conception of physicians as 'facilitators' rather than decision-makers, in the placement process. Besides physicians, families sometimes reach out to local care provider agencies. Rhonda, supervisor with an adult community residence agency, told me that their agency receives many phone calls looking for services but they "redirect them back to their case worker." Rhonda explained the process: "The case worker has to put in the request and the request has to be approved before the funding comes in."

Brenda, Emilie, and Kim told me they contacted their children's social workers when they reached their caregiving limits. Linda, a social worker, explained that those without assigned case workers have to contact the Department of Social Development directly: "There's a 1-800 number to call, and a screener takes the needed information." Debbie, from the Department of Social Development, said that once parents make the call "that starts the ball rolling." A different social worker, Leslie, told me that the information from this call is registered as a new referral and placed in the database at the Department of Social Development. According to Rita, also from the Department of Social Development, the information from this new referral is then passed on to an assessment team. A social worker is then assigned who arranges an appointment with the family so an assessment can be conducted. Debbie, of the Department of Social Development, wanted to make it clear, however, that having a disability does not necessarily ensure eligibility for the program: "You have to have a disability that is long term in nature and an unmet need related to your disability."

Requests for adult residential care for individuals between the ages of nineteen and sixty-four with physical and intellectual disabilities and mental illnesses are processed through the newly initiated Disability Support Program (DSP) that went province-wide July 1, 2010. The long-term care service program, on the other hand, is targeted to individuals sixty-five and older. Although other agencies, such as the Department of Mental Health, the New Brunswick Association of Community Living, and the New Brunswick chapter of the Paraplegic Association, can recommend clients for particular services, it has to be first established, as Debbie noted, that there are legitimate unmet needs. If there is evidence of needs which have yet to be met, a social worker assesses the individual to determine eligibility for services.

In New Brunswick, a Level-1-4 classification system is used to determine eligibility for residential care (Hollander and Walker, 1998:56, 57). According to SD/DS (2012), both level 3 and level 4 care clients are medically stable, require supervision/care on a twenty four hour basis, assistance with personal care, and possibly supplementary professional health care/supervision at times. The main difference between level 3 and 4 clients is that level 4 clients may engage in aggressive behaviours and/or need staff to perform their personal care (SD/DS 2012). On the other hand, individuals assessed as either level 1 or 2 generally require only some supervision and/or assistance with daily living activities, may have mobility issues, and require a low to moderate level of care (SD/DS 2012).

Under the Disability Support Program (DSP), the process of determining eligibility is framed as an application for services rather than the assessment of an individual, reflecting a philosophical shift in how eligibility is conceptualized within the Department of Social Development. As Debbie put it, “It’s now a person centered process that looks at the goals of the individual in addition to particular needs.” Mark, team leader in an adult community residence, said that social workers do “try to please clients.” Debbie discussed the eligibility process further, adding that once a person completes the application, alone or with the assistance of a social worker, independent facilitators take over, and concluding: It’s facilitation in non-assessment.”

For individuals diagnosed with significant cognitive disabilities and/or mental illnesses unable to actively participate in the process, social workers look to family members or other individuals close to the client. According to Sherri, social workers also rely on family members to provide consent for the assessment (non-assessment) process if they have power of attorney and if the individual is unable to give their own consent. Debbie admitted that in such cases, assessments rather than applications characterize the process of determining placement needs. Even then, social workers’ ability to determine eligibility for services is not always clear. Rita of the Department of Social Development explained: “There are gray zones when they don’t know if a person is eligible for services. There’s a lot of gray.” Rita added, however, that in such cases “we provide support service to them when this happens,” referring to the social workers.

Linda discussed her personal experience with the assessment process. She first pointed out that the information gathered from assessments helps her in determining the level of care and supervision an individual will require and, when added to the data from the financial assessment, helps in deciding the amount of funding that will be allotted for care services. Linda also said that conducting assessments can be challenging because of the personal and sometimes upsetting questions she has to ask “while trying to be as kind as possible, because it’s very difficult for everyone.” Linda added: “It’s tough. It’s a conversation that wouldn’t be happening if things were going well.” Linda went on to discuss her approach when family members become emotionally distraught during assessments and her occasional second-guessing about whether she was adequately sensitive during these encounters:

> I remind myself that I'm the person who has to offer information and support and, in the time of difficult conversations, I have to be there for the client. There are definitely meetings sometimes that I come away and I go, 'Oh' . . . You can't help but be human. You can't help but wonder if everything that was said there, was what I would have wanted to be said to me. There definitely are those moments. (Linda)

Trying to manage her own emotions is an integral part of Linda's job during assessments. She turns to colleagues at such times: "It's definitely my colleagues I go to for debriefing." Linda also added that such incidents have caused her, at times, to re-evaluate her reasons for becoming a social worker in the first place.

On the other hand, Sherri, a different social worker, told me she is no longer affected when families become emotionally upset during such encounters because her years of experience enable her to detach so she can deal objectively with the task at hand:

> It's not difficult for me at all because, if you've been a social worker for as long as I have, you learn to separate yourself from that. And certainly, I can have empathy for them, and I acknowledge that it's a difficult situation but, the bottom line for me is what is in the best interests of the client and, if the client is cognitively well, they have the opportunity to decline participating in this process. Certainly clients get upset. They get emotionally distraught, but that doesn't impact on what I have to do. (Sherri)

Sherri's ability to emotionally detach and to stay focused on her role as social worker during assessments is indicative of Talcott Parsons' (1937) affective neutrality. Affective neutrality is pertinent here for, similar to the detached relationship between physicians and patients, Sherri was able to conduct herself in a technically competent manner, subordinating her personal emotions for instrumental purposes. Weber's characterization of bureaucracies is relevant here as well, for Sherri's training (Weber 1958:197,198), applied over time, trained her to carry out assessments and make decisions in an abstract and impersonal manner. Neither parents nor residents of long-term care facilities described their experiences with the assessment process. I did not ask them about this matter because I wanted these individuals to be free to focus on the aspects of placement important to them. Upon reflection, failing to probe about this issue meant that I was not able to analyze this part of their experiences (see Limitations and Suggestions for Future Research in Chapter Ten).

Determinations regarding required care levels for individuals are not necessarily final. For instance, Sherri explained that after a period of time has elapsed since an initial assessment, if caregivers, medical personnel, or family members report a change in the person, a re-assessment may have to be conducted. Sherri told me that changes may include "a decline in physical health, recent hospital admissions, or changes in cognitive status." Although there are cases where it is legitimate to change an individual's level of care requirements, for example, where an individual's needs change, levels of care for individuals can also be readjusted to suit the needs of facilities. For instance, Celeste, operator of adult community residence agency C, told me: "I have a man who was pushed up to a level four. His mental health worker was not happy but it needed to be done so that the residence could stay afloat." Celeste discussed the matter further telling me that "The difference between level three and level four is not much but it makes a big difference in the budget."

It is troubling that Celeste's budget was so tight that one empty bed meant the difference between whether the agency she operated would stay afloat or not, but this reality is consistent with Pedlar and Hutchinson's (2000) contention about how residents can be viewed as commodities. This situation also supports Goffman's (1961) contention that the needs of the institution take priority over individual residents and the argument that management's livelihood is conditional on their roles as care providers (Albrecht 1992, Albrecht and Bury 2001).[102] Changing an individual's level of care requirement to ensure enough revenue to operate a facility also contradicts DSP's characterization of assessments as 'person-centered' and highlights that assessments can be subjective (Barnes 1998).

Amanda, front line worker in an adult community residence, felt that categorizing individuals according to certain care levels was impractical in light of actual care provision:

> Your level of care is supposed to depend on the number of hours of care you require, and that's just impossible! It just does not happen. It is an ongoing process. There is no level one, level two, level three, or whatever. It is what it is for that day. (Amanda)

Foucault's concept of discourse is pertinent to assessment processes because the particular discourses that delineate between care level requirements (SD/DS 2012), reveal that a certain legitimized 'truth' (Foucault 1980a:131) which then makes the categorization of individuals (Allen 2005, Carlson 2005) and determinations about service eligibility possible (Danforth 2000, Oliver 1996). These diagnostic and assessment processes also demonstrate the "dividing practices" Foucault (1982:777,

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[102] See also Dalley 1991, Davis 1993, Oliver 1996, Thomas 2007.

778) spoke of, where individuals are “divided from others” and ‘subjectified’ during such encounters (Foucault 1978b:97).

Another way that Foucault is relevant to assessment processes is with regards to the issue of power. For instance, individuals within the Department of Social Development, social workers, and independent facilitators all have the power to categorize individuals and determine eligibility for services (Gillman et al. 2000, Valentine 2002), illustrating how it is possible to exercise bio-power (Foucault 1977, 1978a, 1980) over the individuals in need of long-term care services and supports. Nevertheless, once it is officially determined that a person requires a specific level of care, the problem is one of finding facilities in which to place these individuals.

Problems Finding Accommodations: Limited Options

A philosophical objective of the Department of Social Development is that residents and their families have some choice regarding placement preferences, and the ideal, according to Rita, is that families visit a facility prior to placement to see if this is a place where they would like their loved one to live. However, four of the five parents were unable to choose the facilities where their children were placed, which is typical according to Atkinson (1998). Evangeline was the exception however, for according to her mother Emilie, Evangeline chose the adult community residence where she lived. Emilie explained that when she took her daughter to a local nursing home. Evangeline said: “It looks like a hospital. I don’t want to!” When Emilie took her daughter to visit an adult community residence in the same area, on recognizing the operator of the facility and a former childhood friend, Evangeline said “I want to come here.”

Lorna talked about the lack of placement options that existed for her son Caleb because of his high care needs:

> There were no options because he was a pretty high level of care. But I just couldn't do it any longer, so I took the first thing that came my way. It has turned out to be okay though because it really is a wonderful facility. (Lorna)

Caleb did encounter problems at the facility however, when moved from a private to a shared bedroom, but this situation was resolved when Caleb was moved yet again into a bedroom with a young man who had similar tastes and care requirements. Lorna explained:

> They weren't happy. They didn't get along. They just irritated each other. They put Caleb with another boy and it worked out fine. He was a lot more like Evan, liked the same kind of music, the same level of disability, that kind of thing. (Lorna)

Rita, Department of Social Development, told me that because there were not many adult community residences the choices for placements were "not that great:"

> We don't have as many community re sidences as other types of facilities so the choices aren't that great. There are seventy adult community residences in the province so that's not a lot. (Rita)

Housing options in New Brunswick are dictated by available government funding, which is similar with other findings (Sandys 1982, Wight-Felske 1982). Clients' choices are also subject to availability, consistent with Parry-Jones and Soulsby (2001) research.

A consequence is that sometimes the Department of Social Development has to offer placement to individuals in areas other than where individuals originate according to Rita, which means that individuals have to "agree to move to the next community if they want long-term care services." Rita quickly added that individuals are not forced to accept these options as "It's still their choice." However, this is really a matter of semantics for individuals are forced to accept whatever is available to them at the time if they want long-term care services. Individuals being placed when and where beds are available, at times irrespective of region of family origin is a problem according to Perry et al. (2007:207) because residents can easily become separated from families and friends. Rita went on to say that if a bed opens up in a facility closer to where an individual is from the Department of Social Development can sometimes arrange to have the person moved but, then again, “sometimes not.”

Olivia and Sharon, executives of different nursing homes, both lamented that younger adults have to live with individuals many years their senior in nursing homes because no alternative care facilities exist for them. Olivia felt bad about this situation and wished there were more appropriate options available:

> I really feel bad that these younger individuals have to live in the same facilities as seniors. I really wish they had a place where they could live among people their own age or in their own apartment with 24 hours support. (Olivia)

Doris, a resident in one of these nursing homes, also discussed the lack of options for young people like her, adding that the area where she lived was “at a real loss for not having a place for younger people to go,” although she was aware that the possibility of such an alternative was not likely: “You need a facility but you are probably not going to get it because of cutbacks.” Theresa, a young resident in a different nursing home, gave her perspective on the matter as well: “I certainly wish there was a place for younger people compared to living, you know, with seniors.”

Language can also be a potential issue when it comes to placement options, according to Rita, because of occasions when services are unavailable in a client’s language of choice or comprehension. She felt this might be particularly the case for some regions of the province although she was confident that efforts were taken to meet the language needs of all individuals:

> We are hearing there were some issues in nursing homes around language but we have not heard that about community residences. The areas that might be a bit more difficult would be places like the Miramichi or Moncton where you have both populations, but in Saint John, or the Peninsula, or Edmundston, Grand Falls, it’s usually not an issue. Not to speak on their behalf, but I’m sure they’re trying to meet the language needs for individuals as much as possible. (Rita)

Byron moved staff or residents around to address language needs at the facilities he operated but, in the end, language was not a major concern:

> We had many bilingual staff. Sometimes I would juggle staff or residents so the language would be all in French in a particular house but it was not that major of an issue. (Byron)

Extended Waiting Periods, the Issue of Fit, and Re-institutionalization

In addition to limited placement options because of the insufficient number of adult community residences in the province there were also fewer beds available for adults compared to children, according to Rhonda. Two care providers told me that when beds do become available in various regions of the province they are protected for clients from those regions rather than being made available as needs arise. Yvette, supervisor with an adult community residence agency, said that in her experience “if there is not a bed available in their region and they are having a hard time to find a placement sometimes they ask us.” Celeste also said that there is occasional competition between the not-for-profit and private for-profit care sectors.

Individuals with higher care needs have even less choices of where to live because of the limited amount of resources targeted to these individuals. Rita explained:

> It can be particularly difficult to find a placement for persons designated as level 4 because the resources are so limited. It's not often that we have it to offer and there are not many. (Rita)

The difficulty with finding placements in New Brunswick for individuals with level 4 care needs reinforces the argument that people with more significant disabilities and higher care needs are particularly disadvantaged in finding placements (Pedlar and Hutchinson 2000), as well as the contention that they are most apt to have their needs unfulfilled (Prince 2006:98). Irrespective of the reason for the lack of placement options, families in crisis often face extended waiting periods before spaces become available for their children. Linda confirmed this state of affairs, explaining that once it is determined that an individual requires formal care it can be "months or a year's time that someone is living at home." Linda added: "There's a waiting list for nursing homes and certainly a waiting list for community residences." According to Sherri, finding placements can be an even greater problem in rural areas "because the services are not as plentiful."

Having to make placement decisions in the context of insufficient funding (Oliver 1996) and in-adequate supports hinders the ability of social workers and others from the Department of Social Development from being able to provide clients with the supports and services they need in a timely manner, which is particularly difficult for families in crises. While difficult choices are an essential part of policy implementation, as Titmuss (1974) and Wharf and McKenzie (2004) argue, the inability to offer the necessary supports and services when needed is apt to erode job satisfaction for these formal care providers. For instance, Linda was frustrated that she could not provide the supports to clients when needed and particularly during family crises:

> It’s hard, knowing that here is a client who needs this and we’re not able to meet that need. There can be crises and unfortunately not a lot of resources to respond in a timely way to address that crisis. (Linda)

Three employees in adult community residence agencies gave their perspective on extensive waiting periods for placements. Amanda told of personally knowing people who have been on the list for years, and added, “There are just no spots for them.” Another staff member shared that a client in need of level 4 care was still in the hospital after a year because they could not find a placement for him. Rhonda related the story of a woman whose son has been on the waiting list with the particular agency she works for since 1997 and the roadblocks this woman faced in finding a placement:

> They won’t allow her to sign a custody agreement because they don’t have a spot for him . . . She wants him at Care Services [pseudonym for the agency]. There’s no other option. (Rhonda)

Custody agreements between parents and the Minister of Social Development are a prerequisite to attaining long-term care services for individuals in New Brunswick deemed incapable of entering into such agreements themselves (Family Services Act (1983, Part I, 17:11). Signing custody agreements with the Department of Social Development means that parents transfer the legal custody and care of their children to this Department. This is something Goffman (1961:75) considered a key aspect of the mortification process. The ability of government officials to require parents to sign custody agreements in order to attain long-term care services for their children also illustrates how it becomes possible for bio-power to be exercised over parents (Foucault 1977, 1978a, 1980).

Rhonda told me as well that there have been occasions when she has counselled families who are desperate to do the following: “If you have a relief weekend, don’t pick them up.” Rhonda told of one mother who followed her advice:

> It just recently happened where one of the mothers didn’t return to pick up her son. The father had left, they were separated and the mother said ‘I can’t cope.’ So she didn’t pick him up and he’s still there. (Rhonda)

It must be terribly traumatic for parents to abandon their children as well as for the children who are abandoned. As difficult as it is for parents to try and explain to social workers that they can no longer provide the level of care their children need, it is unimaginable to be so desperate that abandoning one’s child is the only option to getting services. Rhonda also talked about the situation for a male resident of an adult community residence experiencing a lot of pain: “If something happens with Ernest that we can’t keep him comfortable and he has to be hospitalized, we’ve been told to leave him there.” Rhonda described the difficulty for Ernest and staff members should they follow this advice:

> We’ve got to walk out of the hospital and leave him there screaming. And he will because he’s scared of hospitals, scream for us to come back. We’ve had more staff say, ‘I hope I’m not working there that day’ because he’s been with us so long he’s like family. (Rhonda)

Individuals from the Department of Social Development, social workers, operators of agencies, family members, and individuals in need of care services all reported challenges in finding placement options.

An additional factor that further complicated placements and extended waiting times was having to ensure first that residents would fit into particular facilities. For both operators and employees, fit meant the ability of incoming residents to adjust to their surroundings without compromising the wellbeing of residents already living in the facilities. Five care providers talked about the issue of fit. Mark, team leader in an adult community residence, told of a six month trial period to test clients for fit at the facility, adding that if clients already living at the facility are negatively affected "sometimes we don't have a choice." Whether a client will fit into a facility is also related to whether care providers feel certain individuals will be too difficult to care for.

It was Mark's opinion that residents could generally choose if they wanted to live at the facility but he added that this was not the case for individuals with "more problems than others." Mark expanded: "If they're too heavy or in a wheelchair or a diaper, they don't come here because we're not equipped for that." Mark's comments reveal the capacity of care providers to opt for clients easier to care for, consistent with Lightman's (2003) findings. According to Rhonda, however, care providers do not always have the opportunity to determine if individuals will fit in at the facilities: "We have no say in the clientele we get." Ed, operator of an adult community residence agency, also complained of occasions when the Department of Social Development placed clients in his facilities before establishing that they would fit in. This can happen because social workers occasionally find themselves in desperate straits, to the point that they have to rush clients into facilities without first completing the necessary paperwork and before operators can determine if clients will fit. Celeste described one such incident:

> The social worker decided that Tim needed a place to live and she knew we had an open spot and she was desperate and so here he came without anything. There was no background on him. He moved in and we learned as we went. So it was an experience for me because I had to write to say 'Okay. Let me see the papers, the documentation.' (Celeste).

Most front-line workers had limited knowledge about the deliberations that take place over which clients got to live in the facilities but Amanda did share, “I know that there’s certain criteria. They have interviews, ratings, and so forth.”

The process of testing clients to see if they will fit in at the facilities is consistent with Goffman’s (1991:26) observations that residents are tested for their level of compliance during the in-patient phase to ensure that they don’t compromise the smooth running of the institution (Goffman 1961). Testing clients for fit also reveals the power, in Foucault’s (1977) sense of the term, that care providers possess and are able to exercise in determining which individuals will be able to adjust to others living in the facilities, similar to McConkey et al’s (2011) findings. It should be pointed out however, that new residents are not the only individuals required to adapt. Staff members are also expected to adjust to new residents. Celeste told of staff members at the facility that she operates having to adjust to a new resident because he needed a place to live: “Since it was only the staff that were affected I let it slide because he needs a place, and who are we to say no. He needs us.”

Sometimes parents expected staff to adjust as well. For instance, Lorna said that staff members were going to have to adjust to Caleb’s behaviours when he first moved into the facility rather than Caleb having to adjust to staff members: “They [the staff] thought everyone was going to get used to them and I said ‘I do not think so. I think you are going to have to get used to Caleb.’ Caleb did eventually adjust however, and his behaviours decreased. In the case of clients who engage in such violent behaviours that they pose a danger to themselves or others the Government has been looking into the possibility of re-institutionalization for these individuals. It was Rhonda’s opinion that the behaviors of some individuals warrant re-institutionalization, referring to one particular individual to make her point:

> He's so violent that they can't find a roommate to live with him. Right now, he requires a lot of money because of the extra staffing he requires because of his needs . . . I know when Centracare and Restigouche closed it was said that there are just some people who cannot live in a residential facility in the community, so maybe this is something that has to happen for those people because they don't fit in the puzzle piece. (Rhonda)

Doug, operator of adult community residence agency A, was discouraged that social workers' told him that the larger institutional model of care might be a better alternative in some cases. Despite Doug's concerns the Government has to devise alternative care arrangements for clients who engage in violent behaviours, given the extensive costs of paying individuals to work one-on-one with these difficult clients. Bruce, who operated adult community residence agency D, told me: "A thirty-four bed private facility and a new eighteen-bed non-profit facility for level three and four clients are being built right now." For those individuals deemed eligible for adult community residential care however, families can be left waiting for months and sometimes years for placements.

Linda told me that there are times when she is unable to offer placements to individuals and their families, typically in crises, because of the lack of options, which results in extended waiting periods. She added: "It's certainly a scenario that no one likes. It comes down to the basic needs with no alternatives to offer and it can be bad." Having to wait for placements, however, is not just the consequence of not enough available beds or that some individuals require more intense care. It is also symptomatic of a larger problem, the lack of communication between government departments, between formal care provider sectors, as well as the general fragmentation of government departments.

Lack of Communication between Government and Care Sectors

The fragmentation of mental health services is a problem reported universally (Champney and Weinmann 2004:2), in Ontario (Durbin et al. 2001), in Quebec (Fried et al. 1998), and in New Brunswick (McKee 2009:13). Bruce, operator of Adult Community Residence Agency D, was frustrated that the lack of communication between government departments hindered his ability to provide placements for clients who needed them and his ability to generate revenue:

> A director has to actively seek someone to fill a bed if a bed at one of his facilities becomes vacant, which is frustrating, because we know that there are people in the province who need a bed and can't find one. A level 4 individual constitutes $4,600 a month or $18,000 a year. So if you have a bed empty for 12 months you have lost $18,000 in revenue. The problem lies in the fact that the Department of Health, the Department of Social Work, and the Department of Mental Health all have lists but they must not be communicating. (Bruce).

Bruce went on to say that even though there were probably about 150 people still waiting to be placed, he still had difficulty filling beds at times. According to Bruce, "It would make more sense if there were one list, one data bank where directors could go and provide the needed care." Finding placements for certain individuals can also be frustrated by operators of adult community residence agencies themselves in being able to occasionally refuse care to certain individuals, as noted earlier. The capacity of these care providers to deny care to individuals establishes their own role in determining who gets to live in their facilities. Their ability to deny care was confirmed by Sherri in her comment that the Department of Social Development has to "negotiate with the different agencies to provide that care." Bruce's concern over generating revenue for the facilities also raises another matter. It means that residents are necessarily re-construed as commodities irrespective of the sentimental feelings that may exist towards these individuals (Pedlar and Hutchinson 2000).

Besides the lack of communication between government departments and the occasional ability of care providers to deny care to certain individuals, there was also a lack of communication between non-profit and private for-profit care sectors. Two operators of agencies in the non-profit sector knew little about privately operated adult community residences. For instance, when I asked Celeste if she had an opinion about care delivered by the private for-profit sector compared to the non-profit sector, she responded:

> I have a personal opinion that I've formed but I have never been to a home which is privately owned so I'll keep my opinion [pauses]. Probably it's not a good thing, so if I don't have the right facts I'm not going to say anything. (Celeste)

Bruce, operator of adult community residence agency D, also told me he did not know if the fight for wage parity for staff members in adult community residences included employees who worked in the private for-profit sector agencies: "You know, I think [pauses], I couldn't swear to that. I don't think they do. It's the non-profit sector that they're looking at." In discussing wage parity, Bruce was referring to Bill 35, *An Act to Amend the Public Service Labour Relations Act.* FIGURE II on the following page is an illustration of how the placement process works, while FIGURE III represents the pursuant difficulties finding accommodations for those who need them.

FIGURE II: THE PLACEMENT PROCESS

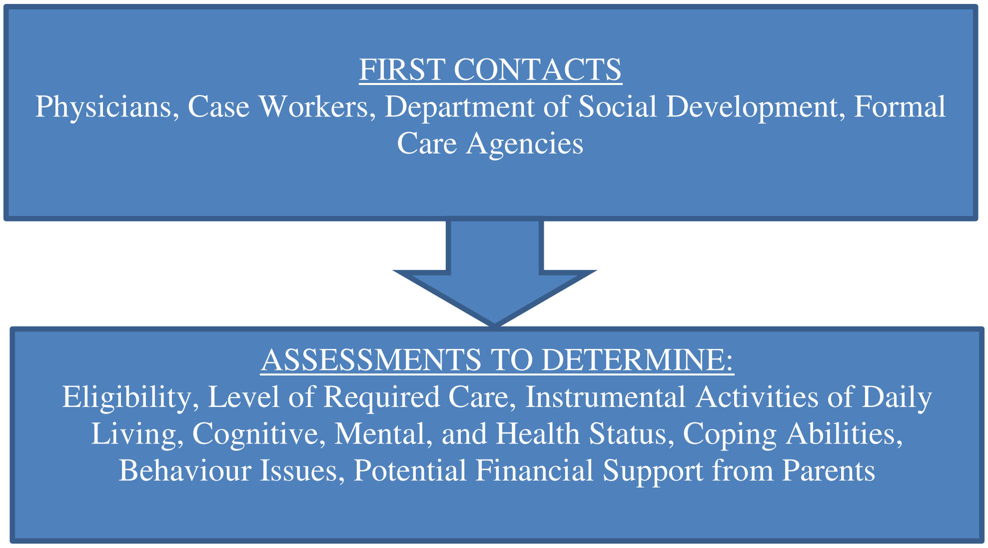
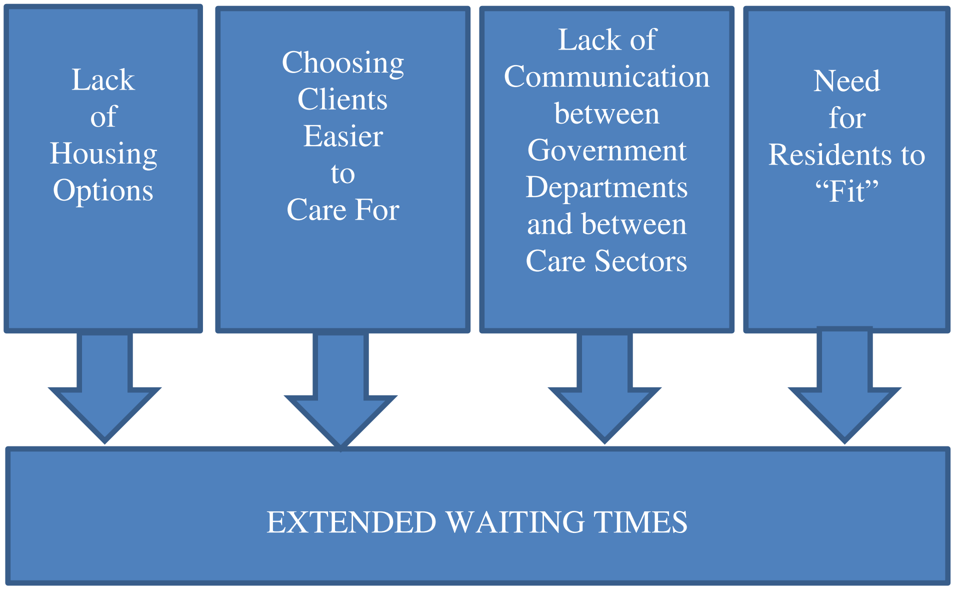


FIGURE III: EXTENDED WAITING PERIODS



Post-Placement Issues

As parents discussed their post-placement experiences a number of themes emerged. Parents faced never-ending adjustments after placing their children placed out-of-home. Three parents described passing over the care of their children as particularly hard, one mother referring to it as much like a death. The transition to the facilities was difficult for their children as well. One mother discussed her new-found freedom post-placement but she and seven other participants also talked about their guilt over having placed their children out-of-home. Two mothers found great difficulty in having to reduce contact with their children once placed as mandated, and three parents talked about the problem of not being able to check on their sleeping children as they once did. Parents also faced challenges when their children asked to return home with them after visits or asked to not go back to the facilities after home visits. All parents told me they maintained contact with their children in the facilities, similar to other findings (Seltzer et al. 2001, de Kock 1988) and supporting Marshall and Baffour's (2011) contention that young adults in care receive more visits. These parents' accounts also support de Kock's (1988:137) argument that individuals cared for by parent, from the point of birth until out-of-home placement experience greater contact with family members.

Never Ending Adjustments, Problems Letting Go, and Feeling Loss and Guilt

Kim told me she was devastated when the operator of the facility where her daughter was placed told her not to visit her child for four months, to allow her daughter time to adjust to her new surroundings. Brenda was also instructed to reduce the amount of contact she had with her daughter. Brenda said: “At first I was going to see her every day when she moved out and they asked me not to do that. Oh, it was really hard.” The instruction to Kim and Brenda to reduce contact with their children resonates with Goffman’s (1961:24) “deep initial break” and the “first curtailment of self” he observed, where barriers were established between in-coming residents and support networks.

Although Francois and Emilie characterized the period after Evangeline went into formal care as ‘hard,’ this transition was particularly difficult for the individuals actually placed into the facilities. For instance, Lorna told of Caleb being unhappy and becoming aggressive when he was placed into a long-term care facility, which made it difficult for staff members and a hard time of transition for Lorna:

> At first, it was very stressful because he wasn’t very happy. He wasn’t happy, and he had aggressive behaviours and the staff didn’t deal with that very well. I mean, he bites when he gets angry, when he doesn’t like something, and he wasn’t coping with the change, and he wasn’t happy, so I wasn’t happy. And the staff was not happy because there was this person biting them. So it was a very hard transition for him and therefore, a very hard transition for me. (Lorna*).*

According to all parents, the time of transition was made more difficult when their children asked to come home. Brenda’s daughter constantly asked to come home for a long time after she was first placed but, according to Brenda, “After 15 years she has adapted. My house is my house and her house is her house, but for years it wasn’t that way. It was, ‘when can I come home?” Francois told me that when Evangeline first went into care she asked to stay with them every time she came home for a visit. Emilie, Francois’ wife, shared that “time after time” Evangeline resisted going back to the facility. Francois and Emilie finally explained to Evangeline that if she wanted to continue coming home for visits she had to be willing to go back when the time came.

Evangeline continues to complain about having to return to the facility however, for according to Emilie, Evangeline says “It’s too early!” Emilie concluded: “There’s no place like home, but she’s happy,” and her husband Francois added, “Yeah, she’s happy.”

Two parents reported that their children became aggressive at times and physically resisted returning to the facilities. Kim told me that her daughter used to throw temper tantrums but eventually became much calmer, except during summer months when she did not have school to look forward to on the same days as returning to the facility. At the time of data collection, Lorna’s son Caleb was also still resisting going back to the facility after home visits and always required a time of adjustment:

> It’s always hard when he goes back. When I take him back there’s always an adjustment period again, so I don’t bring him home as often as it might just upset him again, you know [sighs]. Each time we take him back from Christmas or summer vacation there’s always a period of readjustment. (Lorna*)*

Lorna continued: “Staff just wait for it. They know that it’s a part of the process I guess.”

Another difficulty for parents was stepping back and letting other people care for their children, particularly the mothers who had been their children’s primary caregivers which, according to the literature is generally the case (Norlin and Broberg 2013, Statistics Canada (2006, 2008). Brenda questioned whether she could have done more, lamenting: “You’re a mother and you think you never do enough.” Brenda’s comment is consistent with Baker and Blacher’s (2002) findings that parents feel bad about themselves in their belief that they have failed as parents. There was also the feeling that no one knew their children like they did, as noted in Lorna’s declaration, “I knew him like the back of my hand and what would upset him, but they [staff] didn't" Lorna added:

> They didn't believe me when I would tell them that Caleb doesn't like that. They just kept saying, 'Well he'll get used to it,' and I said, 'No he won't. He won't!' So it was very hard. (Lorna)

Lorna did not like that they medicated her son at the facility because she had not done so when he lived at home, although she did acknowledge that Caleb had become less aggressive as a result:

> They did put him on medication that kind of works like a mood elevator. It did seem to make it easier for him to cope with his surroundings, and he wasn't as aggressive. They work, but I didn't like the idea of him being medicated when he's there, because I had cared for him for twenty-one years and I hadn't. (Lorna*)*

Rhonda, supervisor with an adult community residence agency, told me that there are times when parents take the position that their children did not have certain issues until they went into formal care, so Rhonda reminds staff that they would not be in care if they did not need to be:

> The parents are involved, maybe with a social worker or in a meeting, and the parents will say 'Well, he didn't do that when he lived at home,' or 'He never did that with me,' when we know that *that's* why he's with us . . . 'It wasn't an issue for years when he lived at home,' but they forget what it was like when he was at home. So we often remind our staff that they're here for a reason. They would not be here if things were perfect or they didn't need some aid and assistance. (Rhonda).

Another difficulty for parents was being unable to check on their children as they did before their children were moved into long-term care facilities. According to Kim, she and her husband "can't go in the other room and make sure she is covered up or just check on her, you know. That's the only way I can explain to other people what it feels like." Francois shared, "I used to put my hand on her head every morning to find out how she was doing. With epilepsy you never knew when she was sick." Emilie gestured to show me how her husband tousled their daughter's hair first thing in the morning, at which point Francois broke down and said, "I looked at that empty pillow a lot of mornings." After regrouping Francois concluded: "But we knew it was for the best" and his wife nodded in agreement. Emilie told me she missed the sound of Evangeline's voice as she spoke her name.

Lorna was amazed at the freedom she experienced once Caleb went into formal care but also felt guilty for enjoying that freedom:

> I felt absolutely [pauses] I mean I didn't know what to do with my time! Oh, this is how other people live! You can leave the house! I couldn't leave him so if I wanted to go to the store, I had to take him with me, and that was a major performance, you know, to get him in the car and take him there. That was like work, big work. So I would have to plan every moment of every day to make sure that I had everything I would need. Now I didn't have to make a plan to go get a loaf of bread. I could just do it. It was like [pauses] well, it was amazing! (Lorna) . . . I am enjoying life now like you would not believe! I really can do whatever I want. And I never could, so I'm enjoying every moment and I take every opportunity to do things that I want to do. And it's not like I'm traveling all the time. I'm still working, and still cleaning the house [laughs] but I feel guilty because I feel free. I do! (Lorna)

Lorna's account confirms the argument that while parents often find greater freedom post-placement (Werner et al. 2009), they also feel guilty (Baker and Blacher (2002), which supports Werner et al.'s (2009:37, 38) characterization of post-placement as a 'bittersweet' experience for parents. Lorna told me that she feels occasional guilt if she happens to miss a visit - or not - with Caleb and is concerned about staff members' perceptions of her, although she visits Caleb twice a week and her husband visits with Caleb every weekend:

> I feel guilt if I don't go and I still feel guilt if I do. I still wrestle with the guilt that maybe I didn't get to see him this week. It's terrible! What are people going to think? What are they going to think at the home if I don't come down to visit this weekend? (Lorna)

Lorna told me that while others have assured her that she did all she could have done for Caleb, she continues to feel guilty: "I feel guilty because I can't do it anymore. I just can't!" On the other hand, Lorna shared with me that she does not think her husband experiences guilt, though he found it difficult when Caleb was placed.

According to Brenda, she eventually came to accept feeling guilty about whether she could have done more for her daughter, concluding, "You just have to live with your guilt. You just have to learn to live with it. Maybe it will go away someday. I don't know." Lorna and Brenda's experiences with guilt are similar to the guilt that parents reported in Baker and Blacher (2002) research among 106 families post-placement and Mirfin-Veitch et al.'s (2003) longitudinal study with parents of 36 individuals relocated into residential care. Other participants discussed the guilt they have observed in parents once their children were placed out-of-home. According to Rhonda:

> Parental guilt is a big thing. Sometimes it's worse for some than others and I can't even begin to imagine what that feels like, basically giving up your loved one because you can't take care of them. (Rhonda)

Front line worker Rachel has also observed some parents' guilt but does not believe parents should feel this way:

> The parents feel guilty. I have heard them say that they feel ashamed. They feel like they're neglecting their child but they're not. They only come to us when they've reached their wits end and they can't handle it anymore, whether it's behaviours or physical or whatever. The parents feel very, very guilty. (Rachel)

Rachel added, "We try to comfort them and they realize that their children are well taken care of, but the guilt is still there."

Rachel talked about a specific couple who had placed their son out-of-home because he abused himself and his sisters. The mother was the sole caregiver because of her husband's heavy work schedule at multiple jobs and she had reached the end of her rope. Rachel discussed the guilt and emotional struggle that this woman and her husband experienced over having their son placed:

> They felt very guilty. They would phone to check in on him but they couldn't come to visit. They just couldn't see his face. They would break down. They would break down on the phone too. (Rachel)

Rachel went on to say that it was several years before this couple could bring themselves to visit their son at the facility, which they did on special occasions like Christmas and Easter. In Rachel's words, "I couldn't imagine as a parent what they were going through." Doug, operator of adult community residence agency A, told me that when individuals come to live at one of his facilities he tries to alleviate parents' guilt by assuring them that they are still the parents, that they "did what was best" and that he needs them to remain involved in their children's lives:

> When we accept the clients in our home, the first thing we do is meet the family, and the first thing we say to the family is 'You didn't give your child away. He's still your child. You did what was best.' And we say to the family 'We need you.' (Doug)

Doug was aware that encouraging parents to remain involved is not an approach everyone agreed with but he wanted to give parents a sense of hope, despite having reached the limits of their parenting capacities with these children:

> Some people say it's not good to invite the parents but the parents are the parents. I want them there. I want them to start to see hope in their child and I want them to see that what they did for their loved one was good, but they didn't know how. (Doug)

Norma, of the New Brunswick Association of Community Living (NBACL), said that when parents seek alternative living arrangements for their children "we are certainly not judgmental," adding:

> We try to help however we can and still be their support if things aren't going well there or they need different arrangements or whatever. We certainly help where we can. (Norma)

According to Dr. Faulkner, families also experience guilt if something happens to their loved ones while living in long-term care facilities because of not being there to protect them, but Dr. Faulkner felt such guilt was unwarranted:

> They shouldn't feel guilty when they're gone, for instance, if something happened to their loved ones while there because they think it is their fault because they weren't there all the time. It's really difficult. Yeah. (Dr. Faulkner)

Dr. Faulkner also talked about the burnout she observes among family caregivers. In the following account, Dr. Faulkner explained that caregivers turn to anti-depressants or other means in their attempts to cope, and she believes these caregivers need occasional breaks from their caregiving responsibilities:

> It's a huge issue. They burn out! They really need to have a break. They end up on anti-depressants and whatever else they can do, you know, because they don't have family members to come and give them a break. Sometimes, even with seven kids in the family, it's always one who has to do the care. You know, everyone should take a turn! It's a real issue, caregiver burnout. (Dr. Faulkner)

For Emilie, being unable to care for Evangeline because of her damaged shoulder was, in her words 'awful,' but it was the combination of her shoulder injury and a surgery she underwent for another matter that led her and Francois to conclude they could no longer provide the level of care Evangeline required. Emilie's situation supports the literature with regard to the negative impact of caregiving on mothers' health (Bourke-Taylor et al. 2011, Norlin and Broberg 2013).

Kim, describing what it was like to pass over the care of her daughter to others, put it this way: "I would compare it to a death." She then told me that she was meeting weekly with her psychologist for counselling sessions as she was still grieving the loss of her daughter from her home years later. Kim's experience reinforces Marshall Jr. et al.'s (2012) contention that there are emotional costs associated with passing over parental caregiving responsibilities. Kim found strong support from her own family but recounted her pain of never being asked by her in-laws how her daughter was doing, about her appointments with specialists, the physiotherapy treatments she was undergoing, or anything else. Brenda shared with me that she and her husband found support through their involvement with the local branch of the New Brunswick Association of Community Living and about her own experience with mutual support because of friendships with several women who also have children with disabilities. Lorna realized a great deal of support from her family, particularly her sisters, but did not experience any support network within her community.

Contact between Families and Loved Ones in Care

According to Celeste, the level of contact between families and their loved ones in the facilities varies:

> Every family is different. Some families are more connected than others. We're lucky that two of our residents have a good family connection. Another one has siblings but they live away off. Some live close by but they still don't come to visit. I encourage everybody to come. (Celeste).

However, Kim reported regular contact with her daughter, calling every night and bringing her home twice a week to visit, but she was also troubled that a young man living at the same facility as her daughter never received visits from family: “I feel so sorry for him because he’s not even seeing his family anymore and that just breaks my heart!” Kim added that she knows that this scenario is typical for adults in long-term care facilities but she still finds it difficult to understand: “I know with a lot of the adults, the families aren’t involved. I can’t imagine it.” Emilie and Francois told me that although they eventually had to stop visiting weekly with Evangeline because of Emilie’s shoulder injury they still maintained contact. Lorna and her husband visited Caleb frequently and brought him home for special occasions, including their annual two-week vacations. However, Lorna shared that when the two weeks of vacation are over she always thinks, "My God, how did I do this before?”

At the time of data collection, Brenda and her husband were also free to drop in and visit their daughter at any time and were bringing her home for visits at least once a week. Rachel said that two of the residents at the facility where she worked still received contact from their parents. In this chapter, I discussed parent’s experiences of having their children placed out-of-home into long-term care facilities, assessment processes, extended waiting times for placements, and post-placement issues. In the following chapter, I provide specific information about the adult community residences and nursing homes where I conducted research, the philosophies informing care provision, organizational features of long-term care facilities, and the social, emotional and cultural climates of these facilities.

CHAPTER SIX: PHILOSOPHICAL AND ORGANIZATIONAL FEATURES OF ADULT COMMUNITY RESIDENCES

The purpose of Chapter Six is to present the philosophies undergirding care objectives for individuals diagnosed with disabilities and mental illnesses who live in long-term care facilities, to describe the physical characteristics of these facilities, and to examine the organizational features of adult community residences. Official philosophies of care are contained in government legislations and documents and in the policies, procedures, and Individual Service Plans (ISPs) developed by operators of adult community residences, while non-official philosophies of care are those shared by participants. Attention will be drawn to the consistencies and inconsistencies between care philosophies and care provision and the organizational features of facilities that include daily routines, shift changes, food preparation and consumption, engagement in chores, record-keeping, and the upholding of facility expectations through rules, rewards and punishments. The final component of Chapter Six is a discussion of the varying levels of intensity and emotional atmospheres observed in the facilities.

Philosophies of Care

This section contains information about official and non-official philosophies of care provision and the consistencies/inconsistencies between care mandates and care provision. Two specific, sometimes overlapping themes emerged in official and non-official care philosophies: residents are to be valued or worked on. Philosophies towards valuing residents included attempting to maintain their rights, treat them with dignity, meet their social, spiritual, physical, medical and psychological needs, provide individualized care, opportunities for choices, and ensure that residents take priority in care decisions.

Other philosophies towards valuing residents entailed accepting them as they were, feeling some affection for them, attempting to ensure the best quality of life possible, sustaining a quality assurance of care, and listening to residents' perspectives. Philosophies that required working on residents included efforts to normalize, integrate, and develop greater independence in them. These philosophies not only align with Foucault's (1997:300) 'governmentality,' in legitimizing specific strategies to be taken with residents, but they also reveal a 'morality' (Goffman 1961:83) or set of 'values' (Foucault 2001:173), producing varied cultures within facilities and informing the work required of staff and residents (Danforth, 2000, Levinson 2010).

Official Philosophies of Care

Official care philosophies regarding the treatment and appropriate care of individuals with disabilities and/or mental illnesses, as well as acceptable approaches to operating long-term care facilities, are found in such government documents and legislations as the *2009 Standards and Procedures for Adult Residential Facilities* (SPARF 2009). the *Family Services Act and Regulation 83-77* (Part II), *Health Act, Fire Prevention Act, Family Income Security Act and Regulations, Infirm Person's Act, Mental Health Act, Employment Standards Act, Occupational Health and Safety Act and Regulations 2004-130, Human Rights Act,* and *Smoke Free Place Act*. According to

SPARF (2009:1.3), the stated mission of care provision is enhancing self-reliance, improving quality of life, and protecting those who need it.

The principles reflecting this mission recommend investigating sources of informal support, staying client focused, working towards the inclusion of clients, and quality assurance (accountability, effectiveness, and efficiency), all while recognizing and maintaining clients' dignity (SPARF 2009:1.3). Operators of adult community residence agencies are mandated to "encourage all residents to create a home like environment SPARF (2009:6.1)," which is interesting because, as written, residents not care providers are responsible to generate such an environment. SPARF (2009:2:21) also mandates that residents have opportunities to air any concerns they might have. Residents' well-being is described as "the optimal degree of social, mental, and physical health attainable for each individual" (SPARF 2009:1.2).

Operators of adult community residence agencies are responsible to develop in-house goals and objectives for the facilities to meet the social, spiritual, physical, medical and psychological needs of clients (SPARF (2009:2.4), as well as policies and procedures that work towards providing for the security and development of clients (SPARF 2009: 2.5). The in-house philosophies of care as well as the policies and procedures that operators develop, must comply with all federal, provincial and municipal laws, including the *Family Services Act and Regulation 83-77* (Part II), *Health Act, Fire Prevention Act*, *Family Income Security Act and Regulations, Infirm Person's Act, Mental Health Act, Employment Standards Act,* O*ccupational Health and Safety Act and Regulations 2004-130, Human Rights Act*, and *Smoke Free Place Act* (SPARF 2009:2.6).

Besides being responsible to develop philosophies of care and policies and procedures for each facility, it is also mandated in SPARF (2009:3) that operators fashion Individual Service Plans (ISPs) for each resident, that they ensure the implementation of these ISPs, utilize resident funding to best meets the goals in ISPs, and review ISPs, at a minimum, annually:

> At least annually, operators must develop, implement, evaluate and review an individual service plan for each resident. As well, operators must maximize resident funding for this purpose, for example, Day Programs, recreational activities. (SPARF 2009:5.3)

Rita, of the Department of Social Development, revealed, however, that some operators do not comply with SPARF (2009):

> Each home is expected to do program development or do program planning. They call it individual service plan . . . Not everybody does it. (Rita).

Nevertheless, case managers are to assist operators in the development of ISPs in consultation with clients and significant others (SPARF 2009:5.3). The stated purpose of ISPs is to both maintain and involve residents based on their condition (physical, mental, and emotional well-being), in social/recreational activities in the community, while developing their skills (SPARF 2009:5.4). Another mandate, according to SPARF (2009:5.4), is that programs must "help the residents attain and maintain an optimal personal level of functioning, self-care and independence . . . [and] promote individual decision making, choice, inclusion and participation within the community." According to Smith et al. (2005) and Stancliffe (2001), promoting "choice and self-determination" is an attempt to normalize residents' experiences.

While goals of seeing residents developed and moving towards greater is typical, as MacDonald et al. (1993:197) explain, the particular philosophical objectives in this research reveal the overlap and tension between residents as individuals to be valued because of attention to individualized care, and individuals to be worked on. The specific goals found in Individual Service Plans align with service goals, which are consistent with Levinson's (2010:44) findings and legitimate managing residents' lives, as Drinkwater (2005) points out. Specific guidelines on how to respond to individual residents who engage in violent behaviours are also laid out in ISPs and the physical holding of residents is to be used only as necessary to prevent a resident from self-injury, in self-defence, or to protect a third person (SPARF 2009:5.5). Restraining devices are forbidden (SPARF 2009:5.6).

According to the philosophy of care document particular to adult community residence B, the top priorities were maintaining close links with family members, respecting religious and spiritual values, and trying to ensure "the best quality of life possible for each and every" resident. Specific values regarding the treatment of, and care for residents were included in the same document: respecting residents' privacy, maintaining their ability to make choices, and providing them with the opportunity to live in a comfortable environment:

> That each resident live in a positive environment, to feel in security, all in respecting their private life, That each resident has the right to choose and make decisions that affect their daily life and their personal growth, That each resident has the possibility of living in a comfortable, heart-warming as close to a family setting as possible. (*Philosophy of Care Document, Residence B*)

Nevertheless, Atkinson (1998:22) contends that while the notion of 'family' implies "warmth and care" and shared activities, in long-term care facilities 'family' may entail being restricted, limited, and treated much like infants. The mission statement of adult community residence C is adopted from the New Brunswick Association for

Community Living (NBACL) mandate and reads: "Full participation of persons with intellectual disabilities in <u>all aspects</u> of society" (author emphasis). The mission statement of adult community residence D, also adopted from NBACL, includes the directive "to ensure that people with intellectual disabilities and their families have the option to choose the supports they need to live meaningful lives and participate in their communities as valued and contributing members."

Celeste, operator of an adult community residence C, explained that all in-house policies require approval from the Board of Directors before they can be implemented: "I develop the policies and then have it approved by the Board before I implement it. That's where the Board comes in handy." Celeste spoke to the importance of such policies: "Policy procedure is very important for employees, dress codes to protection to everything," but added that the way policies and procedures are written can obfuscate intentions, such as those developed by the former operator of the agency which she now has responsibility for:

> I was a Board member back then. I read through it and I said, 'Oh my God, I almost need a dictionary to read through this.' It was like lawyers. And you couldn't get any straight answer about 'What if this or that happens?' It was too complicated! (Celeste)

Celeste added, "She didn't get approval" from the Board of Directors because it was so complicated.

Non-official Philosophies of Care

Non-official care philosophies from participants' accounts were as follows: that residents eventually consider the facilities 'home,' that there are appropriate and inappropriate approaches to deal with residents' violent behaviours, that residents are listened to, that residents take priority in an attempt to ensure quality of care, and that front-line workers feel some affection for residents. Five participants talked about the integration, inclusion, normalization, and development of residents, while one individual discussed the value of narrative care, a novel approach drawing attention to residents' individual stories and backgrounds. Other non-official philosophies related to optimum care provision were that residents follow existing rules and respect be shown to others in the facility. There were occasional inconsistencies, however, between care philosophies and the realities of care provision.

Philosophies of Care, Consistencies and Inconsistencies

Debbie, a civil servant with the Department of Social Development, expressed the sentiment that once an individual was moved into an adult community residence "this facility becomes their home," a view consistent with SPARF (2009:6.1). Debbie explained: "Even though they're not at home, their family home, there's a sense of home, because that's where they're going to live. It is, in fact, their home." Blake, a former resident of one of the larger institutions, was emphatic that the adult community residence where he now lived was home: "I'm home to stay now! I love it!" Ethel, of a different adult community residence, also considered the facility where she lived to be home according to her brother Mike:

> I mean, the beauty of it is that Ethel accepted it. I mean, when she was younger and more able, I used to take her out in the car and after the outing she would say, 'It's time to go home.' She was referring to the facility as her home. Yeah, it's a good situation. (Mike)

Mike's comment "I used to take her out in the car" suggests that Mike no longer takes Ethel for drives as he once did.

Theresa, a young adult living in a nursing home, said that it took her some time before she considered the facility to be her home: "It has taken me a long time to call it home. It was a real process because it's geared more for older people." When I asked Theresa why she now viewed this facility as her home, she responded:

> Well, how can I put it? It could be just the atmosphere or maybe that I've just come to that in my heart. But it took me a long time to come to that because I didn't feel like this was my home. (Theresa).

Unlike Theresa, the other two young adults living in nursing homes never came to view these facilities as their home. For instance, Mary said of the facility where she lived:

> It's a nice place. I have everything that I need, but it's not home. I will always miss my home. Even though I have my pictures and some of my things from home, it's still not home. (Mary)

Doris did not consider the nursing home where she lived as 'home' either by her comments: "It's an institution. There's not really much you can say about it, besides the fact that it's institutional care." Rather than conceiving 'home' in geographical terms or where they 'sleep,' Higgins (1989:7) argues that a better analytical framework for interpreting whether residents consider facilities 'home' requires greater attention to the nature of the relationships among residents and between residents and front-line workers.

It was important to Celeste, who operated adult community residence agency C, that residents were able to make their own choices:

> It's important to me for them to have the right to decide for themselves what they want. Even though you may think and you may assume that they can't tell you, there's a way of finding out, of digging, really, what it is that they really want. That's number one. (Celeste)

Celeste was also of the opinion that younger individuals should have other options for where they lived rather than ending up in nursing homes:

> It's also important to keep our young people in the community, meaning, for me, that they're not going to go to ________ [specific nursing home], because if you've never been to [nursing home], walk in, sit down amongst the people that live there and then decide if you're 45 years old 'Is that where I want to be?' That's important. That's really important! (Celeste)

It can be difficult at times, however, to ensure that residents have opportunity to choose where they live. Rhonda, supervisor with an adult community residence agency, told me about a young client who may end up in a nursing home when he turns nineteen because it will cost the Government less money and there are no other alternatives:

> He's been told that when he turns 19 he won't be with us, but he doesn't know or understand where he's going to go. It's very frustrating and it's very, very sad because this young fellow was looking forward to graduating in June and 'going out for a beer with his friends' as he puts it, you know, going to his grad party. But in all honesty, he may be going into a nursing home because they can't find another place for him and it's cheaper. (Rhonda)

According to Rhonda, the Department of Social Development placed an ad in an attempt to try and find a different place for this client which she felt was demeaning to this young man: "They put an ad in the paper to try to sell him, basically, looking for a cheaper place for him to live. I felt it was very degrading to him." Although it is mandated officially (SPARF 2009:5.4) and promoted non-officially by participants, the reality is that it is extremely difficult to ensure their ability to choose the facilities they live in.

Sharon, an executive of nursing home I, held the philosophy that using restraints on residents was never justified: "We're very, VERY strong advocates of NO restraints. It's a big thing with us!" [Emphasis is mine to show her stress on certain words].

Sharon's adamant resistance to the use of restraints on residents is consistent with the official stance (SPARF 2009:5.6). Mark, team leader in an adult community residence, viewed medication as a good control mechanism with residents:

> A lot of people used to be afraid of people like these, but now the pills are so good to control schizophrenia and other serious mental health problems, that sometimes these people are safer than normal people. (Mark)

Using anti-psychotic drugs in lieu of restraints does lean more towards residents' rights and dignity. Doug, operator of adult community residence agency A, told me about a female resident who was particularly aggressive: "The first month she destroyed about three thousand bucks worth. That was how she was used to reacting to situations." Doug then explained the approach taken with her:

> We told her, 'No, don't do that if you want to do this or if you want to do that.' I told her same thing that I would tell you: 'I don't accept that you destroy my stuff. If you destroy, you're not going to be here.' I went through that every time. (Doug)

Doug added: "Now she's working and does cleaning for a person." Rhonda discussed a particular client with the agency she worked for as well who, in her words, was "extremely aggressive," adding, "It's not safe for him to live with a roommate." Rhonda then pointed out that because it was costing the Department of Social Development a lot of money they wanted to find a cheaper alternative for this individual:

> The Department feels it's too much money so they want to put him with somebody else because it's cheaper. It's very hard because landlords are not that accommodating, especially when there's going to be extensive property damage. (Rhonda)

According to Yvette, supervisor with a different adult community residence agency than Rhonda, she responds to residents' aggressive behaviours by switching residents' rooms and taking time to listen to residents' concerns. Yvette's tactics are consistent with the official mandate (SPARF 2009:5.4) that in-house responses and interventions are established to respond to behavioural issues. Listening to residents to dissuade them from engaging in violent behaviours may seem in the best interests of staff members, but this approach reveals that residents' opinions are taken into account which, according to Atkinson 1998:23), is consistent with valuing and respecting residents. Listening to residents also aligns with creating opportunities for their personal growth which, according to Moos et al. (1979:77), is a feature of more positive social climates. Yvette discussed further the rationale for taking time to listen to residents: "We want them to be happy and we want them to talk about their feelings, so if something bothers them we're ready to listen."

I observed that staff members at every facility took time to listen to residents but this was particularly the case with Mark, who spent considerable time each day interacting with residents. Mark listened to everything residents said and addressed all their questions. There was one exception however, when after spending a considerable amount of time reasoning with a resident over a matter which Mark felt the resident was being dishonest about, Mark refused to listen. Taking the time to ensure residents are heard is consistent with SPARF (2009:2.21) mandates about taking efforts to maintain clients' dignity (SPARF 2009:1.3) and address their psychological needs (SPARF 2009:1.3). The specific approaches taken by participants to prevent/and or deal with the violent behaviours that some residents engaged in reveals the tension between valuing residents, and viewing them as work projects. The ability of residents to engage in violent behaviours at times shows that they have some freedom to exercise power, despite living amidst power relationships “completely out of balance” (Foucault 1997:292) that favour formal care providers.

It was Mark’s philosophy that residents must come first in care provision and he considered everything he did to be on behalf of these individuals:

> It’s all about the clients. I cook the food, but it’s for the clients. It’s not for me. Whatever I do here, it’s for the clients. It’s not for me. The clients are the number one. (Mark)

Mark’s view that clients take priority in care decisions is consistent with SPARF (2009:1.3). It was also Mark’s philosophy that employees should feel some level of affection for residents: “You need to love the clients first of all.” Mark did acknowledge, however, that “There are always some you are closer to than others. Like with friends, you have some friends that are closer than others.” At all four adult community residences, various staff members touched residents in appropriately affectionate ways, tapping them gently on the shoulder or patting their hand as they passed by and residents reciprocated affectionately toward staff members in similar ways.

There are certain government documents that clearly define what constitutes inappropriate touching of residents and the required steps to be taken if the boundaries of appropriate touching have been transgressed. The *Adult Victims of Abuse Protocols (AVAP)* (2005) is one such document, wherein abuse is generally defined as the “pushing, pulling or rough handling of the individual” (*AVAP* 2005, 2.3:11), and sexual abuse is described as:

> Any act involving unwanted touching/activity of a sexual nature, or a situation in which an adult with disabilities or senior, consents or submits to sexual activity, because a person in a position of trust or with authority over him/her, has used that trust/authority to gain that consent. (*AVAP* 2005:2.1:9)

In cases where employees suspect co-workers of abusing a resident/or residents, the Access and Assessment Unit of the Department of Family and Community Services must be informed immediately, in keeping with Department of Family and Community Services Intervention Guidelines (*AVAP* 2005, 5.3.1:26).

Narrative care is a newer approach taken by some employees in nursing homes, according to Sharon of nursing home I, to help staff members gain a better appreciation for residents' stories and particular histories. Sharon explained that in the narrative care approach, slide shows or videos are developed from residents' pictures and own accounts of their lives prior to living in the nursing home, which allow a more complete story to be built up about residents. The value of a narrative care approach, according to Sharon, is that staff members gain a greater understanding of individual residents, which then informs their caregiving approaches with residents:

> Narrative care is all about recognizing the individuality of a person and appreciating them, not just for who they are now, but for who they were before they came in here . . . Doing this informs your whole care approach and makes you see the person in a whole different way. (Sharon)

Sharon, referring to a relative who lived at the nursing home where she worked, told me that other staff members had no idea of her aunt's former self as they only knew her towards the end of her life when she was severely demented. Sharon then described her tactic to try and remedy the situation:

> I helped to get her biography done so they could see the woman I knew. I mean, she was a woman to be reckoned with and a role model for me, so that piece is so important. (Sharon)

This approach in narrative care suits official mandates about individualized care derived from SPARF (2009) mandates and my interviews with individual care providers. In addition, the philosophy of care that emerged from my analysis is consistent with what is found in the literature on individualized care. For instance, according to Chappell et al. (2007:527, 528) individualized care refers to a shift from the medical model approach to "a more client centered, social model" that focuses on caring relationships, residents' individuality, and residents' engagement in decision-making (Happ et al. 1996, Suhonen et al. 2000). Formal care providers' recommendations about feeling affection for residents and listening to what they have to say align with attention to caring relationships, while SPARF (2009) mandates about individual service plans (1.2), programs and services targeted to individual needs (1.3), physical, spiritual, social and psychological support (2.4), and promoting individual choice-making (5.4) are ways of promoting residents' individuality their engagement in decision-making.

Integration, Inclusion, Normalization, Development, Rules, and Respect

Philosophies consistent with residents as individuals to be worked on were explicit in goals surrounding their normalizing, integration and inclusion. These goals were key tenets of the care philosophy at the adult community residence where Margaret worked. Margaret, after explaining that the philosophy of care at this facility was "in a book about that thick" and using her hands to show the estimated size, added:

> It's mostly to do with including them in society and stuff like that there, to make sure that they have as normal a life as possible, including them in things and getting them out as much as possible and stuff like that there. (Margaret)

Thomas (2007) argues that envisioning residents' normalization reinforces the myth of a measurable norm, a normal/abnormal dichotomy, and sustains residents as individuals requiring normalization efforts. While Goffman (1961:81, 82) takes the position that normality so conceived is unachievable, it still means endless work and ceaseless intervention in resident's lives. Striving to normalize residents also justifies the exercise of bio-power and normalization strategies on residents (Foucault 1978a, 1979).

Two participants felt that integration and inclusion were not actually taking place. Brenda was aware that integration and inclusion were integral components of the care philosophy at the adult community residence where her daughter lived but she also knew that budget restraints and limited availability for one-on-one staffing for outings hampered such opportunities:

> They're to be based out in the community as much as possible. Through the years with budget restraints, they have less staff working with more clients, but our daughter is fortunate enough to have a day program . . . Some of that is out, really, in the community, working with support, and some of it is done at the sheltered workshop. (Brenda)

Brenda continued to talk about the matter:

> She used to be far more visible in the community than she is now but to be visible in the community is to hold down a job in the community, and she has to have a one-on-one staff with her and, I mean, that's not always available to do that. (Brenda)

While Brenda's daughter had access to a day program and a sheltered workshop, it was Brenda's contention that opportunities for employment as well as more one-on-one staffing were necessary for integration to work. Brenda's assertion that limited supports and funding were a problem reveals that efforts to meet the philosophical care goal of integration was an issue, supporting Levinson's (2010:52) argument that the appropriate supports and community-based options necessary for inclusive policy ideals are not always available. Levinson (2010:41) characterized the integration of residents as "segregation in the community" but I prefer the analogy of residents living in a "parallel universe" since they are largely out-of-sight, and out-of-mind of other citizens. "Parallel universes" is not a new term but one coined by Friesen (2012:13) to characterize the relationship between Mi'kmaq and other citizens of Cape Breton, whose lives "never seem to overlap," despite living in the same area, and eating and shopping at the same locales.

Doug, operator of adult community residence agency A, also saw integration as a goal of care, written and ideally, but felt that living in an adult community residence made it impossible for residents to experience a normal life and that true integration was not happening: "It's okay, but it's still not in community . . . It's not a regular life you know." Bruce, who operated adult community residence agency D, raised the topic of integration as well but came at it from a different angle. Bruce questioned whether striving to integrate residents was something residents themselves were interested in and if it was in their best interests:

> We ask the question, 'Who do you socialize with? Do you tend to socialize with the people who are somewhat similar to you in socioeconomic status or whatever?' When you see our folks together at a party, everybody should have such a good time as they have with each other. If we could take them to _____ [a local club for public dances and events] and they could have such a good time, more power to them, but chances are they're going to have a better time if they're with their own group of people. You and I, if we look at the parties we go to, it tends to be with people who are like us, but if we go to a party that's not in our comfort zone, we probably wouldn't have such a good time. (Bruce)

Bruce's sentiment is similar to Smith and Brown's (1992) assertion that care recipients might choose to spend time with others of similar diagnoses. Bruce also questioned the pragmatism of current approaches to integration in the school system:

> If they were actually taught how to take a bath or to care for themselves, it might make life easier for them as adults. Everyone should have the right to go to school but I'm just not sure that the academic part is what everybody needs. (Bruce)

Doug, operator of adult community residence agency A, told me that if he could sum up the philosophy of care at his agency it would be: "Respond to their needs and accept them the way they are." However, this stance contradicts SPARF (2009:5.4), where operators are mandated to ensure that "residents maintain an optimal personal level of functioning, self-care and independence." This directive means that staff members must constantly work on residents rather than accept/leave them as they are. At the facility where front-line worker Shirley was employed residents were taught practical skills and staff members worked at developing clients, in keeping with SPARF (2009:2.5) mandates:

> Here, it's a training house, so we try to get them to do as much as they can do so that they can be out on their own. Some of them will never be out on their own but they can learn a lot of things. (Shirley).

Striving to help residents to become more self-reliant (SPARF 2009, 1.3: 6.1) by doing "as much as they can" (Shirley) on their own aligns with a conception of residents as individuals to be worked on. Kim's daughter lived in a facility in different area of the province from where Shirley worked. Kim's daughter's ongoing development was important but she had no idea whether there were any philosophies of care at the facility where her daughter lived:

> I don't know. My husband and I have talked about it a lot lately and my impression of the whole system right now is, she is babysat. She's cared for, but there's not much done to help her progress. (Kim)

Kim's inability to see evidence of a particular philosophy of care at work at the facility where her daughter lived does not necessarily mean that established philosophies did not exist or that they were not actively followed, but rather that Kim did not see evidence of this.

Requiring residents to show respect to others and teaching them to abide by established expectations at the facilities were additional philosophies consistent with residents as individuals to be worked on. Rules and respect were important to Mark, as was the recording of all medical and financial transactions, similar to when he worked in the larger institution:

> We have rules and respect. We had the same thing at ________ [the institution where he formerly worked]. We have to respect each other, and chart our Dr.'s appointments, pills, money.

Mark's argument for established rules and showing respect supports the mandate that operators explain "rules and expectations" to residents as part of their orientation (SPARF 2009:6.1). In practical terms however, front-line workers were responsible for presenting facility expectations for self-conduct that residents were required to adjust themselves to, similar to Goffman's (1961:107) findings.

Thus, despite mandates about client-focused (SPARF 2009:1.3) and person-centered care (GNB 2011b), expecting residents to comply with rules and expectations (SPARF 2009:6.1) means that Goffman's (1961) mortification process is still relevant in long-term care facilities because residents must learn to adjust to facility expectations. While showing respect was also important to Amanda, a front line worker who worked in a different facility than Mark, Amanda also felt accountable to encourage residents in whatever they attempted, to treat them fairly and equally, to protect them, and to provide them with the greatest care experience possible:

> It’s a promise to the families, to the society, to take the best possible care, to treat with the utmost respect. To encourage them in a very positive way to try to achieve whatever small thing or large thing it is they want in their lives. For me, the goal is fairness, equality, protection. To be, or try to be, or to provide the best living circumstances possible, with as much encouragement and positive things in their life experiences that could possibly be there. (Amanda)

Amanda’s intention to provide the best possible care experience for residents is consistent with recommendations to strive for “the optimal degree of social, mental, and physical health attainable for each individual” (SPARF (2009: 1.2). Sharon, an executive with nursing home I, also wanted to provide the best possible care experience to the residents where she worked:

> Our goal is to make the years that people spend with us the best that they can be for them and respecting the fact that they are individuals who retain all their rights and privileges to dictate the parameters of their lifestyle, whatever that might be. (Sharon).

Physical Characteristics of the Facilities

The general physical characteristics of the adult community residences and nursing homes where I did fieldwork are discussed in this section. The outer appearance of adult community residences are not atypical of the appearances of the homes of other citizens in the same area, and intentional efforts were taken in both adult community residences and nursing homes to provide residents with interior physical environments that tended towards homey atmospheres. Decorations in these facilities functioned as reminders to residents of seasonal celebrations and residents took particular pleasure in celebrating the various events held in these facilities. However, the physical design of nursing homes meant that the privacy and dignity of at least one resident was compromised.

Adult Community Residences and Nursing Homes

All four adult community residences were located in neighbourhoods among other houses owned by private citizens, were of similar architecture, and were inconspicuous in appearance. Each adult community residence was known by a specific name, two by the streets on which they were located. All four facilities were two-level structures, and three facilities had bedrooms on both levels. The basement of the fourth facility was used for storage purposes but according to the operator, would be finished to make additional rooms for clients as funding allowed. Two facilities had fully functioning kitchens on both levels and residents typically ate on the same floor as their bedrooms. Different front-line workers prepared meals and provided care for residents on each floor. Other than meal times, residents were free to move between the two floors of the facilities as they chose. Two facilities had common areas, or living rooms, on each floor, while the other two facilities had only one kitchen on the main floor and a living room with a television and stereo. All four adult community residences had spaces designated for residents to spend time outdoors if they wished.

Adult community residence A was large, roomy, very clean, and had lots of windows, which meant lots of natural light. Adult community residence B was also clean but there were more bedrooms in this facility because of previous renovations to allow for a greater number of residents when per diem funding was initiated in 1997. Adult community residence C was quite similar to adult community residences A and B:

clean, lots of windows, and decorated throughout. Adult community residence D also had lots of large windows and plenty of natural light but the walls could have used some paint to freshen it up a bit. However, four individuals associated with this facility (a Board of Directors member, the operator, and two front-line workers), reported a constant struggle to stay afloat because of insufficient funding.

The kitchen in adult community residence D was also less tidy compared to the other facilities, but the good natured camaraderie (Levinson 2010) and affection between staff and residents was the predominant feature of this facility and existed to a greater degree than that observed in the other facilities (A, B, C) and involved joking, good natured bantering, and a greater amount of appropriate affection displayed between staff and front-line workers. By appropriate affection, I mean displays of physical affection that do not contravene the 2005 *Adult Victims of Abuse Protocols (AVAP*, such as staff members tapping residents' shoulders, patting their hands, and residents reciprocating in like manner. All four adult community residences were decorated in ways that lent a homey appearance, with pictures, ornaments and on occasion, plants displayed throughout.

Typical of long-term care facilities targeted to seniors, nursing homes I and II housed a far greater number of clients than adult community residences and were, therefore, much larger. These nursing homes were decorated with pictures, plants, and window treatments which, according to the two executives of these facilities, symbolized their efforts to create homey, rather than institutional atmospheres for residents. While touring nursing home I, I saw a live rabbit sitting on the floor beside a resident as she watched television. Sharon, an executive at this nursing home, explained to me that some residents enjoy having pets around and that it made them feel more at home. Sharon then added, “We also have a cat that lives here at the facility and they enjoy that too.” As I continued the tour, a soloist was singing for residents in one of the large rooms at the facility. Olivia, an executive with nursing home II, told me that they have a cost-sharing arrangement with another organization in the same area which enables them to share a full-time chaplain.

Sharon and Olivia both reported benefits with having large volunteer bases that included the provision of musical entertainment for residents and individuals to engage with residents in activities. Each wing of nursing home I was named after a specific geographical location in the same area as the facility and a number of semi-private rooms were available for married residents. The bedrooms of both nursing homes were decorated with pictures and items reflecting residents’ personal tastes, as well as the people and events important to them. The walls outside bedrooms had identifying information about residents that included their names plates and pictures. Both nursing homes were divided into separate wings, with large rooms for group activities and spaces designated for residents to spend time with family members and/or friends if they chose. There were also outdoor spaces created for residents to spend time if they wished. The physical environments of adult community residences and nursing homes favoured positive social climates within Moos et al.’s (1979:77) analytical framework, because of the “pleasant décor and sensory satisfaction” there. Their less restrictive physical environments also contradicted the “encompassing tendencies” that Goffman (1961:15) observed.

Issues with Residents' Privacy and Dignity, and Times of Celebration

Mary, a young adult in one of the nursing homes was frustrated with the lack of privacy she experienced, for when I asked "Can you tell me about the place where you live?" Mary immediately responded:

> I don't like the way the bathroom is laid out. The mirror is right there when the workers are working with you and there's no dignity in that. The mirror should have been placed somewhere else. (Mary)

The design of Mary's bathroom made it impossible to ensure her dignity was maintained, constituting a breach of SPARF (2009:1.3). Mary was also frustrated that male rather than female caretakers bathed, dressed, and toilet her, but concluded: "You have to get over that and forget your modesty." Doris, another young resident in a nursing home, feared that male staff members may be doing her personal care at some point:

> I never want a man with me, certainly below the waist, and I said that and they have been great respecting that and I have never had that experience, but it certainly could happen. And we are vulnerable people and that really has to be nipped in the bud if there's any problem. (Doris)

Brenda struggled with the fact that males provided personal care for her daughter in an adult community residence despite Brenda's ongoing requests for a female:

> There are four full time men who bathe and care for my daughter and look after her personal care. I struggle with that. I guess someday I could be in the hospital and it could be a male nurse looking after me and that's [pauses], but those are all things that you struggle with as a mother, letting go. You can fight it all you want but they have a union and I cannot do anything about it. It's all priority who gets hired next, and I am always requesting that another female be there. (Brenda)

Sharon, executive with nursing home I, gave her perspective on males doing female residents' personal care:

> There's a harsh reality that if you have a finite number of resources, you have to work with what you have. Some have requested not to have males or not to have females toilet them, so we respect that. (Sharon)

Being unable in some cases, to choose the gender of the individuals doing their personal care, reveals another area where residents are not always provided with the opportunities to make choices as mandated (SPARF 2009:5.4).

All residents of adult community residences and nursing homes had private bedrooms where they could spend time alone if they chose, except for two residents at one adult community residence who shared a bedroom which was significantly larger than other bedrooms in the facility. However, neither resident spent much time in their bedroom when I was doing fieldwork. Bedrooms were spaces where residents could talk privately with family members if they wished. Emilie told me that her daughter Evangeline occasionally invited her to her bedroom to talk privately: "Sometimes, when I go to leave, she says, 'Come to my room. I want to talk to you.' So I go in and she says 'Close the door,' and then we talk." The ability for residents to have personal bedrooms was atypical of former residents of the large institutions who used to live in large wards.

Seasonal and special events at the facilities were very important for all residents, so I disagree with Goffman's (1961:102) assertion that events such as seasonal ceremonies and celebrations offer little solidarity because of the camaraderie I observed among staff and residents and among residents themselves on such occasions. By camaraderie, I mean the good deal of mutual friendliness I saw expressed between staff and residents and among residents during a potluck celebration at one facility. By mutual friendliness, I mean that they laughed freely with each other, bantered back and forth, talked about the various foods, and residents were excited to see most of their staff members show up for the celebration, stating excitedly, “There’s _____ [name of staff member]!” as each one arrived. There was also a sense of companionship at a different facility as staff and residents sat together and shared ideas for an upcoming Halloween party. In the facilities where seasonal decorations were displayed, three residents talked with anticipation about upcoming events and parties. For example, Evangeline said of the Halloween costume she would be wearing to the Halloween party at the facility, “You should see my outfit! I’m going to be a witch!”

Tom told me about an upcoming Thanksgiving party to be held at the facility where he lived and rubbed his hands together excitedly as he added, “I can’t wait!” Blake spoke with eagerness about his plans to decorate the Christmas tree and his hope for Santa’s arrival: “Just last night, me and Sandra [front-line worker] brought up all the decorations for Christmas so we can decorate the tree! I hope Santa Claus comes!” Shirley, a front-line worker, discussed the parties that are held at the facility where she worked and the role of the People First organization, comprised of residents, in planning events:

> We have Valentine parties and Halloween Parties, Christmas Parties. We’re going to start up People First again. They run the club on their own [referring to the clients]. They each pay 25 cents and they have a president and a vice-president. Somebody puts the money in the bank and they get to chat about what’s coming up in the month and what they like to do and [pauses] give us some tea [laughs]. (Shirley)

Bruce, operator of adult community residence agency D, described one of the facilities with his agency where I did fieldwork as “party central,” while Brenda talked about the enjoyment her daughter experienced because of parties held at the facility where her daughter lived and elsewhere:

> There's always a Birthday party. And I have to say that the staff are always good in including [pauses] . . . Like some of the staff have grandchildren and when they have birthday parties, she gets to go to those. She is social, she is mobile and she loves a party! (Brenda).

Rachel, front-line worker at a different facility, discussed the value of residents going to parties outside the facility: "When we go out to different functions like Christmas parties or Special Olympics, they have a little get together sometimes and they get to see their other friends." Rachel's comments also reveal that residents at the facility where she works have friendships with individuals who do not live in the facilities.

Organizational Features of Adult Community Residences

The organizational features of adult community residences included daily routines, shift changes, record keeping, meal and snack times, engagement in chores, and the implementation of rules, punishments, rewards. During shift changes, information was shared about residents and there was a sense of camaraderie among all front-line workers, for they seemed glad to see their coworkers, poured coffee for those who did not bring their own, inquired with interest about their coworkers' lives, children, family members, and caregiving experiences on previous shift(s). Records were maintained on residents in four, and sometimes more, books, and there were regularly scheduled meals, snacks and chores. Records and files are part of any bureaucracy, according to Weber (1958:197, 198). Similar to Levinson's (2010:181) research, records in this research provided a database of information on residents, a tool for orientating employees, a source of protection for staff, and accountability. These rules, rewards, and punishments, particularly stressed at the facility where Mark worked, where care was targeted to those with significant mental illnesses rather than cognitive disabilities, were meant to ensure that residents eventually complied with established expectations. The final part of this section is a discussion of the varying levels of intensity and emotional atmospheres in the facilities.

Daily Routines and Record Keeping

Each morning, incoming staff members arrived at the adult community residences to replace those working the night shift. Consistent with Levinson (2010:110) findings, there was a good measure of "camaraderie and mutual support" displayed between all co-workers during shift changes as they shared coffee, stories about children and relatives, words of encouragement, and caregiving experiences. Outgoing staff members briefed incoming staff members on previous shifts, which lasted anywhere from fifteen minutes to a half-hour, and shared coffee as they passed along information. This information typically included whether residents slept well the night before, if residents had experienced sickness, and if they had engaged in non-compliant or aggressive behaviours. Other renderings during these sessions occasionally included discussions about visits or phone calls residents received or particular outings residents participated in. Incoming staff were also briefed about scheduled appointments that residents needed to be taken to. During shift changes when staff members were returning to work after several days off, more questions were typically asked and additional information relayed to bring them up to speed on what had transpired during their time away.

Communication books were an important feature of the briefing process during shift changes, as they contained written information outgoing staff may have forgotten to verbally communicate. Incoming staff often read these books to get the latest recorded information. All staff members had access to these books, which were typically kept in the kitchens in locked cupboards or stacked on kitchen counter tops, but not residents. First, there was a communication book where information was kept about residents' scheduled activities and appointments, their engagement in aggressive behaviours, and the visits they received from family members and/or friends. Mark, a team leader in an adult community residence, explained the rationale for maintaining communication books:

> The purpose of the communication book is to make sure the next shift know how things went in the shift before. Important information is recorded in this book, like the fact that Ray needs to have ice put on his foot or that they need to watch to see if the bottom number of Fred's blood pressure exceeds a certain number. (Mark)

Mark added that particularly important information such as residents' appointments, were circled in red to make sure incoming staff saw them. In facilities where residents lived on two separate floors, staff members maintained different communication books for each floor of residents. There were two additional books with information about residents' medical and financial statuses that were regularly updated. Specific medical information about residents included medical histories, diagnoses, current and past prescriptions, extramural visits, scheduled blood tests and results, and reports from doctors' appointments. Celeste, operator of adult community residence agency C, spoke to the value of having current, up-to-date, medical information on residents: "I find it very resourceful. When I go to the hospital I take that book with me."

Information about allotments of spending money for residents, receipts, purchases by and for residents, and the status of residents' bank accounts, were all recorded and maintained in financial record books at the facilities. Celeste explained that the careful tabulation of residents' spending money and her own expenditures was the type of information recorded in the financial book at her facility:

> They have $135 a month spending money. Each of them gets to the penny $135 [laughs]. If you want to know what I spent today, I can take it out of the file and show you that that's what it has been. (Celeste)

Rhonda pointed out that as supervisor with an adult community residential agency, one of her responsibilities was auditing the financial records of the facilities under her jurisdiction to ensure that the per diem rate of $135 actually went towards residents' comfort and clothing as mandated and that these records were kept in good order for occasional inspections by individuals from the Department of Social Development. Rhonda also explained that some staff members act as Trustees on behalf of residents:

> Every client has a Trustee who is a full time staff responsible for their $135 per diem fee for clothing and comfort every month. Basically, the account is in the staff person's name and reads, 'so and so [name of staff member] for the care of' and the client's name. They're not legal trust accounts, because we don't have legal power of attorney. There are only two banks in the area willing to deal with us because they know us through personal banking, but it's becoming increasingly difficult. (Rhonda)

Rhonda then added, "We don't have legal trusteeship but acting trusteeship." At least one resident in an adult community residence understood that someone other than himself was responsible to oversee his allotted funding, for when I asked Blake, "Can you tell me about yourself?" his response included, "I have a Trustee. _____ [staff member] is her name." When I followed up with, "What does ____ [staff member] do as your Trustee?” he said, “She takes me for my banking and she buys me clothes and stuff that I need.”

A fourth book contained information about residents’ backgrounds, whether they were disruptive, aggressive, or self-destructive, the contact information of family members, and detailed Individual Service Plans. Shirley, a front-line worker, told me that staff members were responsible to update and complete ISP forms for each resident annually, after which she laughed and added: “I should just copy what had been written before and sign my name to it as nothing’s really changed.” I observed during field work that a different front-line worker at the facility where Shirley worked spent substantial time and took careful pains to ensure that every piece of information required in the ISPs was accounted for. Other than this particular incident, however, maintaining records appeared to be less important in this facility compared to the other adult community residences, for staff members spent little time checking or recording information in the communication book.

Besides the record books already noted – communication, medical, financial, and personal ISPs - additional records were necessary for certain residents on occasion, such as Zane. According to Celeste, Zane created difficulties every day by trying to change his morning routine with every staff member as they arrived for work:

> We had to set these rules for Zane where, if you don’t want to get washed at 9:30, that’s your business, but you need to be up by 10:00 or 10:30. If not, then you’ll go to 1:00. And then, when it comes to emptying his urine bag, he could go to the bathroom and empty his urine bag but, no . . . So there are three binders for Zane: his urine, his bowel movements, and when he washes his hair. If he refuses that day, he can only have his hair washed the next day. That’s all set up. (Celeste).

Celeste was frustrated at the amount of time it took to set up the additional book for Zane because it kept her from what she considered to be more important tasks:

> I spent, I don't know how much time doing that, so in doing that I lost a lot of other time to do more important things, like working on medical and policy procedures, because that's very important for the employees. (Celeste)

All front-line workers in the community residences were responsible to record information, particularly in communication books. Rachel, a front-line worker, explained: "We write a little information on what they've done that day." Mark spoke to the importance of recording such information:

> Each shift staff checks the book and tries to record everything. It's important to write it down because it takes care of it, if you don't happen to remember to verbally communicate it when the next shift comes in. (Mark)

The information recorded in communication and other books was beneficial, not only for keeping staff members abreast of what was going on in the facilities, but also for protecting employees. Mark explained: "Recording and reporting are also very important when it comes to incidents because they provide a paper trail." Front-line worker Simone, of a different facility, added to the discussion:

> We all write in it. That book is what everyone did, like if our residents said something or if something went wrong. So if there's something, _____ [operator of the agency where she works] will know about it and it saves us trouble. (Simone)

Shirley put it more succinctly: "Staff members always keep careful records to cover their ass." Besides functioning as a tool to protect employees, keep them informed, and enabling them to stay on top of scheduled appointments and activities for residents, records were also valuable in orientating new employees. According to Mark: "We pass that information book to every staff hired."

Records also enabled individuals from the Department of Social Development, social workers, operators of facilities, and supervisors to stay informed about what was going on in the facilities. Mark explained: “We have the books here, but copies are kept at the office,” referring to the agency he worked for. Bruce, operator of adult community residence agency D, told me that information such as found in incident reports is passed along to social workers who, in his opinion, should still be responsible for individual case management:

> We have to fax some of the stuff over to the social worker, like incident reports. Social workers should really be doing the individual case management thing, but they haven’t been doing that for years, so we just do our own form and send it over to them. (Bruce)

While social workers Sherri and Linda said they occasionally accessed information on residents from the records, files, and individualized reports maintained at the facilities, they were also responsible to maintain their own set of records on residents. Linda described the type of information she recorded and maintained on the residents who made up her case work file:

> I do all their financial. Once a month, I record whatever went on with their health, what they do out around, who visited. I make a monthly statement of whatever happened that month. The office gets a copy, we get a copy, and their parents, whoever. We also have daily notes we can add to. (Linda)

It was critical to Rita of the Department of Social Development that all individuals who benefited in any way from their supports and services, including those receiving formal long-term care, had information recorded about them and maintained at the Department of Social Development. Rita discussed the type of information maintained on residents and the importance of being able to access such information:

> A lot of information is recorded about them. All of their services are registered. The payment system goes through that and in the event that an incident occurs, it's all there so that you can find it. Recording is done regionally but we have access in case there are questions, if there are issues, or families are calling. We have access to all of that information. (Rita)

Kim, whose daughter lived in a long-term care facility, was of the opinion that social workers did not always read incident reports, and when they did, they often failed to deal with the issues. Kim recounted her frustration at failing to get any results from several contacts she and her husband made with a social worker to request that she address concerns for their daughter's safety because of the aggressive behaviours that two large male residents were engaging in at the facility where their daughter lived:

> We went around and around on this and basically, they just kept coming back to this frigging privacy issue, which to me doesn't apply at all, because we didn't want to know anything about the other residents, just why they can't do something about the situation when it is unstable. (Kim)

Kim felt it was ludicrous that staff members were able to freely share general information with her about how her daughter was doing, but also withhold information about matters that had implications for her daughter's safety:

> There are always things you check on with your daughter, and the workers are always very helpful in telling me how things are but, obviously, when there is something like this going on they can't tell me, which is ridiculous! It's alright to call to see if she ate today, if she pooped today, if she was in a happy mood, or if she's had temper tantrums or if she's sad or if she has been sleeping, but you can't tell us if she's in danger! You cannot tell us if the situation is unstable! Isn't it ridiculous! (Kim)

Kim concluded by pointing out to me that the response would be very different if the same scenario were taking place in her home:

> If this type of activity was occurring in OUR home [my emphasis because of the stress she placed on this particular word] they would come and take my daughter out of our home that day, but because she's under the government's care, it's okay to leave her in this danger! (Kim)

Keeping up-to-date records at facilities and providing incident reports to the Department of Social Development were in keeping with proper protocol, but certain information can be withheld from parents, as revealed in Kim's account, and at least one occasion when the Department of Social Development failed to respond to an issue - the one raised by Kim and her husband.

The policies and guidelines operators developed were intended to provide security for residents, opportunities for their development (*SPARF* 2009, 2.5) and function as systems of accountability, but they also had to comply with mandated documents (SPARF 2009, 6.2). The failure to appropriately address Kim and her husband's concerns over their daughter's safety was related to the potential conflict with other residents' privacy rights, which supports Hamlin and Oakes's (2008:51) contention that there are occasions when policy goals conflict. Ultimately, the data in the various records that were kept on residents functioned as instruments of power and knowledge over residents and enhanced the asymmetrical nature of relations between staff and residents, in keeping with the literature (Drinkwater 2005, Foucault 1979, Goffman 1961). Further, "informal monitoring" of residents, such as the exchange of verbal information them and about daily events (Levinson 2010:106), along with records kept on residents are, in Foucault's (date) sense, a means of constructing the subject without the subject and the objectification of the person and are thus a fundamental part of the system of surveillance in today's long-term care residences.

Meals, Snacks and Chores

In addition to record keeping, the preparation and consumption of food was an organizational feature of adult community residence life. Meal and snack times were significant events for residents and for some, the highlight of their day. Some residents were responsible to set the table before meals at all facilities, but at one adult community residence were not allowed to touch the countertop or cutlery which, according to staff, was for hygienic reasons. The inability of residents to touch the countertops or eating utensils at this facility and the inability of residents to access the record books and files that contained information about them, reveal more subtle demarcations between staff and residents, rather than the explicit delineations in Goffman's (1961) analysis. Front-line workers prepared breakfast for residents at all facilities except one, where residents who were able prepared their own breakfast and coffee, cleaned the table where they ate, and washed and put away their dishes after the meal. Staff members at this facility poured the hot water for coffee into residents' cups, however, so they would not burn themselves.

Also at this facility, a staff member explained that if residents were not up, washed, and dressed by 10:00, they had to wait until noon to eat. Breakfast at the facilities ranged from cold cereal and juice mix, to toast, jam and/or peanut butter, coffee and, occasionally, a banana. Harold, a front line worker, told me, however, that he cooked a large breakfast for residents on the Saturdays that he worked. Lunches typically consisted of soup and/or sandwiches or leftovers from the previous night's supper meal. At one facility, a front-line worker brought in leftover pizza to share with residents for lunch but one female resident opted for soup instead. At all adult community residences, large nutritious portions were served for evening meals and typically consisted of meat, potatoes, vegetables, pasta, and on one occasion, homemade corn chowder. All evening meals were prepared by front-line workers, and in facilities with separate kitchens on both levels, the staff members responsible for each level prepared different meals for residents.

Staff members seldom ate with residents. This appeared to be for a number of reasons: There typically were not enough seats for residents and staff to sit at the table at the same time, staff were busy serving food to residents, working at preventing strife between residents, helping those who needed assistance because of certain impairments, clearing the table, and loading the dishwasher for residents unable to do so. Staff members sat down to eat only when residents were finished with their meals, once the table had been cleared, and after residents were settled into other activities. When they did eat, it was often on an individual basis so others were free to attend to residents as needed. Food for regular snack times included store bought cookies and water at one facility and cheese and crackers at another. William, when asked his perception of the facility where his sister Ethel lived, exclaimed, “Oh my God, they get lots of food!”

Two front-line workers with different agencies expressed concerns, however, over the lack of available money for groceries where they worked. Mark told me that if residents wanted fruit they had to pool some of their personal spending money and that “The guys who put in money get to have some of the fruit.” Nevertheless, one day during fieldwork, Mark returned from grocery shopping with some plums he had purchased for residents out of the budgeted grocery money because, according to him, they were on sale. Shirley, a front line-worker at a different adult community residence, on returning to work after several days off, said: “I hope we have lots of groceries because we have $9.52 to last for the next 2 weeks.” Among her other responsibilities, Shirley was responsible to oversee the monthly budget at the facility and it was at this facility that store bought cookies and water were served at snack times. Residents having to pool their spending money to buy fruit at Mark’s facility and there being less than $10 to buy groceries for two weeks at Shirley’s facility, illustrate the occasional difficulties with trying to ensure nutritious food for residents.

Despite SPARF (2009) guidelines regarding the quality of food to be made available to residents, there was a struggle at times to meet these guidelines because of limited funding. This reality, as well as the other inconsistencies between mandated philosophies of care and care provision, confirms Atkinson’s (1998) findings that gaps often exist between care philosophies and actual outcomes and Lakin and Stanfille’s (2007) argument that there simply is not enough funding to meet residential care goals. While the introduction of the CHST in the 90s made for easier budgeting in Ottawa, provided greater autonomy at the provincial level, and facilitated more opportunities for innovation and quicker responses to issues, situations such as this reveal that Prince (2002) and Puttee (2002) were right in contending that insufficient funding and disparities still exist in disability supports and services, making it impossible to meet policy objectives, as Dunn (2006) and Westhues (2006) argue. In addition, the money does not always follow individual residents into the community.

Residents were given the choice each day of going to local activity centers. Some chose to do so, either daily or several times a week, while others opted to remain at the facilities. Chores were assigned to residents who chose to stay at the facilities if able and willing to do so. Breanne, a front line worker, told me that there were set times for residents who do chores:

> We have some on schedules for tidying their rooms and room cleaning, and they know what their days are and when they do their room tidying. So there are set times. And they have their routines and they know that there are some things that are scheduled. (Breanne)

Shirley explained further:

> Henry learned how to do the garbage. He knows what days to do that, what days he does his room. Some of them do the dishwasher, set the table, just basic things that they need to know. (Shirley)

Residents did not appear to be responsible for many chores, although I observed one male resident hang laundry outdoors on a clothesline and bring it indoors later without external prompting. At every facility, residents who were capable were typically responsible to put their laundered clothes away and some were tasked with making their beds and keeping their bedrooms clean.

Mark felt that teaching residents how to do chores was beneficial because it got them involved and kept them busy:

> Everything we do, we try to get the client involved. The first thing we have to do is let the client do his own dishes. If he takes ten minutes to do the dishes or if he takes an hour, keep him busy. (Mark)

There were also occasions when doing chores appeared to bring pleasure to residents. For instance, when a staff member returned from grocery shopping residents, all of the residents rushed outside to help carry in the groceries. It was obvious that they did this regularly as they immediately moved into a single line formation, eagerly anticipating their turn to carry a bag inside the facility. Thinking I would help out, I stepped in line with them to take a turn but two residents quickly stepped in front of me so they would not lose their turn. In another instance, I sat with Kate, a resident of a different facility, to help her fold laundry. Kate said, “I love to fold laundry and I do a good job of it too!,” after which she proceeded to show me how to properly fold laundry, explaining what to do, what not to do, and how to respond should I found a towel with a hole in it. Kate was excited when she came across such a towel. She cut off all loose threads and divided the remainder into small pieces which she said would be used for cleaning rags. Kate folded these cleaning rags and put them in a specific area of the cupboard designated for such a purpose.

Rules, Punishments and Rewards

Part of the orientation process for individuals placed in adult community residences involves making them aware of the rules and guidelines they will be expected to follow (SPARF 2009, 6.1). All operators of individual agencies were responsible to develop their own rules in compliance with existing legislations, which then required approval from Boards of Directors where they existed. Rita, of the Department of Social Development, explained that “The majority of adult community residences are operated by non-profit boards that make their own rules.” However, Doug, who operated a non-profit adult community residence agency, said “We don’t have any rules at the homes.” Doug explained that the employees at each facility affiliated with his agency were free to establish their own rules and expectations for residents and that these differed depending on individuals staff members:

> The only rules are those that individual staff members make. Some staff have personal rules but some are better. Like, some let them go to bed anytime they want and some staff put them to bed at certain times. But here at the agency, we don't have any rules. The only rules we have are those the staff have. If the clients want to go out at night, they go out at night. We're good to them. We give in to them like that. (Doug)

Doug did have one stipulation however: "I tell my staff, 'Don't try to control them.' The minute that they try to use control [pauses] . . . they don't like that you know."

Mark discussed some of the rules at the facility where he worked:

> If you hit somebody or you touch somebody, the door is right there. I think it happened once. They know if they come to my house, they're going to have rules. The other houses [referring to other facilities within the same agency that he worked for] have rules too, but it's their choice. I don't have a rule that they have to be up and washed by 8:00 a.m. I'm not that kind of guy, but by 10:00 everybody has to get up. Anyone not up and washed and dressed by 10:00 has to wait until the noon meal. It's their choice. It's a house like a normal house. (Mark)

Having to adjust to pre-established rules or "the door is right there" is consistent with Goffman's (1961) argument about the importance of developing compliance in residents in institutions and supports his concept of an "attendant culture" (Goffman 1961:81) in the goal of controlling residents at the facility where Mark worked. Foucault (1997:281,282) is also relevant because of his contention that power relationships are always present when some individuals are working to "control the conduct" of others.

Mark felt it would be chaotic without rules at the facility because of his first-hand experience of what is was like before rules had been established at the facility. Mark described the situation:

> The coffee was on the cupboard and that was not locked, and the juice was not locked, and it was a free-for-all. So we set up some rules and, now, you can see that things are going well. Some complain about the rules, but it's like your child, if you don't like the rules or if you think you can do a better job, I always have an open door for that. (Mark)

Mark's comments reveal a number of themes: locks were important in the operation of that facility, not unlike in other long-term care facilities. Mark perceived residents to be like children and there appeared to be room for negotiating better rules. According to Mark, individual residents could influence the rules specific to them, although it is likely that such influence would be restricted to parameters suited to the smooth running of this facility:

> Sometimes, some of the residents make up their own rules and we add it to the sheet. After repeating over and over, 'Don't do that' or 'Don't do this' or 'If you do that you may lose your money for the weekend' or 'Instead of $10 for the weekend, you are going to get $5,' for example. It depends on what their goals are. Each client carries his own rules. (Mark)

Mark's last two sentences seem to imply the goals and expectations reflected in Individuals Service Plans (ISPs). One specific rule pertinent to all facilities was not allowing individuals to smoke indoors in compliance with the *Smoke Free Places Act* (2004, 3.c). This rule was consistently upheld at all facilities for all residents and staff members were required to go outdoors to smoke.

Mark told me that he had discovered a number of effective punishment techniques for residents which included: denying residents certain taken-for-granted privileges such as smoking, having coffee, or having access to their personal spending money. He recounted the story of Adam who, on first moving to the facility "urinated all over the toilet, floor, and everything else" every time he went to the bathroom. Mark said: "I got tired cleaning up after him all the time so I took away his smoking privileges, coffee, and pocket money until he stopped doing it. He never does it now." Adam talked about learning to comply with rules at the facility:

> I like to play basketball but I'm not allowed to cross that line there [pointing to a line at the end of the driveway]. One time the ball rolled across the road and I went into the neighbour's yard to get it, but I have the rule for that now. (Adam)

Adam's comments reveal that he had effectively internalized facility expectations, which Goffman (1961:83) characterizes as residents learning to 'self-direct.' Tremain's (2002, 2005) assertion about the potential of rules, punishments, and rewards to influence the behaviour of individuals helps to explain Adam's eventual docility and self-governance (Levinson 2010:48), which Foucault (1977) envisioned in such scenarios (Carlson 2005, Sullivan 2005). Residents' identities were shaped by the life skills they were taught and the rules and regulations they were expected to follow,[103] molding them into docile individuals and disciplining their identities to conform to the systems of control in the facilities.[104]

According to Mark, a resident at the facility where he worked, Michael, had earned the name 'thief' because of his pattern of taking things that did not belong to him. Several neighbours had called the facility to see if Michael had their missing items. Mark and other staff members at the facility eventually implemented a policy where complainants are told to call the police if they catch Michael trespassing because staff members are unable to supervise Michael when he is not at the facility. Another punishment technique Mark used was taking residents' stickers away from them. Mark explained to me that Michael could "lose a sticker" if he engaged in inappropriate behaviours like stealing. Michael asked Mark one day when I was at the facility about the status of his stickers and became upset on learning that he had to wait an additional

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[103] Rose (1999), however, views such self-governance as not dis-similar to the self-monitoring practices of all citizens.

[104] Although not a focus of this study, this process is likely gendered.

day before receiving his reward. Michael reacted to this news with, “Okay, I’m not going to eat my soup for lunch!” to which Mark responded “No problem.” Mark then turned to me and said, “Everyone has a choice. If they don’t want to eat a particular meal, that’s fine, but they have to wait until the following meal to eat again.” Michael ate his soup when lunch time came.

Some residents were able to go on numerous outings unescorted. Residents at the facility where Mark worked had significantly more freedom to come and go compared to most residents in other adult community residences. A possible explanation is that while the residents at Mark’s facility required level 3 and/or 4 care provision, as did the residents of the other adult community residences, the residents in Mark’s facility were dealing with mental illnesses rather than developmental, cognitive and/or physical disabilities. The greater freedom these residents enjoyed, however, posed problems at times. For instance, besides the issues that resulted from Michael’s reported propensity for stealing, another male resident at the same facility signed a three year contract for a cellular phone while away from the facility which he had no means of paying for. Mark apparently spent a significant amount of time on the phone trying to negotiate with the salesperson to cancel the contract but without success.

On another outing, this same resident sold an expensive item his family had given him for drastically less than its reported value. Trying to ensure residents’ freedom to exercise as much independence and self-determination as possible, a key tenet of ideal care (SPARF 2009), was frustrating for Mark, who was responsible to deal with the fallout of residents’ ill-advised choices. This scenario created ongoing tension between Mark and residents. The mandate that residents become as independent and self-determining as possible (SPARF 2009) requires opportunities for residents to make choices or as Moos et al. (1979:77) put it, some level of "freedom to come and go," but this is problematic for staff members who, as Hamlin and Oakes (2008:51) point out, are typically "socialized to care and protect" residents. In addition, such freedoms are not without limits and residents may only exercise this form of autonomy within the bounds prescribed by what remains an institution of control.

In addition, there were times, as revealed in Mark's experience, when greater risks came with greater freedoms, given the fallout of the choices two residents at Mark's facility made, which makes Levinson's (2010:46) query as to "what shape" freedom takes in long-term care settings particularly relevant. The reality of greater risks lends support to Levinson's (2010:243) contention that "risk administration" is an indisputable facet of work for caregivers in long-term care facilities, particularly given Mark's experience of trying to balance the risks that came with these residents exercising their freedoms. Levinson (2010:232) asserts that involvement in risk administration adds to the endlessness of work for staff members, as seen in Mark case. Levinson's (2010:103) point that independence is not really the goal but the 'pursuit' of it, is pertinent to this research as well, for even those residents with the greatest freedom to come and go were unable to "achieve independence in any conventional sense" (Levinson 2010:103).

The emphasis was on rewards rather than punishments at a different adult community residence from where Mark worked. Front-line worker, Harold felt it was better to reward residents for good behaviour than to punish residents for inappropriate behavior: "Staff are not to punish bad behaviour but reward good behavior. Like for instance, Joseph gets a reward if he doesn't ingest anything." Joseph, a resident at the facility where Harold worked, had a pattern of consuming inedible materials, self-abusing, and displaying destructive behaviour. Apparently, Joseph had destroyed his Medicare card, birth certificate, some furniture in his bedroom, and scraped the skin off his hand and lower forearm by marking back and forth with a pen as hard as he could. These marks were readily visible when I sat across the table from Joseph.

Joseph's destructive actions may be interpreted as engaging in "secondary adjustments" (Goffman 1961:269) to show resistance to facility expectations or as utilizing 'stratagem[s]' that nevertheless, failed to reverse his situation (Foucault 1997:292). Front-line workers recovered the television Joseph had thrown in the garbage in his bedroom and were withholding it until he proved he was capable of going a week without destroying anything else. I overheard Joseph ask Harold when he could have his television back, to which Harold responded:

> If you don't destroy anything else you can have your television back on Monday. You have been doing really good keeping it together, so just keep up the good work and you can have it back then. (Joseph)

Joseph accepted Harold's response. Withholding Joseph's television until he refrained from destroying anything else and denying Adam his cigarettes and other privileges until he stopped urinating on the floor are specific disciplinary techniques (Foucault 1977) used to teach compliance in residents (Goffman 1961). Goffman (1961:53) views such "punishments and privileges" as organizational features "particular to total institutions." These practices also exemplify the exercise of bio-power over residents (Foucault 1979). Adam's ability to eventually regain smoking privileges and the likelihood that Joseph would get his television back point to Goffman's (1961:62) "privilege system" at work in these two facilities because denying Adam his cigarettes and Joseph his television had great significance for them. For Levinson (2010:200), such techniques constitute 'proactive' and 'reactive' techniques to address the improper conduct of residents.

Harold's stance that rewarding residents was a better approach than punishing them was reinforced when he made a trip to the Dollar Store during my time at the facility to purchase picture frames for what he described as a future "wall of merit" to display residents' individual achievements. After showing me copies of two residents' graduation diplomas that he had framed, Harold said:

> Those who didn't get a graduation diploma will be recognized for something else they did well. Like Kate, for example, she will get an excelling housekeeping award for her love of folding laundry. (Harold)

The systems of rules, punishments, and even rewards so important to Harold, all fit with Foucault's (1988:18) assertion about the existence of "technologies of power," for they delineated the boundaries of conduct for residents and required them to submit to "certain ends or domination" (Foucault 1988:18). Subjecting residents to specific practices in order to maintain the 'rules' of these 'culture[s]' (Foucault 1989:312,313) reveals how residents were rendered subjects. More specifically, and consistent with Sullivan's (2005) argument, the rules, punishments, and rewards provided multiple sites for others to exercise power over residents' lives, similar to other findings (Yates 2005, Corker 1999).

The rules, punishments, and rewards, especially at the facility for individuals with significant mental illnesses where Mark worked, revealed something about the cultures in these places, where culture includes those "forms of social life, prohibitions and diverse constraints" (Foucault 1994:582) that exist in certain settings. Being firm and consistent with residents was the sign of a good employee for Mark and helped in ensuring that clients fulfilled their individual obligations:

> Good staff members are those who are firm and consistent, and the clients know who are good staff. When good staff are working they just do what they have to do without being told. Clients have to keep their rooms clean and make their own beds.

Mark was also aware, however, that all staff members did not uphold these expectations:

> Some staff don't maintain these expectations. They can't be scared of clients. You either have it or you do not. Some staff are softer with clients. The problem is, if staff not strict, consistent, then clients try to play staff against staff. (Mark)

The emphasis on maintaining the status quo is related to residents' awareness of "day-to-day routine[s]," the significance of "order and regularity," and that 'rules' are explicit (Moos et al. 1979:77). This scenario characterized the situation where Mark worked, which for Moos et al. (1979:77) allows little opportunity for "systemic change" at this facility.

I observed that in two of the facilities, neither where Mark worked, staff members were not consistent in what they expected from residents. For instance, at one facility, a male resident, Ernest, cursed non-stop for about twenty minutes at a time on and off each day and for no apparent reason. The rule at this facility was that Ernest was free to curse as much as he liked in the privacy of his bedroom but not in the presence of other residents. Front-line workers took different approaches to respond to Ernest's cursing: two asked him repeatedly to "please stop," one threatened to put him in his room, one laughed, and another completely ignored him.

Joseph, who lived at a different facility than Ernest, was allowed to make only a certain number of phone calls each day and at designated times. According to staff members, this rule was established because Joseph repeatedly calls the same person over and over again. One front-line worker upheld this rule while another let Joseph make as many calls as he liked, whenever he liked, and as many times of the day as he liked, which Joseph took advantage of. The reality that rules were in flux in some facilities and that front-line workers and on occasion residents, were able to influence their application, points to cracks of opportunity for change in these facilities which, according to Moos et al. (1979:77), is more characteristic of facilities with positive social climates.

Intensity of Structure and Emotional Atmospheres

Following de Rivera's (1992:97) assertion about the possibility of assessing the emotional atmospheres of social settings, I observed a tenser emotional climate at the facility where Mark worked with residents with significant mental illnesses. By tenser, I mean there was ongoing tension and conflict between staff members and residents and among residents themselves, most interactions between staff members and residents involved emphasizing to residents that they needed to comply with the rules, and staff members were constantly negotiating between ensuring residents' freedom to come and go and dealing with residents' occasional poor decisions on these outings, as seen in Mark's experience. This scenario rendered a state of "permanent provocation" (Foucault 1982:790) between individuals at this facility and, therefore, a less positive social climate (Moos et al. 1977) at this facility compared to the other adult community residences.

Mark told me that staff members had to be vigilant to watch for potential signs of conflict between residents so these situations could be averted before they escalated and got out of hand. I saw first-hand how quickly such crises could ensue when a male resident happened to brush another male resident's arm as he walked by. The resident who experienced the brush immediately became agitated and began hollering at the perpetrator. Mark quickly intervened by talking calmly to both residents, successfully diffusing the situation in a short period of time. After these two residents left the room, Mark informed me that a couple of residents had a history of engaging in violent behaviours, saying of one individual:

> He used to be very violent, killing a pet with his bare hands. He held his mother's hand on the burner on the stove. Since coming here he has punched one of the female staff. (Mark)

Michael, a resident at this facility, told me later that week: "I used to have fits [temper tantrums] but I don't do that anymore." A possible explanation for the greater emphasis on control and vigilance in watching for potential crises at this facility, is that most residents were diagnosed as paranoid schizophrenics, where periodic bouts with anger and anxiety are symptomatic.

Adherence to daily routines was also emphasized at the facility where Mark worked, but a predictable daily structure seemed to be of great importance to Ethan who was diagnosed as a paranoid schizophrenic, for he seemed to thrive on predictability. Ethan was methodical in everything he did, setting his own alarm to get up at the same time every morning, engaging in certain chosen activities at the same times every day, and checking his watch regularly with the kitchen clock to ensure that all meals and snacks occurred at pre-designated times. Cigarettes were important to most residents in this facility and they ordered their days around their cigarette and coffee breaks, checking their watches about fifteen minutes prior to pre-scheduled smoke break times. Smoke breaks occurred exactly the same time every day at this facility: 10:00 a.m., right after lunch, 2:00 p.m., and so on, until residents reached their allotted eight cigarettes per day. Every morning, a front-line worker divided residents' cigarettes into individualized sandwich bags and put them in a locked cupboard.

The tenser emotional climate at the facility where Mark worked was palpable, despite the occasional expressions of attention and affection by staff to residents, the visually appealing physical environment of this facility, and the stated desire to provide a home rather than institutional environment for residents. The combination of being affectionate with residents while having to strictly uphold facility expectations at this facility, reveals the uneasy tension possible between care and control, as Trent (1994) argues. The emphasis on rules and the conflictual and tense relationships also made the demarcation between staff and residents more apparent at this facility. Celeste, operator of a different adult community agency than where Mark worked, told me that one of the first changes she made on becoming operator was to loosen the rigid routines that existed under the previous operator.

For example, Celeste explained that residents were now able to choose where they sat at the table during mealtimes and could take as long as they wished to eat. When I asked Celeste if she noticed a difference with residents after the environment in the facility was loosened, she responded: "The behaviours of one of our female residents went down. She has a lot less behaviours now. It was measurable with her." Celeste then compared the differences she saw in a male resident:

> He gets off his chair more than he used to. It was like there was a magic belt there and 'you are not getting up. You cannot get up,' but now he's acting freer. I find he's taking more charge of his life and he should be. (Celeste)

The three facilities with less emphasis on upholding facility expectations and maintaining rigidly scheduled routines, including Celeste's, were undeniably more cheery and had relaxed environments, for most interactions between front-line workers and residents and among residents themselves were pleasant, congenial, and cohesive which for Moos et al. (1979:77), characterizes positive social climates. There was also occasional shared laughter by both residents and front-line workers and the demarcation between staff and residents was less apparent as a result. It was at the facility with the least attention to rules and structure (facility D), that I observed the most congenial and light-hearted interactions between staff and residents and it was at this same facility that I saw a female resident put her arm around the shoulder of a female staff person as the worker sat briefly with the resident to watch TV.

The only time a more serious tone and restricted atmosphere was sensed in facility D was when a particular staff member was working. This front-line worker showed little interest in engaging with residents compared to other employees. Residents of all adult community residences also seemed aware of the staff members they could be jovial with and those with whom they could not. Residents' discernment in this matter revealed their tacit knowledge in this area, as well as the influence that staff members can have on the emotional atmospheres of the facilities where they work. According to Spender (1996), residents' tacit knowledge about acceptable conduct (Levinson

2010:209, 210) around certain staff members also says something about the culture of a place. It was at this facility with the least attention to structure (facility D) that mornings were quiet, the pace was slow, and staff members allowed residents to choose when they got out of bed and to eat breakfast in their pyjamas if they wished to do so.

In this chapter I presented an analysis of the philosophical, physical, and organizational features of adult community residences, and the social, emotional, and cultural climates that I observed in these facilities. In the following chapter I discuss manager's observations of formal care delivery in the larger institutions, their accounts of the deinstitutionalization process, and their current experiences with care delivery. In the following chapter I also include an analysis of the various difficulties that managers encounter in finding and retaining employees, dealing with bureaucratic red tape, and negotiating for additional funding because of the constant funding shortages that managers' face.

CHAPTER SEVEN: MANAGEMENT'S EXPERIENCES WITH CARE PROVISION

Below, I discuss the experiences of the individuals providing oversight to care delivery in long-term care facilities, and their observations of care provision in the larger institutions and of the deinstitutionalization process. Management is frustrated by a number of issues: the disconnect between formal training requirements (SPARF 2009) and the realities of the job, difficulties finding employees with the required training to work in the facilities, the lack of government incentives or funding to support this training, and the inability to provide wages and/or benefits that employees deserve, further exacerbating problems in finding employees. Management is hopeful that Bill 35 (*An Act to Amend the Public Service Labour Act*), a piece of legislation developed to fight for wage equity and challenge employees' low wages, will help in addressing this issue. Management also has to deal with bureaucratic red tape, constant funding shortages, and their target population (19-64 year olds) holding less government funding priority compared to other groups. Management spends the bulk of their time negotiating with people from various sectors but experience support from Boards of Directors.

Management's Observations of Care Delivery in the Larger Institutions

Byron was involved with the creation of the first agency in New Brunswick to offer residential care for persons with disabilities and/or mental illnesses in the community. As Byron talked about his first time visiting Centracare in Saint John, he described his shock and anger at how residents were being treated and his impression of the facility as being similar to a concentration camp:

> I was totally blown away that in 1977 in Canada we treat people like that. They were just in cages basically! The way I interpreted it, they had the doors, the bars on and the wards and [pauses], we can't be doing this, surely not! This is nuts. This is like a concentration camp almost! It got me pissed off! I thought, My God! I couldn't' believe people still treated human beings like that in this day and age! It made me so angry! (Bryon)

Although Byron considered it to be a horrible living situation for residents, it was no secret to government officials:

> Centracare was an old, old building with people who lived there for many years. It was very institutionalized, a lousy place to live and the Government was aware of that. (Byron)

Byron did allow, however, that this approach was seen as appropriate at the time and that some positive things were being accomplished:

> That was the way they were working for a long time and they thought that they were doing the right thing. And they were doing some good stuff. (Bryon)

Byron concluded however, that the outcome for residents living in this type of environment was a problem:

> They put all the disabled people together and they just fed off each other's weirdness because they had nothing to do all day. That was the problem. Nothing to do! Nothing to stop this from happening! (Byron)

Doug, an operator of adult community residence agency A, who had also been an employee in one of the large institutions, talked about visiting the institution years ago with fellow students as part of a 10-month preparation course to work in the facility. Doug became emotional as he described the living conditions for residents and the way residents responded to he and fellow students when they entered the facility:

> When we went to visit, I never thought that human beings were living that way. It was an awful thing. At that time, there were about eighty-some. And when we went into the door, they were just running to us and touching us and I said to myself ‘That’s awful!’ (Doug)

When Doug first went to work at this institution he wanted to take a different approach with residents but, unsure how to proceed, initially did what was expected of him:

> I didn’t know what to do because I knew the things that they were doing I didn’t agree with. And I didn’t agree with the things they asked me to do, but since it was the way that people were doing it at that type of ward we did it. (Doug)

The first issue Doug wanted to address was the condition of the residents, which he described as follows: “Like their fingers, they couldn’t hold anything. They didn’t have any sense of touch for that. None of that was developed. So I did that.” Doug eventually became program coordinator, which included responsibility for residents who were self-abusing.

Yvette, a supervisor with an adult community residence agency also had previous experience working in one of the larger institutions: fourteen years as a program coordinator and five years providing oversight on the floor where persons with cognitive disabilities were housed. Yvette told me that she had a difficult time working there:

> It was really, really hard to work there. When you’re in charge of the floor, you’re there in the morning and you see, eight to four, you see everything. It is a great big, big, big difference between the community and the institution. (Yvette)

When asked about this difference, Yvette pointed to quality of life as an issue:

> Oh my goodness, it’s a big, big, big, big difference. I think we can talk about quality of life. At ______ [the institution where she worked] - none at all. That’s why I left. (Yvette)

As Yvette continued to talk, she provided additional information about her rationale for leaving her job at the institution:

> Even though I was in charge of the ward, I didn't have that much power because the union are really, really strong there, so there's not that much you can do. And the supervisor was in the same union as the worker so it was really, really hard. And you can see some clients in there staying in their incontinence all day. You have to be behind them all the time, all the time. It was really, really hard to work there. (Yvette)

Mark, team leader in an adult community residence and also a former employee of one of the larger institutions, was offended by the smell of the institution and that large numbers of residents were always grouped together:

> The place stunk. Everybody had the same shower and they didn't like it. It was soldier-like. It's your turn to get in and out. They're all in the same room over there with around twenty-five on a ward. (Mark)

Mark then compared residents' lack of freedom and ward settings in the larger institution with the freedom residents currently experience and the individual bedrooms they now enjoy in the adult community residence where he worked:

> Here, everyone has their own room and their own bed. Over there, they're locked down. Over here, they're free. Some are allowed to work in town, come and go. Over there, they're not free. Sometimes, some are allowed to go in town, but not often. Here, it's every day. If they want to go out they go. (Mark)

The cage-like settings, concentration camp-like surroundings, lack of freedom for residents, and residents' eagerness for some type of physical contact with Doug and his fellow students, all support the "encompassing tendencies" Goffman (1961:15) envisioned with total institutions. Goffman's (1961:17) conception of institutional life is also relevant to this research because of the residents being in "large batch[s]" in the institutions and dealt with in a highly regulated and 'soldier-like' fashion. The scenarios of the larger institutions described by participants also reveals that the power relationships between employees and residents in these institutions were “completely out of balance” as Foucault (1997:292) argues.

Difficulties Finding Staff and Limited Family Contact

According to Francis (1975), the institutions in New Brunswick were consistently overcrowded and understaffed. Doug, operator of an adult community residence agency A, recounted stories of the type of people who used to work in the institution and the problems finding people to work there:

> Most of the people that worked there, most of the time, they didn’t have any education. I remember a guy there telling me one time, ‘I read an old story in a book, like sometimes they need people to work in the institution and they used to take a truck and drive it around town and if they find someone that they wanted to work, but they couldn’t find nothing, they would pick up murderers, rapists. They would pick up anyone to work there.’ (Doug)

This was not just the situation in the large institutions for Byron told me that he experienced difficulties as late as the 1980s with finding people to work in the adult community residences with the residents who were transitioning out of the institutions. Byron explained that he ended up using some individuals serving time at the prison farm at the Westmorland Institution in Dorchester, New Brunswick, to work with residents:

> You know where Westmorland institution is, right next to Dorchester, right? They were in a minimum pen and there was no fence and they could walk away any time they wanted. There was a program and these guys were all approved for that that they would come and do something with disabled people. Some of them would get quite interested with the residents and then they started to go on outings. They would take one or two of the residents and they would go to the park, doing whatever. (Byron)

Although this was an issue that Byron and members of the Board of Directors deliberated over, they concluded that the public should be kept from knowing that cons or ex-cons were working with residents, and that the benefit of free labour outweighed any concerns they might have had:

> Now I [hesitates], the Board, we questioned it to a certain extent. Do we want to have the community know that there are ex-cons or cons - they are still cons - working with handicapped people? The image isn't good. Now these guys didn't wear on their back what they were so, in that sense, they were just people. But they were cons and they [pauses], but no, it worked well. It didn't cost me anything so they put in all the time and effort but no money, so. (Byron)

When Doug worked at the larger institution he saw very little contact between families and their loved ones in the facility: "I started to realize that none of them had visits, maybe one or two." This situation was troublesome to Doug, who said that after seeing his own wife's extended labour with the birth of their first child, "there is no way that a woman who has given birth to her child ever forgets her child!" So, on his own initiative, Doug visited all 178 families whose loved ones were living in the institution. According to Doug, most family members wished they had not placed their loved one in the institution but there were no alternatives:

> Only one said 'This is where my daughter or brother or sister should be.' On top of that everyone said to me 'You know what? If I had the opportunity to do differently I would have done it differently, but I didn't have any choice.' (Doug)

Not having a 'choice' in having their loved ones placed into a long-term care facility is the same sentiment expressed by participants in this research.

Doug also talked about some of the reasons families did not maintain contact with their loved ones in the institution where he worked. These included that their children wanted to go home with them when visits were over and that employees at the institution discouraged families from visiting as they felt it created problems for residents. The opinion that family visits hindered the efficacy of institutional care has been documented in institutional regulations since the mid-nineteenth century For instance, Dr. Waddell (cited in Goss 1998:70), who served as superintendent of the Saint John Asylum, said in 1851 that “visiting interferes much with the running of the house and . . . should be restricted.”

Besides the difficulties of trying to deal with their loved ones’ requests to come home with them and the recommendations that they refrain from visiting their loved ones in the first place, parents were also distressed by the living conditions in the wards where their children were housed. Doug explained: “They didn’t like to see their son or daughter in that situation. It was heartbreaking, you know, so they detach emotionally.” Doug also observed that some parents were very elderly, physically challenged, and had great difficulty trying to climb the three or four flights of stairs at the institution. In an effort to remedy this situation and to reconnect families with their loved ones, Doug developed a space close to the entrance of the institution and in a different area than the wards where families could visit their loved ones.

Management’s Experiences with Deinstitutionalization

Revealing management’s observations of care delivery in the large institutions and their experiences with deinstitutionalization helps to contextualize their current experiences with care provision and provides the historical background of long-term care delivery, consistent with critical theoretical research tactics (Guba and Lincoln

2005) and Foucauldian analyses (Foucault 1988, Tremain 2002) and allowing for a stronger analysis. Although deinstitutionalization in New Brunswick has been more typical of what some characterize as an incremental policy approach (Howlett and Ramesh 2003), deinstitutionalization was frustrated by fears over the loss of, or impact to, jobs for employees in the institutions, the possibility of having the formerly institutionalized as neighbours, that residents might not be able to adjust or be integrated, and that parents might have to take back caregiving responsibilities. There also was not enough government funding to support deinstitutionalization adequately.

Byron had first-hand experience with the deinstitutionalization process, being the first person in the province to provide formal care in the community to the formerly institutionalized. Prior to deinstitutionalization, Byron was already operating several facilities where individuals diagnosed with cognitive disabilities could stay from Mondays to Fridays so they could attend a school for the handicapped that existed at the time. Byron told me about the initial contact he received from the Government, inquiring if Byron would be willing to house some residents from the institutions:

> We were asked if we would be willing to take six young people as a pilot project to see if they could live in the community. This was all brand new. There was nowhere else in the province where this was happening. It was a pilot project. Ours was the only non-profit organization operating community residences at that time. So that's why we were the ones who were asked to do this. (Byron)

Byron described the negotiations that took place between he and institution officials over the type of fencing that would be needed in one of his facilities, before the first six clients would be transitioned from the institution into that particular facility:

> Does the backyard have a fence? (Official)
> Yeah, it has a fence, basket weave, a white fence (Byron)
> We can't send these children there (Official)
> What do you mean? (Byron)
> You need a fence like we have (Official)

Byron went on to describe the fence at the institution that the official was referring to, as well as the open wards, bathrooms, and outdoors areas designated for residents' use that he saw:

> I saw the fence where these kids lived. They have long dormitories. I would think there were maybe fifteen, twenty in one. There were washrooms. None of them had doors in the front. And then there was a door out to a paved area which had an eight foot wire fence around it and that is where they went to air them out. That's what I call it. So I promised the man I would put up the fence as soon as I could, and I never managed it, and the coordinator who came after me never found time either [sigh], but that was the mentality. (Byron)

Having bathrooms without doors for residents, shows the lack of privacy accorded to these individuals at this facility. Doug opened up a second agency in a different area of the province and at a later point in time than Byron. A provincial organization of adult community residence agencies was eventually founded after Doug opened his agency. Byron viewed this organization as beneficial for it "provided a venue for operators around the province to talk and exchange ideas."

There were a number of complications with deinstitutionalization according to those in management. For instance, employees of the larger institutions were concerned about how deinstitutionalization would affect their jobs. Mark told me of fellow employees of the larger institution where he worked being unhappy about the prospect of deinstitutionalization because of concerns that they would probably have to change wards, that it might affect their routines, and that they might lose their jobs. As it turned out, some employees of the institutions did lose jobs. Bryon spoke to the situation in Centracare:

> For the people working at Centracare, this meant the end of their jobs. There were a lot of people working there. All kinds of psychiatrists, nurses, doctors, psychologists, you name it. (Byron)

Employees of the institutions were also skeptical about whether deinstitutionalization would work. Mark explained:

> Many of the employees were cynical about the ability of clients to stay in the community and to find staff who would be willing to work with them. Some clients did have to go back. Two went back, one of their own choosing. (Mark)

Some citizens were apprehensive about having the formerly institutionalized as neighbours. Mark described the approach that was taken to respond to individuals who had circulated a petition to show their resistance when the adult community residence where he worked opened in 1995:

> In my area, we got mostly rich people around, all with big houses. And they made a petition to not have them in their neighbourhood. And we had a meeting and explained to them that we have supervisors for them twenty-four hours a day and we explained to them 'It's just like a child. You have a child and he's not allowed to cross the road, but sometimes he's going to cross. They never kill people and, sometimes, those people are safer than normal people, but we never got a problem.'(Mark)

Mark told me at a later point that neighbours have occasionally reported having problems with residents at the facility. Byron experienced similar problems from neighbours when they learned that the formerly institutionalized were relocating to a facility that Bryon was operating close by. Byron organized a meeting and invited neighbours and civic leaders to attend. Frustrated at his inability to reassure neighbours they need not fear for their safety, Byron finally asked them, "What IQ do you have to have, to be able to live in this neighbourhood anyway?" Byron told me they had little to say after that comment, so the facility opened, and neighbours' fears were never realized.

Wyatt, a front-line worker who worked at an adult community residence in an area different from both Mark and Byron, told of a neighbour who had expressed his fears regarding the safety of his two daughters. According to Wyatt, when this same individual's daughters grew older, he acknowledged to staff members that his fears were unwarranted. Parents also had fears about the deinstitutionalization process but they were of a different kind. Mark explained why parents were fearful of their children being moved into smaller community residences:

> When it came to the families, there were a lot of people who were scared to put the child in the house, particularly if something happened with the houses, because after the houses you don't put the client back in the hospital, like a long time ago. (Mark)

Parents were afraid that if their children found it too difficult to adjust to life in the smaller facilities or if the smaller community residence system of care failed, that they would have to take on caregiving responsibilities again because their children would have nowhere else to go.

While many fears about deinstitutionalization were never realized, initial problems did exist in attempting to integrate the formerly institutionalized into the community. Byron described his experience with trying to integrate some of these individuals:

> They had no idea how to behave in public. We had one young man whose right arm was always up in the air waving. He couldn't speak but he could make sounds, and when he was excited, he would squawk. We would try and walk around the block and each time he squawked, we would walk back home. We tried him at least two or three times a day, and we kept at it, telling him 'If you do not squawk, you can walk all the way around. (Byron)

Byron added: “It took a month before he would walk around with the staff and just quietly look around. Once we mastered the block, he was able to go other places. It was a gradual process” Byron told me that staff members constantly tested different ways to help residents adjust to life in the smaller community residences: “I could tell you many horrendous details of all the things that happened in those early years as we were learning as staff to deal with them and how to introduce them into the community.” Byron then talked about the difficulty for citizens to accept residents who were initially taken to school or on outings in large groups:

> Many in the community just didn’t accept them very well because it was not common yet. They were loaded in a bus and went to the school for the retarded and if there was something happening, they wanted to take them to, they took a bus load full and shepherded them around. And that was the only time people ever saw the handicapped, mentally challenged persons. (Byron)

According to Byron, they finally discovered that integration worked better and the community was more accommodating if residents were taken on individual, rather than group outings. It was only after a year of trying that Byron recognized that integration was possible and these “individuals *could* live in the community” [italicized to show his emphasis]. Byron added: “In 1975 nobody thought this was possible. It’s a different mentality now.”

Government was responsible to provide the necessary funding for deinstitutionalization to be implemented as envisioned. Byron explained that paying individuals to work one-on-one with some clients, and operating the larger institution and smaller facilities at the same time, were costly:

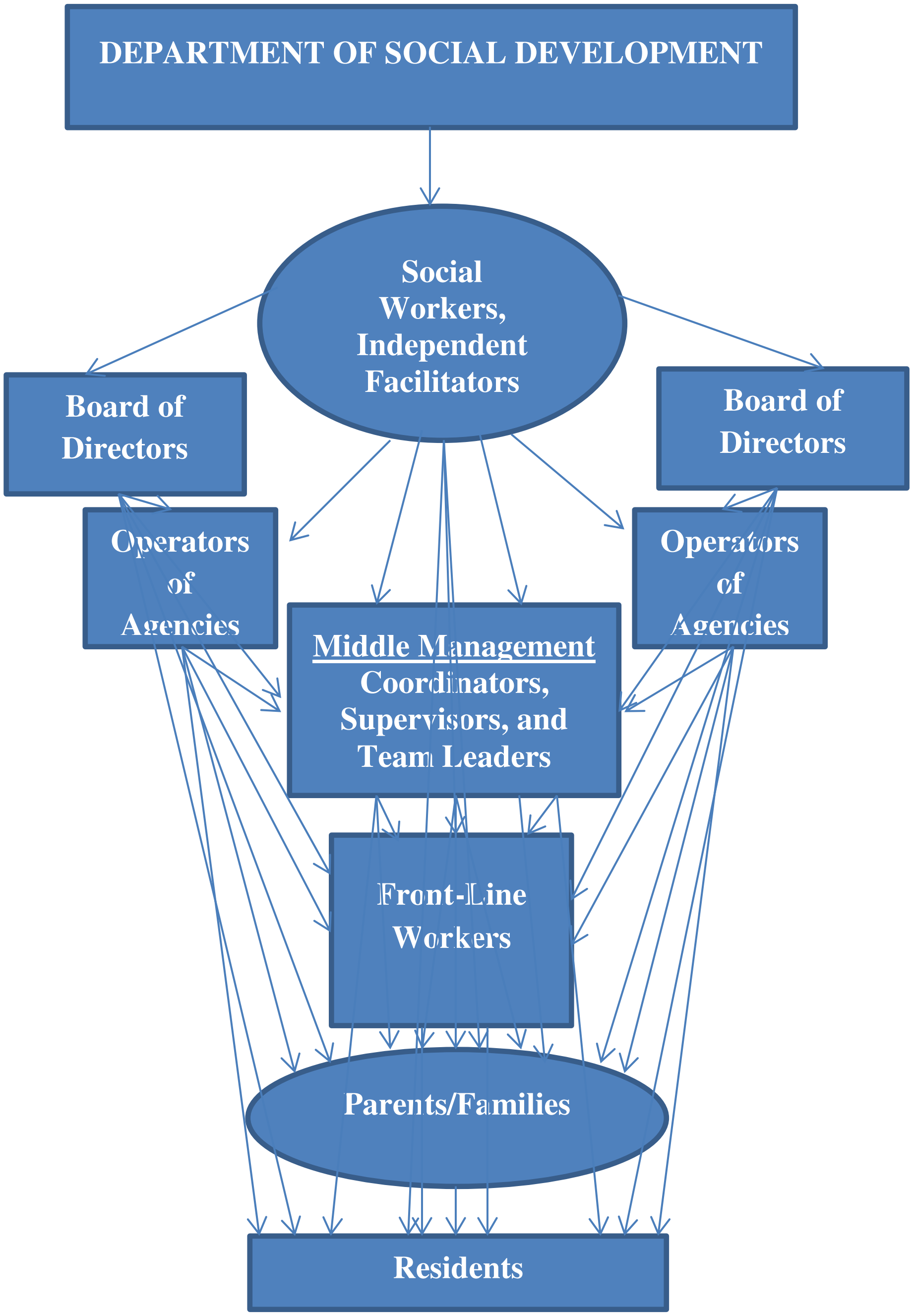
> We had some very difficult people who were very violent, with whom we were only allowed to work one on one. Now that cost a lot of money! For a while, it was a double cost to the Government because they had to provide myself and others with money and still keep the institutions going because they weren't empty yet. In addition, Centracare allowed residents to come out very slowly because there were still a lot of people working there. (Byron)

Government cutbacks initiated in 1985 created a fiscal dilemma for Doug who had opened six additional facilities in the previous year (1984) within a three month period, and hired extra employees to accommodate the increasing number of residents that were transitioning out of the institution:

> I went all over the place to find homes. I built these homes in three months. It was a lot of work and in '85 they cut our budget by thirty-five percent, just like that! (Doug)

At the time of data collection, funding was still a problem for Doug in operating the adult community residences, for in Doug's words: "we were struggling at a thirty-five percent drop." On the following page is a hierarchical model of current long-term care management in New Brunswick (see Figure IV): As this model shows, residents encounter the full weight of decisions made at every level of the long-term care management hierarchy and yet this model still does not fully capture the entire picture, for it does not account for other experts whose decisions affect their lives such as physicians, psychologists, and other health professionals.

FIGURE IV: LONG-TERM CARE MANAGEMENT IN NEW BRUNSWICK



Training and Employee Issues in Current Facilities

The two specific issues that management faced with respect to training requirements were, first, that the required training did not align with the realities of the job and second, that the Government did not provide any funding or incentives to support these training standards. Two managers were also frustrated with the decision of the Department of Social Development to lower rather than maintain training standards for individuals working in long-term care facilities, and all managers were disturbed at their own inability to remunerate employees adequately, which translated into struggles with constant staff shortages. Bill 35 was the latest approach being taken to gain wage parity for the poor salaries that most front-line workers received.

Gap between Training and Realities of the Job and the Lack of Training Incentives

Doug, operator of adult community residence agency A, felt that the formal training individuals received to prepare them to work in adult community residences did not match the realities of the job:

> I find the training at the Community College doesn't fit this type of work because they don't teach students that when they go to work at adult community residences that they're working *for* the residents [italicized to show his emphasis]. (Doug)

There was also a reported gap between training expectation requirements (SPARF 2009) and incentives for that training, which then led to problems finding qualified people to work in the facilities. Ed, operator of adult community residence agency B, was frustrated that the Government did not seem to understand that ending up with $12 an hour provides little motivation to spend three years training for a job:

> One of the things the Standards [referring to SPARF] demanded year after year is that all of our workers are human service counselors, or if we couldn't find them, we could hire people and give them three years to qualify. You bring someone in for twelve bucks an hour, do you think they're going to pay out that kind of money! Come on people! Get real! (Ed)

Team leader Mark also questioned whether anyone would be willing to invest the amount of money it would cost to take a human services counsellor course, given the low wages they could expect and that there would be no benefits in their job package compared to individuals working in other sectors:

> Staff members take a two year training course and end up only making $12 an hour, where people who work in the kitchen at the hospital get $19 an hour plus benefits. Staff at the hospital earn more pay and have less responsibilities. I'm responsible to make up my own pension. Unskilled workers such as janitors at schools end up making $16 to $18 an hour plus benefits, while a person with two years training to work in the community residences ends up making only $12 an hour. There's not enough monetary recognition. (Mark)

According to SPARF (2009:3.1), employees who provide direct hands-on-care to residents requiring care (levels 1-4) must be trained in the "Home Support Worker Program, or Special Care Home Worker Program, or Health Care Aid Program, or Human Services Program, or Nursing Assistant Program," but "operators have up to one year to ensure all staff meet the required training" (SPARF 2009:3.1). The current base fee for taking a thirty-week Personal Care Worker course at any New Brunswick Community College (NBCC) is $7,700, not including the cost of text, student council and other fees as noted on the NBCC web page in the section titled *Personal Support Worker – Acute Care*. Celeste, operator of adult community residence agency C, was also aware of training requirements but had problems finding employees with the necessary training:

> You need to try to hire people with qualifications, according to Social Development, for them to have a full time position. I need to have a full time position for each shift but I can't do that right now. (Celeste)

Ed fully supported the mandate to hire specifically trained front-line workers (SPARF 2009) but was frustrated that training standards were lowered rather than funding the necessary training, with the result that he is unable to find, much less retain, employees to work at the facilities:

> So, year after year after year we have met with these people and said 'Look, we don't disagree with your standards but you have to give us enough money to meet that. We cannot *find* qualified people. We cannot retain qualified people for what you're giving us!' So what did they do? They changed the standards in 2009 so now you don't have to be a human services counselor anymore. You can be a home support worker. We hire these personal support workers who take these twelve-week courses all the time for casuals. And then, these staff are supposed to be under the supervision of qualified staff and we have one year to ensure all staff have the required training. But it's no longer the human services course you have to be trained in, and this is the catcher. I have as many casual employees as I have regular employees. Everybody across the province does it. There's a list of casual employees you call in to cover. (Ed)

Bruce, operator of adult community residence agency D, also spoke to the lack of government funding to support staffing expectations and the implications of reduced training standards:

> Their standards are really high [referring to SPARF] but the money's not there. So it is kind of hard to get somebody to come in when we only have $10.50 to offer them. We were arguing, 'You guys need to pay us enough to hire human service counselors.' So this is what they did. They didn't give us any more money to hire human service counselors or to make the wages more attractive, but lowered the standards of the people who could work in the homes. Now you can hire a personal support worker. (Bruce)

Bruce explained that although personal support workers do a good job in some ways, they do not have sufficient training or experience to deal with residents' behaviours:

> Personal support workers do a very good job with the hands on stuff, cleaning and that sort of thing, but a lot of them have no clue how to handle the behavioral stuff. That's where the human service counselor with some experience comes in, because they have to do a whole hodgepodge of stuff. (Bruce)

According to those in management, insufficient government funding combined with an unwillingness to invest in training for this type of care provision, was behind the decision by the Department of Social Development to reduce training standards for employees in long-term care facilities (SPARF 2009). This scenario not only highlights the tension that Goffman (1961:76) points out between trying to maintain standards and "institutional efficiency," but also government's engagement with bio-power (Foucault 1976) in being able to make such determinations on behalf of this population. Despite two managers' frustration with the decision to reduce training standards, the reality is that making difficult decisions such as this one, is a critical part of policy development and implementation, as Titmuss (1974) and Wharf and McKenzie (2004) point out. Nevertheless, the consequence is that a Taylorized approach to care-giving labour has been affected, which means that employees have been deskilled, credential requirements have been lowered, and wages have been reduced, similar to Baines (2004:45) findings.

Low Wages, Staff Shortages and Potential of Wage Parity

According to Bruce, there were front-line workers at his adult community agency who made such poor wages that he felt they were close to the poverty line and some took on other jobs to supplement their wages:

> Right now, our employees are at least 13-14% underpaid. I'm not sure what the cut off is for the poverty line, but we have staff that have been working for us for X amount of years that I'm pretty sure are really close to being on the poverty line. We know staff that in order to supplement their wages, in order to live, work at other jobs . . . You have a lot of folks having to work at other jobs because they have to pay the bills and drive a car. (Bruce)

Bruce assumed that his agency was not the only one with poorly paid employees: "If you go around the province I expect it's the same as us." Celeste, from a different area of New Brunswick than Bruce, talked about the poor wages employees with her agency received and referring specifically to one employee, pondered the rationale for remaining in this kind of work:

> One employee has been working here for twelve years and she gets $10.75. And I ask myself, 'Why do they still work here?' They work hard for their money and they deserve more than that! (Celeste)

Celeste's comments also revealed that she was aware that the work employees did was undervalued. Bruce, operator of adult community residence D, also remarked on the poor wages front-line workers with his agency received: "At the wages we can pay I think we're lucky to get people to take one year training, let alone two."

Low wages not only meant poor incentives to take the human services counselor or personal support workers training, but they also meant difficulties for management in recruiting individuals to work in the facilities. Yvette, supervisor with an adult community residence agency, discussed her own difficulties with trying to find staff members because of the poor wages they can expect, whether or not they take the necessary training:

> Sometimes we have a hard time to find staff because we only pay between $12 and $13 after they have a two-year course. If they don't have the course, it's not even $11. That's why we have a hard time. (Yvette)

Yvette explained that she takes the following tactics in an attempt to find employees: I talk a lot with people at the Community College. They talk a lot to the students. We use the radio, everything we can to try to find employees." Yvette's need to try 'everything' to find employees supports Lakin and Stanfille's (2007) contention about a scarce workforce to draw from for this type of work.

There were constant staff shortages in all adult community residences. Mark, team leader at one adult community residence, talked about his experience with staff shortages as well as the inability to ensure staff client ratio requirements SPARF (2009:5.7) because of the associated cost:

> If I could change *anything* about the facility where I work, it would be to have more staff and the staff be paid more money. There's a constant shortage of staff. We're just not able to meet the staff client ratio because we can't afford it. (Mark)

Management's challenges with the recruitment, turnover/retention, and lack of adequate wages and benefits for employees are consistent with the literature (Hewitt and Larson 2007, Shaddock et al. 1998) and deserve attention, for it has been argued (e.g. MacDonald et al. 1993) that quality of care for residents can be compromised if delivered by staff with poor qualifications and low pay, though I saw no evidence of this.

Two managers were hoping that Bill 35 (*An Act to Amend the Public Service Labour Act)* or wage parity, would help in addressing the wage for front-line workers. Ed, operator of adult community residence B, explained Bill 35's focus on wage parity, the committees guiding and evaluating the process, and the people who would be affected by Bill 35:

> Wage parity is a program or initiative looking at wage parity for direct caregivers working in adult community residences and children's residential homes. There are two committees, a joint steering committee and a job evaluation committee. A lot of the people sitting on these committees are people like me who represent agencies, and some of their employees. Casuals who work in another non-profit agency are not considered civil service or public service, so they're not affected by this, but other government departments and our employees are affected by it because we're part of the public service. (Ed)

Bruce, who operated adult community residence agency D, was also hopeful that Bill 35 would address the wage issue but was also somewhat skeptical for two reasons:

> I'm hoping the pay equity act will at least try to bring the wages up, but with the new Government coming in and the shape the province is in, you have to wonder if pay equity will not be shoved . . . [ended his sentence there]. I'm on the Steering committee. We plan to get together and review the questionnaire human service counselors around the province fill out.[105] (Bruce)

When asked if wage parity was a fight for employees in both the non-profit sector and the private-for-profit care sector, two managers' responses revealed their lack of knowledge about care delivery in the private sector. For example, Bruce responded to the query with, "You know, I couldn't swear to that but I don't think so. I think they're looking at the level three and the level four in the non-profit sector," and Celeste told me she did not know if wage parity would affect employees in the private sector.

In contrast, Rachel, a front-line worker, told me that part-time workers were due to be unionized, meaning that they would benefit from wage-parity, but it would take time once Bill 35 was passed:

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[105] This questionnaire is available at the following website: http://www.gnb.ca/0012/womens-issues/wg-es/tools/pdf/pe_pdf/6.3%20Adult%20Job%20analysis%20questionnaire%20.pdf

> Up until June [referring to June of 2010], it was just for full time employees, but Sean Graham has incorporated all across the province, so part-time casual staff will be unionized too. But that will not take effect for another two, or three years, because the Government has to contact each individual union which has different contracts. So, it's going to take a while. (Rachel)

As of December 2013 the fight for pay equity/wage parity - Bill 35 - was still unresolved for employees working in adult community residences (*New Brunswick Coalition for Pay Equity* 2013).

Management's Relationships

The information in this section regards management's relationships with individuals from the Department of Social Development and other government sectors and is nothing we did not already know. However, the fact that it is not news reinforces the importance of highlighting these matters yet again, since these voices have been ignored. The nature of management's relationships with persons in Government largely consisted of: negotiating for money to try and alleviate problems with funding shortages, working to overcome bureaucratic red tape, which for one participant hindered his ability to provide the necessary care for a resident when required, and trying to draw Government's attention to their target population who held little priority compared to other clients of the Department of Social Development. Those in managerial positions within the Department of Social Development also had to negotiate with other government sectors for funding, albeit with limited effectiveness, which often resulted in difficult decisions because the necessary money and resources were not available. The remainder of this section is a discussion of management's engagement/non-engagement in fund-raising activities, creativity in cost-saving measures, and the nature of their relationships with Boards of Directors and employees.

Relationship with Government

According to Ed, changes in Government require additional meetings between management and government representatives to re-explain funding needs:

> We meet with *every* new Government, *every* minister of Social Development that has ever been since 1997 [italicized to show his emphasis]. I have met most of them myself trying [pauses], and we're not looking for money for ourselves. We're trying to pay our staff!

Changes in Government also affected funding decisions. For instance, Doug, operator of adult community residence agency A, told me, "In the early 80's, there was a freeze. The Government fell conservative, and they lost their seat, and everything was cut." Ed also talked about the matter of government debt and funding priorities:

> It's always about money. Now they're talking about the debt the provincial government is facing and [laughs], so you can rest assured there's not going to be a whole lot more money pumped into long-term care. It's seniors' long-term care that gets the attention. (Ed).

The focus of attention to senior care rather than care for younger adults between nineteen and sixty-four undervalued the care targeted to this particular population.

As with previous research (Morrisey 2007) management reported constant funding shortages, especially for their particular clientele, as government funding stopped once these individuals reached adulthood. Ed, operator of adult community residence agency B, told me that service options change once clients reach adulthood:

> An individualized placement, which was good for them for three, four, or five years, is all of a sudden no longer available, simply because they're no longer in the right age group. Because of some very high profile incidences in the province like the Ashley Smith case and even the Ryan Turner case, the provincial government has really come out looking bad. (Ed)

Bruce, operator of adult community residence D also said: "There's an awful difference in the services offered between children and adults. Once a person becomes an adult the cart gets emptied pretty quickly." The attention to childhood intervention programs as a funding priority is consistent with Prince's (2001) findings. Investment in such programs make sense because of the importance of remedial and preventative type services (Rice and Prince 2001), and supports current political priorities. As recently as 2012, a $38 million action plan was unveiled in 2012 by the Government of New Brunswick called *Putting Children First* (GNB 2012b) with the rationale of better equipping children for the future.

Another government priority that management failed to mention but which also has implications here is the attention to employing persons with disabilities (GNB 2004-2005). Although a worthy focus that suits current emphases on individualism, egalitarianism, and empowerment, as Graham et al (2003) notes, this particular focus, the concentration on early childhood intervention, and the problems negotiations among government sectors for funding, all effectively divert attention away from long-term care supports and services. This scenario confirms Prince's (2006:98) assertion that people with more severe disabilities are those most apt to have their needs unfulfilled. Bruce pointed to funding as the most critical issue he faced as operator of an adult community residence agency: "The most important thing in my position right now is finances. I could bitch and complain about the finances all day long."

Issues with insufficient funding and resources were not as simple as the Department of Social Development not wanting to pass along more funds. The context of all decisions within the Department of Social Development involves limited money and diminutive negotiating power (Morrisey 2007:61, 62), when trying to compete with the health and education sectors for money, consistent with Battle and Torjman's (1996) findings. Bruce explained it this way: "When it comes down to who's got the power around the Cabinet table, Social Development doesn't have as much power as the Department of Health." What this means is that individuals in the Department of Social Development are faced with ensuring that best standards and caregiving practices are maintained in adult community residences while also dealing with limited funding realities, which then leads to decisions like lowering training standards to help operators meet mandated staff to client ratios.

Not only were managers frustrated over the lack of money to pay employees, that changes in Government destabilized the amount of available money, and that more government funding was targeted to children and seniors than their clientele, Celeste was also disturbed by not knowing where she would find the money to invest in a washer and dryer needed at her facility. She pointed to insufficient government funding as the reason for her situation:

> I think the Government took into consideration what it would take to care for an individual but they didn't take into consideration the cost of housing, like the electricity, the bills, and the food. They didn't take all of those things into consideration. (Celeste)

Celeste also explained that having enough money for a washer and dryer was directly related to whether all of the beds in her facility were filled:

> If I operate on a full house, then it's a good thing. At the end of the year, I'll be left with some money and *then* I could go buy washer and dryer. But let's say if Antoine [a resident] wants to go back home because he *is* from another community, I would probably be good for the first month, but the second month I would be in the red, and the third month [pauses]. So if that bed is not filled up, there goes my washer and dryer. (Celeste)

The need to ensure that all beds in her facility were filled supports Pedlar and Hutchinson's (2000) contention that residents can be treated as commodities. Constant funding shortages required three managers to envision alternative ways of coming up with additional money. Celeste found fund-raising to be effective in addressing this shortfall:

> We need to do fundraising. Everybody fundraises. It has become a norm to go to a grocery store and have to dish out money and buy tickets, because there's so many out there wanting to raise money for needs. So it's very hard for someone like us. But people are very generous in giving and fundraising has profited well this year for me here at the community residence. But still, at the end of the year, if I need a new washer or a new dryer I need to count on some friends. I need to count on some people to help out because the budget is, it's just not there. (Celeste)

Olivia, an executive with nursing home II, also engaged in fundraising. She described a successful fundraising venture that she had participated in to purchase special equipment for the nursing home: a barbecue attended by over 300 people from the surrounding community where over $7,000 was raised.

When I asked Bruce, operator of adult community residence agency D, about the possibility of fundraising to acquire the money needed for his agency, he responded, "That's not in my job description." Bruce added that he would help out if particular fundraising activities were happening, but reiterated "That's *not* my role [his emphasis]." Shirley, a front line worker, gave a different reason for her unwillingness to fundraise: "That would just give the Government another excuse not to provide the funding we need.” Mark, a team leader, and his coworkers took a different approach to deal with inadequate funding, watching for ways to cut costs. Mark boasted about his ability to save $4 per prescription for each resident by switching pharmacies, which Mark considered a significant saving because “it runs into a lot of money when there are 10 clients all on numerous prescriptions.”

The constant discourse of limited government funding that all management encountered and which has persisted from the 1800’s onward, reveals that a certain “regime of truth” (Foucault 1980:131) about the matter has effectively taken hold. The emphasis on controlling the deficit which started in the 90’s, the limitations on social program expenditures (Puttee 2002), the greater surveillance of programs (McGilly 1998), the retrenchment approach (Graham et al. 2003, Puttee 2002) and the offloading of program costs and burdens (Rice and Prince 2001) all help to explain management’s problems with insufficient funding. In addition to the problems with funding, one participant was frustrated at having to deal with bureaucratic red tape.

Bruce, operator of adult community residence agency D, expressed his irritation at the additional workload and paper work required when the Office of the Public Trustee was initiated in New Brunswick, and how this additional bureaucratic red tape hindered his ability to attain the dental work a particular client needed:

> A resident who moved from a different area of the province was referred to the Office of the Trustee by a Social Worker so she could get the dental work done she needed, but nobody was around to sign the paperwork because they were scared the anesthetic might cause some seizure activity. Now I don’t know how much of a toothache she’s having right now, but we’ve been working on the best part of a year, waiting for the paper work to be done. If that was you and you had a toothache, you would go to the dentist. You might have to wait for a day or two, but . . . (Bruce)

Bruce continued to discuss this client's situation by pointing out that residents may engage in behaviours because of pain:

> I don't think she's in a lot of pain, but she's a beautiful young woman who is very handicapped and happens to have a very high pain threshold, but that could be coming out in the behaviours and what-not. You're taught to always find out if there is a toothache or a pain somewhere. Just because someone is acting up it may be more than they are just having a bad day. It could be a medical issue. (Bruce)

Bruce's difficulty in getting the needed dental care for this client illustrates well Weber's (1921) "iron cage" effect. The iron cage effect is characteristic of bureaucracies where individuals face extreme difficulties in having their needs met because of the "red tape" that results from consistent standardization and an emphasis on "means and ends" (Weber 1921/1968:1116). Consistent with Beange and Bauman (1990) and Sutherland et al. (2002), Bruce's inability to get the dental care this client needed for close to a year also reveals how the health needs of persons with disabilities get less attention and experience less effective responses than those of other citizens, except for the very poor. The constant funding shortages managers faced and the bureaucratic red tape in Bruce's case meant that a great deal of management's time was spent negotiating with people from various sectors.

Relationship with Boards of Directors and Employees

According to managers, some of the difficulties of their jobs were lessened by the support they experienced from some of their relationships. Three individuals cited the Boards of Directors as a source of support, although board members are powerless in circumventing the bureaucratic red tape or the difficulties managers experienced in finding and retaining employees because of insufficient government funding. According to Celeste, the Board of Directors over adult community residence agency C was her main source of support:

> I can’t thank the Board members enough because I get all my support from them. The President of the Board of Directors told me she was very satisfied with the work I am doing, because she had almost forgotten the residents existed when the other director worked here. (Celeste)

The sentiment expressed by the President of the Board of Directors to Celeste reveals the potential of individual managers to ensure that the focus of care delivery is on residents. Byron, retired operator of an adult community residence agency and Doug of adult community residence agency A, also told me they experienced support from their respective Boards of Directors. Byron particularly enjoyed the fact that the Board of Directors took some of the pressure off of him during the time when he operated his agency because, in his words: “The Board is ultimately responsible for the facilities.” Celeste expressed a similar sentiment: “Directorship is a good way to manage without holding responsibility because the Board is responsible for everything at the end of the day.”

Although Celeste, similar to Byron and Doug, enjoyed a positive relationship with the Board of Directors, she was frustrated at her inability to establish collegial relationships with employees, despite her repeated efforts. She lamented: “They never ask me anything about my life outside of work, about my family or anything else.” I observed during fieldwork that Celeste’s employees were always friendly with her but they maintained more emotional distance between themselves and Celeste than among their co-workers. Perhaps their actions represented specific attempts to establish that

Celeste, as their boss was not and could not be one of them. Celeste was also aggravated that employees seemed to gang up on her at times during staff meetings:

> I always let everyone know that they will have an opportunity to discuss their concerns, but when it comes time for meetings one speaks up and tries to get everyone to join with her into some form of a clan, asking others 'How come you guys are not talking?' After one of these meetings, I asked her privately, 'Why would you try to gang up on me? Because that's the way I felt,' to which the individual gave no response. (Celeste)

Another frustration for Celeste was her inability to make decisions that satisfied all employees:

> Sometimes you just have to tell them 'That's just the way it's going to be. I looked at everything, I listened to everything, and this is the decision I came up with.' Sometimes I feel good. Other times I struggle with trying to please everybody. (Celeste)

In this chapter I presented findings related to manager's observations of formal care provision in the larger institutions and deinstitutionalization as well as their experiences of providing care to people with severe disabilities and mental illnesses that included staffing and funding challenges and difficulties with bureaucratic red tape. In Chapter Eight I present a front-line workers' account of care delivery in the larger institutions, as well as my analysis of the issues that front-line workers experience in the course of their work and their relationships with residents and management personnel.

CHAPTER EIGHT: FRONT-LINE WORKERS' EXPERIENCES OF PROVIDING CARE

I begin this chapter with an account of care delivery in the large institutions at both Saint John and Restigouche as told by one front-line worker, and then discuss front-line workers' current experiences in adult community residences and job responsibilities. Front-line workers are insufficiently paid for their job responsibilities, they enjoy little recognition for the type of work they do, people have little understanding of the type of individuals they work with, and their first-hand knowledge about residents is dismissed by others, all pointing to the undervaluation of their particular skill sets and knowledge about residents. In Chapter Eight I also examine front-line workers' rationales for becoming engaged in this type of work in the first place and why they remain at these jobs for years, despite the sometimes negative work environments they experience. In the final part of Chapter Eight, I discuss how front-line workers characterize their relationships with residents and those in management.

Observations of Care Delivery in Restigouche and Centracare

Front-line worker Amanda described her impression of Centracare in Saint John as well as the institution in Restigouche:

> Centracare was a really old decrepit building. And it was dark and it was smelly, and it was just not very nice. The Hospital in Campbellton was a little newer and it was painted nicely and [pauses], not that any institution was good, but it was better than Centracare. (Amanda)

Amanda's description of Centracare was much like Mark's comment that a particular institution 'stunk.' Her description also reveals that Moos et al.'s (1979:77) notion of less positive social climates is relevant here because of the lack of 'pleasant' surroundings. Amanda also talked about the significance of keys in these institutions, for it appeared to her that the individuals carrying keys were important and had power over others in the facilities:

> The person who has *real* [her emphasis] power is the one who has the keys. Keys equate power. People of worth carry keys. People of importance carry keys. People with power carry keys. Keys open doors. In the institutions, the person with the keys is all-important because they can go anywhere. They have freedom. They have power over other people. They're like little demi-gods. (Amanda)

Amanda re-emphasized her point with, "The power is in the keys!"

Amanda then told me that a number of the residents living in adult community residence facilities who once lived in the institutions and now carried keys because, in her estimation they recognized that power comes with having keys:

> They have key rings with totally meaningless keys. But they have keys, and they have them in their pocket. They have them in their night table, whatever. When they first came here, there were issues with keys, because they meant something to them. (Amanda)

Amanda, referring to a particular resident who had passed away several years prior, said:

> He always had a big jumble of keys in his pocket on a big ring. They were his keys and nobody could touch his keys. They were his keys and that was that. (Amanda)

Amanda then explained the current situation with keys in adult community residences:

> Even today we have keys because of the problems we could run into when we are not in the kitchen. We keep all of the medication locked up, because we have people that go in there and they could choke to death when you're not looking or down something. So it's a real health issue. That's why the kitchen has to be locked. You're also a person with power if you have the keys to unlock the kitchen, because the food is in there. (Amanda)

If former residents of the larger institutions were carrying keys because it made them feel powerful even though these keys did not unlock anything in the facility, this does not mean residents had actual power in this matter, for staff members were those who had access to the keys that really mattered in the facilities. It is possible to discuss Amanda's ascribed significance to keys in long-term care facilities by using a Foucauldian framework, for keys in past and current long-term care facilities can be construed as "technologies of power" (Foucault, 1988:18), tools for 'constrain[ing]' (Foucault 1994:582) residents and mechanisms for exercising power over residents, exacerbating the already imbalanced power relationships (Foucault 1997:292) between caregivers and residents.

Job Responsibilities and Reasons for Choosing Care Work

I observed during fieldwork that front-line workers' job responsibilities fell into four main categories: hands-on care, general housecleaning that included doing laundry and cooking, administrative tasks, and emotional work. Specific hands-on care tasks included toileting, bathing, and heavy lifting of residents, cutting hair in some cases, accompanying residents to medical and other appointments, changing residents' dressings, testing blood sugars, working with feeding tubes and catheters, providing overnight vigils with more seriously ill residents and in one case, tucking a resident's extended bowel back into place. Front line workers also did house work including: dishes, laundry, dusting, vacuuming, scrubbing floors, cooking meals and sometimes baking. Then there were the administrative tasks front-line workers were responsible for such as maintaining records on residents, enforcing in-house rules and expectations for residents, overseeing some residents' expenditures, negotiating the balance between risks and freedom for residents, and running errands.

One, and sometimes two front-line workers at each facility had responsibilities over and above these that included budgeting for and purchasing groceries, finding individuals to cover for staff who called to say they would not be coming to work, filling pill containers and dispensing medications to residents, and conducting fire drills. Last, but certainly not least, front-line workers' jobs entailed considerable emotional work. For instance, they had to anticipate and prevent crises and deal with aggressive behaviours as they occurred. Emotional work was also involved in helping residents through grieving processes, occasionally accompanying them to funerals, and helping residents work through relational issues with fellow residents. Dealing with various professionals such as physicians can also be emotional work at times if their input on residents is not taken seriously. As seen above, front-line worker' jobs were complex, confirming Hewitt and Larson's (2007:179) findings, and the breadth of skills required to deal with their job responsibilities was extensive, similar to the literature (Hewitt and Larson 2007, O'Nell and Hewitt 2005).[106]

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[106] See also O'Brien and O'Brien 1992, Taylor et al. 1996.

Front-line workers gave a number of rationales for becoming engaged in this type of work. One cited altruism, another desired a change, and two participants pointed to the influence of others as the motivating factor. The predominant reason front-line workers became involved in care work, however, was because of previous relationships or encounters among individuals with significant disabilities and/or mental illnesses. For instance, Rachel's previous encounters with residents and formal care-givers stirred her interest in becoming involved in hands-on-care work:

> I used to work in a grocery store when I was in high school, and I used to see the older workers who were younger then. And they had the clients with them, out and about in the community. And I always, I don't know, it always seemed interesting to me. (Rachel)

Breanne told me that her previous experience babysitting a girl with Down syndrome as well her time sitting with a lady with mental illness year later, led to her decision to take a job in an adult community residence facility. Breanne talked about her experience babysitting the girl with Down syndrome:

> I remember the family with the Down syndrome child had another child a little bit older, and I always remember for some reason, that they favoured the Down syndrome girl. I also remember that even though I did not understand why her tongue protruded at that time, I was doing early infant stimulation because I was pushing her tongue back in her mouth. (Breanne)

Breanne's observation that the parents "favoured the Down syndrome girl" is consistent with Francois' comment about his own daughter Evangeline where he said "you love them . . . even more than your regular children" (see Chapter Five). Breanne went on to say of the adult community residence where she worked: "Once I got there I really liked working with the clients so I just stayed at it. It is forty years later and I'm still here!"

A different front-line worker, Amanda, gave her rationale for becoming engaged and remaining in this work:

> I always had an interest in people with disabilities, having met some in high school. After high school, I got a job at ___________ [one of the institutions]. I *loved* the work [her emphasis]. I worked at geriatrics and tried a couple of other little things but I always came back to this. Eventually, I finished my course in Saint John in 1980 and the rest is history. (Amanda)

Amanda told me that her son had also developed an interest in working in adult community residential care and she talked about taking her son and his siblings to visit residents at the facility when they were still children:

> The first day I brought my son to the facility was back when he was a baby, and I said to one of the clients in this house, 'Would you like to hold him?' and she said 'Yes.' And she held him as though she had held fifteen other babies before and it was really wonderful! I actually have pictures of her holding him, so as he grew, there was no awkwardness, no hesitation [pauses]. I shouldn't use normal in the sense that other people use normal, but it was accepted. It was okay. There was no fear. No gray area he was unsure of or whatever. And he's been in and out of here, they both have [referring to her two children] from the time they were very small children, and are quite comfortable in these places. (Amanda)

Issues for Front-Line Workers

Front-line workers reported a number of issues with working in adult community residences. There were frustrations that people questioned their rationales for becoming engaged in this line of work, that misconceptions existed about the type of individuals they worked with, and that they chose to remain in these jobs. Although front-line workers took pride in the care they delivered to residents, they also felt undervalued and underappreciated. For instance, one participant's first-hand knowledge about residents was dismissed and another participant was disturbed at the lack of financial recognition she and her coworkers received for the work they did. The combination of these issues exacerbated the difficulties that front-line workers encountered in the course of their work.

Undervalued Work

Caregivers appeared to take pride in showing me through the facilities where they worked and introducing me to the residents they worked with. They also seemed proud of the type of work they did and viewed their work with residents as important. At the same time, they felt others had little knowledge regarding the type of work they did, much less the type of people that they provided hands-on care to. Shirley talked about her feelings on the matter:

> I don't like it when people say 'Oh, you must be special to work with them,' because anybody with a heart could work with them. I mean, it's not always sweetness. Some days they don't like me and I don't like them and we know that. It's all right not to like me, but you know, I love it as a job. (Shirley)

I asked Shirley if she could tell me what she loved about her job. She responded with: "It's not like I *have* to do this [her emphasis]. I get back just as much as I put out if not more." Shirley's comments support Pottie and Sumarah's (2004) estimation of relationships between staff members and residents as 'reciprocal.' In a Foucauldian analysis, reciprocity suggests an "open and dynamic" group dynamic (Olssen 2002:495). These relationships were still 'in-egalitarian' however, because residents still depended on caregivers, in keeping with Higgins' (1989:10) conclusion that residents are predominantly reliant on front-line workers, a key finding of his research on the nature of relationships between care providers and care recipients and the characteristics of institutional life.

Wyatt was also frustrated with the way people talked about the residents: "It really bothers me when some older people say 'Oh, they're retarded.' By the grace of God go you or I." Breanne told me she enjoyed working with the people living at the facility where she worked and she wished people had a better understanding of residents:

> They're fun! I enjoy working with them. We all have needs, maybe some of us more than others, but we're here to assist. And I think by explaining to people that are not in this field they get a better understanding. I think being outside and introducing them to others, like to my kids.

Breanne's comments also reveal that she perceived her role as assisting residents rather than caring for them. Breanne was also intentional in educating her children and granddaughter about the type of people she worked with:

> They [her children] have a good understanding now. Maybe because of being in the homes and stuff, my kids are very comfortable. And now I bring my granddaughter and they [residents] look forward to seeing her, just to educate them early. My own family has always been around so they've never had any problems. (Breanne)

Front-line workers frustration over the lack of understanding about the people they worked with points to the lack of contact front-line workers observe between residents and the public and therefore the "liminal status" of residents in the public conscience (Foucault 1965, 1988), which (Murphy 1990) considers to be characteristic of the experience of persons with disabilities. This reality further supports my contention that residents live in a "parallel universe" (Friesen 2012:13) to other citizens. The consequence of this scenario is that society is left to develop ideas about the type of individuals living in adult community residences from whatever nonverbal sources of information they happen to pick up from formal service systems, as Cocks and Allen (1996) and Hamlin and Oakes (2008) assert.

In addition to their frustrations that people were unaware of the work they did, the people they worked with, and the assumption that they must be 'special' to do this kind of work, one front-line worker felt undervalued because her views regarding residents were seldom taken seriously. Amanda spoke with frustration about two separate incidents where physicians dismissed her input on residents:

> There was one client we thought had scoliosis and perhaps needed a brace. We took her to the Dr. and he said 'She's mentally deficient. It won't help with her brain. Why bother with a back brace?' I couldn't believe that! Attitudes have changed a bit over the years, but there was one incident when we took a client in, I forget what it was for, but the male doctor said, 'Well, what would you know? You're just a worker. You're just a keeper.' A keeper! Oh yeah. I mean, people in our profession, sometimes they don't listen to us. They don't take us seriously. We're with these people day in and day out you know. I just don't get it. I really don't feel our concerns bear any weight. (Amanda)

These two incidents help to explain how it is possible for the voices of some individuals to be silenced (Foucault 1980b) in certain scenarios. For example, Amanda's input during the encounters with the physicians had no 'weight.' The physician's decision to ignore Amanda's contribution that a resident might be suffering from scoliosis was also typical of the tendency to dismiss the first-hand knowledge and insights that front-line workers have about residents, as Levinson (2010) and Lipsky (1979) point out. The physician's decision to decline treatment for this resident also substantiates Sutherland et al.'s (2002:428) argument that many conditions for adults with intellectual disabilities are "inadequately managed." Amanda's frustration over the unnecessary suffering of this resident also confirms the "involvement cycle" that caregivers can occasionally experience (Goffman 1961:79).

Dr. Faulkner, a female physician who practiced in a different area of the province from the facility where Amanda worked, was more positive about the insights formal caregivers can offer during consultations, confirming Amanda's comment on the previous page that "Attitudes have changed a bit over the years." Dr. Faulkner appreciated the first-hand knowledge one specific caregiver had about a patient with fetal alcohol syndrome because it enabled her to diagnose and treat this individual:

> He was always well looked after because she knew what was wrong with him, just through his physical behaviours and observing him from over the years. I could never tell. And he ended up having to have surgery for his abdomen and pneumonias, and different things. She could pick up on those things because she knew all of the different nuances of his behaviours. (Dr. Faulkner)

Dr. Faulkner also told me that it was this particular caregiver's ability to communicate with that same patient that facilitated her ability to treat this patient:

> The only person who could communicate with him was this one worker who had known him very well for many years. Without her, we would never have been able to treat him. They looked after him very well where he was living. When this woman quit her job and got married she took him to live with her at her house, because she just couldn't think anybody else would look after him as well as she did and she didn't want to leave him there. So she took him to live with them. Isn't that amazing! (Dr. Faulkner)

Dr. Faulkner was impressed that this caregiver felt such a responsibility to this patient's well-being that she brought this individual to live with her and her husband, and her amazement over this decision reveals her perception of this action as being extraordinary.

Rachel explained that she felt undervalued because she and her coworkers did not receive wage increases as often as other employees in the same agencies:

> The union fought for higher wages for us but we didn't quite get what we were looking for. Supervisors did a little bit better. Youth care workers who are also in our union did well too. I'm talking for them [front-line workers], but we're kind of, you know, it didn't seem like we were appreciated. Maybe those are the words I am looking for. Our union president is always more than willing to help. They do try their best. It just all comes down to money, you know, and how much the Government is willing to pay out. (Rachel)

Rachel's statement, "It didn't seem like we were appreciated" was unmistakeable when it comes to whether front-line workers were undervalued. All of the issues in this section show that the work of front-line workers was undervalued, challenging, and as Shaddock et al. 1998:315) argue, undertaken in "difficult circumstances" which made them feel unappreciated. These factors, combined with the complexity of their work and extensive job responsibilities, similar to Hewitt and Larson (2007) and O'Nell and Hewitt (2005) findings, confirms Shaddock et al.'s (1998:310) concerns about the potential of burnout for front-line workers.

Front-Line Workers Relationships

Front-line workers experienced a number of relationships in the course of their work. Most front-line workers spoke warmly in discussing their feelings towards residents. I observed during fieldwork that three of these individuals were willing to go above-and-beyond their job requirements on behalf of these individuals. Front-line workers were also protective of residents' privacy, and one front-line worker was protective of the way that persons living outside the facility interacted with residents.

Two front-line workers placed great importance on the appearances of residents, for in their estimation a resident' appearance reflected the quality of care they were experiencing. Although the work of front-line workers was undervalued, one front-line worker felt supported by a member of the Board of Directors and three participants expressed appreciation for their bosses.

Relationships with Residents

The warm nature of most relationships that I observed between front-line workers and residents in adult community residences destabilized prior assumptions about the entrenched boundaries between caregivers and residents, as Allen and Ciambrone (2003) argue, and exceeded their job requirements. For instance, Tom, a resident in one of these facilities, asked a front-line worker to get him his black leather jacket as he was is preparing to go on an outing. I commented, "I think you like that jacket" to which he smiled and responded, "Yeah! Margaret gave me that jacket. It makes me look like the Fonze!" He then gestured with his thumbs to imitate the TV character. I also saw Margaret arrive at the facility on her day off with some foam padding that she had taken time to shop for because one of the residents needed it for his bed. Antoine, a resident of a different adult community residence, brought a hymn book out of his bedroom one day during fieldwork, told me he wanted to sing for me, and proceeded to do so. Antoine had a wonderful voice. A front-line worker shared with me that Antoine used to sing in a church choir and that Phyllis, a different front-line worker, gave him a hymn book on learning of singing background.

Mark also talked about personally maintaining regular contact with a resident who had moved from the facility where Mark worked to a different facility until this resident passed away. According to Mark, “The family were amazed that I cared enough about him to stay in contact,” which Mark said he had difficulty understanding. The warm nature of some relationships between front-line workers and residents and the willingness of three staff members to go above-and-beyond for residents, contradicts Goffman’s (1961) argument about the social distance between staff and residents in institutional care. Still, the warmth of these relationships did not prevent some front-line workers from characterizing disability as a tragedy given Wyatt’s comment one day: “By the grace of God go you or I.”

Staff members were also protective of residents. One of the ways front-line workers proactively worked to protect residents was by withholding certain information about residents from other employees as they were being orientated into working at the facilities in case these individuals decided not to stay on the job. Rhonda, supervisor with an adult community residence agency, explained: “We provide very little personal information about the clients because a lot of casuals that we orientate don’t come back.” This tactic did not contradict the narrative care approach discussed in Chapter Six because the information withheld from potential employees was shared only with those employees who remained on the job after orientation.

The fact that many individuals did not choose to remain in these jobs once orientation was complete is not surprising given the lack of incentives in wages or benefits to engage in this type of work, as pointed out in Chapter Seven, much less the responsibilities associated with this work. Another way that front-line workers took efforts to protect residents was by paying careful attention to how people living outside the facilities treated and interacted with residents. Rachel, a front-line worker, was happy with the way a certain hairdresser interacted with residents during hair appointments, and particularly with Michelle, one of the female residents: “The man who does Michelle’s hair is really good to her and interacts a lot with her.”

Two front-line workers discussed the importance of residents’ appearances and their opinion that their appearances indicated the quality of care they received. Shirley told me:

> The motto is always have them looking as good, if not better than, you, so that when you take them out, nobody can look at them and say [pauses], you know they might notice the wheelchair, or they might notice something else, but they don’t see something that’s not appropriate. (Shirley).

Wyatt, of a different adult community residence, said that he and fellow staff members were greatly concerned about the current appearance of a certain individual with significant mental health issues who once lived at the facility where Wyatt worked. Wyatt lamented that now every time he and his co-workers saw this individual out and about in the community, his clothes were not clean, he was unshaven, and basically unkempt. Wyatt expressed his frustration about the matter:

> We would *never* let him go out looking like that [his emphasis]. Now when we see him up singing in the choir at church, he looks dirty. Mental Health told him he could work towards being assessed at a level two, instead of staying at a level three or four. Now, they moved him into the special care home, and he’s really dirty again. (Wyatt)

If those from Mental Health did feel it was possible for this individual to “work towards” needing a lower level of care, as Wyatt pointed out, this points to occasions where it is possible for those being assessed to influence assessment outcomes. As a point of interest, the lady operating the particular bed and breakfast where I stayed during data collection, on learning that I was doing research into long-term care provision, immediately began talking about a certain individual she saw from time to time out in the community:

> There's a special needs guy I see out on the streets now that I didn't used to. He's *really* dirty [her emphasis]. I don't know if he's living in a care facility but if he was in my care, I would *never* let him go out in public looking like that [her emphasis]. (Bed and Breakfast Operator)

She may or may not have been referring to been the same individual Wyatt was speaking of, but Wyatt's concern "They represent us" was certainly worth noting in light of this lady's interpretation of the situation.

Although Wyatt and Shirley's concerns over residents' appearances were related to their opinion that residents' appearances were visual representations to outsiders of the quality of care residents received and their own identities as care providers, these concerns reinforce residents as individuals to be worked on. It also means that front-line workers with the same concerns as Wyatt and Shirley must discriminate between ensuring residents look acceptable and that residents' are able to exercise their rights in this matter, which confirms Bigby et al.'s (2009:374) findings from their research on individuals with significant cognitive disabilities and front-line staff members in five group homes. There is also the potential of interpreting Wyatt and Shirley's concerns over residents' appearances as being protective of residents, similar to Rachel's attention to how residents are treated by outsiders, Some would view this protectionist stance as paternalistic within Dworkin's (1999:121) characterization of paternalism as interfering with an individual's personal freedom with the rationale that it is in the best interests "of the person being coerced."

It has also been argued that paternalism is characteristic of situations where people diagnosed with disabilities and mental illnesses are not considered to be self-directing consumers of services, as Dunn (2006) and Joiner (2006) point out, but are more typically viewed as being either ‘worthy poor’ or in biomedical terms, as having problems that need fixing according to Dunn (2006) and Rioux and Samson (2006).[107] The problem for front-line workers, however, is that these staff members are explicitly mandated to work at protecting the best interests of residents (SPARF 2009:1.3), so working to ensure that residents’ appearances were acceptable and watching to make sure others treated them well are both approaches consistent with protecting residents (SPARF 2009:1.3).

Relationships with Management

A number of front-line workers cited various sources of support for the work they did. For instance, Shirley viewed a certain male member of the Board of Directors as a source of support for herself and her co-workers. She turned to me as he left the facility after picking up his daughter to take her on an outing and said:

> Felicity’s Dad is great! He’s on the board. You might get a strip ripped off you once in a while but you usually have it coming. But, you know, we have all that support. (Shirley)

Three front-line employees talked about having good bosses and that although two did not always see eye-to-eye with their bosses, they still felt that they were able to have their say and that they were listened to. For example, Amanda said of her boss who operated the agency the agency that she worked for:

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[107] See also Bach and Rioux 1996, Rioux 1993, Rioux and Prince 2002.

> I have only good things to say about him. He's a fair man and he listens and we have some good meetings. We get into it sometimes in those meetings, but we fight it out and come to an agreement at the end of it, so it's good. (Amanda)

Shirley shared similar sentiments about the operator of the particular agency she worked for: "My boss is real good. I can go and talk to him about anything but that doesn't mean that I'm going to get my own way." Simone, who worked at still another facility, felt supported by her boss:

> She's very supportive. She gives me good compliments and makes me want to go further because I know I'm doing a good job. I can see that I'm in the right place. (Simone)

The support front-line workers experienced from three of their bosses, as well as a member of the Board of Directors, was important because it has been argued that supportive relationships can effectively "lower burnout scores" (Shaddock et al. 1998:310) and Reid et al. (1989) report better care experiences for residents where strong employer/employee support networks exist.

In this chapter I presented my findings of observations of the large institutions in the province, the issues that front-line workers face in their jobs, and the characterizations of their relationships with residents as well as with those in management positions. In Chapter Nine I turn to residents' experiences with care provision and include analysis of the various ways these individuals self-identify, how they interpret their relationships with others, areas where these individuals are able to exercise autonomy, and the specific factors that limit that their autonomy.

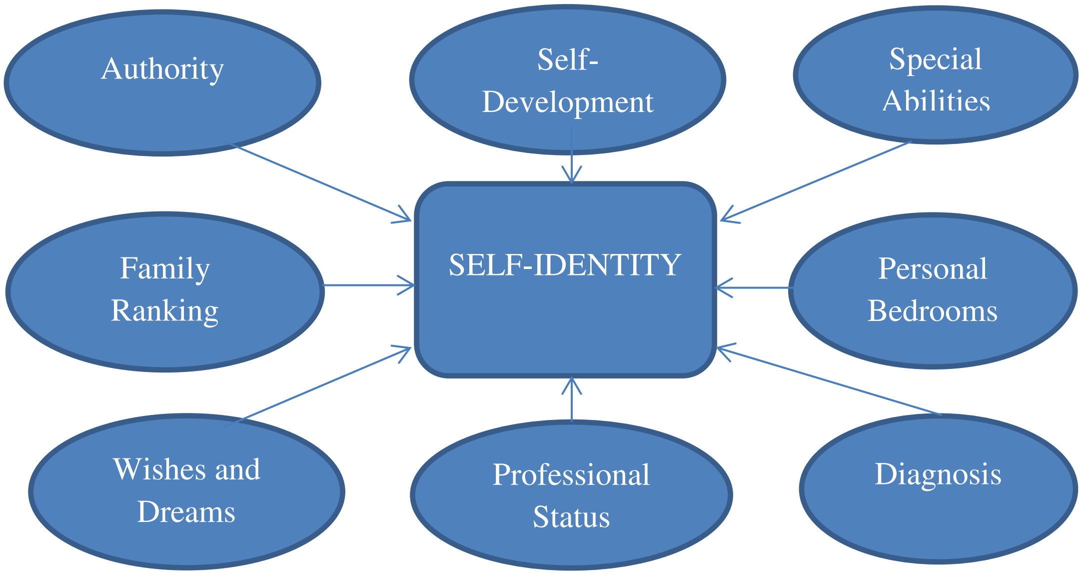
CHAPTER NINE: RESIDENTS' EXPERIENCES OF CARE PROVISION

This chapter contains the experiences of the individuals living in long-term care facilities. Three main themes emerged from the data collected among residents: how residents self-identify, how they characterize their relationships with other individuals, and those areas where residents are able to exercise some autonomy. Residents self-identify by drawing distinctions between their current and former identities, between themselves and others, and according to what they consider their predominant characteristic. The un-elicited wishes and dreams that residents shared, as well as their discussions of spiritual matters, revealed additional ways that these individuals view themselves. Residents also talked about their relationships with fellow residents, staff members, family members, and others outside the facilities. The final section of Chapter Nine surrounds the matter of autonomy for residents and includes information about the specific ways residents are able to exercise autonomy and the issues that hinder their ability to be autonomous.

How Residents Self-Identify

Residents used a number of discourses to self-identify: they drew distinctions between their current and former identities, compared themselves with others in and outside the facilities, identified according to diagnoses, family ranking, and professional status, employed discourses which spoke to their self-development and special abilities, and finally, they used discourses identifying themselves as having authority over others. Residents also distinguished themselves from fellow residents by discussing the photos and personal possessions in their bedrooms, as well as through their conversations about spiritual matters. The information they shared about their wishes and dreams for the future provided additional insight into how residents self-identified. I provide a conceptual model of the ways that residents self-identified below (see Figure V).

FIGURE V: WAYS RESIDENTS SELF-IDENTIFY



Discourses of Self-Identification

When I asked residents “What can you tell me about yourself?” their predominant response was to draw comparisons either with themselves or with others. For instance, Devin drew comparisons between his former and new identity:

> Do I drink? No. Do I take drugs other than those that are prescribed by my doctor? No. Do I have mood swings now? No. I get mad sometimes but I’m not as bad as I was before when I first arrived here. I was a real hell raiser towards everyone [laughs] Oh yeah. (Devin)

Devin credited a particular staff member for his new-found identity as one who had learned self-control:

> It took a lot of work though and I have to give a lot of credit to _____ [name of front-line worker acting as the third party during the interview] and the rest of the team. Like, every time I would do something wrong, bang. _____ [naming a different front-line worker] would be ready to jump on myself. (Devin)

Devin's self-identification in terms of development which he attributed to the persistence of a staff member, is consistent with Levinson's (2010:135) finding that group home work provides residents with 'practical' ways to work on themselves, and Mead's (1967:199) view that self emerges through social interactions and that individuals adjust themselves to others' attitudes of them. That Devin identified himself in terms of self-development also reveals the pertinence of Foucault's (1982:790) ideas about government as a form of power that authorizes the "conduct of individuals" (Carlson 2005, Hughes 2005, Sullivan 2005).[108]

Blake also self-identified as different from the person he used to be when he lived in one of the large institutions now that he has moved into an adult community residence: "I had brain damage when I lived there but I'm all right now." It is possible to explain Blake's changed self-identity within Schutz's (1967, 1970) notion of 'life-world' as being the product of Blake's interactions with staff members and residents in the adult community residence, which must have been significantly different from those in the large institution for him to draw this conclusion. Since front-line workers and fellow residents are those most proximate to Blake they would have the greatest influence in his reinterpretation of himself (Schutz 1967, 1970). Fred, a resident who

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[108] See also Foucault 1977, 1978b, Hughes and Paterson 1997, Tremain 2002.

lived in a different adult community residence than Blake, saw himself as abnormal. Fred told me on two occasions that he had a “fried brain,” although on another occasion he told me he was sane and no longer wanted to live with fellow residents who, in his words, were “a bunch of crazy people.” Fred’s comments about having a “fried brain” and referring to the individuals he lived with as “crazy people” reveals that Fred has internalized his stigmatized and “spoiled identity” (Goffman, 1963:129).

Some residents self-identified by comparing themselves with other residents along diagnostic lines. Mark, a team leader, told me that several residents diagnosed with varying mental illnesses made it clear to him that they were not interested in socializing with people not diagnosed with mental illnesses. In their words, “Mental health should be with mental health” and persons with developmental disabilities were ‘sick.’ When Mark attempted to explain to these residents that they all required some form of medication, one resident responded: “But we’re not sick like *that*!” Devin talked of wanting to meet new friends at the local activity center who as he put it, “are like me.” The lack of interest by some residents to socialize with individuals they saw as unlike themselves is not unlike other citizens who, as Gregory et al. (2001)[109] assert, tend to gravitate towards others with common interests and experiences. This lends support to Cummins and Lau’s (2003:153) argument about refraining from ‘devaluing’ relationships among individuals with developmental disabilities.

Being categorized in various ways such as being mentally ill, as Foucault (1982:781) explains, forces a certain ‘truth’ about the matter on individuals and affects the way that they come to self-identify. In addition, Foucault (1982:781) points out that,

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[109] See also Cummins and Lau 2003, Emerson and Pretty 1987, Higgins 1989.

categorization has reached its full effect when individuals - like the residents in this research - internalize these new identities. The self-characterizations that residents with mental illnesses employed show that these individuals have effectively adopted and internalized biomedical and abnormal (Michalko 2002, Prince 2004)[110] self-interpretations, and that how others have labeled these residents are now "solid facts" (Cooley 1902:87) to them. Nevertheless, Devin also viewed himself as distinct from his fellow residents with mental illnesses by the following comments he made:

> Like, I'm not trying to say that I'm better than anyone else here. No, we're basically all in the same boat. But with my illness I have and the pills I take, and with my doctor's permission and my social worker's permission, they find that I'm good enough, I safe to be living on my own, and that's what they're going to provide for me. (Devin)

Two female residents living in nursing homes self-identified by diagnoses immediately after telling me their age, and drew comparisons between themselves and other residents of the nursing home much older than themselves.

Doris, another young female living in a nursing home, self-identified by occupational status when I asked her "What can you tell me about yourself?" for she immediately responded with the professional moniker by which she identified prior to moving to the facility. Doris then explained some of the ways she has incorporated the skills she developed in her previous career in her interactions with residents at the facility:

> I have those skills and I do try to use those some here. Like, when I see something, seniors hitting each other, I try to do some nonviolent intervention, that kind of thing, and do the talking, that kind of thing, to see what I can do to help them change. All we're looking at is changing behaviour, not changing them. (Doris)

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[110] See also Davis 1995, Kleinman and Kleinman 1997, Linton 1998, Oliver 1996, Thomson 1997.

The fact that Doris still identified by the same professional moniker and that she was using the skills of her former trade in her new living environment, makes Goffman's (1961) argument about the stripping away of one's former identity when transitioning from the pre-patient to in-patient phase irrelevant in this case. Only after Doris explained her professional status and the particular skills she used, did she self-identify by diagnosis.

Henry of an adult community residence self-identified as "the first born in my family," revealing that his predominant self-perception was couched in his family ranking status. Kate saw her distinction from other residents at the adult community residence where she lived in the "good job" she did with crafts. No other residents where Kate lived engaged in this type of activity. Tom self-identified as one who defended others:

> Sometimes the guys pick on ____ [one of his friends living downtown]. So I get fed up and I go to the police and make a complaint but, sometimes, they don't want to do nothing. I told them I would take it into my own hands (Tom).

Tom then gave an example of where he intervened on behalf of a fellow resident who, in Tom's words, was being "picked on" by another resident. Tom told me that he asked the offender why he was picking on the other resident and then proceeded to explain to me the approach he was going to take if the same guy picked on him: "If he does that to me I say, 'Here, hit me! Make my day!'"

Residents with cognitive and/or other disabilities never self-identified in derogatory ways but rather according to their special abilities (e.g. Kate who did a "good job'" and Tom who defended others), family ranking (e.g. Henry) or professional moniker (e.g. Doris). A possible explanation for their use of positive self-identifiers is that these residents were still able to determine their own discourses of self-identification despite being objects of knowledge and being labeled by others (Foucault 1980b). Another possibility is that these residents have developed these self-images because they have internalized positive judgments others have made about them, consistent with Cooley's (1902:87) "looking glass self."

In addition to self-identifying in the ways described above, two residents self-identified as having authority over others. For instance, Kate said of a female staff worker: "She's not only my staff worker. She's my friend," and Tom described a volunteer who regularly drove him to and attended hockey games with him, as "my chauffeur." Similar to Kate, Tom considered this individual to be "my friend." Tom also believed that he possessed some authority - or at the very least influence - over sports officials: "One thing I always do is pick on the umpires. I pick on the umpires and on the referees in hockey." Kate and Tom's estimation that they had authority over other individuals tenuously contradicts the one-sidedness of power in long-term care settings as some argue (Thomas 2007, Drinkwater 2005).[111] I intentionally use the term tenuous because the particular areas where Kate and Tom believed they were exercising authority over others had already been predetermined by others, making these residents' authority deceptive at best. While their perceptions of being in authority contradicted reality, this is not the issue, for as Thomas and Thomas (1928:571, 572) note in other situations, these perceptions were very real to Kate and Tom.

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[111] See also Devlin and Pothier 2006, Foucault 1977, Hughes and Paterson 1997, Tremain 2005, Yates 2005.

Personal Spaces, Bedrooms, and Residents' Self-Identities

Irrespective of the particular facility where I did fieldwork, the first thing some residents did on meeting me was take me to their bedrooms to show me specific items important to them, after getting permission from front-line workers. This was a regular occurrence and appeared to be an important way for residents to communicate something about who they were. Pictures of family members, peers, and/or friends, personalized décor, doll and movie collections, jewelry displays, and awards and trophies, all appeared to symbolize ways for residents to distinguish themselves from fellow residents. The ability to bring their personal possessions to the facilities reveals intentional efforts to maintain residents' rights and dignity as they transitioned into the facilities (*Family Services Act, Human Rights Act*, SPARF 2009), unlike the previous stripping away of indicators in their pre-patient status (Goffman 1961). Individuality for residents was further enhanced by their freedom to spend time alone in their bedrooms if they wished, to watch television, spend time on their computers (for the few residents with the capacity to do so), do crafts, or spend quiet time away from others.

The ability of residents to enjoy personal preferences regarding the appearance of their bedrooms and to enjoy some privacy in these spaces, were specific ways that residents were shown respect, consistent with Atkinson's (1998:23) findings. It was clear that the staff members working in the facilities recognized residents' bedrooms as spaces to be respected, for Mark expressed his frustration to me over a social worker who sat on a resident's bed to check it for comfort. Mark told me that he regarded her action as showing a complete lack of respect for the resident, adding: "I doubt if she [referring to the social worker] would appreciate it if a stranger went into her home and sat on her bed!” Mark felt a better approach would have been to test the comfort of the bed with her hand. Having personal bedrooms and belongings supports individualized care mandates (SPARF 2009), and the ability for residents to sense their individuality is no small feat, particularly for people in long-term care settings, as Atkinson (1998:24) finds. The ability for residents to have personal bedrooms is also a departure from former asylum life where, as (Goffman 1961:17) explains, patients were always grouped together, even when it came to their sleeping arrangements.

Wishes, Dreams Spiritual Matters and Residents’ Self-Identities

I did not ask residents if they had any notions about what the future might hold for them but eventually realized my short-sightedness and error in assuming that wishes and dreams conflicted with living in a long-term care facility. Despite my failure to ask residents about this matter, three individuals talked to me about the wishes and dreams they had for the future. Had I asked all residents about their hopes and dreams, it is likely they would have articulated them. The conversations that three residents had with me about the possibilities they envisioned for their future revealed additional information about how they perceived themselves and their living situations, information that would have been impossible to capture had I not simply asked, “What can you tell me about yourself?” Kate told me that she dreamed of travelling to Nashville one day to see Charley Pride, and Fred spoke of waking up every now and then from dreaming about Vancouver and that he would love to go there someday.

Devin explained to me that there was a strong possibility that he might become famous one day if some of his poetry got published. Devin then talked about his sister who had connections with a billionaire in Los Angeles who helped other famous musicians to get their start. Devin concluded: “I’m just waiting for my big break.” One resident’s dream was that things remain just as they were however, for when a front-line worker asked Ethan, a male resident “How do you see yourself in ten years?,” Ethan responded with: “Here, very good here.” When this same front-line worker asked Ethan about the possibility of moving into an apartment by himself, he answered, “Maybe I can fall sick again” which revealed his desire to stay where he was. The wishes and dreams these residents held demonstrates that hopelessness is not essential to living in a long-term care facility, for these individuals saw a future with possibilities. While their dreams may be perceived as naïve or impossible, this research supports Wehmeyer and Metzler’s (1995) position that such hopes about the future should not necessarily discounted. Further, this research confirms that the dichotomy between false and true hope in such scenarios is untenable, as Demaresse (1989), who spent much of her early life in an institution, contends.

Similar to un-elicited discussions about their future, residents also initiated conversations with me regarding spiritual matters. Rhonda, a supervisor with one of the adult community residence agencies while driving me to a facility for my first day of fieldwork at that location, gave a brief explanation of the particular residents I would meet there. In the course of her conversation, Rhonda warned me that Sally, one of the residents, would probably ask me about my religious background. Rhonda’s prediction was accurate for, on my first day at the facility, Sally asked if I was Catholic. When I answered ‘No,’ Sally took it upon herself to find out why I was not Catholic. Finally, Sally asked me “Well, what are you then?” After initially responding ‘No’ to the first question, I followed Rhonda's advice by responding to the remainder of her questions about the matter with, "That's personal." A front-line worker who worked with a different agency than Rhonda, told me that one of the residents, Blake, prayed regularly at meals and always included employees' or residents' names if they became ill.

Two residents talked about being formerly involved in church communities. For instance, as Kate showed me her bedroom she drew my attention to three different pictures of Jesus on the wall and talked about the particular church she used to attend. Kate then asked if I attended church anywhere and if I had a Bible at my house. Henry told me he was no longer able to attend church since his father died because there was no one to take him. Antoine, of a different adult community residence, also used to sing regularly in a church choir as noted in earlier in this chapter. Although three of the residents that I met during fieldwork attended church on a weekly basis with family members, the residents who still identified with particular churches were no longer actively engaged, as they once were. In Henry's case, this was because there was no one to take him. This is a concern, for attending to residents' spiritual needs is part of care standard expectations (SPARF (2009:2.4).

Residents' Relationships

This section focuses on residents' relationships with staff members, fellow residents, family members, and individuals living outside the facilities. Residents described staff members as friends, as being supportive, and occasionally, as sources of frustration. Residents' characterized their relationships in ways similar to non-institutionalized individuals as being friendly, romantic (Levinson 2010:78), affectionate, or frustrating. While Levinson's (2010:78) use of the term romance includes expressions of romantic sentiments and sexual activity, in this research I use romance to refer to the romantic sentiments three residents expressed about others, as they did not talk to me about sexual activity. Residents talked affectionately about family members, including how special a parent was, that a parent loved them, and of special memories shared together. Residents were also hurt and frustrated by relatives, however, for failing to visit them, and one resident, because of the teasing he endured. The relationships that residents experienced never seemed to be settled, but continually shifting back and forth between cohesiveness and conflict. Cohesiveness was related to the support they experienced from staff members and fellow residents and conflict had to do with the anger expressed between residents (Moos et al. 1979:77)

Relationships with Fellow Residents and Staff Members

At least eight of the individuals living in adult community residences that I met during fieldwork have lived in more than one long-term care facility. One resident has moved four times, four have moved three times, and three, at least twice. Despite these transitions, relationships were still important to resident's experiences. Responding to the question "Can you tell me about the place where you live?" Tom said, "I like it." When I followed his response with "What do you like about it?" Tom replied: "Uh my roommates, Ernest my roommate, and Michelle and Sally, my roommates." For Henry of a different facility, the people at the facility were the reason he liked where he lived:

> Well, I can come back to this place when I leave my Mom's place. And when I come back here I am happy to see Shirley [front-line worker] and Kate [resident] and Ben [resident] and most everyone here. (Henry)

Fieldwork was beneficial for observing how residents interacted with each other and noting some of the friendships between residents. Friendships were detectable as residents watched television programs together like game shows, as they joked with each other during meals, and as they occasionally stood up for each other. In one facility, most residents exercised together after supper under the direction of fellow resident Kate. A nursing home resident, Doris, told me she had "two main friendships" in the facility where she lived. She reported being particularly close to one lady near her age who had the same diagnosis, while her other friend was a senior lady who was seventy-one years old. Mary, another nursing home resident, did not share the same experience as Doris when it came to having friends in the facility. She explained:

> I don't really have any friends. I mean, some of the seniors are nice and friendly but they're not really my friends. I had friends when I lived in my own home but since I have come in here, I don't see any of them very much. I know they're busy and stuff but . . . [end of her statement] (Mary)

A third nursing home resident, Theresa, told me that she felt alone at times because the few older residents with whom she could talk were from a different time period and unable to relate to her. Theresa concluded: "It's kind of a struggle for me."

One resident, Isabelle, was not interested in friendships with fellow residents in the adult community residence where she lived. Isabelle told me she did not know the other residents at the adult community residence where she lived and seldom interacted with them. When I asked her 'Why?' she responded, "Because I don't feel to," adding "I like to be quiet." At the same time, Isabelle told me that she did not like the other facility where she used to live, because no one talked to her. Isabelle was the only female resident at the facility at the time of data collection. There were times when residents engaged in defending each other. For instance, I observed one resident attempt to cover for a fellow resident who was in a bit of trouble by telling the front-line worker that he had been with him at the facility all day. This was not actually the case however, as I had been at the facility during the time in question and the suspected resident was gone a good part of the day, though I said nothing. Tom, as noted earlier in this chapter, also actively engaged in defending fellow residents, considering this as key to his self-identity.

Three residents of adult community residences used romantic terms to refer to fellow residents. Blake called Michelle his 'sweet' and Kate referred to Ben as her 'boyfriend.' Isabelle told me that she had a boyfriend at the facility where she used to live but that she was sad when he failed to return her romantic affections and focused on a different woman instead. Apparently, Isabelle also had romantic inclinations for a male staff member as she told this staff member that she planned to marry him and assured him that she would be there for him if his wife cheated on him. I also observed romantic interactions among several residents as they listened to music, watched television and videos, or played games together. For instance, I saw a male resident flirt with a female resident, wink at her, and make specific gestures to get her attention, after first looking around the corner to make sure no front line workers were watching, This female resident was wearing a bracelet several days later that she said was a gift from the male resident I saw flirting with her. That this resident checked first to ensure no staff members were watching may suggest that romantic interactions between residents were discouraged at this facility, although this was not the case at another adult community residence for a front-line worker told me one day about a female resident having a crush on a fellow male resident.

Despite the friendships, romantic liaisons, and defense of fellow residents, there were occasions when fellow residents were sources of frustration which, of course, is no different for people not diagnosed with disabilities and/or mental illnesses. None-the-less, residents had to deal with such frustrations. For instance, Tom was clearly frustrated with a fellow resident one day during fieldwork, for he declared emphatically to me: "Sometimes Gordon gives me a pain in the rear end!" In another instance, Adam, while being interviewed, described his fellow residents as follows:

> Sometimes they're loud and make me angry. Sometimes _____ [a fellow resident] makes me angry! Me don't like that! If one guy makes the other guys angry, the other guy gets worse angry. (Adam)

Adam's last statement reveals the tensions that can escalate between residents. The front line worker acting as the third party during Adam's interview confirmed Adam's characterization of the matter, interjecting that he and other staff members have to closely monitor all hints of frustration between residents so they can diffuse matters before they get out-of-hand.

Some residents also had to endure occasional aggressive behaviours from fellow residents. Yvette, supervisor of an adult community residence agency, talked about the difficulties residents sometimes face because of having to deal with fellow residents' behaviours: "Sometimes there are a lot of behavior problems, and the others live with that person so, sometimes it is hard." Although Kim's concerns over her daughter's safety was already pointed out in Chapter Six, Kim account below provides further explanation about the individuals engaging in aggressive behaviours at the facility where her daughter lived:

> Our daughter has been put in extreme danger twice with other male residents . . . Both these boys are, they're young men, but they're men. They're like over six feet tall. Great big boys! The situation is unstable. (Kim)

The difficulties residents faced because of the sometimes aggressive and violent behaviours of fellow residents is not atypical according to Baines (2004:46), who recommends "minimizing changes" in the everyday operation of facilities to prevent such "disruption of clients" (Baines 2004:43). Facilities where behaviours are a problem, such as where Kim's daughter lived, typically have social climates characterized by conflict (Moos et al. 1979:77). Residents' engagement in aggressive or violent behaviours can also be efforts to assert their individuality, as Atkinson (1998:24) explains.

Two residents considered front-line workers as sources of support. For instance, Blake described a time when he was sick and the interactions that took place between he and Breanne, a front-line worker:

> 'You know something Blake. You don't look good,' but I told Breanne, 'I don't want to go to Moncton Hospital' and Breanne said 'Blake, you got to go buddy.' So that was all right. The minute I got down there, Dr. ______ [name of physician] had a room for me. He said 'Blake, we would like for you to stay,' so I did. (Blake)

Mary characterized one of the executives at the nursing home where she lived as helpful: "Olivia is really good. If I have a problem I talk to her about it." Mary appreciated other employees at the nursing home as well, by her comment "If I need anything they come right away. They're really good like that. Most of them are nice." Nevertheless, some staff members frustrated Mary:

> Most of them interact with you while they’re looking after you, but there are a couple of them who don’t even want to really look at you or talk to you. It’s all business. That’s hard. (Mary)

Theresa, another nursing home resident, lamented that although staff members were generally good she had very little real meaningful interaction with them: “They don’t have a whole lot of time to intervene with you because they’re on the fly all the time doing things. So they don’t have a whole lot of time to talk.” Teresa felt less connected to fellow residents because of the difference in her age and that of seniors who made up the bulk of residents, and she was frustrated that staff members treated her like a senior citizen at times:

> If you’re younger like me, they really don’t know. Well, some of the staff does. But even from the top down they’re not sure how to address my needs. So, I challenge them if something comes up. I’ll fight with them. I say ‘Look at me! I’m not your [pauses].’ They sort of try to box you in with older people so I’m there going, ‘Wait a minute. I don’t have the same needs as the older people do.’ So I challenge them all the time on it - *all* the time [her emphasis]. (Theresa)

Theresa concluded: “Thank goodness for the younger staff!” probably reflecting her potential to interact with individuals other than seniors. A third nursing home resident, Doris, felt that staff members treated her as less than human:

> You have your voice and you have your mind and you want to be treated that way. Like, people will have conversations in front of you! Talking about other residents, and I think, ‘What are they saying about me when I’m not there?’ They shouldn’t be talking in front of residents about shortages of staff because the residents can’t do anything about it, so it just makes you feel like, well, you probably won’t get the service because there are not enough people. (Doris)

Devin, a male resident in an adult community residence, disliked a particular staff member, stating emphatically to me one day, “I am not one to lie. I cannot stand _____ [a front-line worker]!” In facilities with interpersonal relationship problems, such as between Devin and this particular staff member, a less than favourable emotional climate is engendered (de Rivera 1992).

Front-line workers spent one-on-one time residents in various activities but, as with previous findings (Felce et al. 2002, Mansell et al. 2008)[112] it was typically well under six minutes per hour assisting residents in meaningful activities. In this research, the amount of time that staff members spent with residents had more to do with their job responsibilities that did not allow as much time as they might have liked for the relational aspects of care, which is consistent with other research (Baines 2004, Cushing 2003). Another factor associated with the amount of time staff members spent with residents was related to residents' own level of interest. Even so, there was less distance between care providers and residents than Goffman (1961) envisioned. Since most residents at the adult community residence where Mark worked came and went as they basically pleased and were busy with their own individual activities and interests, there was not a lot of one-on-one time between residents and front-line workers at this particular facility.

At the three other adult community residences, front-line workers occasionally spent one-on-one time with residents, playing cards, doing crafts, singing songs, watching television, or listening to music with them. Residents from all four adult community residences went on occasional one-on-one outings with staff members to restaurants, take-outs, coffee shops, local shopping malls, as well as to run errands, if they wished to do so. A front-line worker told me that Ethel, a resident, had a favourite song, which this worker then played for Ethel on her I-Pod and sang along with her.

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[112] See also Emerson and Hatton 1996, Emerson et al. 1999, Jones et al. 1999, 2001.

Ethel sang this song with the front-line worker, word for word. I also observed that Ernest loved the attention he got from various front-line workers who occasionally sang to him the particular songs that he liked.

Relationships with People in the Community and Family Members

Theresa, a nursing home resident, told me she has a best friend several hours from the nursing home who "tries to keep me grounded" and, although Theresa talks to her friend occasionally by telephone, she said she seldom received visits from her. A number of residents of the adult community facilities talked about their friendships with people outside the facilities. Tom shared his experience:

> I have a lot of friends. I talk to them for a while. I meet them at ____ [local pool hall] downtown, the bartender and the guys, and then I take a taxi and come back home, have supper, watch TV. (Tom)

Zane had a friend who visited him weekly and sometimes brought him coffee. Ben told me that he had a friend and added, "Sometimes I go to different places with him." I saw first-hand Ernest's enjoyment at receiving a card in the mail one day from a lady with two dollars in it. Apparently, this older lady has been sending Ernest a card with two dollars in it every month or so, for years.

As noted earlier in this chapter, Devin liked going to the local activity center to meet friends. While Adam told me he did not have any friends at the activity center, he said, "I like to go there and enjoy the music and things." According to front-line workers, a number of residents enjoyed friendships with people at the local activity centers, coffee shops, shopping malls, and through their association with Prime Time

Pals,[113] an organization that facilitates community involvement, the development of social skills and greater independence for residents, which is operated by and for, people diagnosed with disabilities, and is under the jurisdiction of the Department of Mental Health.

According to Celeste, who operated adult community residence C, relationships between residents and people outside the facilities can be hard to attain, much less maintain, concluding: "It's hard. I wish they all had friends." Celeste told me about taking specific measures to try and initiate new friendships for residents and to support the friendships that already existed between residents and people living outside the facility. For instance, Celeste used Antoine's birthday party as an occasion to try and initiate some friendships for him. She invited individuals from People First (see website) to celebrate his birthday with him because, in her words:

> He is in dire need of friends. Antoine wants friends bad because he said, 'When I had money, I had friends, and now that I don't have any money, I don't have any friends anymore. (Celeste)

Celeste also talked about the issue of friendship for Eugene, a resident with more severe disabilities than most at the facility: "One of the staff at the vocation center is very fond of Eugene and one of the girls [a front-line worker] here is really fond of him, but he doesn't have any friends." Two other residents at Celeste's facility, Evangeline and Lily, enjoyed friendships with individuals at the local vocational center. Celeste described Lily's friend as 'fun,' adding, "You would love her!" The following is one way that Celeste attempted to show support for Evangeline and Lily's friendships:

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[113] See http://primetimepals.com/index.php?p=1_4.

> Last Christmas, the staff wanted to plan this big Christmas supper and I told them to go ahead, but Evangeline and Lily's friends needed to be invited as well. Their friends were going to be part of this group. (Celeste)

The friendships that Evangeline, Lily, Devin, and Tom enjoyed with people outside the facility refute Goffman's (1961:15) assertion about the barriers to socializing with individuals outside the institutions.

As residents talked about their family members, a number of themes emerged. The first theme surrounded pleasurable memories of times spent with relatives and the affection they felt for their loved ones. Pleasurable times spent with family members included going on drives, sharing meals, enjoying treats such as ice cream, going to church together, and having overnight stays with relative. Residents also told of watching television or sharing coffee together during overnight stays. Three residents talked specifically about their visits with relatives. For instance, Tom told me that he occasionally stayed overnight with two of his sisters, and said of one sister: "She picks me up at the ball field and takes me over to her place. I have a snack. I watch TV and I go to bed. Then I go to church the next day. It's fun!"

Blake also talked positively about the visits he had with his father: "I go home and see him every second Sunday. He just loves that when I go!" Adam found home visits more difficult however, for when I asked him "Can you tell me about the facility where you live?" he drew the following comparison between staying at his parents and remaining at the facility:

> This place is good. This house is good. My mother, my father, my home, I don't, I can't sleep at night. I take movies there sometimes. I take the [DVD player?] on the TV at my mother and father's. I watch the TV all the night and so, in the morning, I go to bed and my mother see me. Here it's good. I sleep here all night. Here sleep good. (Adam)

Kate enjoyed occasions when her relatives visited her at the facility, explaining: “I make them a coffee and I associate with them. I ask them what they like.” Devin spoke fondly of his mother and the times they shared together: “She likes taking me to the ball game. I go down to her place for ice cream. Stuff like that. My Mom’s very special to me.”

The affection some residents felt towards their family members made it difficult when loved ones died. Isabelle raised the topic of her mother’s death with me during her interview, telling me that she did not go to the funeral home to see her mother because it was too hard for her, and that her family did not understand her refusal to go. According to Isabelle, she could not believe that her mother had died and she did not want to go to the funeral home because she felt like crying. Isabelle quietly added: “I cry sometimes when I think of my mother. Everybody [has] to die, and after you die, everybody here is without here.” Isabelle said she knew that God loved her but that “after death, some not scared, but some does.” I reached over, touched her hand to comfort her, and redirected the conversation to lighter matters in an effort to ease her sadness and in an attempt to conduct the interview with her in an ethical manner.

A front line worker told me that Adam ran away on hearing of his father’s death. This same staff member described taking Adam to his father’s funeral and staying with him, not knowing what Adam’s reaction would be. As it turned out, Adam was okay. After the funeral, his mother bought Adam some cigarettes and he barely mentioned his father again. Taking Adam to his father’s funeral and making sure he was okay afterwards were consistent with showing respect for residents when their loved ones die (Atkinson 1998:23). Relatives were also a source of hurt to residents at times. For instance, Devin said of his brother: “He teases me all the time. When I was younger he used to beat me up at school every day." Residents are also hurt when relatives do not visit. I overheard Sally of a different adult community residence ask front-line workers nearly every day during fieldwork why her sister never called. Isabelle told she came from a large family with many nieces and nephews but bowed her head and added: "They don't come to see me. They all too busy." When Isabelle left the room the front-line worker told me that Isabelle tried almost daily to call her sister, but her sister never answered the phone and came only once to the facility to visit Isabelle

Mark, a team leader at one of the facilities, told me, "Out of ten guys here, I have maybe two families come and visit." Referring to one resident, Mark said "His brother was married for seventeen years and his wife had never met his brother [the resident]. When I asked if he had an explanation for the lack of family involvement, Mark said:

> They don't want to get involved because they're scared that the clients want to go back there and they can't control the client. They're scared that the clients are going to be too close to them, going to get involved in the family directly. (Mark)

Two staff members with experience working in both children's group homes and adult community residences reported that families were typically less involved with adults in care compared to children. Amanda described her observations from when she worked at children's facilities:

> There aren't too many days when there haven't been phone calls. If there are hospital visits, the parents are there. They are there on a regular basis every week. (Amanda)

Although Amanda's observations were consistent with Baker and Blacher's (2002) finding that children receive more visits compared to adults, it is still insufficient to establish that children in long-term care facilities receive more visits compared to adults.

A staff member told me that the reason Adam’s mother seldom visited him was that since Adam’s father died, she was elderly and it was a long drive for her, which may suggest that being an adult rather than child in care is not the only explanation for why relatives did not visit. Various front-line workers said that it is extremely difficult for residents when family members do not maintain contact. For instance, Mark talked about the situation for Jacob who, despite being a grown man, “cried like a baby” when family members failed to show up for a Christmas party that staff members had organized for residents and their loved ones. Mark believed that if other individuals visited residents this might alleviate difficult situations like the one faced by Jacob and provide residents with more positive experiences. Mark concluded his discussion of the matter with: “Clients would be happy if they had visitors.”

The parents who participated in this research seem to be the exception in maintaining contact with children in long-term care facilities, according to both residents’ and front-line workers’ accounts, which contradicts Seltzer et al.’s (2001) assertion that families usually maintain contact with loved ones irrespective of their age. In those situations where there contact is maintained, there can be occasions when families frustrate residents. For instance, I saw first-hand the frustration that a mother caused for one particular resident. Joseph, a young male resident in his twenties, paced back and forth one day for hours as he waited for his mother to pick him up for a drive as she had promised. Joseph said, “I hope my mother doesn’t betray me. I hope she shows up like she’s supposed to.” His mother did show up but not until the next day and she arrived significantly later than she said she would. Joseph was happy and excited to see his mother, however, quickly grabbing his coat and hurrying out the door to get into the car with her. As they drove away, the front line worker on duty at the time grumbled, “Mothers! They are either smotherers or they are like her!” Family members were also sources of frustration to residents because of setting unreachable goals for their children, according to Mark, who complained that one mother who was a nurse, should just let her son be.

The Matter of Autonomy

Autonomy had to do with whether residents were able to act in self-determining ways. While Biklen (1990) contends that autonomy for people diagnosed with disabilities is a contested term, it is significant to this research because of the mandates that residents have opportunities to engage in decision-making and make choices (SPARF 2009:5.4) and that they become more self-reliant (SPARF 2009, 1.3, 6.1) and become independent (SPARF 2009:5.4, ISPs), though Lakin and Stanfille (2007) argue that the reality usually contradicts residents’ life experiences. Residents typically chose the clothing and accessories they wore each day, the way their bedrooms were decorated and occasionally, the food they ate. Most residents also chose the activities they engaged in, both in and outside the facilities, whether they did these activities alone or with others, and sometimes, who these other individuals would be. There were at least three residents who had paying jobs and several residents were able to go on outings unescorted. The ability of residents to exercise autonomy was hindered, however, by a number of factors. The lack of money and/or volunteers, and occasionally, severity of disability, limited the range of opportunities for individualized activities, and residents exercised little choice in when they went to bed, ate, or had coffee and smoke breaks. A lack of information also hindered one resident's ability to make an informed decision about where he would live.

Opportunities for Autonomy

Most residents in adult community residences selected what they wore each day, including jewelry and other accessories, unless uninterested. A front-line worker who previously worked in a large institution in Western Canada discussed the significance of residents being able to choose what they wear each day, explaining that where she used to work "There was this wall of clothing. Everybody wore the same thing. The only difference was size: small, medium, or large." This standard issuance of clothing was a technique integral to Goffman's (1961) notion of mortification. Nevertheless, I saw an isolated incident where a resident's choice about a particular item of clothing was denied. Tom came out of his bedroom wearing a pair of jogging pants and announced that he was heading downtown to meet some friends. A front-line worker told him he could not wear jogging pants and needed to put on a different pair of pants, to which Tom responded "Why? My friends ask me 'How come you can't go downtown with a pair of jogging pants?'" The front-line worker replied: "Well, because it looks . . . We can't talk about that right now." Tom retorted: "One of my buddies I talk to, he wears jogging pants too." Just then the phone rang. Tom giggled and said, "Oh, Oh! Telephone!" at which point he went to his bedroom, changed his pants, and headed out the door.

Residents also had specific ideas about how they wanted their bedrooms to appear. For instance, one resident who was nonverbal waved his hands and made gestures to staff members one day to show them where he wanted certain objects placed in his room. He used the same approach with me on a different occasion, gesturing to show me where he wanted his model cars on the night stand. Residents chose what they ate at times, though these instances were rare because of funding problems that generally limited such choices. Most residents appeared quite happy with their meals nonetheless, and food was one of reasons that Tom liked the facility where he lived, for he told me, “We have pizza for dinner and stuff like that.” At all facilities, residents decided whether they would participate in the various activities available to them each day. Being able to do what she wanted each day was the rationale behind Isabelle’s description of the facility where she lived as “good enough” and ‘passable.’ When I asked her why she felt this way, Isabelle giggled and said “I like to colour.”

The activities residents engaged in fit into two categories: activities they chose to do alone at the facilities or other locations, or activities they chose to do with others at the facilities or other locations. Solo activities included: spending time on the computer, watching television and movies, playing games such as solitaire, making crafts, knitting, drawing and colouring, writing poetry, shooting baskets (basketball), and listening to, singing and/or playing music. As for solo activities that residents chose to engage in away from the facilities, these included going for walks, picking blueberries, and tending a garden. The residents who preferred solo activities included Ernest who listened to his favourite music CDs every morning, Kate who worked on crafts, and Antoine who watched movies from his private collection.

The main activities residents engaged in with other residents at the facilities were watching television and movies or playing games together. Activities that residents participated in with individuals at locations other than the adult community residences, included spending time together at local activity centers. Every adult community residence where I conducted fieldwork had activity centers nearby. Other activities residents participated in with individuals at locations other than the facilities included attending church functions, hockey, and baseball games, meeting friends for coffee, and going on outings with relatives. Tom told me he liked to "go downtown and meet the boys: "Yeah. Then I go to ____ [a particular identifiable location] and watch the trucks, watch the traffic." Activity centers were important places for residents when it came to special events such as dances, playing games, making crafts, playing on the computer, and meeting old friends or establishing new relationships.

Bruce, operator of adult community residence agency D, explained how they come up with various activities for residents to participate in outside the facilities:

> The houses are left up to their own devices. A lot of it comes down to the drives and the staff that are going out grocery shopping or pills, you try to take someone along with you as much as possible. (Bruce)

Taking residents on outings during errand runs revealed two matters. First, this tactic supports Marquis and Jackson's (2000:414) contention that choices are often made on behalf of, rather than by residents, in determining opportunities for outings, and second, that this option was available for reasons of efficiency (Levinson 2010), as it meant no additional cost to the agency. Bruce was pleased at one lady's recent success in organizing activities that helped residents to become more engaged in the community outside the facilities:

> Since she has taken it over there is no lack of the sort of activities residents can get in on throughout the community - bowling, curling and snow shoeing, all that sort of thing. (Bruce)

The ability to make choices about how they spend their time was important to most residents and, according to Blake, was one of the main reasons that he liked the adult community residence where he lived:

> I have movies of my own. I have television. And I watch movies on Friday nights. I go down to ______ [activity center] and I enjoy that very much. And I go upstairs from six to seven, and I enjoy that very much.

Being free to go on outings unescorted was also important to residents. As pointed out in Chapter Six, residents at the facility where Mark worked experienced the greatest amount of autonomy in this area. It was at this same facility that residents were occasionally reminded that they had the option of living elsewhere if they chose, although a front-line worker told me that most stayed as they have nowhere else to go. Two residents at this facility had opted to move back to the larger institution, although this front-line worker did not explain why these individuals had difficulty in the smaller facility.

In adult community residence B, all residents chose when they got up each morning and staff allowed them to set their own pace each day. Residents at another community residence had freedom to access their personal medications, which Wyatt, a front-line worker in this facility, had concerns about. He pointed to the Department of Mental Health as being the problem with this issue:

> The Department of Mental Health is a real problem. They have one mental health client, and they say if the client wants to come up and get his own meds, he can. But it's not practical. We don't like Mental Health very much here. (Wyatt)

Residents were able to have paying jobs if they were capable and wanted to. One male resident worked at a local store for an hour or two each day, and Wyatt told of a second male resident who had a good job in the community because of a contact this resident had at church. Wyatt laughed and commented: “He works and makes more money than us.” Wyatt pointed out however, that this type of situation was rare because, “When it comes to jobs, friends and social networks, no matter what people say, it’s the looks and the abilities of clients that count.”

Margaret, a front-line worker, told of a female resident who worked “at the church folding bulletins for $6 or $6.50.” Amanda, a front-line worker who worked at a different facility than Margaret, was frustrated that a job paying $1,800 a year for six residents to do cleaning work was phased out, despite the quality of their work:

> It wasn’t because the job itself was nonexistent, because there was still a need for it. That was a cost saving measure on behalf of some of the parish members. They decided that the $1,800, to have 6 people in there for a year, was too much to pay for getting the cleaning done. I don’t know why. I have no idea why, but some of those people were working for $2 an hour because they were grandfathered in, before they had to have minimum wage offered. And they were still $2 an hour. (Amanda)

Amanda added: “Five days a week at $2 an hour! And she worked like a crazy person! She’s a better cleaner than I am. And they let her go.” Amanda discussed the matter further, saying: “I was astounded by that! I don’t know what they’re doing now, but let them do it! I have no pity for them.” The ability of some residents to have paying jobs is consistent with policies about accommodating and promoting their employment (Jongbloed 2003, Rioux and Samson 2006),[114] but their work was seriously undervalued, except for the individual making better money than the staff at the facility where he lived.

Having their work undervalued and underpaid diminishes the distance between residents and front-line workers because of similar experiences in this area. Residents’

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[114] See also Corker and French 1999, Dunn 2006, Groeneweg 1992, Neufeldt 2003, Prince 2001, 2002, Rioux 1994, Rioux and Bach 1994, Rioux and Prince 2002.

appearances and physical features also reportedly affected their ability to get jobs. Besides the money some residents earned at their jobs - albeit meager with the exception of one individual - according to front-line workers, residents had personal spending money which, for several lucky individuals, was topped up by family members. Residents generally controlled whatever extra money they had and were able to make decisions about how to spend it. At the facility where Mark worked, residents were free to go on outings every weekend and spend their money as they wished which, Mark said ranged "between five dollars to ten dollars per client." The ability of residents in all facilities to pursue certain activities and to act autonomously was mitigated by a number of factors however.

Hindrances to Autonomy

Most residents were autonomous in at least some way but, as with other findings, their choices were still limited compared with other citizens (Jaskulski et al. 1990, Wehmeyer and Metzler 1995)[115] and could only be exercised within a range of pre-determined choices, which means they we still subject to a system of control For example, most residents were not able to decide when they went to bed at night, ate, or had coffee and/or smoke breaks, but this was particularly so at the facility with the most emphasis on upholding rules. For Devin who lived at this facility, the inability to choose when he went to bed or the number of cigarettes he smoked was a problem, and he

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[115] See also Houghton et al. 1987, Kishi et al. 1988, Murtaugh and Zettin 1990.

described the facility as follows: “It is nice, but it is strict at times.” When I asked, “What do you mean strict?” He responded by saying:

> I find it strict because we’re only allowed to stay up until 9 o’clock and I like staying up longer. And we’re only allowed a certain amount of smokes per day and like, say if we go out and we don’t have money to buy our own smokes, we don’t get any from that. I don’t like that because it’s our money that’s paying for the food, paying for the smokes, and paying for all of the other necessities that we . . . so I’m totally against that. (Devin)

The ability of front-line workers to make such determinations reveals the predominance of power that caregivers possessed at this facility but, in reality, the situation was the same for staff members at the other facilities although residents in these facilities were probably less aware. If residents still lived at home however, they would still possess less power than their loved ones in having to depend on these individuals to meet their basic needs.

Still, Foucault’s (1981) contention that there has to be an “equalization of power” for individuals to act autonomously (Olssen 2002:491) is pertinent here, though difficult and probably impossible in long-term care settings. Foucault (1991:18) recognizes that power relations are not ‘bad’ and are necessary to society, but he also argues that the key is finding out ways for the “games of power” to be exercised with the least amount of domination possible (Olssen 2002:18). It is unlikely however, that residents will be able to bring about “a reversal” (Foucault 1991:12) in their situation, although Theresa’s challenges to staff members that they not treat her the same as seniors noted earlier in this chapter, may be a step in that direction. Residents at the other three adult community residences mostly decided when they would get up in the morning and if they would take an afternoon nap.

Not being provided with adequate information was a factor that hindered Devin’s ability to exercise autonomy regarding where he would live. Devin told me that the reason he was living in the facility where he was at the time of data collection was because of signing a piece of paper he did not understand:

> They said, ‘Well, we have a lady here that wants to speak to you and see if you will sign a sheet.’ So I never signed the sheet because I didn’t know what the sheet was about. It was for coming here and living here for good. And my social worker Phyllis was there too, so I signed the sheet and that and here I am now. (Devin)

Devin’s comments reveal the influence his social worker’s presence had in him eventually signing his name to something he did not understand. A lack of monetary resources was another hindrance to residents’ autonomy when it came to their ability to opt for certain activities. Such was the case for Isabelle:

> I like to go shopping but I don’t have enough money some days . . . There’s no money for shopping. These homes are poor and we only get paid once a month. If there was more money we could do more activities, instead of stay at the house. (Isabelle)

In addition to the lack of money, residents’ inability to exercise autonomy regarding activities was the result of insufficient staffing. Bruce, operator of adult community residence agency D explained the situation:

> When it comes to outings, in some cases it comes down to staffing ratios. You can’t always use it as an excuse, but sometimes there is just not enough staff to get everybody out as much as they should be going out. (Bruce)

Henry had touched on this issue earlier in this chapter in his comment that there was no one to take him to church. When Henry made this comment, the front-line worker, sitting with Henry during the interview interjected “We just don’t have the extra staff to take them on individual outings.” Additional staff required additional funding. The limitation of choices because of inadequate staffing and the extra money it would cost for additional staff is consistent with other findings (Bigby et al. 2009:369) and, similar to Smith et al.'s (2005) and Rioux and Prince's (2002) research, these factors hindered residents' abilities to exercise autonomy and be self-determining.

Amanda felt that the residents where she worked receive good care but she also believed that residents needed more contact with people outside the facility:

> The level of care is there. I think what's missing is outside contact, the community contact. I mean, we have clients that go out, but this particular house can't be the end all and be all. There has to be more for everybody. One particular client would be very happy never leaving here you know, but I think the opportunity has to be provided. (Amanda)

Amanda saw volunteers as a possible solution:

> I think the need for volunteers is very high. Anymore cutbacks in staff or increases in clients would be very detrimental to the whole program, to each and every individual. Get someone to take a client and join a dance class, or join a hiking club, or curl. They have curling for the Special Olympics teams and they're very good, but why not try to integrate somebody into a regular curling team. (Amanda)

Amanda added, "But therein lays the problem because there are no extra bodies to help to provide that." Possible explanations for looking to volunteers to take residents on outings include funding cuts and the downsizing and offloading of programs (Neufeldt 2003) and the reduction of the welfare state (Mishra 1990, Rice and Prince 2001). There were also a limited number of activities targeted to individual residents which some residents preferred. The inability to focus on individualized activities reveals that the needs of the group tend to take precedence over individual choice-making in these types of settings, as Atkinson (1998) posited. Another consideration is that the severity of disabilities rendered some residents incapable of being self-determining about many activities, consistent with Bigby et al.'s (2009) findings. Nevertheless, the individuals with cognitive and/or other disabilities in this research appeared quite content and happy, and even more so in some cases than those with mental illnesses, despite the greater autonomy this latter group experienced.

CHAPTER TEN: CONCLUSION

In this research I analyzed life inside long term care facilities for people diagnosed with severe physical and/or cognitive disabilities, as well as those with significant mental illness. My analysis included the perspectives of, and interrelations among, residents living in these facilities, their families, frontline workers, operators of adult community residence agencies, executives of nursing homes, and civil servants from the Department of Social Development, GNB who administer long term care in New Brunswick. Among the important contributions of my research are the original conceptual models I provide that explain processes in the field of long-term care for people with severe disabilities and mental illnesses, as well as recommendations for policy change to improve the delivery of long-term care for people with severe disabilities and mental illnesses in New Brunswick.

While aspects of the theories of Foucault and Goffman were both pertinent to my data, there were some areas where Goffman's concepts no longer had relevance for my analysis of the care provided in long-term care facilities. I begin by pointing out how I found a Foucauldian perspective useful in framing my data analysis. His concept of bio-power (Foucault1978a, 1979, 1980) was helpful for understanding the assessment processes that residents underwent, where they were labeled, categorized, and effectively 'divided' off (Foucault 1982:777, 778) from other individuals. A number of residents internalized these identities (Foucault 1982:781), by the descriptors they used to self-identify, such as the participant with mental illnesses who talked of having a fried brain, and the three nursing home residents who referred to their diagnostic labels in self-identifying.

Assessment processes reflect a particular “regime of truth” (Foucault 1980a:131), or discourse that had been accepted with respect to what constituted normality. The ability of physicians to diagnose and for social workers to put residents into certain care level requirements, revealed the power imbalance (Foucault 1997) between these professionals and the individuals needing formal care supports. The relevance of Foucault’s bio-power (Foucault1978a, 1979, 1980) to this research was reinforced by the government’s ability to require parents to sign custody agreements to get out-of-home placements for their children, and the capacity of some to test clients for fit into facilities and occasionally, deny care. The power imbalance (Foucault 1997) between caregivers and residents were more obvious in situations where greater emphasis was paid to controlling residents’ conduct. Keys in long-term care facilities also constituted a technology of power (Foucault 1988). The philosophical values informing care provision and the various practices they legitimized, revealed the various cultures (Foucault 2001:173) that existed in these facilities.

The exercise of bio-power (Foucault1978a, 1979, 1980) was also made possible through official and non-official care philosophies because working on residents to integrate, normalize, develop, and make them more independent, in addition to keeping detailed records about them, determining their daily routines, and teaching them what was expected of them are part of the system of surveillance within what today, despite changes, remains an institution of control. Rules, punishments, and rewards were disciplinary techniques (Foucault 1977) used with residents that constituted subjective practices to teach these individuals adjust to facility expectations and, when done effectively, meant residents engaged in self-governance (Foucault 1977) and became docile (Foucault 1977), such as with Adam. Rules, regulations, and record keeping on residents were also forms of surveillance in Foucauldian terms. Moreover, as Foucault (1977) would argue, they are more insidious than the overt mechanisms of panoptic surveillance.

A Foucauldian analysis also facilitated the ability to conceptualize the potential for residents to exercise agency, despite their living situations. For instance, residents' engagement in aggressive and/or destructive behaviours can be interpreted as 'stratagem[s]' (Foucault 1997:292), or struggles to exercise some freedom as were the descriptors some residents used to self-identify which were unrelated to diagnoses or abnormality (Foucault 1980b). It is important to recognize, however, that residents' identities remain shaped by the life skills they were taught and the rules and regulations to which they were expected to comply, rendering their bodies docile and disciplining their identities to conform to the systems of control in the institutions. Foucault's (1965, 1988) liminal status was also pertinent to this research because of residents' general invisibility to people outside the facilities. The dismissal of Amanda's insights on residents is an instance of the silencing of certain voices (Foucault 1980b) and talk about the lack of government funding is a discourse of accepted 'truth' (Foucault 1980a:131).

Goffman's (1960) insights about total institutions were also relevant to this research in a number of ways. Observations about former care delivery in the larger institutions in Saint John and Restigouche aligned with Goffman's conception of total institutions (1961:17) in terms of the standard issuance of clothing, total lack of freedom for residents, living amidst a "large batch of others" (Goffman 1961:17) and being highly regulated. In addition, the 'encompassing' nature of these larger institutions were seen in the cage-like settings, concentration camp-like surroundings, lack of freedom for residents, and in how families were discouraged from visiting their loved ones (Goffman 1961:15). Goffman still has relevance in current long-term care practices as well. For instance, aspects of mortification (Goffman 1961:75) were revealed in requiring the transfer of legal custody of children from parents to the Department of Social Development and testing residents for fit, or level of compliance (Goffman 1961:26) with existing rules and expectations (SPARF 2009:6.1).

A "privilege system" Goffman's (1961:51,52)) was also seen in the tactics used to teach compliance with two residents and Goffman's (1961:269) notion of "secondary adjustments" helps in understanding Joseph's destructive actions. Adam's eventual internalization of facility expectations was consistent with Goffman's (1961:83) assertion that individuals eventually learn to manage themselves. In addition, front-line workers were still responsible to present facility expectations to residents (Goffman 1961:107) and to work on residents until they come around to facility expectations. The "deep initial break" initiated between two mothers and their children was a tactic constituting the "first curtailment of self" for residents during the in-patient phase, for barriers were established between these individuals and familial supports (Goffman 1961:24). In addition, while efforts were taken to address issues of dignity of the person and to give residents more autonomy by allowing them choices and to go on outings unescorted, these were opportunities for autonomy that had been already pre-determined by the facilities, and were thus still mechanisms for controlling residents. Residents did not have complete choice but were only able to choose from the range of options provided by the facilities.

Ongoing efforts to normalize, integrate, develop, and make residents more independent are collectively meant to have residents conform to social expectations of normalcy. This requires residents to engage in front stage activities in Goffman's (1956) sense of the term. The decision to reduce training standards for employees by the Department of Social Development (SPARF 2009) was typical of the type of struggles that arise between maintaining standards in the facilities and taking cost-effective approaches (Goffman 1961:76). Goffman's (1961:79) concept of an "involvement cycle" (Goffman 1961:79) was also relevant in Amanda's concerns about the resident with scoliosis. In addition, the descriptors surrounding abnormality that some residents used to self-identify was consistent with having spoiled identities (Goffman 1963:129).

Despite Goffman's (1961) relevance in a number of areas of this research, significant changes in formal care delivery makes some of his observations no longer applicable. The stripping away of residents' identity during the in-patient phase is one such area, for residents chose what they wore each day and brought their personal belongings to the facilities with them. There were also examples where residents self-identified in ways that had nothing to do with their diagnoses or current living situations. Other than the mandated 'break' for two mothers, long-term care facilities no longer have the "encompassing tendencies" (Goffman 1961:17) envisioned, for the facilities where I did fieldwork had comfortable and pleasing physical environments, and residents had personal bedrooms rather than being grouped together in a ward setting (Goffman 1961:17).

Another significant area where Goffman's insights do not apply is the nature of the relationships between most front-line workers and residents I observed, which did not always reflect the social distance and explicit demarcations between staff and residents he observed (Goffman 1961). Based on this research, as well as official records of former institutional care in New Brunswick prior to deinstitutionalization, residents are of long-term care are now valued to a far greater degree and treated far more humanely than they were in the larger institutions in the past, which refutes Drinkwater's (2005:232) assertion that deinstitutionalization has brought little change in the lives of the institutionalized.

Recommendations for Policy

Below, I make recommendations for policy change to address a number of problems reported in this research. These recommendations include ways for the Government to support families prior to out-of-home placements, to deal with insufficient placement options and staffing issues, to address unattainable care goals as mandated, and in their negotiations for federal funding. Additional recommendations are made for those operating long-term care facilities, and other organizations, to enhance the care experience for front-line workers and residents.

1. Increase government funding of extra-institutional support services for parents – To address the problems parents in this research reported that led to the decision to place their child in care, I recommend that respite services be made available and further strengthened prior to out-of-home placements. Doing so would alleviate some of these issues with caregiving and help to prevent, or at least delay, out-of-home placement. In addition, some parents in this research complained about the loss of school supports.

Therefore, I recommend that the Government develop and make available educational materials to families that compile information about local supports, programs, and organizations for children with disabilities, as well as how to deal with problem behaviours, which can be an issue for families whether they have a child with special needs or not. In addition, information about employment opportunities should be provided to all high school age students, with the contact information of organizations like the New Brunswick Association of Community Living, whose mandate is assisting persons with disabilities in finding jobs.

2. Increase government investment in placement options and staffing - Managers, social workers, and individuals from the Department of Social Development reported problems finding placements for individuals in need of formal care. Therefore, I recommend that Government invest in more placement options and long-term care facilities. In light of concerns raised by nursing home executives and young adults living in nursing homes, I also recommend alternative housing be developed for young nursing home residents. To address managers' difficulties in recruiting and retaining a skilled work force, and to address front-line workers' experiences with having their work undervalued, I recommend that Government mandate increased wages for front-line workers.

3. Adopt a philosophy of reverse integration - According to a number of managers and one parent who participated in this research, integration is not working as planned. Although efforts should still be taken to integrate residents as much as possible, I recommend reverse integration. In this approach, outsiders go into long-term care facilities and get to know residents on residents' terms, in their space, and at their pace, and the onus is on outsiders to adjust. In addition, as one participant noted, living in an adult community residence makes it impossible to live a normal life, so I recommend striving for uniqueness rather than normality. This constitutes a better philosophical starting point as it would allow recognizing and celebrating the uniqueness of each resident, and be a tactic consistent with existing legislated mandates about individualized care (SPARF 2009:5.3).

4. Take greater efforts to ensure residents' dignity – Participants reported frustration with male front-line workers assisting female residents with personal care. To address this issue, I recommend that government documents and in-house care philosophies be rewritten to allow residents and/or family members to choose the gender of care workers providing intimate personal care, such as bathing. To respond to the young nursing home residents' concerns about lack of dignity while being toileted, I recommend that it be mandated that bathroom doors in nursing homes be closed when staff members are toileting residents.

5. Take seriously front-line workers' insights on residents - The dismissal of a front-line workers' input during two specific encounters between residents and physicians leads to the recommendation that front-line workers' insights about residents be taken seriously. This would facilitate better physician-resident encounters, greater attention to residents' health needs, and work towards protecting residents from abusive situations.

6. Value relationships between front-line workers and residents - In this research, I observed warmer relationships between front-line workers and residents in facilities with less structured atmospheres. Therefore, I recommend that legislated and in-house care philosophies be rewritten to accord greater freedom to front-line workers to focus on their relationships with residents since relationships are important to resident's care experiences.

7. Increase opportunities for resident outings - Two factors hindering residents' opportunities for outings in this research were insufficient funding and staffing. To address this matter, I recommend that operators of adult community residences investigate cost-sharing arrangements between facilities and agencies to allow hiring an additional staff member, whose sole mandate would be taking residents on one-on-one outings. Alternatively, I recommend developing a band of volunteers to fill this role. This would require rigorous screening processes (police checks, interviews, and letters of recommendations), but aligns with government's mandate to make use of local community supports.

8. Develop appropriate activities for young nursing home residents - Young residents in nursing homes were frustrated that the activities in nursing homes were targeted to the senior residents. Therefore, I recommend that activity directors in nursing homes develop and incorporate age appropriate activities to accommodate the younger adults in these facilities.

9. Pay greater attention to the spiritual needs of residents – Some of the residents in adult community residences that took part in this research raised the topic of spiritual matters with me during fieldwork, and four others told me they were no longer involved in their church communities as they once were. Given that attending to residents' spiritual needs is part of official care standard expectations (SPARF (2009:2.4), I recommend that spiritual leaders and church congregations be educated on how to meet residents' spiritual needs and encouraged to visit long-term care facilities to engage with the particular residents' interested in spiritual matters. This would also benefit residents interested in re-engaging with their church communities.

Limitations of the Study and Suggestions for Future Research

Although mine was an extensive study of institutional care for people diagnosed with severe disabilities and mental illnesses, no single study can provide a complete representation of institutional care in New Brunswick with respect to care provision in adult community residences. For example, I was unable to gain access to for-profit adult community residences to conduct research because unlike non-profit adult community residence agencies, for-profit adult community residences are not listed on the Department of Social Development's website nor are they listed under charitable organizations, and privacy rights prevented me from discovering private citizens operating adult community residences. A contact from the Department of Social Development said they would inquire if any private for-profit operators were interested in participating in the research, but I received no responses. Finally, on contacting operators of several community residences listed on google search sites as private for-profit, I was told these were non-profit operations, which contradicted google information. Thus, I was unable to compare and contrast care provided in the non-profit sector with that of the for-profit sector as I had hoped. For that reason, comparative research is needed between care provisions in the private-for-profit and non-profit care sectors.

A further issue was failing to ask parents about their experiences with the assessment process involved in attaining out-of-home placements for their children, which meant this important area was left unexplored. However, Charmaz (2002) contends that certain topics left out of participants' narratives may point to experiences too difficult to put into words. I, along with my husband, know first-hand the terrible pain of having to convince a social worker you can no longer provide the level of care your son requires, for it transgresses what it means to be a parent. While this matter requires investigation, as discovering parents' and residents' experiences with the assessment process would be instructive for determining best approaches and better outcomes for everyone, the painful nature of these decisions may account for why parents did not bring this issue up during interviews. In addition, the varied individuals involved in conducting assessments, as well as situational factors such as economics make assessments arbitrary and more difficult to address, so more research from the perspectives of assessors, family members, and those being assessed, is necessary to adequately respond to this matter.

Another problem was that I had to rely on front-line workers in determining which residents were willing to be interviewed. Although this was a condition of access, it meant being limited in the number of residents to interview, and raised the issue of whether certain residents were chosen because of their compliant nature with front-line workers. Nevertheless, by spending considerable time in the facilities, it was possible to ascertain data from conversations with, and observations of, residents. A further potential limitation of this research was in allowing operators of agencies to determine the particular facilities in which to conduct research, rather than me personally making the selections. I did so because I had no prior knowledge about these facilities. This raised the potential for bias, as they selected what they thought were the best facilities. I could have asked them to describe the available options and then made my choice. However, this would not have guaranteed that they would not have tried to steer me to certain facilities by giving favourable impressions of these facilities. In retrospect, an alternative method would have been to select facilities on the basis of the age of most residents or geographical location.

There are a number of areas requiring future research that are suggested by my findings. There is no research on the range of supports currently available to parents and children with disabilities in New Brunswick, their experiences in attempting to access these supports, as well as the supports they would like to have access to but which are currently unavailable. A second important area of inquiry would involve investigating whether it would make better economic sense for the Government to provide financial support to parents to care for their own children at home rather than fund their care in long-term care facilities, as Francois' queried. Therefore, it would make sense to examine how paying parents to care for their adult children with disabilities is working in New Zealand, Sweden, and the Netherlands to see whether these models would be effective in the New Brunswick context.

Research is also needed into the various tactics that some parents have discovered and adopted which they find helpful in coping with caregiving demands. Another interesting area of investigation would be compiling rates of denial or delays of services in the province, the reasons behind these complications to services, and how - or if - the severity of individual's disabilities and/or mental illnesses are implicated. An in-depth examination of why persons with mental illness in this research typically self-identify as abnormal, unlike persons with cognitive disabilities, would also be insightful. Future research is also needed on integration, but not as typically carried out, which tends to measure the different ways, and how well, residents are involved in their communities. I am more interested in residents' perspectives about past experiences in the school system, the people they now engage with outside the facilities, whether these are the individuals they prefer to spend time with, and the types of activities they would engage in if given the choice.

Future research would do well to examine the way rules and procedures within long-term care facilities are gendered and whether gender affects management styles in long-term care facilities. More in-depth information is needed on how bureaucracy, communication problems, and the dismissal of first-hand knowledge of front-line workers are implicated in meeting the health needs of individuals in long-term care. Finally, future research is needed on successful advocacy efforts in New Brunswick, as well as on the development of effective volunteer bases which have already been established throughout the province. Such information will be essential for those interested in supporting long-term care services in these ways. Irrespective of the research foci pursued residents of long-term care facilities must be able to tell their stories as part of any future research in this area.

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APPENDIX I

General Interview Consent Form

Research Project Title: “A Study of the Institutionalized System of Long-Term Care for People with Disabilities in the Province of New Brunswick”

Researcher: Barbara Morrisey: PhD Student, Department of Sociology: University of New Brunswick.

I understand that Barbara Morrisey will answer any questions that I have concerning this study and that she can be contacted by phone at 506 734 3083 or email at u2nmz@unb.ca. I may contact Dr. Jacqueline Low if I have questions or concerns about this research. I am aware that while not directly involved in this study, Dr. Low is Associate Professor with the Department of Sociology at the University of New Brunswick and is the Supervisor of this doctoral research project. She may be contacted at 506 458 7439 or e-mail jlow@unb.ca. I also understand that I may contact Bernd Kurtz, Chair of the Research Ethics Board at the University of New Brunswick by email at ethics@unb.ca.

I agree to participate in a face-to-face interview with Barbara Morrisey. I understand that this interview will last approximately one hour and will be arranged to take place at a time and location that is mutually agreed upon by Ms. Morrisey and myself. I also agree to allow her to take notes during this interview and for it to be audio-taped, and for any interview materials to be retained by Barbara Morrisey for scholarly purposes only, such as writing papers for presentation at scholarly or professional meetings and publication in scholarly or professional journals, as well as the partial requirement for a Doctor of Philosophy Degree in Sociology. I have been informed that a summary of the research findings will be sent to me for my feedback prior to completion of the final report. I have been assured that all information will treated with the utmost confidence, that all tapes and transcripts will be stored a locked file cabinet in the locked office of her supervisor, Dr. Jacqueline Low (Room 132, Carleton Hall, UNB), that only Barbara Morrisey and Dr. Low will have access to interview materials, that all identifying information will be removed from the interview transcripts, and that all interview materials will be used for research purposes such as those described above. I understand that I may refrain from answering any questions asked in the interview and may withdraw from the study at any time prior to the completion of the final research report. I have been assured that, should I withdraw from the study, any pertaining interview material will be destroyed.

I have read the consent form and agree to participate in an interview as described above.

Name ____

Signature ________________________________Date______________________

APPENDIX II

Participant Observation Consent Form for Administrators

Research Project Title: "A Study of the Institutionalized System of Long-Term Care for People with Disabilities in the Province of New Brunswick"

Researcher: Barbara Morrisey: PhD Student, Department of Sociology: University of New Brunswick.

I understand that Barbara Morrisey will answer any questions that I have concerning this study and that she can be contacted by phone at 506 734 3083 or email at u2nmz@unb.ca. I may contact Dr. Jacqueline Low if I have questions or concerns about this research. I am aware that, while not directly involved in this study, Dr. Low is Associate Professor with the Department of Sociology at the University of New Brunswick and is the supervisor of this doctoral research project. She may be contacted by phone at 506 458 7439 or email at jlow@unb.ca. I also understand that I may contact Dr. Bernd Kurtz, Chair of the Research Ethics Board at the University of New Brunswick by email at ethics@unb.ca if you have questions about the research.

I agree to allow Barbara Morrisey to spend approximately one week at my facility conducting participant observation. As such, I agree to allow her to take notes, and ask questions from time to time. I understand that Ms. Morrisey will do this in the least intrusive way possible. I also agree that field notes from this participant observation will be retained by Barbara Morrisey for scholarly purposes only, such as writing papers for presentation at scholarly and professional meetings and publication in scholarly or professional journals, as well as partial fulfillment of the requirements for a Doctor of

Philosophy Degree in Sociology. I have been informed that a summary of the research findings will be sent to me for my feedback prior to the completion of the final report. I have also been assured that all information that I provide will be treated with utmost confidence, that all research materials will be stored in a locked file cabinet in the locked office of her supervisor, Dr. Jacqueline Low (Room 132, Carleton Hall, UNB), that only Barbara Morrisey and Dr. Low will have access to these materials, and that all of the materials will be used for research purposes only such as those described above. I understand that persons at this facility may refrain from answering any questions and that I may cease to allow Ms. Morrisey access to my facility at any time prior to the completion of the final research report. I have been assured that should I do so, any materials pertaining to this facility will be destroyed.

I have read the consent form and agree to grant Ms. Morrisey access to my facility for the purposes of participant observation.

Name ____

Signature____Date________________________

APPENDIX III

Assent Form

Hi. My name is Barbara Morrisey.

I am talking to some people who live in group homes and special care homes in New Brunswick.

I was wondering if you would be interested in talking to me too.

I will only be asking you a few questions, but I want you to know before we start that you can talk about anything that you want to.

Do you think you would like to do that?

I also want you to know that you can stop at any time and that ____________________ will be with you at all times.

Name of Individual ____

Signature of Witness that ________________________ assent was given.

Date __________________

CURRICULUM VITAE

Education:
Graduate of Caledonia Regional High School: 1974.

Graduate of Crandall University: Bachelor of Arts in Sociology - Honours with Distinction, 2004.

Master of Arts Degree: Department of Sociology: University of New Brunswick, 2007.

Lecturer:
Crandall University: SOCI3013 Sociological Theory I - Fall 2003.

Crandall University: SOCI3023 Sociological Theory II - Winter 2004.

University of New Brunswick: SOCI3371 Institution of Health Care, Winter 2009.

Publications
Ethics and Research Among Persons with Disabilities in Long-Term Care. *Qualitative Health Research*, 22: 1284-1297. This article was cited as an article of interest in the Yale Friday Newsletter –02–22-13.

A Study in the Delivery of Long-Term Care for Adults with Disabilities in Southern New Brunswick. A Thesis submitted in Partial Fulfillment of the Requirements for a Master of Arts Degree, 2007. Fredericton, N.B.: University of New Brunswick.

The Valuation of the Vulnerable and Implications in Policies and Practices. A Thesis submitted in Partial Fulfillment of the Requirements for a Bachelor of Arts (Honors) Degree, 2004. Moncton, N.B.: Crandall University.

Paper presentations:
The Experiences of Adults with Severe Disabilities and Mental Illnesses Living in Community Residences in New Brunswick. Canadian Disabilities Studies Association, 2011 Congress of the Humanities and Social Sciences. University of New Brunswick and St. Thomas University, June 2011; and at an omnibus session at the Congress of the Humanities and Social Sciences. University of New Brunswick and St. Thomas University, May 2011.

Ethics and Research Among People with Disabilities in Long-Term Care. 28th Annual Qualitative Conference. Wilfred Laurier University, May 2011.

The Impact of Administrative Structures in Long-Term Care Agencies. Qualitative Conference. University of New Brunswick, May 2008.

Long-Term Care for Adults with Disabilities in Southern New Brunswick. Qualitative Conference. Saint Thomas University, May 2007.

The Issue of Justice for People with Disabilities in Long-Term Care in Canada. Graduate Student Conference. University of New Brunswick, February 2007.

Participation at Professional Meetings:

Worked at registration desk at Qualitative Conference, Saint Thomas University, May 2007.

Worked at registration desk at Qualitative Conference, University of New Brunswick, 2008.

Session Chair of *Omnibus: Sociological Research and Health Policy*, Congress of the Humanities and Social Sciences, University of New Brunswick, 2011.

Associations:

New Brunswick Social Policy Network