LIVING IN XTC:
AN AUTOETHNOGRAPHY AND INSTITUTIONAL ETHNOGRAPHY OF MY EXPERIENCE RESIDING IN A GOVERNMENT FUNDED LONG-TERM CARE INSTITUTION

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Scott Jeffrey Fellner, candidate for the degree of Master of Arts in Sociology, has presented a thesis titled, ***Living in XTC: An Autoethnography and Institutional Ethnography of My Experience Residing in a Government Funded Long-Term Care Institution,*** in an oral examination held on July 4, 2018. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

This thesis is an autoethnography and institutional ethnography of my experience as a disabled young adult within a publicly funded long-term health care facility. By way of explication and analysis of a number of factors, including my personal experience, health region and long-term health care facility formal policies, practices, reviews, reports and nurse charting, I investigate and illuminate a relatively obscure unjust societal phenomenon: disabled young adults living in an old folks' home. My research examines how the ruling power relations in a government funded health region and a long-term health care facility, organized through a bureaucracy, form a total institution for young adult residents. Bringing together autoethnography and institutional ethnography creates a unique social scientific methodological tandem that suits my set of circumstances and goal of changing the research context for the better. Both methods were developed to investigate societal problems as socially just acts.

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Dedication

For Wilfred Fellner

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Key Words and Abbreviations/Acronyms:

1. Long-term Care (LTC)
2. XTC – The pseudonym I gave to the long-term health care institution that was the research context for this thesis.
3. IE – Institutional Ethnography (IE)
4. AE – Auto-Ethnography (AE)
5. Total Institution

INTRODUCTION: Total Institutions, Long-Term Care Facilities & Disabled Young Adults

"Old man take a look at my life. I am a lot like you." - (Neil Young)

"Someone once said, 'Hell is the impossibility of reason.'" - (Oliver Stone)

I grew up on the edge of the southwest end of Regina, Saskatchewan. About a mile north of my family home is a lone high-rise building. It stands amongst a stretch of residential houses, baseball diamonds and open prairie. Throughout my childhood, my parents and I must have driven past the building a thousand times. I recall asking, "Does anyone live in there?" One of my parents replied, "That is where old people live. It is called an 'old folks' home.'" Being enamored with skyscrapers and tall buildings at the time, I probably thought to myself, "Awesome! I can't wait to get old!" It is ironic that I did not have to wait very long before I acquired first-hand knowledge of what it is like to live in an old folks' home or a long-term care institution, as they are formally called. As a young adult I lived in one for nine years. It was not awesome.

Most people experience health care as inevitable, short detours in one' s life. The concept of long-term health care for young adults is confounding, even antithetical to the idea of life itself. We tend to think of people who need long-term care as aged, not young. Yet, living in a nursing home or long-term care facility is a dismal reality for many young adults. The power dynamics in long-term care institutions, organized through a government bureaucracy, creates "total institutions" for young adult residents that are incapable of handling their complex needs.

Sociologist Erving Goffman (1961) adopted the term "total institution" to describe the bureaucratic administration and control of people residing in such facilities.[1] Goffman's primary research for his book on total institutions, called *Asylums* (1961), took place within a mental institution. Think of the movie "One Flew Over The Cuckoo's Nest" (1975) as a visual analogy to that research setting. Both Goffman's book and the film depict residents being subjected to a formally administered round of life, care and authoritative control that robs the patients of their individuality, dignity, joy, spontaneity – their humanity. Indeed, I have often thought that both *Asylums* (1961) and "One Flew Over The Cuckoo's Nest" (1975) produced very similar feelings of anger, outrage, loss and indignation. I would even go so far as to say that a fair amount of Goffman's academic work makes a moral argument for humanity through emotions.[2] Goffman does not explicitly argue for the abolishment of total institutions, instead, he allows his descriptions of their conditions and social processes to morally speak for themselves.

In other words, while the film utilizes typical antagonist and protagonist character development to elicit the visceral responses of audiences, *Asylums* (1961) provides detailed description of the processes by which patients/residents have their identities assaulted.[3] The purpose of the assaults is to degrade and change a patient/inmate/resident's ego in an

[1] In addition to nursing homes, mental asylums, P.O.W. camps, legal penitentiaries, convents and monasteries and even boarding schools have characteristics that qualify them as total institutions.

[2] In particular, *Asylums* (1961) and *Stigma* (1963).

[3] Goffman also uses the words "attacked," "defiled," "debased" and "profaned" interchangeably to describe the nature of the mortification processes.

effort to make them controllable and submissive. Goffman (1961) calls these processes "mortifications of the self." They can occur in several different manners including:

- Property Dispossession - Being dispossessed of property when one is admitted into a total institution like a LTC facility can be identity altering. Most people invest time, money and emotional energy into the items they own. Property also can be associated with lifestyle and social status. So, if one has to forfeit their homes, automobiles et cetera, and move into a tiny room of a LTC facility, emotional trauma is probably to be expected.
- Role Dispossession - In the everyday able-bodied world, we tend to navigate life often seamlessly fulfilling numerous and disparate roles: friend, husband, mother, policewoman, adulterer, and so on. If an accident occurs that necessitate living in a LTC facility, for instance, it is reasonable to assume that some roles may be incapable of being fulfilled, while others may have to be modified.
- Identity kit Dispossession – This can be equated with not having easy access to the things one needs to superficially cloak oneself with in order to present an ideal image of oneself to others. The most obvious examples of this include make-up and shaving kits, hair styling products, jewelry and clothing.
- Contaminative Exposure - Is analogous to experiencing privacy violations. This type of mortification, arguably, is the most direct and temporally powerful in the scheme of identity altering social processes.

It should come as no surprise that when you add up the identity assaults one may be subject to within a total institution, an identity crisis and a corresponding emotional and psychological tsunami may ensue.

The salient question to gather from Goffman's analysis of total institutions is whether institutions need to be walled, fenced or otherwise formally prison-like for them to be dehumanizing and soulless. In other words, the concrete physical structures of most total institutions may be "demolished and are of a bygone era, but we may wish to reflect upon the degree to which the social processes of total institutions also lie in ruins, to be replaced by respect, dignity, autonomy and beneficence" (Goodman 2015:1).

For Goffman, the real architecture of total institutions are "mortifications of the self." But where do such social processes come from? To some extent they originate from the formal policies of total institutions. Policies serve as directives for staff – patient interaction and form the basis of social processes in institutions. What I mean by "social processes" within a total institution, or more specifically within LTC institutions, is social interaction between residents and nursing staff where bureaucratic care policies, such as residents' regimentation of daily life, become recurring patterns. Through such social interaction residents become socialized, assimilated and socially controlled.

Additionally, social processes are both produced and are reproduced by staff, patients and their interactions based on their values, culture and taken for granted assumptions. Arguably, this is why it is difficult to change the way present day long-term care institutions, socialize their staff and their interactions with patients/residents. Take

the Saskatchewan government's fairly recent Patient First Review (2009) in health care as an example. Increasing patient happiness with their experience and overall efficiency within the health care system were the main objectives of the review. I resided in a LTC institution at the time the aforementioned review was undertaken. On several

occasions, the manager of the nursing unit in which I resided stated to me that she would have to hire all new nursing staff in order to make desired changes of the review bond. The point is, veteran nursing staff influence and socialize newer staff with taken-for-granted institutional social processes – the way things have been and are – thereby thwarting progressive policy direction (Farber 2006; Foner 1993; Hughes 1988). Of course, social processes in health care institutions often coincide with existing power relations between nursing staff, patients, and management. Progressive policy direction often entails redefining and reshaping those existing power relationships. It is easy to see how the social processes of total institutions can transcend the archives of history and insidiously integrate into modern day health care facilities.

Mortifications of the self primarily emerge from the bureaucratic control of the organization of care and life in total institutions, rather than malice or intent of the staff.[4] In LTC facilities, role, property and identity kit dispossession are just not something that can be easily mitigated by nursing staff. For example, a newly disabled adult typically abdicates their career and ownership of their home when they move into a long-term care facility. Likewise, the roles one is accustomed to fulfilling are subject to a sea change. Role changes and/or dispossession undoubtedly cause emotional turmoil for new LTC residents, but nursing staff can only do so much to ease this transition. Some aspects of identity kit dispossession are also not in the control of frontline staff. For example, as a young adult living in LTC, I found the bathing limitations of only being allowed one shower or bath per week mortifying from an identity kit standpoint. For most young adults, showering

[4] Please see chapter two for examples of bureaucratic organization of life in LTC.

everyday is a central part of one's identity. For me, it is an integral part of feeling alive. Management's bureaucratic control of unit staffing levels, bathing rules and routines accounts for most mortifications of the self linked to bathing.

Not all mortification experienced by residents result from the contingencies of simply being physically disabled, or the bureaucratic control of everyday life on a LTC nursing unit. Some of the most mortifying experiences a young adult living in a LTC institution can have comes in the form of privacy violations. This is where the staff have a large measure of power and control over residents. There is good reason why resident room doors are left open by staff at almost all times. Institutional architecture and/or the social practices of frontline staff define possibilities for interaction or privacy. Doors are a human event of significance equal to the discovery of fire (McGinley 1959:55-56 cited in Schwartz 1968:746). If a resident's door were closed, as mine usually was, staff would regularly open the door and walk in with little or no notification as if it were their domain and right to do so.[5] Basic privacy, or "backstage," where one can easily express distance from interpersonal interactions and daily events in order to recharge their energies is an essential human need. Not being able or allowed to express distance from staff, other residents and people, in general, can make an individual tired, docile and pliable. This is perhaps the main hallmark of total institutions of the past, and I believe one of their surviving malevolent social processes found in contemporary LTC facilities.

[5] Even with large and bright "do not disturb" signs taped onto my door, staff would regularly walk into my room with little or no notification.

Not only are privacy violations symbolic of the unequal power relations between residents and care providers, but they also reflect the degree to which such inequality is taken for granted and accepted. The lack of privacy in LTC facilities, or privacy violations by staff out of malice or institutional practice, is tantamount to treating residents as objects instead of human beings who deserve the dignity and respect of privacy. If this is as evident as I claim, perhaps other kinds of abuse should not come as a surprise.

Recently in Saskatchewan, some ninety public allegations of abuse and neglect in long-term care facilities have been made, and several provincial ombudsmen investigations into the state of Saskatchewan's LTC facilities resulted from those complaints (Healy 2015). Who is at fault - if anyone? According to the provincial ombudsman, Donna McFaddyen, most of the complaints point to a strain on our health care system (Healy 2015). Sure, health care funding and staffing levels could be improved, but aren't they easy scapegoats?

Perhaps the ruling power dynamics within government funded health regions and long-term care facilities, mediated through policy and practice, shape social relations between health region and long-term care facility management, nursing staff and residents in a manner that the experience of residents is controlled, subordinated and silenced. By combining the qualitative social scientific methodologies of autoethnography and institutional ethnography within a long-term care context, I explicate how this can happen to young adult residents and provide some policy prescriptions needed for positive and progressive change. My strategy for this methodological approach entails drawing upon and analyzing:

1) Personal accounts and illustrations from my experience living in a long-term care facility as a young adult.

2) Documented correspondence between health region and LTC facility management and me

3) Health region and facility policies, practices, reports, reviews and LTC facility nurse charting.

4) A formal program proposal for young adult residents my friend and I drafted and presented to health region and facility management.

How will the forthcoming chapters unfold? I begin chapter one by narrating how I ended up in LTC, the struggles I initially faced, and the difficulties I encountered trying to formally gain traditional qualitative research access to the LTC facility I resided in. I then explain and illustrate, with heuristic examples, the qualitative methodologies of autoethnography and institutional ethnography.

Chapter two examines how the LTC institution I resided in, organized through a government bureaucracy, is stifling and change resistant and is, therefore, incapable of handling the needs of young adult residents. I also explore the broader issue of whether LTC bureaucracies are inextricably tied to paternalism and are, thus, inherent albatrosses for young adult residents.

In Chapter three I thoroughly discuss Erving Goffman's (1961) aforementioned theory of total institutions and elaborate how it applies to LTC facilities. Specifically, I devote much of the chapter to focus on how his concepts of "mortification," "looping", and "adaptation strategies" apply to the LTC facility I lived in.

The fourth and final chapter of this thesis is focused on four main themes. First, I discuss what led to my decision to move out of XTC. Second, I consider the relevancy of Goffman's (1961) work on total institutions when applied to long-term care facilities, the importance of Dorothy Smith's (1987; 2005) work on institutional ethnography, and what autoethnography brings to the methodological table. Third, I present a number of policy recommendations tailored to improve long-term care facilities for young adult residents. Finally, I discuss how this thesis may contribute to an understanding of total institutions.

CHAPTER 1: Health Care Narrative And Thesis Methodology

1.1 Road to XTC

It was early 2003 when my life took a radical turn. I was an active musician, playing electric guitar in two bands. I had also just finished the research process and was beginning to write my Master of Arts thesis in Sociology. I planned on defending my thesis in early September and then applying to some doctorate programs in Sociology. Although I have nothing but good things to say about the musician and graduate student lifestyle, at age twenty-eight I had spent years playing in one band or another while working and going to school part-time, and I was ready for a change. I was eager for a new life experience and challenge, but I did not know what was lurking just around the corner.

On February 25th, 2003, I started to develop a very stiff neck and headache. That night I spoke on the phone with my friend, Nathan, and joked that it was nice knowing him, but that I thought I was dying of meningitis. The next day I had a fever as well as a stiff neck and headache. I briefly spoke with my mother that morning and she encouraged me to see a doctor. I went to a medical clinic to get checked out, but they sent me home thinking I had the flu. The next two days the symptoms grew worse. On Friday, February 28, I awoke with a fever, stiff neck and headache, and I was also seeing double. I called my dad and asked that he come to my apartment and take me to a hospital emergency.

On Monday, March 2nd, 2003, after two days spent waiting in an emergency hospital bed, I was finally moved to the neuroscience unit. I stayed there for a day until paralysis quickly descended upon my feet and then rapidly moved up my body until it reached my

lungs. At that point, they had to ventilate me and move me to intensive care. For the next three weeks I was in a morphine-induced coma. During that time, my neurologist made of diagnosis of Guillain-Barré syndrome and initiated a treatment plan. However, a week and a half passed without any expected sign of recovery. Anxious and worried, my parents insisted upon obtaining a second opinion from a different neurologist. What resulted was a diagnosis of Acute Disseminated Encephalomyelitis (ADEM), and a new treatment regiment that slowly began to work.

I awoke from my coma unable to move or speak. I had feeling everywhere, but I was completely paralyzed. With feeling came pain, particularly in my hips, legs and feet. I remember waking up repeatedly in the night because my hips were in excruciating pain. During this time I couldn't communicate at all. But if I could have spoke I would have yelled, "Bring me some fuckin' morphine!" It wasn't long before I was able to move my eyelids. This enabled me to communicate my basic needs by blinking once for "yes" and twice for "no." Over the course of the next two months, I regained movement throughout my entire body and was able to breathe on my own.

I was transferred to a rehabilitation centre on June 29, 2003. My routine in rehabilitation consisted of going to my therapies and then to sleep in an effort to escape the condition and situation I was in. I was deeply depressed that my body for the most part still betrayed me. I couldn't stand to look in the mirror and see how emaciated and pale my body was. However, the nurses would insist that I get washed up for the night with a cloth at a sink in the corner of a shared room that offered very little privacy. It was as if the nursing staff was telling me, "this is your body now, and you better get use to it!" I was

mortified. But I still had hope things would turn around for the better while I was still in rehabilitation.

What was by far the most depressing aspect of my condition was being unable to communicate effectively. Speaking was a demoralizing challenge. My communication problems caused many disputes with the nursing staff, and it also caused me great periods of loneliness and depression. I think the only reason I didn't kill myself at that early point at the rehabilitation facility was because of my parent's tremendous support, and because of the sense of humor and friendship with one of the night shift nurses.

Through lifting weights five days a week in exercise therapy, I managed to regain some of the muscle mass I had lost during my three months in acute care. After four months in a therapeutic routine, the physiatrist and his team of therapists started talking about moving me into long-term care, making me feel anxious and panicked. All I could think about was how my personal accomplishments, and the person I was had been stolen. Now I was about to be shoved into a lonely home where broken and forgotten people live out their remaining days.

In what seemed like a matter of days, but was actually months, I was informed that I would be moved into one of the long-term care units in the rehabilitation centre. Both my parents and I felt that, in contrast to acute care and rehabilitative environments where there was an air of hope, the long-term care units were forlorn places. The presence of several residents slumped over their wheel chairs while sitting directly in front of the nursing station is what greeted us as we made our way down a hall to my new home.

What confronted me in long-term care was a truly alien environment that challenged my sociological perspectives, and my desire to live, like it had never been before. Please consider the following thought experiment.

Thought Experiment

Imagine you are 28 years old and you come down with what appears to be flu, but turns out to be a rare neurological disease that initially steals your ability to walk, talk, eat, drink, see clearly, move your arms with precision, and use your hands and fingers with dexterity.

In rehab, a physiatrist and his team of therapists tell you that you are progressing too slowly and will be moved into long-term care. Once in long-term care (LTC), the nursing staff assumes ownership over your body, telling you when to eat, shit, shave and shower/bath (once a week). Not being able to speak clearly, you experience a great amount of conflict with the nursing staff. To make matters worse, staff gossip about said conflict effectively labeling you "difficult," or emotionally unstable.

In long-term care, you receive the same amount of therapy that a seventy-year-old person receives. They explain, "Everyone is equal, but is unique." I've heard this statement several times from various LTC managers. Funny how unique residents do not automatically receive unique amounts of therapy tailored to meet unique needs!

No speech therapy is offered in LTC; communication problems are ubiquitous, resulting in feeling so lonely that any human contact causes anxiety attacks. Friends begin

to drop off the face of the earth; they feel uncomfortable, helpless, or scared of being leaned upon too much.

All of these events occur in little over a year, leaving you more depressed than you thought was humanly possible.

Now assume you are of the belief that it is only through therapies that you have any chance at all of improving your physical condition and quality of life. What would you do if this were reality staring you down? What would you do if the LTC nursing units, at best, served to maintain your condition, reinforced one age fits all formal and informal policies and practices, and encouraged dependence versus rehabilitation. What would you do if facility and health region management denied every request for more therapy? What would you do if the LTC institution tried to subject you to an unusual and unwanted regimented pattern of life?[6] What would you do if the LTC facility did not recognize your need for respect, privacy and personal dignities, such as bathing or showering?

I don't know what other people would do, but I felt I was faced with a "fight or flight" dilemma. Either I would fight management at the rehab/long-term care facility for an adequate amount of appropriate therapy or I would withdraw completely from this horrible nightmare. I was ready just to give up even at this early stage of my existence in LTC. However, my dad incessantly called me a quitter until I gave in and began advocating for more showers per week and an increased amount of therapy sessions.

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[6] Please see chapter three for clarification and discussion of this point.

1.2 Thesis Topic

Regarding my academic pursuits, I did not know how to begin, but I decided to change my masters thesis topic in Sociology from that of Critical theory and popular music to disabled young adults living in an antiquated government system of LTC. I thought that combining my understanding of critical theory with my experience residing in long-term care would allow me to make sense of the alien reality confronting me. Up to that point, my experience in LTC was brimming with intolerable indignation. Although I knew that harsh criticism could lead to pessimism and apathy, I developed the following research hypothesis: The ruling power relations in government-funded health regions and long-term health care facilities, organized through a bureaucracy, create total institutions for young adult residents that control, subordinate, and silence their experience.

1.3 Methodology

In order to make my thesis valid, reliable and generalizable, I had to choose social scientific methodologies that fit my topic and my unique set of circumstances. Initially, I was intent on conducting a series of open-ended interviews with disabled young adults who lived in the same LTC facility as I did as my primary data source. However, the health regions research ethics board (REB) reviewed and rejected my research proposal on the grounds that I did not sufficiently identify how I would recruit research participants. What's more, they stated in their research ethics application review email that, as a student, the only way I would be allowed to go forward with open-ended interviews was if one my thesis supervisors would become the lead investigator of my project and an affiliated researcher of the health region. My thesis supervisors did not want to entertain

that option. Instead, they wanted me to choose a qualitative research methodology centered on my own experiences and circumstances. Such a choice would not require research participants or the health region's research ethics approval to go ahead with my thesis project.

My academic advisors suggested two methodologies: autoethnography and institutional ethnography. I chose to combine both methods. Autoethnography has been described as a qualitative method that connects the "self" to the "social" (Reed-Danathay 1997), or seeks to understand and analyze personal experience in order to understand cultural or institutional experience (Ellis, Adams, & Bochner 2011:sect. 1). The emphasis in autoethnography is on writing the researcher's personal experience within a social organization or institution in a creative, evocative and emotional manner (Ellis & Bochner 2000, 2002; Wall, 2006). However, there has not been as much impetus placed upon the analysis of the researcher's experience and the possible need to incorporate other research methodologies in order to understand how that experience is shaped. Most importantly, there is not a clear description in the autoethnographic literature of how such analyses methodologically materialize. How then are reliability, validity, and generalizability determined in autoethnography?

Strictly defined, in autoethnographic studies reliability comes down to the believability or credibility of the narrator. "Could the narrator have had the experiences described, given available 'factual evidence'? Does the narrator believe that this is actually happened to her or him" (Bochner 2002:86 cited in Ellis et al., 2011:sect. 4.4)? If the credibility of the narrator is, more or less, synonymous with reliability in autoethnography,

how is validity determined?

As Nicholas Holt (2003) has demonstrated in his study regarding the struggle to have his autoethnography about the pedagogy of teaching at the university level published, there is by no means a clear consensus on what should constitute validity in autoethnographic research. To simplify, the reviewers of his submitted article for a journal publication predominantly employed a realist qualitative validity research criteria (e.g., a reviewer wanted extracts from his research diary) when judging his autoethnographic study (Holt, 2003:14). As to why the reviewers did not judge his study on the merits set out by Caroline Ellis and Arthur Bochner (2000), two of the major proponents and experts of autoethnography, such as whether his study captured one's imagination, entertained one, and taught one something rich and new about the cultural context of the author, Holt could only assume that the reviewers of his study were unfamiliar with the entire autoethnographic genre of academic research (2003:14).

Autoethnographies are also judged in terms of whether they help or offer a way to improve the lives of readers or the author's own (Ellis 2004:124). "In particular, autoethnographers ask: 'How useful is the story?' 'To what uses might the story be put'" (Bochner 2002:34 cited in Ellis et al. 2011:sect. 4.4)? They also may be judged by their verisimilitude or resonance with the reader's knowledge and experience. Now, all of this may sound a little flaky. And critics of autoethnography have pointed out its lack of canonical social scientific methodological rigor (Andersen 2006; Atkinson 2006; Taber 2010). Taber (2010) argues that, " Autoethnography as a research methodology must do more than explore the self. There must be an argument and an empirical basis to research,

otherwise it is perhaps more aptly termed storytelling, which is an important contribution to understanding our world, but cannot be necessarily categorized as research" (p. 14). However, Ellis et al. (2011) dispel such criticism by quoting one of their interview respondents who clearly and astutely states that an autoethnographer should,

> look at experience analytically. Otherwise [you're] telling [your] story—and that's nice—but people do that on *Oprah* [a U.S.-based television program] every day. Why is your story more valid than anyone else's? What makes your story more valid is that you are a researcher. You have a set of theoretical and methodological tools and a research literature to use. That's your advantage. If you can't frame it around these tools and literature and just frame it as 'my story,' then why or how should I privilege your story over anyone else's I see 25 times a day on TV? (Personal interview, May 4, 2006)(Sect. 2)

By way of the above quote, Ellis et al. (2011) can be said to be emphatically making the claim that in order to do autoethnography you do not stop doing the things that make you an academic researcher!

Indeed, as social researchers, autoethnographers will analyze, theorize and develop arguments and make use of research literature and secondary sources. Autoethnographers may also utilize other research methodologies, such as content analysis of institutional texts, interviews with members of the social organization or institution they are a part of and are studying, and even sample surveys to make their autoethnographies more valid, thorough, convincing and interesting. Moreover, if a researcher's experiences are the subject of an autoethnography within a publicly funded institution, as mine are, the requirements for reliability and validity ought to be tough.[7] When this is the case, I think

[7] In general, the policies of public/government institutions are plentiful and available to the public.

the following question must be asked: Are one's experiences and analyses demonstrably traceable to formal and/or informal (e.g., formal policies, reviews and reports, and informal emails from management) institutional texts? Adhering to these standards will only strengthen and enrich an autoethnography.

The issue of generalizability in autoethnography is certainly not the same as that of traditional social science where it originates from and applies to large random sample surveys (Ellis et al. 2011:sect. 4.4). The goal there is to produce data that is accurate across a population of people. In autoethnography, generalizability is equated with whether your story and your analysis that stems from it speaks to another person or others they know of in a similar situation (Ellis 2004:194-195 cited in Pace 2012:3; Bochner and Ellis 2000). In this sense, what makes an autoethnography generalizable is also an important element of what makes it valid. For example, a young adult residing in a LTC facility somewhere in Ontario could identify with my personal account and analysis of navigating the bureaucratic hierarchy of a Saskatchewan LTC institution in an effort to advocate for others and myself.[8] You don't have to be a member of academia to judge the worth or merit of an autoethnography.

Further criteria for determining if an autoethnography is generalizable in a more traditional social scientific manner would be to gauge whether the characteristics of the context of a study are replicable across a geographic area. In reference to my thesis topic, the characteristics of the publically-funded LTC institution I lived in, such as the physical

[8] Please see chapter two for a detailed example and analysis of said advocacy.

structural lay-out of nursing units, the policies, incident and security reports, bureaucratic structure of power, hierarchal structure of nursing units and the day to day operations are, more than likely, consistent in all the government funded LTC facilities that fall under the same central authority of a particular health region. Therefore, it may be reasonable to generalize that all the government-funded LTC institutions throughout the same health region as XTC have characteristics that make them total institutions for young adult residents.

Ultimately, the goal of autoethnography is to not only produce well researched, analyzed and written texts, but also ones that are evocative and accessible to a wide-ranging audience, not just the university community. Autoethnographers are, arguably, more interested in affecting cultural change than their own career advancement through academic publishing.[9] "Autoethnographers view research and writing as socially just acts; . . . the goal is to produce analytical, accessible texts that change us and the world we live in for the better" (Holman Jones 2005:764 cited in Ellis et al. 2011: sect. 4.4).

Although autoethnography suits the investigation of my thesis problematic fairly well, especially with its focus on the self as a research subject, and an emphasis on changing the research context for the better, it simply does not explain any analytic processes it claims are integral to the method. This is where, at least for my methodological needs, institutional ethnography comes into play.

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[9] Perhaps more accurately, Holt (2003) honestly describes the tension he felt over the desire to share his teaching experiences and contribute to deeper learning about teaching and the university's requirement of publishing (pg. 7).

Developed by Dorothy Smith (1987, 1990, 2005), institutional ethnography is both a theoretical and methodological sociological approach that enables one to map and analyze the complex interconnections between everyday experience and institutional texts (e.g., polices), institutional workplace culture, and institutional relations of ruling shaping that experience. Institutional ethnography entails an analysis of ruling relations and ruling practices; those on the side that have power rule, while others challenge (Campbell 2003). Thus, institutional ethnography or IE falls into the power/conflict perspective within sociological theory.[10] IE is not politically innocuous or apathetic. In fact, IE has been referred to as research for activism (Campbell 2003).

Smith (1987, 2005) stresses institutional ethnographers must seek to explicate: 1) How the relations of ruling, that is, how the lives of people are regulated and governed by institutions and individuals vested with authority, and how such authority is manifested in and through institutional formal and informal texts and practices. Long-term care institutions provide many illustrations of how this happens. For example, XTC's antiquated Bill of Rights explicitly stipulates that they will provide a private space for intimate liaisons or residents who are "married couples." [11] This policy not only discriminates against residents who are not married but also formally desexualizes them.

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[10] Institutional ethnography is also an integral part of Smith's (1987) feminist theory. Originally called "a sociology for women," she has since changed it now calling IE "a sociology for people" (2005).

[11] Please see chapter four, section 4.3, for a discussion of this policy.

2) How power is not one-directional (e.g. top down) but is dialectical or relational. The lives of people may be governed or regulated by institutions and individuals vested with authority, but that doesn't mean that people are wholly submissive. Everybody has power or agency, though not in equal amounts. In LTC facilities, residents do not simply collude with nursing unit policies and practices by strictly following them everyday; they resist some of them as well. For instance, a resident may be a model of perfect nursing unit behavior during the day, but may also habitually stay out past evening curfew. Or a resident may conform to all the nursing unit policies, but may regularly participate in resident council meetings, where she voices her complaints with fiery indignation about privacy violations, age-inappropriate recreational therapy or disrespectful nursing staff, with the hope that they may resonate with other residents and eventually affect change. These are some general examples of how the relations of ruling work within LTC facilities.

3) How ruling concepts, held by rulers and ruled alike, are reinforced by institutional policies and practices. For example, take the widespread notion that disabled people are not sexual beings. This is reflected in the lack of sexuality/intimacy policies amongst Canadian LTC institutions.[12] I hope all disabled LTC residents have not internalized this notion and tried to repress their sexuality for this reason, let alone to make the work lives of nursing staff and management easier.

[12] Please see the unpublished results of the sexuality and intimacy survey my research assistant conducted in the chapter one appendix.

Texts

In IE, textual analysis plays a crucial role in understanding how an institution or social organization works. "Institutional ethnographers trace the ways in which texts stitch together smaller social groupings into larger institutional contexts, which in turn leads to even larger power structures" (Taber 2010:12). In publicly funded LTC institutions, formal health region texts, such as occurrence and security reports detailing events between nursing staff and residents, can become official institutional knowledge, however inaccurate and misleading it may be. It is certainly one-sided information as nursing staff perspectives are all that is included and all that matters in such reports. Resident perspectives must not be relevant, because there is no formal space or section on occurrence reports or nursing charts for resident representation of events. Not only is this textual knowledge epistemologically problematic, but it can also form a profile of residents for nursing and security staff affecting future staff – resident interactions. In this sense, texts have the power to form new relations of ruling for both individuals vested with authority and those without any.

In addition, you have to question whether the one-sided knowledge within nursing charts, occurrence reports and/or security reports is kept confidential and within one's "circle of care." On LTC nursing units a "circle of care" is a concept that is relative to each specific episode of resident care. In my experience as a LTC resident, this usually includes a designated care aid/provider, a licensed practical nurse and a registered nurse for every morning, afternoon, evening and night shift. A circle of care does not apply to all nursing

staff on a particular nursing unit at any given time.[13] However, nursing chart room communication is, generally, "open" and fodder for staff gossip that can easily breach resident confidentiality causing information to leak from a resident's circle of care to potentially the entire nursing unit, a large institutional context.[14] Moreover, security reports lead to health region security, an even larger power structure. All of these texts reinforce and may form new institutional relations of ruling/power dynamics. Please consider a personal experience as an example.

On the morning of March 26, 2010, a nurse came to my room to give me my scheduled medications. After I had taken them, she politely left, but not before she noticed what she thought might be drug paraphernalia, "a small wooden box with moveable part on top," under my bed.[15] She told the unit charge nurse and unit manager what she saw. The charge nurse went into my room and confiscated the supposed drug paraphernalia, charted her actions and what the original nurse saw, filled out an occurrence report and attachment with the original nurse, called health region security, and gave the confiscated item to a security member.[16] Security filled out a security report and called the city police to collect said item and to talk to me. The unit manager told one of my family members that nursing

[13] With the exception of the night shift (11PM – 7AM) where a care provider, a licensed practical nurse, and a charge nurse (who usually covers two nursing units) staffs an entire nursing unit.

[14] All the more so when the information is provocative.

[15] The occurrence report indicates "wooden box with moveable part on top" and the nurse charting indicates, "small flat wooden-type box & swirl lid."

[16] If the reader would like to examine a copy of the nurse charting, occurrence and security report they can contact me, or the Department of Sociology at the University of Regina.

staff had found and confiscated drug paraphernalia in my room and that city police had been called and were on their "way;" thus, frightening my family member and legally breaching my confidentiality. Although the city police never talked to me, I am curious as to what they would have said. Would they have given me a well-intentioned lecture on the legalities of possessing what may appear to be drug paraphernalia? Or would they have simply informed the health region security, unit nursing staff and unit manager that it is *not* legal to search for and/or seize item(s) from a LTC resident's room - or otherwise their residence - by security, nursing staff and even city police without a warrant? A warrant would certainly not be issued on the basis of a nurse who claims she spotted what appeared to be drug paraphernalia, while administering meds in a resident's room?[17]

From the above example we can clearly see how:

1) My experience connects to institutional texts (i.e., nurse charting, occurrence and security reports).

2) Said texts create the official knowledge or version of events and can lead to the spread of misleading malicious information from a small social grouping (i.e., my circle of care) to a larger institutional context (i.e., the nursing unit) to an even larger one (i.e., health region security), and beyond (i.e., city police).

3) Said texts are a vehicle through which the institution and health region's relations of ruling become manifested, affecting my experience and that of my family.

I felt indignation over how the above matter was handled. It felt as if I was being publicly shamed over something the institution had no business, legally or otherwise, being

[17] Evidently, I am not over this experience yet.

involved in. I also wondered whether I was being taught a lesson in dominant – submissive institutional power relations through what could be considered underhanded legal and textual bullying. Additionally, I became tremendously anxious as I thought I was being labeled as a suspicious troublemaker and rule-breaker by nursing staff and health region security. This is how modern day LTC institutional power dynamics can unfold (Foucault 1995).

Processes of Institutional Ethnography

The above description of LTC institutional textual processes, personal experience and the analysis of that experience and institutional texts are an example of what actually doing IE looks like with myself as the only research subject. A more methodical approach to understanding the key processes of institutional ethnography would be where the research follows a sequence:

A) Identify an experience. This could be any personal experience that speaks to living in a total institution. Regarding LTC institutions, this could mean a resident who is experiencing conflict with a staff member and yearns for resolution. Or, it could mean an experience where a resident's fundamental human right of "freedom of speech" has been undermined during meetings with management.

B) Identify some of the institutional processes that are shaping that experience.

Again, with regard to LTC institutions, "institutional processes" could mean a facility's investigative practices involving staff - resident incidents of conflict. It could also mean a LTC facility's staff - resident conflict resolution procedures or lack thereof.

C) Investigate those processes in order to demonstrate analytically how they operate as the grounds of the experience (DeVault and McCoy 2002:775 cited in Taber 2010:11).

Lets see how this research process actually works. Please consider one of the most important disability issues, in general, and discriminatory challenges I faced while residing in LTC. (It should be noted that the following is a formalized illustration of the IE research sequence. In chapters two, three and four the IE and AE descriptive and analytic processes are not formally written as it is below.)

A) EXPERIENCE: I had repeatedly brought up the issue regarding my speech/communication problems in face-to-face meetings with management of the LTC facility I resided. I felt quite disadvantaged and bullied when I advocated for others or myself in face-to-face meetings with management because I was not able to begin to express myself fully.

B) INSTITUTIONAL PROCESSES: My protests regarding this matter were in vain. Facility and health region management, and the client representative for the health region have all stated to me in emails and/or formal meetings that they strongly feel that, as a form of correspondence, writing, especially in emails where it is difficult to convey tone, pales in comparison to actual meetings. Furthermore, the institution refused to provide speech

therapy for me while I resided in LTC, or provide training for a communication device the facility had assisted me in acquiring.[18] What was I suppose to do?[19]

C) ANALYSIS: After years of trying to manage my speechlessness during ad hoc and formal meetings, I began to cite an official institutional text that makes my protests regarding my inability to communicate freely, defensible and valid. Please examine the, below, email exchange with the director of the LTC facility in which I resided and the following analysis.[20] In this email dialogue I infuse a quotation from the LTC facility's "Resident Bill of Rights". [21]

[Note: The security topic the director is referring to below regards locks being installed in rooms belonging to physically disabled young adults. I advocated for this after another young adult had his computer stolen from his room. Not only would door locks protect against property theft, they would also give young adults the option of added privacy.]

The Director – to - Scott Fellner

March 22, 2010

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[18] Three years after I received the communication device, and months before I was discharged, the facility finally provided some funding to hire someone to train me on the device.

[19] I may be wrong, but I think this would be considered discrimination.

[20] In the interests of protecting the confidentiality of the director and all other employees their names and the name of the Health Region and LTC facility have been removed or given a pseudonym.

[21] Please see the chapter one appendix for a copy of this document.

Hi Scott,

The security team contacted me today with an update, but we were unable to touch base afterwards.

In terms of an update . . .B and I talked with you where we are when we met in early March – and we would be happy to meet with you again to discuss progress in working towards a more resident centered approach on the main floor if you like*. **I've got to admit that I much prefer a personal discussion – rather than going back and forth on email .....*** (bold and italicized font added)

Thanks,

Director

Scott Fellner - Replying – to the Director

March 22, 2010

Hi D,

I know you don't like to put things in writing, but I can't speak without an effort you could not begin to understand. #4 of the Institution's Resident Bill of Rights states:

All residents have the right to freedom of speech.

Surely you agree that "freedom of speech" is predicated on the ability to speak or otherwise communicate freely. We have been down this "road" before and it is still littered with potholes. Hence, do you think you can make one exception out of 270 + residents at the institute and correspond with me via writing?

Respectfully,

Scott

It is important to note that the director would, more than likely, approach all residents, both young and old, with speech problems the same. However, take into consideration that for six years prior to the above email exchange, only I had been advocating for young adult resident rights, legal and human rights issues, many policy and program changes, and so on. I am sure the reader can imagine just how difficult and frustrating such advocacy can be when you are not permitted to communicate freely. Whether intentional or not, refusing to give me a full voice in said advocacy matters gives health region and facility management a discriminatory and, consequently, unfair position of power to shape the experience of young adult residents that are warehoused on nursing units.

Methodological Issues

I am an insider with an outsider's sociological theoretical knowledge. What are the methodological implications of my autoethnographic and institutional ethnographic research approach? Does this combination of methodologies entail an elitist conception where I know best and more than other residents in the research setting? I was formally barred from having any research subjects but myself by the health region's research ethics board. I am sure there is a great amount of knowledge sitting in wheelchairs on the nursing unit I resided, or throughout the LTC institution. On the other hand, I do think my academic experience and perspective combined with my "don't mess with me" attitude, honed from years of experience in the independent music industry, gives me a unique perspective from which to analyze my experiences and how they are interconnected to the complex system of domination within the LTC institution. This spirit and drive has helped me survive and given me purpose, which I am expressing in this work.

Ethical Considerations

Are there any outstanding ethical issues associated with my autoethnography? Generally speaking, informed consent should be obtained from all participants – especially if the personal lives of anyone discussed could likely be identifiable (Tollich 2010:1602-1603). However, since I maintain the confidentiality of anyone discussed other than myself by using pseudonyms throughout this thesis, informed consent is not a requirement in my study. Ensuring the confidentiality of the LTC facility and health region that this study took place in, the nursing staff and health region and facility management to anyone outside of my university academic advisors is a given.[22]

1.4 Chapter Summary

I began this chapter by narrating how I ended up in LTC, some of the struggles I faced while living there, and the difficulties I encountered trying to formally gain traditional qualitative research access to research subjects within the LTC facility. As a consequence of the health region's research ethics board evaluation I chose the qualitative research methodologies of institutional ethnography and autoethnography. These two methodologies enabled me to:

1) Write about my personal experiences residing in a publicly funded long-term care facility in a creative, and emotional style.

[22] In an effort to protect the anonymity of the LTC facility that my study took place in beginning in chapter two I will refer to it only with the pseudonym of XTC.

2) Connect that experience to formal and informal texts, and practices of the institution and health region.

3) Link those texts and practices to the LTC facility and health region's relations of ruling.

4) Relate those relations of ruling back to my personal experience.

CHAPTER 2: An Analysis Of Bureaucracy In A Long-Term Care Institution & The Potential For Change

2.1 Max Weber & Bureaucracy

The word "bureaucracy," more than likely, evokes feelings of helplessness, frustration, and images of trying to navigate a maze of unnecessary and excessive rules, procedures, and paper work: the proverbial red tape. Within classical sociological theory, the term "bureaucracy" and Max Weber are almost synonymous. To (over) simplify, Weber thought that as bureaucracies proliferated into the fabric of society, the excessive rules and the prescribed reasoning needed to follow them would plunge Western civilization into a "polar night of icy darkness" (Weber 1958:128). Why was Weber so pessimistic about the future of Western civilization? Basing his prognosis on studying the development and characteristics of government bureaucracies during the turn of the 19th – 20th century, Weber saw a once-promising mode of social organization become excruciatingly stifling.[23]

According to Weber, bureaucracies are essential to large-scale societies because they are the most technically superior, efficient and predictable forms of social administration (Swedberg & Agevall 2005:19). It should come as no surprise that governments, comprised of publically important departments, such as finance, environment, culture, justice, education, disability, and public health are essentially run by bureaucracies. Weber identified six different principles an organization must adhere to if

[23] Government bureaucracies may significantly reduce the occurrence of nepotism, bribes and favoritism. This clearly demarcates modern bureaucracy from feudalism as a historical system of social administration.

they are to successfully function as bureaucracies. They are: Hierarchy of authority, Impersonality, Written rules of conduct, Promotion based on achievement, Specialized division of labor, and Efficiency (Weber 1958:196-198). Let us take a look at Weber's principles of bureaucracy and see how they apply to the public health field, and in particular to XTC.

There is a definite formal "hierarchy of authority" on the LTC nursing units that I have resided. However, this does not mean authority always functions in a formal top-down fashion. There is a large amount of room, for instance, for a clique or individual nursing staff to impose their personality onto policy interpretations as a means of gaining power over residents or management and/or other nursing staff. On numerous occasions, I asked a care aid to bring a registered nurse and my care plan into my room to correct or clarify a misinterpretation of my care plan by a care aid/provider. The care aids did not like the inevitable delay of time these clarifications took, but I thought they were essential in order to receive proper care. There is an unmistakable will to power that some nursing staff can exhibit in certain situations. For example, residents can be treated like simple objects by some nursing staff when they are pressed for time and/or residents do not react as they would like.

"Bureaucratic impersonality" on a LTC unit means that age, race, disability, gender, et cetera are formally equal before the policies of the LTC institution, and that rules are to dictate action, not personal relationships. Of course, every staff member and resident has their favorites, and treatment to an extent follows that, not impersonal rules. For example,

a care provider may go the extra mile to help a resident with an extra shower per/week, even if it is outside of the formal rules or time slot.

LTC nursing unit bureaucracies are governed by "written rules of conduct." For example, care plans, incident reports, policies of all kinds, nursing union agreements and medical and nursing charts all contain forms of written rules of conduct and procedures for nursing staff. Nursing charting, for instance, can form a profile or sketch of a resident based on a nurse's one-sided representation of a conflict between a resident and him or her. Furthermore, nursing union agreements can circumvent the establishment of formal conflict resolution procedures between nursing staff and residents out of fear or concern that such procedures may be used to reprimand or discipline nursing staff.

"Promotion based on achievement" and reprimands based on poor performance in a LTC facility is complicated with all the many different union collective bargaining agreements there are for nursing, cleaning, kitchen and therapy staff. As in most unionized environments, promotion is based on seniority more than anything else. LTC facility management is the exception, with meeting budgetary goals as the criteria for promotion.

Within XTC, each LTC nursing unit has its own jurisdictional authority, but with uniform organizational structure and rules. Each unit has its own manager with the following "division of labor."

A) Resident care coordinators/registered nurses (RNs) – their function is to plan and coordinate all residents care plans to ensure they are followed and to resolve issues between residents and their caregivers. Resident care coordinators are also usually charge

nurses on nursing units. A charge nurse is typically the registered nurse on one or multiple nursing units who has the most seniority and, hence, the most authority. Any problems that arise on nursing units are directed to the attention of the charge nurse to solve.

B) Licensed practical nurses (LPN)– their main function is administering medications to residents. If a problem or issue arises regarding resident medications that the LPN is not able to solve, then the matter will be deferred to the charge nurse. In addition, if the unit is short staffed, an LPN may provide basic care to residents and in some cases may even take on the function of a SCA – (see below for explanation).

C) Special care aides (SCA)– their function is to provide direct personal physical care such as bathing, feeding, and transporting residents to and from the dining room, various appointments within the institution, and so on. On every morning, afternoon and evening work shift, one SCA is assigned to a small group of residents - usually four - except during the night (11 pm to 7 am) where there is only one SCA for a whole nursing unit.

D) Dietary and cleaning staff – the function of dietary staff consists of preparing breakfast, lunch and supper in the unit kitchen for residents to eat in the unit dining room. Residents who choose not to eat in the unit dining room have their meals delivered to their rooms by the facility dietary staff. [24] The unit cleaning staff consists of two people who have to adhere to a strict routine. The cleaning of resident rooms is coordinated with resident schedules. Usually this entails cleaning rooms while residents are eating in the

[24] These meals are prepared in XTC'S cafeteria kitchen.

dining room, or are otherwise out of their rooms at therapy appointments or for other reasons.

When implemented, all of the above principles of bureaucracy are designed to make a LTC facility function at maximum efficiency. If a resident deviates from his set, written routine, it can cause an inefficient chain-delayed-reaction that plausibly affects many other residents' care. For example, if a resident is not ready for his or her scheduled bath and a care provider(s) has to spend extra time preparing the resident then this will delay another resident's care. This is considered disrespectful behavior, whether it is intentional or not. Residents are advised to discuss changes/deviations from their care plan with the resident care coordinator (RN) on the unit so he/she can ascertain whether changes, temporary or permanent, can be managed by the current staffing levels and if they will infringe upon the care of other residents.

Hopefully, you are beginning to see how multi-layered and complex government-funded LTC institutions/ bureaucracies can be for residents and their friends and family. LTC bureaucracies can be stifling and change-resistant. Using some of my experiences as a resident at XTC as case studies, I will take an in-depth look at a set of email correspondence between management and me and a formal policy proposal regarding young adults my friend and I presented to management. I will then provide a summary analysis of the case studies in order to tie them together. These case studies demonstrate how discouraging and futile it can be to communicate with management about institutional change, let alone actually trying to affect the transformation of a nursing unit to better suit the needs of young adult residents. In addition, the case studies demonstrate that what is discouraging

about changing government-funded LTC bureaucracies may not be intrinsic to them and that, therefore, it may not be necessary to be wholly pessimistic, a la Weber, about the possibility of meaningful change.

2.2 Case Study # 1

The benchmark for autoethnographers, arguably, is whether the subjective experience they have chronicled suggests that, in some way, they have actively tried to change a core element of a social problem they've both lived, and investigated. This case study explicates and examines the formal effort a friend and I put forth in that direction, as well as the institutional policy response to that endeavor. In this sense, the following case study can be seen as combining the methodologies of autoethnography, and institutional ethnography.

Knowing my new thesis topic and my deep personal and sociological concerns regarding the living situation for young adults residing in LTC, my friend Jean - a recently retired vice president of primary care in the same health region as XTC - came to visit me. Jean took me outside for a short walk along the grounds of the institution. While he pushed my wheelchair along the sidewalk, he asked me if I would like his help in developing a formal program proposal for the planning of a young adult unit inside XTC. Jean said that when the proposal was finished we could then present it during a meeting with health region and XTC management.

Moreover, Jean pointed out that the timing of such a proposal fits well with the Saskatchewan provincial government's Patient First Review outlined by commissionaire

Tony Dagnone. Speaking about the Saskatchewan health care system, Dagnone says, "Is this the best we can do? That is the core question driving the Patient First Review. Canadian governments have asked this question before, from the perspective of clinical outcomes or economic value for money, but never from the perspective of the patient " (Dagnone 2009a).

The review was based on two questions. First, what is the patient experience? Secondly, is the health system achieving the best value in care delivery and system administration (Dagnone 2009b:1)? An independent research company, KPMG, was contracted to do all of the research for patients. Through email correspondence with a Saskatchewan government health representative, I discovered that out of over four thousand interviews with current and former patients, not a single interview was done with disabled young adult residents of a LTC facility (2011:1).[25] Indeed, where did the LTC facility I reside in obtain their information regarding young adult patient/resident experience? This is an important question as it speaks to the paternalistic character of LTC bureaucracies. Apparently, no actual research was required because management thought they knew best.

Here are the key points of the (2009) proposal Jean and I presented to health region and XTC management:

- XTC is to be commended for its foresight in developing a young adult unit. The reasons why young people take up residency at XTC are different from those who are placed there in their old age. Young persons may well live

[25] Please see the chapter two appendix for a copy of said correspondence.

a majority of their lives at XTC unless they can access other residential opportunities or they have a significant change in their health status.

- Many of the young people living at XTC have experienced a catastrophic injury or disease that has dramatically affected their physical health to the point that they may not be capable of living independently. Their lives have been suddenly and significantly altered and the recovery and acceptance of their circumstances and planning for a meaningful future are challenging. Family members are also traumatized by the experience and need help in their "recovery."

- A caring, healing and vibrant living environment goes beyond physical health care and needs to address the emotional/physiological, social, spiritual, intimacy/sexual, financial, legal dimensions of one’s life and assist individuals to identify talents and skills that can be used to re-engage in work or giving back to one's community in ways that are personally rewarding.

- It is proposed that the health region’s LTC management team develop a program plan for a young persons unit and that funds be made available to engage a person(s) on contract for one year to develop the plan on the institute’s behalf.

- The plan would be the property of the health region’s management and would serve as the basis for developing an implementation plan that would coincide with the annual budget.

- Given that other agencies in the community have a stake in the care and future of these residents, an advisory committee would be established, chaired by the vice president of the health region, and representation would be sought from agencies such as the University of Regina, SIAST, Community Living Division, Social Services, Legal Aide etc. and 2-3 young adult residents from XTC, and other program areas within the region. The participation of other agencies would not only help contribute to the development of the plan, but also provide education on the needs of young adult residents.

- At the lead of the vice president of the health region, objectives and critical factors would be established to advertise and engage a person, on contract with the health region, to do the substantive work required to write a program plan for the region's final consideration. Young adult residents would participate in developing the objectives and critical factors and a representative would participate in interviewing applicants, however, management would have the sole right to determine who is hired.

- With input from the advisory committee, the contractor's work plan would be established. It could include the submission of quarterly reports that would go towards the compilation of the final report. The first quarter could include such things as:

1) Catastrophic illness and its impact on young people.
2) Interviews with willing residents (family members).
3) Profiles of their experience, needs and aspirations.
4) Interviews with management and staff.
5) Literature review on best practices and service models.

Subsequent quarterly reports would result in a program plan specific to XTC (Fellner and Lager).

In the spring of 2010, after some very receptive and promising meetings with the vice president of LTC for the health region and XTC management, our proposal was rejected. Much to our confusion and dismay, the health region and XTC management opted for a one-age fits all concept of client-centered care that ostensibly met Tony Dagnone's mandate for patient/resident first care.

The client-centered model of patient first care at XTC politically marginalizes young adult residents. How does this happen? First of all, any changes that may happen on nursing units affecting residents are going to be individualized in relative isolation via a resident's care plan. Secondly, management and nursing staff will look after resident needs and wants to the best of their ability so that the resident feels like they are at home. Differences, such as age, are rendered irrelevant by the new individualized client-centered policy. It is as if the new model of care is based upon the misconception that residents are radically different from one another, or that it is inconceivable that residents might want to handle some needs, grievances, and concerns by collectively advocating for and/or demanding change. By isolating and marginalizing residents and their common grievances, nursing staff and/or management are able to contain and shoot down dissent over age-related issues, such as bathing and appropriate recreational activities. For example, if a

resident complains about getting only one shower per/week during an individualized care meeting, they will most likely be inundated with talk of staff shortages and budget restrictions. In other words, residents will be stonewalled. They will also likely be outnumbered and intimidated by nursing staff and/or management.

Moreover, it makes very little difference the further up the chain of command you go. Every meeting I had with management over the ludicrous number of showers allowed per week to LTC residents was very intimidating by how outnumbered by management my advocates and I were. Usually the ratio of those present at the meetings was two to one, and sometimes three to one in favor of management. The meetings went on for months as I traversed the bureaucratic hierarchy. They began with just the unit care coordinator and myself, progressing on to a meeting with the unit manager. My advocate and I then met with the executive director, and the director of XTC, and the care coordinator and manager of the nursing unit I resided on. Finally, we met with the VP of long-term care for the health region, the executive director and director of XTC, and said care coordinator and unit manager. In the end, in order to obtain formal approval from management to have seven showers per/week, I had to go on a water and hunger strike and threaten to inform the media. Apparently management did not want a media driven headache. Instead they tried to appease me and hope that by giving into my demands I would become silenced. They were wrong!

The point is, in private meetings residents will, more than likely, be ganged up upon and straight-armed by management and/or nursing staff. As it works, the individualized client-centered approach to meeting Dagnone's mandate is little more than self-serving

paternalism. Such paternalism is time, energy and cost efficient; everything is self-contained in the institution by and for health region and XTC management. The paternalism of management preserved existing nursing unit power dynamics and the LTC relations of ruling.

The Paternalistic Trap

The relationship of bureaucratization to paternalism is a curious one. Historically, paternalism has been a form of Weberian-like authority within institutions; hospitals, prisons, nursing homes are obvious examples. Yet, the question looms as to whether paternalism is inextricably tied to bureaucracy. The answer is very important for the lives of young adults residing in LTC facilities/nursing homes.

What is the face of paternalism in LTC facilities? Thomas Halper (1980), who has studied paternalism in nursing homes, argues, "paternalism is a claim by those in authority of a right to interfere coercively or deceptively in someone's life for their own good" (p. 472). The image of a wise, altruistic, yet authoritarian, father is apt here. Consider Halper's (1980) four arguments against paternalism. The first three concern objections to paternalisms' real-world applicability. The fourth contends that paternalism is inherently offensive.

The first of Halper's (1980) arguments against paternalism is that residents will better appreciate their interests than will bureaucrats or even family members (p. 474). The veracity of this argument is, arguably, greater for young adults than the aged for no other reason than young adults have the bulk of their lives ahead of them.

Second, paternalism generally stifles the potential for challenges and accomplishments, since personal security may not be the primary value of people with disabilities (Halper 1980:474-5). I think that, in particular, young adults with disabilities do not hold personal security as their primary value. Aren't risk and uncertainty central to feeling alive? I would wager that love, friendship, autonomy and self-determination are more highly coveted values among disabled young adults residing in a LTC facility. Furthermore, isn't having a "say" in how an institution is running their lives exponentially more important than personal security?

Third, paternalism may serve as a convenient rationalization for morally dubious self-interest, be it personal or institutional (Halper 1980:475). Disabled people, young or old, may be put in a LTC institution because they are an annoyance, or a burden. Likewise, a LTC institution, such as XTC, may infantilize its residents for no other reason than laziness and cost-squeezing. Take the above discussion of the individualized client-centered care initiative as an example of this.

Fourth, government paternalism necessarily implies "an official . . . subordinate relationship that counters the presumption of equality, and violates democratic values" (Halper 1980:475). People treated this way have no opportunities to learn from mistakes, have little privacy, and are denied as human beings (Halper 1980:476). Indeed, in the failure to rigorously explore the young adult patient/resident experience - half of what the Patient First Review, in general, was supposed to be based upon - and the implementation of a policy predicated upon the assumption that they know best, the health region and XTC management tragically make Halper's fourth point against paternalism a concrete reality

for young adult residents residing at XTC. I feel as if the young adult experience was not worth the energy, time and financial cost of formally exploring what they need. So, whom does this client-first model of care serve?

Ironically, individualized client-centered care serves the interests of the health region and XTC: individuals officially vested with authority - not young adults residing there. People expect standardized care to be client-centered. By violating the presumption of equality, paternalism negates that expectation. Formal and informal policy and practices securely rest in the hands of health region and facility management and staff. Marginalizing and isolating young adult residents denies even the possibility of democratic action. So much for the concept of young adult resident self-determination! The dangerous logic of paternalism should not be missed: that officials know better than LTC citizens/residents, and the consent of the latter is not required (Halper, 1980, pg. 495).

2.3 Case Study #2.

What is required before qualitative change can occur in a LTC facility? Why is such change not likely to happen in a LTC institution? I believe Jean and I provided one possible answer to the first question, presented in the first case study. An analysis of an email exchange between a unit/ward manager and me will answer the second question.[26]

Scott Fellner – to -Unit Manager

Saturday, May 28, 2011,

Hi,

[26] To protect the confidentiality of the unit manager his name has been removed.

On Saturday, I experienced some conflict between two LPNs and me. We did work out that their sarcastic approach to what they said to me was the trigger of the conflict. I also told one of the LPNs that I felt provoked, and ganged up on by their approach with me. She responded by saying that both of them feel provoked if and when I call a trusted friend to mediate such situations. **What do you think is going to happen if I don't "provoke" these two or any staff member by calling an advocate when they are on a "power trip"? Obviously, if nothing is done then the status quo "relations of ruling" remain the same. Furthermore, if I remain silent when such provoking (and I do think it is intentional) happens, and take it up with you later then I will be further labeled as a "trouble maker" who should not be trusted! What is the informal institutional and/or unit message here?**

Do you have a solution? Should we all have some type of conflict resolution? What has to happen?

Respectfully,

Scott

Unit Manager – replying to – Scott Fellner

June 2, 2011

Hi Scott. You had a question in the email (bold letters) and I don't quite understand when you ask, "What is the informal institutional and / or unit message here?"

In our discussion we talked about a culture change and the work that we will be doing to promote and work through the mandate of Patient First. It is important that we are not labeling people as 'trouble makers' and that residents/patients can bring concerns forward without being afraid to do so.

"What can inhibit long-term care institutions from qualitative change? I think the answer to that question is when there is no desire to or for change. With Patient First it is recognized that there are changes that need to occur. I think it is a good first step. The next step is actualizing this – making it happen, walking the talk – all of us walking the talk.

Regards,

Unit Manager

The preceding email from the unit manager contains an incorrect explanation as to what accounts for the lack of substantial change in the institution. The XTC manager's email indicates that a lack of interest and desire for change is the most significant reason change doesn't occur. I believe that is wrong for the following four reasons.

First, there is a probable fear of reprisals from staff and/or management if residents speak out. This may sound far-fetched, as institutional employees are professionals after all. However, if you have ever been dependent on professionals who have power over you in any organizational context you probably know that rocking the status quo institutional boat will not come without a certain amount of trepidation. Now imagine you are a quadriplegic who is almost completely dependent on LTC staff. Almost everything you do requires help from caregivers, nurses et cetera. Creating institutional waves may, more than likely, cause suspicion and distrust among nursing staff and residents alike. The fear or anxiety such suspicion and distrust can cause is one way modern LTC power dynamics take shape (Foucault 1995). There doesn't have to be actual reprisals for one to feel like there are.

Second, there is a palpable amount of apathy among young adults residents. Before management opted to go with individualized client-centered care, I emailed several other young adult residents at XTC in the hope that they would come to a focus group Jean facilitated. Only three residents showed up at the focus group meeting. Furthermore, on June 20, 2011, The Individuals with Disabilities Equity Alliance of Regina held a forum titled "The Convention on the Rights of Person's with Disability: Compliance,

Implementation and Monitoring" with guest speaker Vangelis Nikias, the Canadian Council on Disability project manager, in the auditorium of XTC. Only one other resident besides me attended this forum. I am at a loss to explain resident apathy.[27]

Third, the large number of residents with speech and movement disorders plays a significant restricting role in forming alliances to resist policies and practices and/or to organize and demand change. By virtue of having said disabilities, it is not as if LTC residents have the same ability as correctional inmates, for instance, to riot if they don't like management policies. I can attest that simply having a conversation with other residents can be extremely difficult. Naturally, any type of political organization can be problematic.

Fourth, the new patient first policy the manager speaks of in the above email actually precludes the possibility of widespread resident want and need for change. Residents may come to believe their needs are being taken care of by a benevolent paternalistic institution. While such a belief is unfortunate, it does account for resident indifference to collectively addressing disability issues at XTC. Living with a disability can be extremely tough and the promise of a policy that purports to look after most of one's needs is alluring. However, it is not worth relinquishing one's voice in a collective struggle for disability rights at XTC in exchange for the false promise of isolated comfort and happiness, as discussed in the first case study.

[27] Please see chapter three for further explanation.

2.4 SUMMARY ANALYSIS OF CASE STUDIES

Regarding the first case study, I could not have imagined a more proactive, formally organized and presented idea for qualitative change in a LTC facility. Even the Ranch Erhlo Society, a non-government organization that engages several types of charitable work, was ready to fund the building of a young adult unit on the grounds of the existing facility. Still, health region and facility management decided to turn down our proposal. Ostensibly, it is cheaper, and much less hassle, to opt for a policy of client-centered care than it is to actually rigorously investigate what young adults need. Again, researching the patient/resident experience was what the Patient First Review was supposed to be based on. Any policy initiatives that are in reality - one age fits all - contradicts the client-centered intent of the official government review. Just because there are many disabled young adults living in government funded LTC facilities does not mean they are the same as the aged!

In each of the case studies, management chose a path of least resistance. That is, both involve choices by health region and facility management that made their jobs/workload/portfolio more controllable. In addition, as I have demonstrated, the two case studies strongly reflect a troublesome paternalistic tendency to not investigate before choosing a course of action.

When analyzing why LTC bureaucracies are seemingly change resistant there are many reasons to let pessimism become fatalism. The motives of management are human. Too often machine and bureaucracies are made analogous. “To err is human.” The motives of management may be morally dubious. Individual members of management or

factions thereof can make or not make policy changes, for instance, in order to gain or preserve their power. It follows from this that, in LTC facilities, fear can play an important role in management failing to try to make changes that fall outside of the institutional box. Why? Simply because it may come back to bite them in the ass from potentially all levels and directions: their superiors, nursing staff, other residents and/or their families, resident council, the media, and other nursing unit managers or other government funded LTC institutions et cetera.

Of course, LTC institutions may only be change-resistant if paternalism is inextricably tied to the nature of bureaucracies. Paternalism is a mind-set that has long since been dearly held by LTC institutions, but arguably, they do not have to be two cheeks of the same bum! If paternalism is not intrinsic to LTC bureaucracies, then change is possible. That is, if management gives up their affection for paternalistic logic with the assumption that they know best, they will have no choice but to actually investigate resident needs and issues before designing and implementing policy directives that maintain the status quo relations of ruling. Of course, my experience advocating with management over young adult issues, program and policy direction, suggests that they are incapable of letting go of paternalistic logic.

Whether or not the motives for management action or inaction are paternalistic, personal gain, self-preservation or laziness, it may not be the nature of bureaucracy that is at fault. The pitfalls of being a public servant are, no doubt, many. However, we cannot bury our heads in the sand and surrender to a fatalistic attitude. As this chapter ends it is worth repeating a quote from Tony Dagnone, the man who led the government of

Saskatchewan's Patient First Review. As Dagnone (2009a) put it, "Is this the best we can do?"

CHAPTER 3: The Goffmanian Architecture of a Total Institution

In the previous chapters I briefly described some features of living in a government funded long-term care facility. In this chapter I focus more closely on the characteristics of total institutions and how they relate to my experience as young adult living in a LTC facility. With heuristic examples, I describe how and explain why contemporary LTC total institutions can create deplorable living conditions for young adults.

Throughout most of his academic career, Erving Goffman focused upon how societies and their institutions exert control over individuals and how those individuals adapt to such control. In his book *Asylums,* Goffman (1961) identifies five different types of institutions he calls "total institutions" and explicates how they try to control individuals and their sense of self: who they were/are. Why are total institutions relevant fifty-seven years after the initial publication of *Asylums*? As the politics of fear, control and domination take center stage in America, the vulnerable and those who care about them can not miss the vital threat: will to power over others is about to gain unabashed approval from the world's political and cultural superpower. In Canada too, the place of disability and human rights within public discourse will likely diminish with the "might is right" ethic of Trump's presidency. All the more reason for activists, academics and the like to continue to push for compassionate and equal treatment of those with disabilities, especially those living in contemporary total institutions posing as publicly funded residential care facilities.

3.1 Total Institutions

What are total institutions? "A total institution may be defined as a place of

residence and work where a large number of like-situated individuals, cut off from wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. Prisons serve as a clear example, providing we appreciate that what is prison-like about prisons is found in institutions whose members have broken no laws." (Goffman 1961:11-12). This is an important point, though probably not in the way you, dear reader, are thinking. For Goffman, what is "prison-like about prisons" has little or nothing to do with barred cells, barb-wired fences or the ubiquitous presence of guards. What are some of these features and how are they relevant to the experience of young adults residing in LTC?

In our broader society it is commonplace for us to work, play, eat, sleep, in separate contexts, among separate people, separate hierarchical authority, and without a consistently organized rational plan/goal (Goffman 1961:17). However, within total institutions the reverse is true. Consider Goffman's (1961) following explanation:

> First, all aspects of life are conducted in the same place and under the same single authority. Secondly, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials (p. 17).

Being subject to such regimentation clearly entails severely diminished personal freedom and control. It is also disturbing that daily activities are predominantly held within the same context and with the same people. Not only is one's identity unlikely to be as fragmented and multiple as it is in regular contemporary society, but they are now

confronted with an alien mono-reality specific to total institutions. For most able-bodied people not living in a total institution, daily life consists of occupying numerous roles in several environments with many different people. This brings out dimensions of one's personality and allows personal growth to occur. Such is not the case with living in a total institution.

3.2 Experience & Analysis

How does XTC fall into the above general characteristics of total institutions?[28] Unlike some total institutions, such as mental health hospitals or prisons, all daily activity of residents of a LTC facility, such as XTC, do not necessarily occur under the authority of the same institution. For example, it is quite common for young adult residents of XTC to leave the facility to attend university, go shopping or go to a movie with friends, et cetera. There are no formal rules prohibiting residents from leaving XTC during the day or evening, but there is an eleven p.m. curfew that one must adhere to if they want or need help going to bed.

On the other hand, like Goffman's (1961) general characteristics of total institutions, most of the residents at XTC carry out their daily activity alongside their fellow residents. This entails getting up and ready for breakfast, going to the dining room to eat, going back to their rooms, going to the dining room to eat lunch, returning to their rooms for a nap, getting up and going to the dining room for supper and then returning to their rooms and then going to bed for the night. All this happens for residents with varying degree of help

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[28] Again, in an attempt to ensure the confidentiality of the LTC institution that I resided I have given it the pseudonym of XTC.

from the nursing staff.

The vast majority of young adult residents do not comply with the institutions herd-like goals of efficiency. They choose to eat in their rooms with nursing assistance or help from family and friends, or on their own. Independently eating, bathing, and dressing are the only way one can circumvent the facility's cattle-call routines and have some control over their lives.

3.3 Mortification Processes

Mortification/humiliation processes are affronts or assaults to one's personal sense of self (Goffman 1961:24). The point of such treatment is to mark a clear separation between residents' former selves and their institutional selves (Sociology Hub 2016). However, the purpose of mortification processes is not simply to emphasize a disparity between the past and present. The goal is to make its subjects into pliable objects that are respectful of themselves, other inmates/residents, the institution and its authority figures (e.g., prison guards, nursing staff etc.) and are, thus, controllable and predictable.

Goffman (1961) contends that a person's self can be mortified through the following processes.[29]

1) *Role Dispossession*: When one moves or is moved into a LTC institution typically one experiences a radical shift or redefinition of what it means to fulfill roles (Goffman 1961:24-25). For example, friendships with one's able-bodied, non-

[29] Due to the antiquated and disparate nature of Goffman's descriptions and examples, I have tailored the explanation of the mortification processes to match the physically disabled young adult LTC resident experience.

institutionalized peers can be extraordinarily different and difficult for both parties. The type of activities friends may be accustomed to participating in together may not be possible due to disability or institutional curfews, regimentation of life, et cetera. As you can imagine, this entails the loss of some friends and other roles. I have had very close pre-disability, and pre-institutionalization friendships dissipate and vanish from my life. I also lost my roles as a musician and a student for a number of years.

2) *Property Dispossession*: Goffman (1961) claims that property and its dispossession is one of the most obvious and key elements of the mortification processes (pgs. 27-28). Moving into a long-term care facility normally means abdicating one's ownership of personal property like a car, motorbike or home. Items like these may hold great symbolic meaning to some people. Cars, for instance, play a significant role in the identity of some young adults. Further, owning property is arguably a rite of passage into adulthood or independence. Being dispossessed of property can mean a return to pre-adulthood and dependence. Such a loss can conceivably cause a psychological and emotional monsoon for young adults. If they are not independent adults, then who are they? Seemingly useless and devoid of purpose – are they burdens to society?

3) *Identity Kit Dispossession*: Role and property dispossession are losses that can profoundly affect an adult's sense of who they are. For a young adult, identity kit dispossession can arguably be just as devastating. An "identity kit" is what enables a person to present their desired image or appearance of themselves to others (Goffman 1961: 29). Clothing, make-up, shaving kits and hair products are the most obvious examples of an identity kit. A daily shower or bath is another. Similarly, in today's world, it

is likely a gym for physical fitness may be integral part of one's identity kit. Physical characteristics are, arguably, one of the most important dimensions of a young adult's identity. Naturally, for a young adult LTC resident who has had a sudden on-set physical disability, conceptualizing a desirable identity kit can be difficult, let alone possessing one.

4) *Contaminative Exposure of Self*: Mortification involved in exposure of the self is largely synonymous with physical and informational exposure (Goffman 1961: 31). In a LTC facility, this can happen when a resident concludes that confidential information contained in medical reports, nursing charts, incident reports, and so on, can be accessed by all types of staff, or that information has been leaked to staff which may not be regularly within one's circle of care.[30]

Mortification deriving from the physical exposure of one's self can occur, for instance, when a nursing attendant unexpectedly walks in on a resident when they are in various states of undress. Given the nursing staff's aforementioned penchant for leaving resident doors open and opening resident room doors unannounced, inadvertent resident exposure of self to other residents, non-nursing staff (e.g., cleaning, therapy and administrative staff) or strangers who may be passing by could also happen.[31]

5) *Contaminative Exposure of Others*: Goffman (1961) also defines exposure of others as mortification experienced as a result of being in the immediate company of residents or staff who are deemed to have lower social status than oneself or vice versa (pg.

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[30] Please see chapter one or two for a definition of this concept.

[31] Please see the introduction to this thesis for an example.

35). I do not have any stories of this type of mortification based on my own personal experience. However, a friend of mine who works at XTC as a care aid shared a work anecdote that will serve as an illustration. A new resident who was a wealthy, practicing lawyer was admitted to the unit she works on. Apparently, this new resident was quite upset over a number of things, one of which was being stuck with a roommate who used to work as a janitor. According to my friend, the new resident must think she is too good to be roommates with a former janitor - even earning the nickname of "princess" among some of the other care aids.

6) *Contaminative Exposure of Significant Others*: Goffman (1961) was not entirely clear with his explanation of mortification resulting from the contaminative exposure of significant others (pg. 38). I understand this type of mortification to occur, for instance, when a patient with mental illness or a disability has an intimate relationship with a non-stigmatized individual revealed or exposed. By this logic, mortification would then result from feeling that the significant other feels mortified or deeply embarrassed by having the relationship exposed. Both people may in fact become mortified. However, *Asylums (*1961) was published in the very early nineteen sixties when mental illness and physical disability were both highly stigmatized, and intimate relationships between people with these conditions and able-bodied persons were also highly stigmatized. Such may not be the case anymore. While those stigmas still exist, and their exposure may still be a source of embarrassment, I do not think they are strong enough to cause considerable mortification within an institution.

While residing at XTC, there were several times when nursing staff unexpectedly

walked in my room and startled my girlfriend and me during a private moment. I recall briefly anxiously pondering what my significant other must have been feeling, but such anxiety quickly gave way to anger and frustration at what I believed were unnecessary and possibly intentional privacy violations. Although I did not experience any significant mortification from this type of exposure, I believe my significant other did. I base this belief on the fact that she was very reluctant to engage in some types of intimate activity with me in my room as long as locks on resident room doors were prohibited by XTC policy.

7) *Looping*: The term "looping" was coined by Goffman (1961) to refer to the situation of patients reacting defensively to what they view as a personal attack, leading to their responses becoming the target of the next staff criticism (pgs. 40-42). For instance, on several occasions a caregiver gave me a terse reminder regarding the institutional bedtime curfew. On one of those occasions, I became visible angry and agitated upon hearing said reminder and refused to get ready for bed as I steadfastly believed curfews are for children and I was not a child. The caregiver became defensive and critical of my anger and stormed out of my room. The care aid probably interpreted this behavior as evidence of a maladaptive disorder, because I had refused to admit that the staff's definition of the situation was the correct one. [32] The correct definition of the situation is always the institutional one!

> Goffman defined this as one of the basic features of the mortification process in that patients were not allowed to spontaneously express their own

[32] Namely, that every resident of XTC, regardless of age, must adhere to the bedtime curfew.

> definition of the situation. This meant that they had to react in a prescribed manner, or in a way that further consigned them to the sick role by a display of anger for example. They were unable to maintain social distance from the staff, or preserve a sense of autonomy because this was destroyed during the interaction (Anna Auden Soc 2011).

Reducing anger and indignation at mortifying situations could be the product of looping whether such looping is intentional or not. Thus, where anger or indignation is concerned, looping may actually contain a therapeutic element. However, I do not think intentional looping is ethical. Intentional looping is designed to affect psychological and emotional pain and is, therefore, morally dubious. Even utilitarian arguments where the "ends" are supposed to justify the "means" are unable to deal with this fact.

8) *Loss of Autonomy:* Although Goffman (1961) never used a LTC environment for illustrations to explain this concept, losing one's autonomy is primarily associated with physical limitations and challenges, and having to adhere to the above-mentioned regimentation of life (pgs. 42-43). For instance, having to wait until it is your scheduled time before you can have your weekly shower or bath can be considerably mortifying. I do not know what is worse, only being allocated one bath or shower per week by the institution, or being expected to cheerfully wait for that one tightly scheduled weekly time slot. Furthermore, you can experience mortification by simply having to ask a care provider to complete a mundane task that, pre-institutionalization, you would have no problem doing for yourself. Simply put, this type of mortification occurs in a LTC context because you are not able to regulate and meet your own needs as you would like, or are used to.

3.4 Experience & Analysis

It has been my experience residing at XTC that Goffman's depiction of mortification processes and purpose are accurate and common. Consider the following brief personal vignettes as illustrations of this process.

I have previously mentioned how the nurses strongly encouraged me to wash-up at a sink that offered very little privacy, and how mortifying that was for me. Another time, while I was still in the rehabilitation unit/ward of XTC, a nurse tried to empty my leg bag full of urine (at the time I still had a catheter) in front of a group of my university colleagues. This humiliating example was more than likely unintentional. It is important to note that most mortifying experiences within total institutions occur unintentionally (Goffman 1961:24-25). For example, every time I have had to speak—especially in formal contexts—with people I hardly know or have just met, I feel vulnerable and mortified or humiliated.[33] In most instances at XTC I think this has been unintentional. On the other hand, I believe some experiences of mortification, such as, exposure of the self and looping have been intentional on the part of the nursing staff. Consider the following excerpt of an email I wrote to health region and facility management regarding an exceptionally mortifying experience I had.

To Health Region and XTC management:

October 2010,

[33] I have already (in chapter one) included an email exchange with the director of XTC illustrating part of the institutional processes involving my communication problems.

Hi,

At 9:30 a.m. I rang my call bell for my caregiver. When she came I told her what I needed. She did not understand me and I motioned to her to give me my keyboard and she never understood that either. And then I was prepared to wheel myself to the shower room but the caregiver wrapped me up in a sheet and I could not wheel myself because the sheet gets caught in the wheels. I tried to tell her that and motioned once again for my keyboard but she never understood that and I said, "fine" to myself, and let her push me to the shower. She did the same thing on the way back from the shower. She wrapped me in the sheet and I could not express myself to her despite my best efforts. Then once she pushed me to my room she took off the flannel sheet and left me naked in my chair and told me to put on the clothes that I had earlier tried to tell her were dirty. I tried once again to tell her to bring my keyboard to me, but she never understood and then she said, "I have to go because you were late," and that she was told by someone to leave me to dress myself. Once again I said and motioned to bring me my keyboard and this time she brought it to me and I tried to type the question, "When was I late?" but she still never understood what I typed for her. Then I became frustrated and accidentally knocked my drink over on my table and she got scared I think and just left my room.

All of the above took place while she left me naked in the chair and this was extremely embarrassing for me. I felt very disrespected especially considering how many times I asked vocally and gestured for my keyboard. My keyboard is my only real means of communication and I was denied my right to communicate my needs time and time again.

Respectfully,

Scott Fellner

When I first analyzed this incident, I was content to let it be nothing more than an example of intentional mortification and looping. It felt as though I was being provoked in a way that could consign me to a maladjusted role by a display of anger, for example. Years have now passed and I still stand by my original analysis, but I now look at the experience a little

differently. First of all, the charge nurse should not have assigned the new care aid to my care without having ample time to review and understand my care plan. In particular, the care aid should have known to patiently allow me to use my keyboard to communicate. Secondly, the experience can be seen as an attempt to reassert the nursing unit's and the institution's power and control over a resident who is trying to add to and/or change their policies and practices, while at the same time bucking the system. It follows from Weber's analysis of bureaucracy that these two arguments are cogent. Being at the top of the authority hierarchy on LTC nursing units at XTC, charge nurses are primarily responsible for unit efficiency. Resident attempts at policy making and bucking the system, in general, challenge the established hierarchy of authority.

Why would a young disabled adult feel mortified at any of the examples at XTC I have provided? Is it not true that to a very real extent our able-bodied cultural milieu still looks down upon the disabled as less than "differently" able; that is, as undesirable, damaged goods and burdensome, or simply invisible? There are very good reasons why disabled young adult residents might feel this way. The disabled are vastly under-represented in the media and popular culture as a whole (MediaSmarts 2015). Likewise, it is very difficult to locate sexual images and representations of disabled persons in our culture. The media, predominantly, teaches society what personal attributes and identities are desirable. If physical disability is barely on the cultural "map", then by what other standard, other than that of the able bodied, do the disabled have to judge themselves and their lives? How do physically disabled young adults develop sane self-images? This is problematic because self-image is to a large extent contingent upon what others think. The

sociologist Charles Horton Cooley calls this type of self-conceptual thinking as seeing yourself through the “looking glass self,” or in other words, thinking of yourself as you think others think of you (Ritzer 1992:198).

Then there is the further challenge of coping and managing society’s contradictory demands. In addition to the under-representation of the physically disabled throughout the media, there is also a part of our culture that hypocritically tries to tell us that the disabled and able bodied are equal. This may be inherently true like the saying, “All human beings are equal.” But by what measurable life indicators are there to base such a viewpoint upon? Society "requires that the stigmatized individual cheerfully and unselfconsciously accept himself as essentially the same as normals, while at the same time . . . normals would find it difficult to give lip service to their similar acceptance of him . . . "(Goffman 1963:122). The physically disabled may not avoid being conscious of their simultaneous unequal yet supposedly equal place in the social hierarchy of able-bodied culture. But how does one cope with such a paradoxical situation?

In my experience, self-exclusion from activity with the able-bodied will, more than likely, produce isolation and hermitic behavior. On the other hand, familiarity may not reduce contempt. In spite of the common belief that openness and exposure will decrease stereotypes and repression, the opposite, in some instances may be true. Some people simply cannot feel comfortable around difference. One can only do their best to bring change to the external world. Aside from that, if you don’t want isolation, you really have little hope in cultivating a conventionally rich life unless you try to believe that the able-bodied try their best to be understanding and inclusive.

3.5 Labeling

Goffman (1961) did not systematically write about the phenomena of "labeling." What I mean by labeling within a LTC institution is the assigning of positive or negative (mostly negative) characteristics to residents by nursing staff. My intention here is to examine how the relations of ruling of the health region and XTC are manifested through labeling processes; that is, through formal institutional reports and practices. This will entail discussing one of my own experiences at XTC.

On Saturday morning, Sept. 11, 2010, a care aid was doing a medical procedure on my backside that suddenly and unexpectedly hurt like hell. At that point I yelled, "Ow!" and instinctively and simultaneously swung my right arm back. According to the care aid, I hit her head. I believe that she unintentionally hurt me, and I certainly did not intend to hit her.

As soon as the incident occurred, I asked to talk to the charge nurse in an effort to tell her what happened and hopefully resolve the incident as quickly as possible to try to put a stop to the potential staff gossip about the incident. Later, during an informal conflict resolution meeting that I initiated, the care aid listened to my explanation of my reaction to the pain I felt and she said she believed I hit her unintentionally. I also reiterated that I thought that she did not mean to hurt me. We had been friends before said incident happened and remain friends to this day. We ended the meeting peacefully and shook hands (as stated in the nurse charting). In spite of this, the unit manager filled out an occurrence report indicating that I had struck the care aid and the charge nurse charted

that in the future I may hit other care aids when they are providing personal care.[34]

In philosophic terms, the facts of the incident, however malicious and misleading, are only the “necessary” but not the “sufficient” conditions for labeling to take effect. The sufficient conditions are the formal practice of unit nursing staff gathering in the unit chart room shortly before a shift change to give report, both orally and in writing. This ensures that unusual events between a resident and nursing staff is charted and talked about to those on the same shift and the next shift. Because of the nursing unit practice of occurrence reporting, charting, and oral reporting, the "labeling effect" can happen with or without some degree of malice or intent on the part of nursing staff. It just so happens that in this case, malice, arguably, played a part in the labeling processes. It is almost as if the unit manager and charge nurse had their “noses out of joint” over the fact that I circumvented their power of defining the situation by initiating a conflict resolution procedure that tried to both define the situation and foster mutual understanding and empathy.

Moreover, the unit nursing staff and management reporting of incidents involving residents demonstrates: a) how the ruling power relations involved with defining the situation are embedded in institutional textual processes (e.g., occurrence reports and nurse charting) and the practice of oral reporting; and b) how residents are excluded from those processes and are, thus, subordinated and misrepresented. In other words, residents have no power to define who they are before the institutional apparatus of LTC facilities.

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[34] If the reader would like to examine a copy of the nurse charting, occurrence and security report they can contact me, or the Department of Sociology at the University of Regina.

Although Goffman never discussed this process, when we apply Smith's institutional ethnography we see another level of how total institutions can be draconian and prison-like. Round and round we go, when and where the incomplete and/or (mis)information will stop nobody knows. In the above labeling example we can clearly see how the charge nurse and unit manager employed "alternative facts."[35] Their version of reality excluded the representation of events from those directly involved in the incident: the care aid and myself. Can these power plays stop once they start? The labeling processes make XTC an "iron maiden" of institutional control that is very difficult to escape from.

You may think that I am placing too much emphasis on the genesis, efficiency, and incidence of gossip on the nursing units. It would be naïve to underestimate how damaging gossip and its effect of labeling residents may be to residents. The alterative facts that can be present within occurrence reports, security reports et cetera have real potential to lead to new relations of ruling affecting staff-resident interactions. For example, if the alternative facts are that I struck a care aid, and may hit other care aids when providing personal care are accepted as real then, of course, such textual warnings and the gossip that no doubt spread as a result may have altered the way care aids interacted with me.

Institutions are adept at assigning labels to individuals and extremely inefficient at removing such labels and their stigmatic effects both within institutions and the community (Clark and Kelly 2003:11). In most cases, this could hardly be interpreted as

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[35] I chose to use the term "alternative facts" because it has become synonymous with the misuse of power.

beneficial or therapeutic for residents. Indeed, the existence of labeling processes at XTC implies that there are systemic vulnerabilities that can put residents' confidentiality, dignity and personal integrity at risk.

3.6 Adaptation Strategies

How does one deal with all the possible aforementioned identity assaults?[36] Goffman (1961) identified four different strategies that individuals living within total institutions employ to help them cope with daily reality. These are situational withdrawal, disobedience, colonization, and conversion.

'Situational withdrawal" occurs when an individual retreats to a context where his/her perception of his/herself and their surroundings is all that matters (Goffman 1961:61). In Goffmanian (1957) terminology, people situationally withdraw to a "backstage" where a person can let their guard down. Obviously avoiding face to face interaction is the most effective way to achieve situational withdrawal.

The adaptation strategy of "disobedience" refers to a high rebel morale wherein a resident or inmate "intentionally challenges the institution by flagrantly refusing to cooperate with staff" (Goffman 1961:62). According to Goffman (1961), after a prolonged period of time, staff will take the position that the chronically intransigent individual must

[36] Mortification, looping and labeling processes and the resistance to them are a form of identity politics. In LTC institutions these processes are hidden and insidious. Speaking or writing about one's experiences with these processes while residing at XTC and in the community, as I have done, is almost as painful as living them. Believe me when I tell you that experiencing the effects of those processes felt like I was in psychological and emotional torture. Maybe some day I will feel myself again; whoever that is.

be broken and dedicate as much attention to him/her as he/she devotes to institutional rebellion (p. 62).

"Colonization" occurs when a resident of a total Institution, more or less, accepts the house rules: the norms, formal and informal policies and one's supposed egalitarian position within it. Instead of bucking the system, one will utilize all the institutional resources available in order to improve their quality of life (Goffman 1961:62-63).

"Conversion" refers to not only accepting the institution and its rules, but also wholeheartedly embracing it. With conversion, "The inmate appears to take over the official staff view of himself and tries to act out the role of the perfect inmate" (Goffman 1961:63). The convert no longer critiques the system but supports the institutional rationale for almost everything. Converts may take on the dress, mannerisms, attitudes, and so on, of various institutional staff (Goffman 1961:63). It is logical to think that converts may even assume an informal policing role and report disobedient inmates/residents to official staff.

3.7 Experience & Analysis

I argued in this chapter that young adult residents situationally withdraw to avoid the experience of mortification. And I reported in chapters one and two they may also situationally withdraw to seek connection via social media. During the first two years I resided in LTC, I spent so little time outside my room that I was known as the "Brian Wilson" of XTC. Both rationales were the cause of my situational withdrawal.

Aside from retreating to one's room to situationally withdraw, young adult residents who smoke cigarettes take social sanctuary within a very small smoke-room. Aside from being a designated space for residents to smoke cigarettes, the room acts as a safe house where mostly young adults participate in normal social interaction. Camaraderie predicated upon jokes and so on is not easily found in other institutional contexts or recreational events (e. g., card games, bingo, "happy hour" – all of which occurs with recreation staff) where quasi-authority figures lingered, altering the social frame where interaction occurs.[37] Without a doubt, the smoke room – all fifty square feet of it – is the only place in XTC where all types of staff members are prohibited. It is ironic that an activity that leads to physical death is the only one where social life can happen naturally.

Regarding disobedience, I am sure every resident of XTC employs this adaptation strategy from time to time simply to self-validate their own sense of power and control over their surroundings. In so far as chronic insolence is concerned, I think it will only lead to negative emotions and stress for residents. One can rebel all they want, but unless disobedience manifests itself in organized advocacy it will never amount to anything other than impetuous protests. Of course, what institutional staff may interpret as troubling behavior or chronic disobedience may in fact be the result of an inability and/or lack of knowledge to effectively communicate and/or advocate for themselves or others. This is where the concept of individual choice becomes contested.

[37] This is not to be confused with Goffman's concept of "frame analysis" or his book of the same name.

Not all choices of physically disabled young adults residing in LTC institutions are equal. It is important to note—if it has not been impressed upon the reader so far—that because institutional living invariably involves enormous forces of stress and alienation placed upon young adults, choice often hardly qualifies as choice at all. The processes of mortification and labeling along with a recreational agenda for the aged, the constant presence of staff, curfews, oppressive bathing rules, and a regimented pattern of life are among those "enormous forces of stress." Why would they cause stress particularly for young adults? A LTC institution is a context that is alien and degrading for both young and old. Young adults, however, have an additional stress of not being at the end of their lives. They are faced with a seemingly insurmountable task of rebuilding their lives while they are subject to the aforementioned enormous forces of stress specific to LTC institutions.

The longer a person resides in LTC, the greater the likelihood of colonization taking hold. I have witnessed young adult residents who were quite rebellious for the first couple of years residing at XTC accept institutional living and participate in most of the facility's antiquated recreational activities. Utilizing all of the resources XTC has to offer a resident can be one way to create an acceptable life. So what happened to my insolent spirit?

I directed my rebel morale and energy toward sociologically analyzing and explaining the indignation I experienced as a young adult trapped, in many ways, in an inhumane and antiquated publicly funded system of long-term care. Of course, the more I explored the plight of young adults in LTC at XTC, the more I became filled with anger, frustration, outrage and exasperation. Several of my friends encouraged me to talk with a counselor at XTC about my anger, and to take advantage of the recreational activities

offered at XTC. I felt that although that pathway might help temporarily, in the way of a self-help remedy, the primary cause of my anger, indignation and overall discontent would not be altered at all. That was not something my sociopolitical convictions and humanistic morality would allow me to accept. Indeed, strong political or religious beliefs were found by Goffman (1961) to insulate an inmate/resident from breaking as a result of all the identity assaults a total institution had to offer (p. 65). Colonization remained an option I would flirt with, but I never gave it more than a perfunctory effort.[38]

Although "Stockholm Syndrome" never entered public consciousness until long after Goffman's *Asylums* (1961) was first published, I believe it captures the essence of what he was trying to convey with the concept of "conversion." Stockholm syndrome is "a phenomenon in which a hostage begins to identify with and grow sympathetic to his or her captor" (The American Heritage Dictionary 1992). Wait a minute! Are residents of LTC institutions hostages or prisoners? No, they are not – at least not formally. However, if residents of LTC need physical help with various activities of daily living they cannot just simply leave.[39] Furthermore, when you add up some of the Goffmanian architecture of everyday life in a total institution, such as XTC, it would be crazy to think that a young adult could ever become a convert. Ironically, if one accepts that they will, more than likely,

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[38] "I need to feel the anger, I need to feel the pain. Cause in a moment of sobriety I am alone" (FTA, "Coming Home", 2000). Anger and pain can be quite intoxicating.

[39] Discharge planning may take six months before all of a LTC resident's care needs will be capable of being handled properly within the community.

spend the rest of their life in a LTC institution the only way to fend off clinical insanity may in fact be to somehow morph into a convert.

Arguably, it is only natural to want to feel pride about one's living situation. This may even entail defending a total institution, such as XTC, becoming friends with staff, and supporting the policy direction of management. While living at XTC, I found that most young adults there were apathetic and seemingly content to let management make many of the important decisions affecting their living situation. This is unfortunate as the policy directives of management will likely not be in the interests of young adult residents.

3.8 Chapter Summary

In this chapter, I have attempted to describe with personal narrative some of the Goffmanian architecture of life within a total institution, in particular, a long-term care facility I previously resided in named XTC. Throughout, I have explored how: 1) the ruling relations of the health region and XTC can undercut resident identity and disregard their dignity through mortification and labeling processes; and 2) XTC subjects the individual to a regimented pattern of life that has little or nothing to do with a person's own desires or inclinations.

Before proceeding, I would like to pose the following question. Fifty-seven years after Goffman described the malevolent characteristics of total institutions, why would features such as mortification processes still be found within modern day LTC facilities like XTC? Even if we concede that such processes may produce respect for institutional staff and other residents, different self-images, and overall institutional control, do the ends

justify the means? Is there not a more humane method of producing such characteristics if they even are considered necessary? Make no mistake; I am not conceding that mortification, looping or labeling processes produce anything but misery. More than any other possible outcome, the young adult experience in LTC at XTC will likely produce a silent, passive, beaten down and submissive type of LTC resident.

Goodman (2012), writing on the state of the UK's long-term care institutions, argues that if a resident or patient experiences mortification they are receiving very poor care. In Canada, the same type of LTC resident experience is supposed to be protected against by our Constitution. That is, in so far as methods similar to what Goffman (1961) calls "mortification," and what I refer to as "labeling," affect psychological and emotional pain, their use by a LTC facility may constitute a violation of Section Seven of the Canadian Charter of Rights and Freedoms.[40]

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[40] Please see Juliana Ho (2013) for a brief discussion of Section Seven of the Canadian Charter of Rights and Freedoms.

CHAPTER 4: Emancipation, Policy Recommendations & Concluding Thoughts

4.1 Road To Freedom

Throughout most of the final year I resided at XTC, I was mentally and emotionally exhausted. Perhaps the institutional identity assaults I withstood had taken their toll. Maybe it was the fact that despite my best intentions, XTC was still a total institution. Health region and XTC management had negated or ignored all of my efforts at reforming its antiquated policies and practices. Since I had more than proven to myself that I was not a quitter, but a fighter, I began preparing myself for an imminent move from XTC into the community.

When I moved into my apartment in March of 2012, I felt ready to tackle any immediate obstacles in my new, post-institutional, living environment. While happy to have left the dependency of living in XTC, I was quickly overwhelmed with fury and frustration resulting from my uncoordinated body. Spilling drinks, knocking over plates of food, and running into tables, doorways and other furniture were occurrences every day. Having to incessantly clean up spills, pick items off the floor, and rearrange furniture was exhausting, and would cause frequent bouts of anger.

What was new to me was that I was seeing myself struggle with basic daily activities. If I had similar experiences while living at XTC, I would have simply asked the nursing staff to complete the tasks for me. Being on my own meant I had to manage such trying experiences with the often-accompanying intense negative emotions by myself. It has been an extremely humbling experience seeing and feeling myself struggle these past

years. Not only has it helped tame my anger, but it has given me insight into what I presently can do, what my limitations are, and what I need help with. For me, the concept of accepting help is no longer synonymous with weakness and shame. Don't get me wrong, I don't like it, but I have observed that those who are skilled at asking for and accepting help utilize that skill to make connections and develop friendships. Perhaps there is an upside to being physically disabled after all.

4.2 Relevance of Goffman, Institutional Ethnography & Autoethnography

Why is Goffman (1961) and his theory of total institutions relevant today? Simply because they exist right under our noses. As this thesis explicitly points out with numerous heuristic examples, total institutions can masquerade as modern-day nursing homes or long-term care facilities for disabled young adult residents. As long as there remain no unique programs for young adult residents, they will continue to be lumped together with the aged in LTC facilities. This is problematic because we have an aging population that is bound to put pressure on an already stressed health care system that may result in more totalizing LTC facilities. "Max Weber warned of bureaucratic control as a feature of modern societies; perhaps we should be vigilant and re-examine the social systems we have designed to provide health and social care for vulnerable [young] adults" (Goodman 2012: 3). Goffman's *Asylums* (1961) serves as a descriptive reminder to do just that.

In addition, Goffman (1961) is relevant from a sociological methodology perspective. Within the field of sociology Goffman was a methodological rebel. He had disdain for traditional social science that had a strong theoretical bias and that used so-called "objective" quantitative social science methods like statistics. For his book, *Asylums*

(1961), Goffman spent a considerable amount of time posing as an assistant athletic director in a mental hospital. Without the covert participant - observation methodology, Goffman (1961) could not have captured the detailed and nuanced descriptions of life in what he called total institutions. *Asylums,* is often credited with providing impetus and momentum for the deinstitutionalization movement, but without ethnographic methods, such as participant - observation, *Asylums,* as we know it would not exist. According to theorist Dorothy Smith it is difficult to understand just how ground-breaking Goffman's use of ethnography, combined with his sharp analysis was in America in the early nineteen sixties (Carroll 2010: 7). Smith describes his focus on actual people, not theoretical abstractions, as a "Goffman move" (Carroll 2010: 10). This is high praise from one of his former graduate students who became a theoretical/methodological trailblazer in her own right.

How does Smith's (1987; 2005) theory/method allow (or demand) a researcher to go beyond Goffman's (1961) descriptions and insights on total institutions? Smith's theory enables three very important actions. First, her method of institutional ethnography enables a researcher to concentrate on actual, real people in their daily lives. This would usually mean employing textual analysis, participant observation and research interviews of people living in a total institution such as modern long-term health care facilities. Goffman (1961) has been harshly criticized for writing about total institutions and their residents or inmates, and not from his subject's experience (Simpson 2016). This criticism puts Goffman in the paternalist camp of academics, researchers, and policy-makers. Of course, as argued above, *Asylums* was first published at a time when using ethnographic

methods was very progressive. Thus, comparing Goffman with contemporary paternalists would be a false equivalency. Nonetheless, one of the central messages of Smith's (1987; 2005) institutional ethnography, more or less, is: Don't ignore your subject's voice - especially your own!

Secondly, Smith (1987; 2005) blends Marxism and ethnography. Now, don't worry dear reader, I am not going to provide a hasty comparative analysis of how their theoretical concepts are similar or different in a paragraph or two. However, I will say that Smith's concept of ruling relations contains the same ontological assumption as Marx's class based theory of capitalism. That is, everyday life is always shaped by the relationship between rulers and the ruled. The basic difference is that in the modern era of capitalism, Smith is more concerned with how the social relations of the ruled and rulers play out, for example, in public schools or health-care systems, rather than a traditional economic focus of capitalists and workers. This theoretical construct is not present in Goffman's *Asylums* (1961). Furthermore, by not representing the experience from residents, patients or inmates - the ruled - Goffman is unable to fully grasp the power relations of life embedded inside total institutions. It is very strange to read about total institutions and their malevolent characteristics when the experience of those living in them is apparently not relevant or required.

The third action Smith's theory of institutional ethnography enables a researcher to do is uncover and illuminate how everyday lives of people are interconnected with the ruling relations of an institution. Throughout this thesis I have repeatedly written about experiences living in XTC where I have predominately felt systematically, as opposed to

maliciously, controlled, subjugated, labeled and silenced. Of course, merely writing about these experiences, arguably, might meet the standards of autoethnography, but it would definitely not fulfill the requirements of institutional ethnography. I traced my problematic experiences directly to institutional or health region texts/documents as a form of corroboration, evidence or data. You have to tie personal narratives to institutional practice and texts. This is, by the way, the key factor in what separates institutional ethnography from autoethnography. Ignoring the possibility of findings or evidence to support one's claims could jeopardize any emancipatory potential of an autoethnography. If validity and reliability of an autoethnography are to be equated with the credibility of the author, then it strikes me that alienated, marginalized and isolated people are exceptionally vulnerable to attempts to dismiss and/or discredit their autoethnographies by those in positions of power. For instance, I had a unit manager at XTC who in an email questioned the validity of my thesis because I was one of many residents who smoked Marijuana. I might have been concerned if my thesis was just storytelling.

To be fair, there is a considerable amount of ambiguity surrounding the methodological requirements of autoethnography. This is partly due to the fact that there is no clear explanation or consensus as to how you actually do autoethnography within the academic literature. This is further complicated with there being two different academic schools of thought on the methodology. Evocative autoethnography is primarily associated with Caroline Ellis and Authur Bochner (2006; cited in Taber 2010: 11) who ultimately believe that storytelling is the best way to say something new about cultural phenomena

(Taber 2010:12). On the other hand, analytic autoethnography is equated with Leon Anderson (2006). Anderson believes that it is the analysis of links between the self and the social, or between the narrative and the textual data that really matter (Taber 2010:12). Personally, I side with the analytic version of autoethnography. And I support Taber (2010) when she writes that autoethnographers should ask the following questions to analytically guide their respective research: "To what institutional texts does the narrative lead? How do the narrative and texts interconnect? How do the texts connect to institutional ruling relations? And finally, how do institutional ruling relations connect back to the narrative" (p. 12)

When I was in the rehab unit at XTC I quickly realized that nurse charting had the power to construct reality. This experience triggered my memory of Dorothy Smith's theory/method learned through three sociology classes and two books: *The Everyday World as Problematic* (1987), and *Texts, facts and Femininity* (1990). Critical theory may have provided some of the soul for my analysis but it was Smith's theory/method that taught me how to proceed. When I moved to long-term care at XTC, I tried to organize a young adult resident council. With the help of my research assistant, friend and former band-mate, Kirk, I personally visited and tried to enlist the membership of every LTC resident under the age of forty at XTC. I wrote a script and Kirk did the talking. Although this attempt failed, it did mark the beginning of my advocacy of young adult resident issues at XTC. Through making - the personal political - to borrow a feminist slogan I fought for rights and brought many young adult resident problems and issues to the attention of various levels of management. Through a legion of emails sent and/or exchanged with

management, I tried to understand and work through problematics I encountered living in long-term care. These emails became my research diary/narrative of sorts for my thesis. In addition, I had access to my nurse charting, health region forms, reports and policies et cetera at my disposal. So, long before I had even heard of autoethnography I was doing, more or less, institutional ethnography from an insider's perspective.

4.3 Policy recommendations

I will now turn to making a number of policy recommendations designed to improve the lives of physically disabled young adult residents.[41] Many of these prescriptions reflect the overwhelming importance of the issue of privacy in long-term health care, and the ubiquitous lack of it within total institutions like XTC. Consider the following policy remedies.

1) Young Adult Resident Council

During my tenure at XTC, I tried to start a young adult resident council aimed at identifying XTC'S institutional policies that need reforming in order to improve the quality of life for young adults. Attempting to create an organization like that involved somewhat unorthodox methods. As previously mentioned, I prepared pamphlets detailing notable young adult resident issues. Next, a former band-mate and I visited every resident who was roughly under the age of forty and tried to enlist their support and participation. With

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[41] Although there is obviously some common ground between aged and young adults in long-term care, it is out of the scope of this thesis to discursively consider or discuss them.

the exception of a few cantankerous residents who did not see the need for a separate council of young adults, our message was well received. Of course, when it came to formally getting together and deciding next steps, pretty much everyone who we talked to demonstrated apathy.

Nevertheless, a young adult resident council that identifies direction, goals, and values in the pursuit of self-determination, and effectively handles grievances with management is potentially a key component of healthy and happy lives in a LTC facility. "It is especially important that persons with disabilities living in institutional/segregated settings have considerable say in how they function when alternatives to these arrangements are limited" (Asch, Blustein and Wasserman 2009:166).   A young adult resident council would give young adults a sense of control and power over their lives that were taken away by disability and XTC. Allowing young adults to participate in the administration of their lives would conceivably reduce the occurrence of social withdrawal and disobedience by increasing social interaction. It could also help establish a sense of community, social pride and purpose. I am not saying there would not be any conflicts of opinion or personality clashes in such a resident council, but who ever said democratic politics, regardless of their scale, were a blissful free-ride?

2) Sexuality Policy For Physically Disabled Young Adults In LTC

Throughout Western Canada, some LTC institutions have policies that have dealt with, or are trying to deal with resident needs for sexual expression. Without a formal sexuality policy governing what is and is not appropriate behavior, staff in any LTC facility like XTC, may likely discourage all types of sexual expression.

Now, take into account that young adults, who comprise fairly large percentage of residents in LTC, are naturally more prone to be sexual and, arguably, know their rights and demand them. What if a LTC facility does not have a sexuality formal policy, such as XTC? Staff may formulate paranoid utilitarian and "slippery slope" arguments to justify their possible repression of the sexual behavior of disabled young adult residents. What should staff and management do in order to treat physically disabled young adult residents as complete human beings?

Regarding XTC, point number five of the Resident Bill of Rights states, "Each resident has the right to meet privately with their spouse in a room that assures privacy." The implication is that a context can be provided for a married couple where the two can be intimate without privacy being an issue. However, single disabled young adults are discriminated against! On repeated occasions, I respectfully requested the same treatment as a resident who is married for my girlfriend and me to health region and XTC management and the client advocate throughout the health region.[42] Their answer was a polite, but resounding, "No." I wish somebody had given me a time machine because I was, evidently, stuck in 1955. Why didn't someone, such as an XTC manager, upon admission to LTC tell me or other unmarried physically disabled young adults that it is mandatory to check one's sexuality and need for intimacy at the door?[43]

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[42] Please see the "Human Rights and Charter Freedoms" document in the appendix of this chapter for a detailed discussion of this issue.

[43] The issue of sexuality in LTC facilities is gargantuan in scope; too big to be thoroughly discussed within the confines of this thesis.

3) Resident Newsletter

An on-line and/or hardcopy newsletter encompassing resident interests and opinions on current events, disability issues, LTC facility issues and events et cetera should be strongly encouraged. This type of publication would give young adults an opportunity to express themselves and their interests in a constructive manner. It is very important for the young adult writers of the newsletter to have complete editorial freedom and accountability.

4) Independent Living

As mentioned in Chapter Two, Jean and I had a source ready and eager to fund the construction of some independent living apartments on the existing grounds of XTC. Had this been allowed to come to fruition, it would have made the lives of many young adult residents very much better. But the health region and XTC management rejected our young adult resident program proposal before we even had the opportunity to introduce the prospective funding agency. The bureaucratic path of least resistance won the day! The health region and XTC management, with their insidious paternalism, blew an opportunity to do something trailblazing in the area of long-term health care. Perhaps Weber was right to be pessimistic about the possibility of meaningful change within bureaucracies.

A number of independent living apartments should be made available to young adult residents who are viable candidates of such living arrangements. Residents of these apartments should receive an assessed amount of homecare. A specifically trained team of

homecare workers should be put in place to track the transition from a LTC setting to an independent living residence. If independence is the goal of some young adult residents of a LTC institution, and maximizing the independence of residents is an explicit institutional goal, then such apartments are invaluable.[44]

5) Resident Room Locks

Having the choice of increased privacy in the form of locks on resident doors is imperative. Installing locks on resident doors could eliminate untimely invasions of privacy. It is ironic that disabled young adults can legally choose to end their lives with doctor-assisted suicide, but do not have the choice to lock their doors.

Obviously, this policy only would pertain to private/single rooms – which every room on a young adult ward/unit should be. I proposed this policy to XTC management several times and each time they said, “It is in the works!” To my knowledge locks were never put on any resident room doors, young adult rooms or otherwise.

6) Building Trust & Resolving Conflict

Why would there be a need for a policy of this nature? Publicly funded LTC institutions are staffed by trained professionals who always have the best interests of resident/patients in mind. Right? Don’t get me wrong; some care providers are simply inept at working with the younger population in LTC institutions. This is not a criticism of personal character so much as it is a by-product of the fact that there are, arguably, at least

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[44] The XTC ”Bill of Rights” states that its goal is to help residents be as independent as possible.

four different categories of young adult LTC residents. As Eleanor Barbera (2008), a psychologist who has worked extensively in New York's LTC institutions, argues, different categories of disabled young adults require different staff approaches. In her words,

> - Some of our younger residents arrive with illnesses with which they've been coping for years, such as MS or ALS. These residents need assistance adjusting to the facility, but are likely to be able to integrate into the existing programming with only modest changes.
> - Many younger (and older) residents with serious mental illnesses have found their way into our system. They need regular psychiatric monitoring, but can often attend existing activities.
> - Young adults who have been ill from birth are sometimes behavioral problems because they have been institutionalized from a very young age and know how to work the system. Other times they were exempted from the discipline of their able-bodied siblings. Placement in the nursing home is the first time they are expected to behave, and experience consequences, like everyone else. Intensive initial work will help them integrate into the environment.
> - Young residents who have sudden onset of physical problems [disability] related to their lifestyle choices are generally the most difficult and time-consuming residents to work with. They require special programs and assistance with prior mental health and substance abuse issues, in addition to adjustment to their physical illnesses and loss of control over their lives. (Barbera 2008: 2)

Judging by her four categories of young adult LTC residents, LTC care providers who work with the younger population would require a considerable amount of training. In so far as building trust between young adult LTC residents and care providers go, my experience, which may only speak to a part of Barbera's fourth category, suggests LTC institutions adopt some different practices. Before proceeding in that direction I would like to take a word or two and address Barbera's fourth category of young adult residents.

Barbera's (2008) fourth point or category is almost completely misguided. She

writes as if the young adult LTC residents in her fourth category all have sudden on-set disabilities related to lifestyle choices. Further, she assumes that all young adult residents have psychiatric and substance abuse problems. This is ludicrous and just plain insulting. Not only is she victim blaming, she misunderstands the maladjusted behavior of young adults residing in LTC institutions. Her view can be seen as a self-serving justification of a burgeoning cottage industry of psychiatric, nursing, pharmaceutical, social work and management consultant professionals working with LTC facilities. According to Barbera (2008) young adults are merely the proverbial "canaries in the coal mine" serving as examples for the forthcoming historical onslaught of the baby-boomer generation in LTC facilities. If the problem young adult residents present to LTC facilities can be managed by blaming young adult resident psychology, lifestyle choices and substance abuse issues, then managing potentially demanding baby boomers may be possible without having to overhaul the whole LTC system.

Perhaps the behavior problems of young adults should be looked at as the result of a LTC institution's ruling relations mediated through antiquated and paternalistic policies and programs of social control. To be fair, behavioral issues are likely to be expected for young adult LTC residents who have suffered a sudden on-set disability. They are more than likely very angry because of physical limitations, loss of independence, control, and dreams – just to name a few. Factor in having to move into an alien environment that is more prison-like than one thought possible. In reality, both the LTC institutional relations of ruling and physical disability constraints play a role in most young adult behavioral issues. Often all it takes is a privacy violation to occur to cause trust between young adult

residents and care providers/nursing staff to begin tumbling down a very steep slippery slope towards adversarial conflict.

I can attest that young adult LTC residents who have experienced sudden on-set disabilities are quite prone to have conflict with their care providers. If conflict is fairly irregular, I recommend working out problems in an informal manner. Simply talking things through with individual care providers will probably suffice. However, if conflict is frequent a more formal approach may be required. One manner to remedy the inherently imbalanced power dynamic found in LTC facilities is to establish or strengthen the presence of ombudsmen (Nelson, 2000:59). This remedy is surely cogent and long overdue for LTC institutions, in general. However, simply balancing the perceived amount of power between residents and care providers may not solve the occurrence of conflict. Giving potentially angry residents an increase in power may just produce more confident agitators. On the other hand, the attempt to achieve harmony through equality should be attempted and applauded, not derided. That being said, neutral ombudsmen, who do not report to the health region or LTC facility management, are likely needed to investigate resident issues, complaints and incidents.[45] Additionally, I think neutral conflict resolution specialists are needed to step between a resident and nursing staff and attempt to resolve serious conflict when presented and build trust through, more or less, the following procedures.[46]

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[45] The health region's board of directors is likely to be whom such specialists would report to.

[46] Please see the "conflict resolution" document in the appendix of this chapter for a more detailed presentation of said procedures.

Key Points of Conflict Resolution Procedure

Presently and in the past at XTC, when a resident has a concern with a care provider, he/she takes the concern to the unit manager who hears the concern and then discusses the concern with the care provider. The manager gets to speak with all parties, but the resident only speaks with the manager, and the care provider hears his/her concern through the manager, not through the resident. The manager then makes a decision as to what should be done to resolve the concern. The care provider returns to care for the resident, but the resident has no idea how the care provider feels about him/her, the situation, and the resolution. Likewise, the care provider does not know how the resident feels about him/her or whether the concern has been resolved for the resident. The resident must receive care by the care provider and the care provider must provide care to the resident, but they neither have had the opportunity to fully discuss their feelings about the concern. From the resident's perspective, feeling vulnerable must be terrible. Moreover, the resident must feel that the conflicting situation was handled in a biased and secretive manner, possibly producing further agitation and conflict.

To greatly improve or fix the manner through which XTC handles concerns between a resident and care providers, it is advisable that a conflict resolution specialist and unit manager meet with the resident and the care provider so that both can discuss what happened, sort out the concerns, and arrive at a mutually agreeable solution. Having the opportunity for a resident to meet with the care provider and hear their perspective and feelings, and vice versa, is an approach that can be taken in the future to avoid difficulties

and arrive at a better understanding of each other.[47] There would need to be some rules of engagement, and certainly mutual respect would be an overriding principle. There would have to be a feeling of safety in these discussions, and I would think that the discussions would need to take place without any display of anger, name-calling, sarcasm, blaming, or any of these emotions that would result in no resolution and only ill feeling (Client Advocate, Health Region, 2008, pgs. 1-2. Amended by Scott Fellner, 2015).

This type of conflict resolution should probably be initiated in the very early stages of a newly disabled individual's residency in a LTC hospital/institution. The reason for this is simple: if a resident and care provider do not share their feelings regarding an incident involving conflict the possibility of mutual understanding, empathy and trust may be lost. For a patient, such lost opportunities may manifest themselves in antipathy, suspicion, anger or hostility and mistreatment of care providers. Similarly, for care providers, lost opportunities to foster empathy and build trust may result in indifference, neglect, suspicion and mistreatment of difficult or resistant patients/residents. Without empathy or understanding both care providers and residents are likely to treat each other as mere objects. This would not be a healthy situation for anyone, and existing unequal power dynamics between residents and care providers are likely to remain the same.

As stated above, when I lived at XTC, there was no conflict resolution between residents and nursing staff. Throughout most of my stay at XTC I had quite an adversarial relationship with the nursing staff. Since being adversarial typically requires a modicum of

[47] The union for care aids may object to this form of conflict resolution on the grounds that it may be used as a performance evaluation. That is clearly not the intent of said proposed procedures.

anger it was perfect for me at that time. At least, anger made me feel alive, as opposed to being buried by depression. Inertia, apathy and depression are as thick as thieves. I held on to anger as long as I could in order to let the activist part of me remain at the forefront long enough to hopefully alter the landscape of LTC for young adult residents.

The harsh afflictions created by unresolved conflict in LTC facilities, such as ill feelings, disrespect, anxiety, paranoia, isolation and disengagement, et cetera, can only be mended if the facility management takes some measure of responsibility for the emotional rehabilitation of its young adult residents with sudden onset disabilities. A conflict resolution policy is an essential place to start.

4.4 Concluding Thoughts

How does my thesis contribute to an understanding of total institutions? My research technique of using informal institutional texts in the form of emails with facility and health region management is, perhaps, unique and innovative. Often these emails allowed me to gain insight into issues, such as, transparency, privacy, conflict resolution, management apathy and paternalism et cetera that was not available to me through usual institutional texts. Sometimes, these emails revealed contradictions between nursing staff practice and management directives, or contradictions between nursing staff practice, formal policy and actual lived experience as a resident.

As discussed in Chapter Two, the formal program proposal for disabled young adult residents my friend Jean and I drafted and presented to facility and health region management enabled me to see and write about paternalistic and apathetic bureaucratic

ruling relations at work. After our program proposal was rejected, I began analyzing and writing about the contradictions between the health region's client-centered policy approach and what that actually means for disabled young adult residents living at XTC. Having these experiences made it clear to me just how difficult it may be to affect change within a total institution that is part of a larger bureaucratic and paternalistic health care system. Health region and facility management clearly saw the importance of creating an empowering environment for disabled young adults, but then they turned around and implemented a policy that did the exact opposite.

In the third chapter of this thesis I took Goffman's (1961) concepts, definitions and descriptions of total institutions and tested them against my own personal experiences living in a LTC facility. Despite Goffman's antiquated and disparate examples he used to support his descriptions, for the most part, they remain very appropriate and telling. I believe that interpreting and explaining Goffman's general characteristics of total institutions through the lens of my personal experience is a contribution to our understanding of them. Moreover, focusing on existing power dynamics in a long-term care facility permitted the further development of the concepts of "labeling," "looping," "mortification" and "conflict resolution," et cetera.

Goffman's (1961) concepts gave names to what I was experiencing. And even though I was a resident of a LTC facility for nine years, and not a formal prison, Goffman's use of the term "inmate" to denote people who lived in total institutions was a breath of honesty and truthfulness. In fact, regarding nursing homes or LTC facilities, residents should be referred to as death-row inmates. Once you have been admitted to and live in a

LTC facility, it is very difficult to get out alive. One has to have an extraordinary will to live to just physically exist when you reside in an otherwise hopeless total institution. These facilities are not centers for respite. Most LTC residents are aged and infirmed. According to the Saskatchewan government, the average length of stay in a LTC facility is approximately two and a half years (2018:1). [48] Now, consider that most young adult residents of LTC facilities live for much longer than two and a half hopeless years as an inmate - as Goffman (1961) would put it.[49] These inmates have committed no crime whatsoever. This is the injustice, rationale, relevancy and impetus of my thesis work.

Regardless of whether you think and feel my experience, methodologies, evidence, analyses, arguments, theorizing and recommendations are reliable, valid and generalizable, at the very least, I hope we can agree with the following three points. The health region and XTC management must: 1) actually explore the young adult LTC experience instead of assuming they know what their experience is and should be, as in the case of the Patient First Review; 2) recognize just how psychologically and emotionally harmful mortification and labeling processes can be for young adults; and 3) develop more humane and caring policy and program alternatives that foster empathy and understanding between management, nursing staff and residents.

For those of us fortunate enough to have the physical ability, mental and emotional fortitude, resources and supports to get and stay out of LTC institutions, we have the

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[48] Please see a copy of my correspondence with a representative from the Saskatchewan Ministry of Health in the appendix of this chapter. It should be noted that a statistical breakdown of age and mortality rate is not provided here.

[49] This is my inference based on lived experience as a former LTC resident.

responsibility to find the goodness, happiness and meaning to this life. Of course, this is easier said than done.

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APPENDIX: Chapter One

A) Sexuality and Intimacy Survey

<u>The Status of Specific Policies and Procedures Regarding Resident Sexuality and Intimacy in</u>

<u>Canadian Capital-District Long-Term Care Facilities</u>

Written and implemented by Alex Colgan

The purpose of this study was to gauge the prevalence of policies in long-term care facilities with regard to intimacy and sexuality among residents. It was conducted over the course of months, from December 2010 to April 2011, with each facility receiving up to three separate telephone inquiries. The author identified himself as a researcher at the University of Regina, briefly described the nature of the study, and requested to speak to the director of care, resident care coordinator, or similar authority. If the individual was forthcoming, the author would leave messages, either with facility staff or on voicemail, with his name, the nature of the study, and a return telephone number.

The research was limited to capital health regions in all Canadian provinces except Quebec, as well as the Vancouver Coastal Health Authority, which originated the 2009 document, "Supporting Sexual Health and Intimacy in Care Facilities: Guidelines for Supporting Adults Living in Long-Term Care Facilities and Group Homes in British Columbia, Canada," one of the motivating factors of this research. Due to time constraints, it was determined that the author would be unable to undertake numerous proceedings with ethics boards and other panels across the country in order to obtain policy documentation, so that any documents received and any comments given were granted freely to the author shortly after establishing contact with the relevant authority.

The results were separated into four categories. Most facilities did not respond to inquiries. Others did respond, but declined to comment upon or release any policies. Some contacted individuals stated that their facility had no policies with regard to resident intimacy or sexuality. Finally, some individuals did state that their facility had such policies; it is noted below whether or not the policies were actually released.

The following table indicates the results of the survey.

HEALTH AUTHORITY / REGION	FACILITIES CONTACTED	FACILITIES RESPONDED	POLICIES	NO POLICIES	DECLINED TO PARTICIPATE
Alberta Health Services: Calgary Zone	29	16	5	7	4
Capital District Health Authority	21	4	2	2	0
Eastern Health	14	3	0	3	0
Health Prince Edward Island	9	0	0	0	0
Regina Qu'Appelle Health Region	14	5	1	4	0
River Valley Health	15	5	0	5	0
Vancouver Coastal Health Authority	54	19	3	15	1
Victoria Island Health Authority	18	2	0	2	0
Winnipeg Regional Health Authority	38	6	1	5	0
Toronto Central Local Health Integration Network	36	4	0	4	0
TOTALS:	248	64	12	47	5

B) XTC Bill of Rights

Note: The name of the Health Region and LTC facility have been removed or given a pseudonym for the purposes of confidentiality.

XTC

Resident Bill of Rights

XTC provides health services to individuals with disabilities. The goal is to meet resident needs and assist residents in achieving their highest level of personal independence and quality of life. If an individual cannot speak on his/her own behalf, a substitute decision maker speaks for the resident.

We believe that:

1. All residents have the right to courteous, respectful, and understanding treatment.
2. All residents have the right to appropriate care and shelter.
3. All residents have the right to information about their medical condition and to make choices of treatment.
4. All residents have the right to freedom of speech.
5. All residents have the right to privacy.
6. All residents have the right to develop their potential.
7. All residents have the right to manage their personal and financial affairs.

1. **All residents have the right to courteous, respectful and understanding treatment.**

Explanation:

- Each resident's dignity and individuality is fully recognized. There is to be total freedom from mental and physical abuse.
- Each resident has the right to know who is providing care, to be spoken to, and to be listened to.

2. **All residents have the right to appropriate care and shelter.**

   Explanation:

- Each resident has the right to live in a clean and safe environment.
- Each resident has the right to suitable shelter, nourishment, dress, grooming, and care in a manner consistent with the resident's needs.
- Each resident has the right to keep and to display in their room personal possessions, pictures, and furnishings, within reason and in keeping with safety requirements and other residents' rights.
- Each resident has the right to be given access to areas within the facility and outside the facility to enjoy other activities.

3. **All residents have the right to information about their medical condition and to make choices of treatment.**

   Explanation:

- Each resident has the right to information about his or her medical condition, treatment, and proposed course of treatment.
- Each resident has the right to give or refuse consent to treatment.
- Each resident has the right to make decisions in regards to general medical condition as well as intermittent health problems and to get an independent medical opinion concerning any aspect of care.
- Each resident has the right to access their medical records according to District policy and to have their medical records kept confidential under the law.
- Each resident has the right to appoint a person to receive information about the resident's medical condition, treatment, and any transfer or emergency hospitalization of the resident.
- Each resident has the right to choose an Advance Directive. The level of treatment indicated will provide a reference point for the care team should the resident's condition worsen.

4. **All residents have the right to freedom of speech.**

   Explanation:

   - Each resident has the right to exercise the rights of a citizen and to raise concerns or recommend changes in policies and services on behalf of themselves or others to the Residents' Council, extended care staff, District administration, government officials, or any other person inside or outside the facility without fear of reprisal, reprimand, or abuse.
   - Each resident has access to the policies and procedures affecting the operation of the facility.

5. **All residents have the right to privacy.**

Explanation:

   - Each resident has the right to communicate in confidence and to consult in private with any person without interference. Residents are expected to follow established decorum and respect rights of others.
   - Each resident has the right to meet privately with their spouse in a room that assures privacy and where both spouses are residents in the same facility, they have a right to share a room according to their wishes.
   - Each resident has the right to privacy in treatment and in caring for personal needs.
   - Each resident has the right to have all research and surveys explained and to have the freedom to refuse participation.

6. **All residents have the right to develop their potential.**

   Explanation:

   - Each resident has the right to assistance towards independence consistent with individual requirements and abilities.
   - Each resident has the right to pursue social, cultural, vocational, political, religious, community, and other interests, to develop their potential, and to reasonable provisions by the facility to accommodate these pursuits.
   - Each resident has the right to choose his or her own friends.

7. **All residents have the right to manage their personal and financial affairs.**

   Explanation:

   - All residents have the right to manage their own financial affairs. Where a trustee or the facility manages the resident's financial affairs, all residents have the right to receive, on request, accounting of any transactions undertaken on their behalf.

- All residents have the right to manage their personal affairs, and have the right to appoint a responsible party to act on their behalf if health conditions prevent personal representation.

<u>Resident Responsibilities</u>

Residents not only have rights but also have responsibilities to fellow residents and to health care providers in the Program.

1. To treat fellow residents, roommates, and staff with courtesy and consideration, and to bear in mind others' rights at all times.

2. To consider that other residents may require more aid, and more urgently, than oneself. One cannot always receive service first/immediately.

3. To report promptly anything one feels needs attention; that is, safety hazards, security concerns or anything that is not right.

4. To follow the policies and procedures of the District as in effect at the time of admission and as altered from time to time.

5. To follow the no smoking regulations for one's own protection and that of other residents and staff.

6. To participate always, and with promptness, in fire and disaster drills.

7. To use with care, all supplies, linens, and furnishings as if they were one's own.

8. To give staff an opportunity to correct a complaint or grievance by speaking to them directly. If satisfaction is not obtained within a reasonable time, write or to go:

   - An elected officer of the Residents' Council/Veterans' Council
   - Management staff
   - A higher authority (i.e. Program Manager, Director of Long Term Care)
   - The Client Representative should only be approached when all attempts to communicate with the management team have not resulted in a satisfactory resolution.

APPENDIX: Chapter Two

Email From A Saskatchewan Government Representative On The "Patient First Review" Methodology

Note: To protect the confidentiality of the author of the below email I have removed his name.

Subject: RE: For Action: - Inquiry re Patient First Review. Attn
Date: Mon, 19 Sep 2011 18:13:23 -0600
From:
To: scottfellner@hotmail.com
CC:

Hi Scott,

In absence, I've been asked to provide you with the information you require.

For the patient experience component of the Patient First Review, a number of focus groups, two-hour triad meetings, and one-on-one telephone interviews were conducted during the first phase. It is not known whether young-adult long-term residents or their family members were a part of the focus groups since the names of participants were kept confidential, though I do know they were not targeted for the triad meetings nor the one-on-one telephone interviews.

However, anyone in the province was invited to complete an on-line workbook and submit it to the Commissioner's consultant team to provide their thoughts. Again, it is not known whether young-adult long-term care residents or their family members submitted such a workbook since those who submitted their thoughts were not required to submit a name and contact information.

During the second (front-line providers) and third (stakeholders) phases of the patient experience component, on-line workbooks were available to anyone who wished to share their thoughts during those phases.

The fourth and final phase of this component was a random sample telephone survey to over 1000 people living in Saskatchewan. Because this survey did not require participants to give their name and contact information, it is not known whether the group you identify below was represented in the sample.

I do not believe there was any research conducted during the Patient First Review involving young-adult long-term care residents and am not aware if any has occurred since the Review. I will forward your request for information to others in the Ministry who may

be able to answer that question, however.

I believe I've answered all of your questions, but should you require further information, just let me know.

APPENDIX: Chapter Three

Email to XTC & health region senior MGT Re: October 7, 2010 “mortification”

Note: In An Effort To Protect The Confidentiality Of Health Region And LTC Facility I Have Removed Their Names From This Email.

From: scottfellner@hotmail.com

To:
CC:
Subject: Incident today October 7, 2010
Date: Thu, 7 Oct 2010 13:47:30 -0500

Hi everyone,

At 9:30 a.m. I rang my for my caregiver, however she didn't come until 10:15. When she came I told her that I need new clothes and that the clothes on my chair were dirty from yesterday. She did not understand me and I motioned to her to give me my keyboard and she never understood that either. And then I was prepared to wheel myself to the shower room but the caregiver wrapped me up in a sheet and I could not wheel myself because the sheet gets caught in the wheels and I tried to tell her that and motioned once again for my keyboard but she never understood that and I said "fine to myself" and let her push me to the shower. She did the same thing on the way back from the shower she wrapped me in the sheet and I could not express myself to her despite my best efforts. Then once she pushed me to my room she took off the flannel sheet and left me naked in my chair and told me to put on the clothes that I tried to tell her were dirty. I tried once again to motion to bring my keyboard but she never understood and then she said "I have to go because you were late and that she was told by someone to leave me to dress myself" Once again I said and motioned to bring me my keyboard and this time she it to me and I tried to type a question to her,” When was I late?" but she still never understood what I typed for her. Then I got frustrated and accidentally knocked my drink over on my table and she got scared I think and just left my room.

All of the above took place while she left me naked in the chair and this was so mortifying for me. I believe that the staff that told her to leave me alone in the room was just trying to embarrass me and I felt very disrespected especially considering how many times I asked vocally and gestured for my keyboard. My keyboard is my only real means of communication and I was denied my rights to communicate my needs time and time again. She did not respect my dignity or my care plan.

I have brought to your attention the staff provoking me before (in a meeting in August) and

I believe intentionally because the SCA left my room briefly while she left me naked in the chair and then came back in and told me that someone told her to make me dress in those dirty clothes because I was late which I wasn't. If she would have taken the time to let me spell my needs out she would have understood that those clothes were dirty from the evening before. I know I got very frustrated but I can only be so patient and understanding, but when the caregiver acts like I am completely unable to communicate my needs all morning I am completely fatigued but I feel bad but justified in feeling very frustrated, who wouldn't under these circumstances? It is like they want me to get angry so that they can say that I got angry therefore everything the caregiver did wrong is forgivable and forgettable. I feel like staff are trying to provoke me so that the may think they are justified in further labeling me as volatile. Stressful situations in a total institution causes stressed behavior.

I don't know how much more of this I can take. The stress and not feeling safe (And feeling provoked is part of not feeling safe) has health consequences

Respectfully,

Scott Fellner

APPENDIX: Chapter Four

A) Human Rights And Charter Freedoms

Note: In An Effort To Protect Confidentiality I Have Removed The Names Of Health Region And LTC Facility & Their Employees.

Does the Canadian Charter of Rights & Freedom apply to the actions of the Health Region?

Yes. According to section 32.1(b) of the Charter, the Charter applies "to the legislature and government of each province in respect of all matters within the authority of the legislature of each province." This can be deferred only under the special circumstance of the notwithstanding clause (section 33). Although there remains some uncertainty about the exact extent to which the Charter applied to quasi-public institutions such as universities and long-term care facilities, the Supreme Court declared in that the application of the charter under section 32 applies to provincial legislation in two ways.

Firstly, legislation may be found to be unconstitutional on its face because it violates a Charter right and is not saved by s. 1. Secondly, the Charter may be infringed, not by the legislation itself, but by the actions of a delegated decision-maker in applying it. The legislation remains valid but a remedy for the unconstitutional action may be sought pursuant to s. 24(1) of the Charter.
According to Heather MacIvor,

> The Charter applies to any action that is empowered by, and undertaken in direct consequence of, a particular statute. Purely private actions and those that do not engage the relationship between the state and an individual (e.g., labour relations within a university) are not subject to Charter review. However, the resolution of private disputes under the common law must conform to Charter values, as defined by the courts.[50]

In short, any provision of the Health Information Protection Act, and any action that emanates from the application of any provincial legislation, falls well within the bounds of the Charter.

As the Health Region is governed by the Regional Health Authority, the members of which are appointed by the Minister of Health under the Regional Health Services Act, it is

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[50] M. MacIvor (2006), *Canadian politics and government in the Charter era* (Toronto: Nelson), 24.

undoubtedly a public body and thus the interactions between its administrators and residents must be construed as being under the authority of the Charter and its provisions. **Charter s. 15. (1) Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability.**

Mr. Fellner asserts that the written policy of the Health Region discriminates against him on the basis of his unmarried status. The facility's Resident Bill of Rights states that "each resident has the right to meet privately with their spouse in a room that assures privacy." He claims that he requested the same treatment as a married person by asking for the right to meet with his girlfriend in a room that assured privacy. He made this request on at least several occasions to, VP of Long-Term Care & Rehabilitation throughout the Health Region, and, the Client Representative/Advocate throughout the Health Region and was denied.

Discrimination can be identified through a three-step process called the Law test, a key Supreme Court decision that outlined how equality right claims under s. 15 of the Charter could be established. Specifically, courts must answer three questions in the affirmative in order to determine whether a law violates s. 15(1).[51] Recall that the policies of XTC, because they exist under the auspices of a public body, fall under this rubric.

> *A) Does the impugned law (a) draw a formal distinction between the claimant and others on the basis of one or more personal characteristics, or (b) fail to take into account the claimant's already disadvantaged position within Canadian society resulting in substantively differential treatment between the claimant and others on the basis of one or more personal characteristics?*

Yes. The distinction between married and unmarried residents fits the first definition.

> *(B) Is the claimant subject to differential treatment based on one or more enumerated and analogous grounds?*

Yes. The differential provision of space between married and unmarried couples constitutes a violation of s. 15 on analogous grounds. While marital status is not an enumerated right, it has been found in certain Supreme Court cases that marital status may not be grounds for discrimination.[52]

> *(C) Does the differential treatment discriminate, by imposing a burden upon or withholding a benefit from the claimant in a manner which reflects the stereotypical application of presumed group or personal characteristics, or which otherwise has the effect of perpetuating or promoting the view that the individual is less capable or*

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[51] *Law v. Canada (Minister of Employment and Immigration),* [1999] 1 S. C. R. 497
[52] Cf. *Miron v. Trudel*, [1995] 2 S.C.R. 418; *Nova Scotia (Attorney General) v. Walsh*, [2002] 4 S.C.R. 325.

worthy of recognition or value as a human being or as a member of Canadian society, equally deserving of concern, respect, and consideration?

Yes. Sexual expression is a vital aspect of human life, and the institutional infantilization and desexualization of people with disabilities is a significant issue in contemporary long-term care.[53] Furthermore, as argued in a recent Vancouver Coastal Health Authority policy document,

> the law allows human beings to do whatever is not specifically prohibited. Any attempt to deny non-prohibited sexual expression to people who are unable to remove themselves from a facility is contrary to section 15 of the Charter, which prohibits unequal treatment and discrimination based on a disability.[54]

The policy of XTC embodied in the Residents' Bill of Rights amounts to an effective denial of Mr. Fellner's right to non-prohibited sexual expression, and thus violates s. 15(1). As there is no overriding social value, within a free and democratic society, in denying unmarried disabled residents the opportunity to express their sexuality in private, it is highly unlikely that such a policy could survive by invoking section 1.

Addendum: Saskatchewan Human Rights Code

Many of the same arguments that were outlined in the arguments related to Charter s. 15(1) apply to the Saskatchewan Human Rights Code. Marital status is an enumerated ground under the SHRC, but of course the question arises as to whether or not the discriminatory practices of XTC fall under the scope of the Code.
According to SHRC section 2(1)(i.01),

> "'marital status' means that state of being engaged to be married, married, single, separated, divorced, widowed or living in a common-law relationship, but discrimination on the basis of a relationship with a particular person is not discrimination on the basis of marital status."

Section 2(1)(m.01)(iii) defines marital status as a prohibited ground. Mr. Fellner's partner has been rejected by XTC on the grounds that Mr. Fellner is not married, and not due to any actions or behaviours of his partner. Thus the policy and its enactment are discriminatory on the grounds of marital status. But does the Code apply?
XTC fulfills the definition of a housing accommodation as outlined in section 2(1)(i):

> "housing accommodation" means **any place of dwelling and includes any place where other services are provided in addition to accommodation,** but does not

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[53] Cf. Robey, K. L., Beckley, L., & Kirschner, M. (Dec. 2006). Implicit infantilizing attitudes about disability . *Journal of Developmental and Physical Disabilities 18*(4), 441-453.
[54] Breen, S., Carlson, M, et. al. (July 15, 2009*), Supporting sexual health and intimacy in care facilities: guidelines for supporting adults living in long-term care facilities and group homes in British Columbia, Canada* (Vancouver Coastal Health Authority), 14.

> include a place of dwelling that is part of a building in which the owner or the owner's family resides and where the occupant of the place of dwelling is required to share a bathroom or kitchen facility with the owner or the owner's family."

Section 11(1) of the SHRC states that

> "No person, directly or indirectly, alone or with another, or by the interposition of another shall, **on the basis of a prohibited ground**: (a) deny to any person or class of persons occupancy of any commercial unit or any housing accommodation; or (b) **discriminate against any person or class of persons** with respect to **any term of occupancy** of any commercial unit or **any housing accommodation."**

It would be this author's contention that XTC is in violation of clause (b), as it is, on the basis of marital status, denying Mr. Fellner the right to engage in private activities with his partner. The terms of occupancy at XTC favour married over unmarried individuals. This violation is redeemed neither by subsection (2), which makes an exception for same-sex housing accommodations, subsection (3), which applies only to much smaller accommodations, or subsection (4), which allows offerings of exclusive occupancy for people 55 or older.

In summary, XTC is a housing accommodation that is forbidden from denying residents privileges that are available to other residents solely on the basis of their marital status. Its policy against allowing unmarried couples conjugal time is thus in violation of the Saskatchewan Human Rights Code.

B) Email from a Saskatchewan Government Health Representative on the average length of stay in Long-Term Care by Health Region

Note: To protect the confidentiality of the author of the below email I have removed his name.

Subject: FW: Statistics or information on Average length of stay in long-term care facilities in Saskatchewan
Date: February 16, 2018 at 8:54:06 AM CST

RHA	LTC Beds - (March 2017)	Average Length of Stay (Years)
Athabasca	5	3.87
Cypress	518	1.80
Five Hills	549	1.99
Heartland	517	2.28
Keewatin Yatthé	25	3.57
Kelsey Trail	482	2.45
Mamawetan Churchill River	18	3.22
Prairie North	516	2.60
Prince Albert Parkland	598	2.80
Regina Qu'Appelle	1,916	2.81
Saskatoon	2,261	2.46
Sun Country	666	2.86
Sunrise	825	2.65
Total	**8,896**	**2.52**

Source:
Special Care Home System
Notes: