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How Does a Foucauldian Genealogical Approach Enhance the Study of Long-Term Care through a Critical Disability Lens?

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Abstract: Younger disabled adults in long-term care, particularly those with physical disabilities and chronic illnesses, receive care that does not fit their needs. This article looks at whether a Foucauldian genealogical approach would enhance a study that focuses on the societal values that have allowed this situation to persist. It looks at the historical and cultural contingencies of genealogy, and its ability to explore the complex power relations at play, in normalization and biopower. It concludes that there is a place for this approach–one that can be adapted from the 1970s approach of Foucault to fit power dynamics and positioning in care in the 2020s.

Keywords: Foucault; genealogy; long-term care; disability

1. Introduction

"All my adult life has been spent in institutions amongst people who, like myself, have severe and often progressive physical disabilities. We are paralysed and deformed, most of us in wheelchairs, either as the result of accident or of diseases like rheumatoid arthritis, multiple sclerosis, muscular dystrophy, cerebral palsy and polio. So naturally this personal experience forms a background to the views on disability that follow ... But apart from the obvious value of writing from my own direct knowledge, it is also true that the situation of 'the young chronic sick' (as we are officially and rather unpleasantly termed) highlights, or rather goes to the depths of, the question of disablement". ([1] (p. 145))

"It's dismal. I'm just here, treading water ... it feels like I'm just waiting to die like everyone else ... you see so many people pass away. I went out one day last week and one of the residents died at my table. That's upsetting to see. Because that's where we are all heading. So, we've got a conveyor belt happening here; and you know this is the last stop. (Female, 46)" ([2] (p. 477))

It is presumed that long-term care facilities are senior's homes-that only seniors live in them. The statistics [3] show there is some truth to this, as the average age in our long-term care facilities is 85, and the average resident tends to have some form of dementia. Their lives are institutionalized, with regimented schedules and a lack of independence. However, this is not the only truth. The same statistics show that 7% of the residents of our long-term care homes are younger disabled adults, aged between 15 to 64. These people could be parents of school-aged children, and they want to study, work and volunteer, and have a life expectancy way beyond that of the typical resident in long-term care. As can be seen by the two quotes above, the care they receive in long-term care does not appear to meet their needs and the situation for this group with physical disabilities and chronic illnesses has not changed in over 50 years. However, much in our society has changed in this time, with a number of landmark pieces of legislation for disabled people, from the Canadian Charter of Rights and Freedoms in 1988, to the ratification of the United Nations Convention on the Rights of People with Disabilities in 2010 (with the Optional Protocol signed in 2018), to the Accessible Canada Act in 2019. These disability rights have

been present in Canadian law for over 30 years, but it would appear that these rights are not present in the care provisions for this group of younger disabled adults who live in long-term care. Care provisions are the product of layers of policies, rules, practices, and legislations that create the institution of care, the medico-industrial complex that is ever present in the lives of these younger disabled adults.

This article discusses a proposed approach to researching the social practices that have created this situation by using a Foucauldian genealogical approach combined with a Critical Disability lens. After establishing my position as a researcher close to the inside of this issue, it examines which aspects of a Foucauldian genealogy are most impactful in the research of long-term care (LTC), particularly by problematizing concepts of power/knowledge, biopower and normalization in a history of the present.

2. Examining My Critical Disability Lens

As a disabled woman researching alongside disabled people, my work is intimately connected to a Critical Disability (CD) lens. I see that lens-and its application-as a personal statement, rather than a theory selected from someone else's work and applied by me.

Morris [4] said "[i]f ever 'the personal is political' was a fruitful and powerful concept it is in its application to the experience of disability" (p. 9). For disabled people, the need for change in crucial aspects of their life is often controlled by labyrinthine politics, localized in policies, practices and values. Viewing my research through a CD lens sets up a dichotomy in research directions between examining the everyday lives of disabled people in detail, and pursuing the socio-historical conditions that underpin the societal practices that control disabled lives. It is no easy decision. As Price [5] said, "positioning oneself in relation to disability is not a simple announcement; it is part of a complex web of discourses and politics" (p. 172). Ultimately, however, I believe we can only create lasting systemic change by tackling the deeper, historically contingent issues on which our value system is based.

My research focuses on people with chronic illnesses, particularly multiple sclerosis (MS), who are younger disabled adults living in LTC facilities. I want to understand how our society created a system where it is acceptable for these younger adults to have no other option than to live in LTC facilities, where they are often the only person under the age of 65, and, most importantly, the care they receive does not meet their needs ([2,6,7]). These younger disabled adults with chronic illness tend to be cognitively strong, but require assistance with the Activities of Daily Life (ADLs), such as dressing, eating, washing and so on. My connection to this research area comes as a disabled woman, a recipient of care, and an advocate. Advocating for age-appropriate care has been a priority of the MS Society of Canada since at least 2006. In reports such as "Finding My Place" [8] and "Continuum of Care" [9], the MS Society of Canada made the case that home care options are often inadequate for those with advanced multiple sclerosis (MS), and that those in need of more advanced care often found no other option than to move into LTC facilities ill suited to the needs of young disabled people. Furthermore, as my own disability increased, along with my increased immersion in the disability community, my concern for friends who were either living in LTC facilities or feared that LTC facilities would be in their future against their wishes increased. Through my volunteerism with the MS Society, I became friends with Mary, a pseudonym [10], who was 42 years old and had been living in a long-term care facility for five years. She spent 23 h a day in her room, she was the only person under the age of 65 in a facility of 105 people, and just 10 years previously she had been a barrel rider in the rodeo. Mary lived a dismal life, waiting to die. Interacting with people like Mary ultimately made me combine my advocacy with a return to academia, so that I could research the situation of these younger disabled people in long-term care more thoroughly.

Younger residents are isolated by their age, and their physical and emotional characteristics differ significantly from the older residents who make up the vast majority of LTC facility residents. Riazi, Bradshaw, and Playford [11] and Newland, Wilke-Tevis, Williams, Rantz, and Petroski [12] highlight that MS residents are usually at least 20 years younger, more physically disabled, more cognitively able, and with different symptom profiles than

the seniors they live with, of which as many as 90% are cognitively impaired and 65% have dementia. Newland et al. further comment on the lack of research into younger disabled people with MS living in LTC facilities, saying that those at advanced stages of the disease that require complex care have specific needs relating to pain, fatigue, and depression. They highlight that these "young, cognitively intact, well-educated" residents with MS were "more physically disabled and had a higher prevalence of pain, pressure ulcers and depression" (p. 1494) on admission than other residents presenting with pain. In addition to this, Janardhan and Bakshi ([13] (p. 51)) report that up to 90% of people with MS present with fatigue as one of their most disabling symptoms. Residents regularly report that they are not able to lie down and get up at times of their choosing, such as John's request to rest not being facilitated ([8] (p. 4)). Spending time in bed, unable to move, directly contributes to the development of pressure ulcers, so it is no surprise that Newland et al. ([12] (p. 1496)) say that "residents with MS present a significant challenge to LTC staff" and that there is a need to educate staff as to the needs of people with MS.

The lack of research in this area is seen as concerning. There are examples of research that perform the important task of documenting the lived experiences of these younger people in long-term care. For example, Barber et al. [2] use photovoice to "collect, analyze, and portray the generation of first-person accounts of younger LTC residents" (p. 480), while Hay and Chaudhury [7] say that the purpose of their study was "to conduct in-depth interviews with younger residents to increase our understanding from their points of view and lived experience" (p. 678). However. As Aubrecht et al. [6] say, "there is limited of knowledge of research that engages disabled persons and disability communities as researchers and knowledge holders, including research driven by the expressed needs of disabled people who live in long term care homes" (p. 2). Furthermore, younger disabled people in LTC cannot wait until a sizeable body of work documenting their lived experience has been achieved for this research to move on to other questions. They need research to move from "what" to "how" and "why" so that there can be deep, systemic, lasting change, from a place of knowledge and understanding. If this shift to deeper understanding does not take place, we run the risk replacing one system with another that, given the experiences Gibson et al. [14] document across a variety of care situations, may not be successful either. A Foucauldian genealogy offers opportunities to consider the "how" and "why" of this situation, offering a different approach to documenting lived experience, while working towards the same goal of systemic change for younger disabled adults in LTC facilities.

3. What Is a Foucauldian Genealogy?

The popular understanding of the word genealogy often relates to ancestry and the family tree, revealing secrets from the past. Foucault's genealogy, in essence, is no different. It looks at an issue in the present and researches its past, with a view to interrogating not just what happened, but why it happened-how did the problem emerge. While Foucault sees genealogy as "grey, meticulous and patiently documentary" ([15] (p. 139)), at the same time it is more than a record of history, of those "great" events that have managed to etch themselves firmly into our present. History is made of paths chosen, but also paths rejected, ignored or not recognized. These paths are the moments Foucault says genealogy must also define-"even those instances when they are absent, the moment when they remained unrealized" ([15] (p. 140)). For Koopman [16], a Foucauldian genealogy "involves the articulation of that which comprises a singular problematization out of a multiplicity of otherwise disentagled elements" (p. 24). He therefore implies that our current actions and problems are built on a complex historicity, embedded in a present with a developing context of its own. Tremain [17] examines Foucault's work through her disability lens and says that "Foucault's studies of abnormality, madness, and deviance . . . were not intended to provide normative responses to these phenomena, but rather were designed to show how these phenomena . . . emerged as problems to which solutions came to be sought" (p. 5). Bringing together the problematization of a genealogical approach within the context of

long-term care allows me to examine how and why the current situation for young disabled adults came to be–how issues relating to long-term care may have emerged as problems, and how the solution of younger disabled adults living in long-term care came to be seen as an appropriate response.

Foucault describes his genealogies as "histories of the present". Tremain [17] explains it by saying "Foucault's genealogies are concerned with questions about the conditions of possibility for who we are now, that is, questions about how our current ways of thinking and acting came into being" (p. 66). For Linton [18], "the social, political and cultural analyses undertaken by disability studies form a prism through which one can obtain a broader understanding of social and human experience, and the significance of human variation" (p. 117). The concept of a "history of the present" also fulfills this role of a prism through which this socio-political cultural analysis begins in the present, and is refracted through the multitude of paths descending into the past. Hence, the analogy of the prism plays a dual role; both in the creation of the problematic through a Critical Disability lens and in the unique genealogical journey through which the problematic has travelled.

There is no one way to write a Foucauldian genealogy. As Foucault says "I would like my books to be a kind of tool-box which others can rummage through to find a tool which they can use however they wish in their own area". ([19] (p. 523)). Garland ([20] (p. 366)) expands on this by saying "Foucault provides to us . . . a series of quite specific, precisely theorized analyses, each one mobilizing a customized methodology designed to address a theoretically defined problem from a strategic angle of inquiry". Hence, this research will be my Foucauldian genealogy-making the best fit that I can of the techniques and tools I see in the work of Foucault, and creating my own customized methodology. I choose to concentrate on:

- The creation of a history of the present as a place to problematize the lived experience of younger disabled adults in LTC.
- The apparatus of the institution of care, using the lived experience of these younger disabled adults as an access point, with particular emphasis on power/knowledge, biopower, and normalization.

4. Problematizing a History of the Present

In "Discipline and Punishment" [21], the first of his genealogical works, Foucault clearly states what he means by a history of the present:

> "*What was at issue was not whether the prison environment was too harsh or too aseptic, too primitive or too efficient, but its very materiality as an instrument and vector of power . . . I would like to write the history of this prison, with all the political investments of the body that it gathers together in its closed architecture. Why? Simply because I am interested in the past? No, if one means by that writing a history of the past in terms of the present. Yes, if one means writing the history of the present*". ([21] (pp. 30–31))

Hence, a history of the present of LTC is not a detailed account of daily life–of the food, or the lures that in places, or any of the other daily practices that adversely affect younger disabled adults. Instead it problematizes the "political investment of the body"–those mechanisms of power that have come together over time to create the present–such as legislation, policies, training and assessment.

Within a history of the present, Foucault recognizes the need to deal with more complexity, saying that "[t]he world we know is not this ultimately simple configuration where events are reduced to accentuate their essential traits, their final meaning, or their initial and final value. On the contrary, it is a profusion of entangled events" ([15] (p. 155)). Koopman ([16] (p. 48, p. 136)) refers to this "simple configuration" as "necessary" or "ready-made" givens, these attitudes of events that society has adopted as accepted practices. However, problematizing moves us from seeing the present in this way to open up our view of the present as a series of historical and cultural contingencies, each formed tenuously from the decisions made in the previous "present". Great danger exists in the role of

necessity in our present, to use another Foucauldian concept. Medicalized approaches to disabled people often use what could be termed as "the common sense rationale"–the reasoning given to the way that something is done, the way that it has "always" been done, and that often holds little merit. For example, care within a LTC facility follows a regimented schedule, often only allowing one bath or shower a week for residents. The reasoning behind this is "common sense" from the lens of the institution–every resident needs bathing and this is the most efficient way to do it. However, this "common sense" approach has danger attached–the danger of dehumanizing the people who require bathing, and reducing them to bodies on the conveyor belt of institutionalization. This does not have to be a "necessary given", it is a policy choice to treat disabled people in this manner. Foucault sees through this reason of necessity, saying

> "[w]hat reason experiences as its necessity or rather what different forms of rationality present as their necessary condition one can perfectly well do the history of, and recover the networks of contingencies from which it has emerged; which does not mean however that these forms of rationality were irrational; it means that they rest on a base of human practice and of human history and since these things have been made, they can, provided that one knows how they were made, be unmade". (1994, 448–49, in [17] (p. 66))

The idea of "unmaking" the basis of the "common sense" propositions that disabled people are so often presented has strong appeal. There is a need to rebuild this "base of human practice" so it is built on disabled voices, not their exclusion.

Risk and danger are concepts that are regularly applied to disabled people and the situations they live in. Foucault articulates his position on danger being intrinsic to problematization by saying

> "[m]y point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad. If everything is dangerous, then we always have something to do . . . I think that the ethico-political choice we have to make every day is to determine which is the main danger". ([22] (pp. 231–232))

Conceptually, danger and risk are mostly unrealized. Potentially, you can see that an approaching situation is dangerous, assess the risk, and, hopefully, avoid it. For example, staff in LTC facilities are often not allowed to accompany residents outside of the facility, a decision it is said to be based on the perception of risk. However, the another danger in such a practice is that it has an adverse effect on the quality of life for residents, particularly younger disabled people, for whom access to life beyond the confines of the institution is crucial. Who gets to say "which is the main danger" is a critical part of having agency, autonomy and dignity over your life, and a decision that disabled voices appear to be missing from.

Problematization represents the fundamental approach to how genealogy unfolds. Dreyfus and Rabinow [22], quote Foucault in personal correspondence as saying "people know what they do, they frequently know why they do what they do, but what they don't know is what what they do does" (p. 187) Consider the life of a younger disabled adult in long term care with fatigue as a major symptom of their multiple sclerosis. Reports gathered by the MS Society of Canada ([8,9]) tell us that while staff will put them in bed for a rest, they often do not have the time, or it is not seen as a priority in their care, to get them out of bed again, often meaning they're "put to bed" for the day at an extraordinarily early time-one person said she goes to bed at 5:30 p.m. every day. So, the facility staff know *what* they do–they put her in bed and they do not get her out of bed again. They know *why* they do it–she needs to rest, and they say they only have time to put her in bed, or it is not listed as a priority in a care assessment or some other document that guides their work. However, they *do not know* what putting this 43 years old woman in bed every day at 5:30 p.m. does to her–they do not know what it does to her quality of life, her independence and her desire to live the life of a 43 years old. This is where the danger lies, as left unchallenged, these institutional practices become embedded to such an extent that they become those "necessary givens". However, it is not my role as the genealogist to

challenge every institutional practice that fails to use a disability lens-a lens that would prize the viewpoint of the disabled individual over the need for institutional order. Instead, my role examines the complexities that led to this point, to look for underlying values that became enhanced or solidified, to look for unintended consequences in the "necessities", and therefore illuminate the contingencies that can lead us to the conditions of possibility for the present. These conditions of possibility have been built on a structure of power–a matrix of mechanisms that Foucault calls an apparatus.

5. The Apparatus of Institution of Care

Problematizing the present demonstrates that it is a complex and chaotic place made up many competing legal, economic, medical and social situations, which Foucault describes in the following way:

> "*What I'm trying to pick out with this term is a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements, philosophical, moral and philanthropic propositions–in short, the said as much as the unsaid. Such are the elements of the apparatus. The apparatus itself is the system of relations that can be established between these elements*". [23]

Tremain (2017) elaborates on this to say that the apparatus of disability allows her to move away from restrictive conceptualizations–conceptualizations that conform to the medical model of disability, and as such are at odds with my critical disability lens. She says "to understand disability as an apparatus is to conceive of it as a far-reaching and systemic matrix of power that contributes to, is inseparable from, and reinforces other apparatuses of historical force relations" [17]. My apparatus, given the scope of my research, is more precise than this. It is the apparatus of the institution of care, as viewed through my critical disability lens, and my access point to this apparatus is through the viewpoint of lived experience–the view of younger disabled adult living in long-term care. Howarth [24] says that "while traditional historians take history to be an objective process distinct from the historian's gaze, genealogy is committed to a thoroughgoing perspectivalism in which events are perceived from the particular point of view of a 'situated' researcher" (p. 128), demonstrating this key linkage between my Critical Disability lens of lived experience and genealogy. It allows me to interrogate the mechanisms within the apparatus, asking questions such as

- How is the embodiment of disabled people communicated, implicitly and explicitly?
- What technologies of power control disabled people's bodies?
- What systems of power are in place? How do these systems interlock through time, or do they? How have they been modified over time?
- How do systems of domination and subjugation work? Within the complexity of care, how are disabled people positioned as agents of resistance, or subjection, or domination?

The construction of an apparatus of the institution of care is a political process, and the ultimate product of my research, a genealogy, is a construction of reality–reality as I see it-through time and through my Critical Disability lens. An analysis, guided by questions such as these, allow for this genealogical account to legitimate the lived experience of these younger disabled adults, by demonstrating the actualization in their lives of the technologies of power the apparatus of the institution of care contains, through power, normalization and biopower.

5.1. Power

Tremain [17] says that "social power is productive of the objects on which it acts and is diffused throughout society and culture rather than first and foremost repressive and centralized" (p. 20). This Foucauldian approach to power focuses on the force relations that make up our society. More often, discussions on power are only concerned with

the terminal outcomes of power–rules that are enacted, or freedoms that are curtailed, for instance–where power appears oppressive and destructive. Rather, power is always present, and diffused throughout society. Therefore, the policies and practices we see in LTC facilities reflect this societal power relation within the institution of care, rather than the other way around. Without challenging this power structure, systemic change will not happen.

Foucault sees power relations as unstable and local, and while he calls power omnipresent, he says that this is not because "it has the privilege of consolidating everything under its invincible unity, but because it is produced from one moment to the next, at every point, or rather in every relation from one point to another" ([25] (p. 93)). Hence, for Foucault, the omnipresence of power is in the multitude of these power relations, that resolve and move on, that linger or coalesce, that exist in actions, words spoken, or seep into the fabric insidiously and silently. He goes on to say

> "[p]ower is everywhere; not because it embraces everything, but because it comes from everywhere . . . power is not an institution, and not a structure; neither is it a certain strength we are endowed with; it is the name that one attributes to a complex strategical situation in a particular society". ([25] (p. 93))

This complex strategical situation describes the apparatus of the institution of care. This institution is not a physical edifice; instead it is the power that seeps from the coalescence of legislation, rules, practices, beliefs and values that silently occupy LTC facilities. For these younger disabled adults, this power surrounds every interaction they have with staff, the choices they make in how to interact with those around them, and ultimately impacts the agency they are able to bring to their own lives, to be able to live with independence, dignity and autonomy. As Foucault says, there is a "moving substrate of force relations which, by virtue of their inequality, constantly engender states of power" ([25] (p. 93)). It is this substrate of inequality, gradually building over time, that plays such a crucial role in the governing ethos of long-term care institutions, and problematizing its creation will be a fundamental part of my genealogy.

5.2. Normalization

Foucault sees that power can be enabled through normalization-the process where ideas, practices or values come to be seen as "the norm" or "normal", with an expectation that people conform to them or be labelled "abnormal" and excluded. In Discipline and Punish [21], he says

> "normalization becomes one of the great instruments of power at the end of the classical age. For the marks that once indicated status, privilege and affiliation were increasingly replaced-or at least supplemented-by whole range of degrees of normality indicating membership of a homogeneous social body but also playing a part in classification, hierarchization and the distribution of rank". (p. 184)

Disabled people regularly face normalization as a technology of power. Hacking ([26] (p. 169)) says that:

> "the normal stands indifferently for what is typical, the unenthusiastic objective average, it also stands for what has been, good health, and what shall be, our chosen destiny. That is why the benign and sterile sounding word "normal" has become one of the most powerful ideological terms of the twentieth century".

Expectations of "normality" often become "techniques of surveillance, the 'physics' of power, [and] the hold over the body . . . It is a power that seems all the less 'corporal' in that it is more subtly 'physical.'" ([21] (p. 177)). It could be thought that life in LTC allows these younger disabled adults to be normal–that in this environment of care, they fit in. However, the data [3] shows that this is not necessarily the case, as they are not "typical" residents-85 years old and has some form of dementia. Hence, my research will examine

the ways that this lack of normality challenges the mechanisms of social control that the institution of care exerts over these younger disabled adults, explicitly and implicitly.

Rosemarie Garland-Thomson [27] flips the notion of having to "fit" the norm to concentrate on those who "misfit". A structuralist, Garland-Thomson argues that

"[f]itting occurs when a generic body enters a generic world, a world conceptualized, designed, and built in anticipation of bodies considered in the dominant perspective as uniform, standard, majority bodies. In contrast, misfitting emphasizes particularity by focusing on the specific singularities of shape, size, and function of the person in question". (p. 595)

Therefore, in a world purposely built for those that fit-for "normal" people-the consequences for those who "misfit" are that they are destined to live in a world purposely designed to exclude them. Garland-Thomson goes on to describe the privilege of anonymity given to those who "fit", concluding "[w]hen we fit harmoniously and properly into the world, we forget the truth of contingency because the world sustains us" (p. 597). However, she cautions that there is a "fragility of fitting", given that "[a]ny of us can fit here today and misfit there tomorrow" (p. 597), a reminder that disability is the only minority group that anyone can join at any time.

The consequences of "misfitting" in LTC facilities not designed with these younger disabled adults in mind are huge. Long-term care resident Vicky Levack describes LTC facilties as places people go to die, not to live, with food that is "flavourless and mushy", designed for residents with no teeth [28]. These younger disabled adults simply do not "fit" into this existence. They don't fit the norm outside of LTC facilities, and they don't fit the norm inside it either. Younger disabled adults facing aging and death on a regular basis, as the average LTC resident only lives for 2.5 years, whereas they potentially will live for decades. While documenting experiences of aging, one resident told Barber et al. [2]:

"I'd rather be with younger people. I mean when you stop and think about the reality of it. "Oh, my best friend is ninety-eight years old. They could die tomorrow, you know". Like, it's not a good idea to make too close an attachment with these people". (p. 476)

Hay and Chaudhury ([7] (p. 682)) examined these younger adults in relation to the quality of life, finding "frustrations with other residents and living with the ill and dying were reported by numerous residents . . . "I feel like I'm going to be like that. I'm going to be one of those patients"", and for Persson and Ostwald ([29] (p. 28)), the direct contact with death on a regular basis surfaced, with one resident saying "[s]he passed away due to a heart attack. I didn't get to say goodbye or anything like that. And those things are tough. You have a lot of people who pass away here. And that never goes away". It is no surprise to see these comments repeated across time, space and place. Just as the profile of the average resident is consistent across Canada and a number of other countries from the Global North, so too are the experiences of these younger adults living in long-term care facilities. In her discussion on crip time, Kafer [30] addresses this situation by saying that "the present takes on more urgency when the future shrinks" (p. 37). She goes on to set the "fetishization of longevity" (p. 40) against "a culture that continually supports cutting services to disabled poor people and that continues to warehouse disabled people in institutions and nursing homes, two practices that very well may ensure those disabled people do not live long lives" (p. 41). Hence, the issue of living in this "non-normative" situation may be directly contributing to shortening the lives of these younger disabled adults.

Foucault sees such power in the norm that he sees it as having the strength to regulate-even replacing juridical power, saying that "[a] normalizing society is the historical outcome of a technology of power centered on life" ([25] (p. 144)). He goes on to say that the law operates more as a norm, and "is increasingly incorporated into a continuum of apparatuses (medical, administrative, and so on) whose functions are for the most part regulatory" ([25] (p. 144)). For people who live in long-term care facilities, the power of the institution of care positions them as bodies incapable of achieving "normal" societal standards and therefore they are institutionalized away from view. The power/knowledge paradigm is

used to collect data from their own bodies, through regulated assessment procedures over which they have no control, providing data that further emphasizes their distance from this constructed, contingent societal norm.

5.3. Biopower

　　Tremain [17] defines biopower as "a historically specific combination of normalization and population management conducted through vast networks of production and social control" (p. 56). This combination of normalizing and population control techniques make biopower an all-encompassing tool for managing lives, and is felt most keenly by disabled people.

　　Biopower is exerted in many ways, from surveillance, to data collection, to medical case notes to all manner of population measure and control that allow governing forces to control lives. For Foucault, bodies that can be controlled in this manner are seen as "docile bodies"—"[a] body is docile that may be subjected, used, transformed and improved" ([21] (p. 136))-and "docile bodies" that self-regulate are easier to manage and manipulate than those that have to be controlled by force. Within the context of care, docile bodies do not push back against the institutionalized practices that they live under. Anecdotally, I was at a meeting for staff from a variety of LTC facilities a few year ago, where it was asked why people with MS have behavioural problems-a position shared by many in the room. After some discussion it became clear that these "behavioural" problems were from younger disabled adults with MS who refused to accept institutional practices as the norm, and refused to behave as "docile bodies". The expectation of docility coupled with the biopower exerted by the institution of care creates tensions in the lives of these younger disabled adults.

　　Foucault says "*[h]ierarchized, continuous and functional surveillance may not be one of the great technical 'inventions' of the eighteenth century, but its insidious extension owed its importance to the mechanisms of power that it brought with it. By means of such surveillance, disciplinary power became an 'integrated' system, linked from the inside to the economy and to the aims of the mechanism in which it was practiced.*" ([21] (p. 176)).

　　Here, Foucault strikes at many of the elements of biopower that make it a crucial concept for my research. Power that reinforces hierarchy, or norms, typically also reinforces societal practices that see disabled people as worthless. Further, when this power is linked to the economy, disabled people in long term care become part of a massive system that creates jobs for staff, requires resources to run the institution, and therefore, must by measured and managed by a system of government. They become a commodity in this "integrated system", rather than a person. Brown [31] says that "neoliberal political rationality does not merely marketize in the sense of monetizing all social conduct and social relations, but, more radically, casts them in an exclusively economic frame, one that has both epistemological and ontological dimensions" (p. 62). Reflecting on this economic frame is crucial to tracing the emergence of decision making in our LTC facilities. The cracks within our long-term care system were cruelly exposed in the early months of the COVID pandemic, with many disabled lives lost from inadequate policies and procedures. Simply, the system, with its reliance on its technologies of power rather than the lives of those it was meant to care for, failed. Understanding why the institution of care was constructed in this way is crucial to preventing it from happening again.

　　Foucault goes on to say that "[t]hanks to the techniques of surveillance . . . the hold over the body, operate . . . without recourse . . . to excess, force or violence. It is a power that seems all the less 'corporal' in that it is more subtly 'physical'" ([21] (p. 177)). This "subtly physical" use of power, this "insidious" use of surveillance, is enacted on disabled bodies in such a manner that it creates the illusion of necessity. Shildrick and Price [32] examine the application process to the Disability Living Allowance in the UK. The twenty-eight page report requires applicants to give increasingly personal details about their bodily incapacity, because, as they note, "the state sponsored model of disability promotes individual failing above any attention to environment and social factors" (p. 102). They talk of the need

for the applicant to "take personal responsibility in turning a critical gaze upon their own bodies" (p. 102), demonstrating the power of this remote surveillance, that disabled people are forced to present themselves at their worst to access the assistance they require. Perhaps most insidious is the request that "the more you can tell us, the easier it is for us to get a clear picture of the help you need" (p. 103). Recalling Garland-Thomson [27], there is no privilege of anonymity for the disabled body. Instead, there is the expectation that docile bodies will readily submit detailed personal "failings" in order to submit to the judgment of an unseen power that will form its own "clear picture" of the help needed. The role of assessment and judgments, implicit and explicit, is seen in formal assessment tools such as those created by interRAI, "a collaborative network of researchers and practitioners in over 35 countries committed to improving care for persons who are disabled or medically complex". InterRAI has produced a number of "instruments"–assessment tools"–that have become accepted as industry standards in many countries for the assessment of disabled people potentially requiring care at a variety of levels. However, the approach tilts firmly towards the medical model of disability, the expectation for docile bodies. Choosing just one example of many, within a section on psychosocial wellbeing, a question to assess unsettled relationships includes the statement "covert and/or open conflict with or repeated criticism of staff" [33]. As previously mentioned, attitudes expressed by younger disabled adults are seen as "behavioural problems", and through these assessments, these expressions of independence are codified and ratified in a way that give preference to the docile body, over their desires to live an age-appropriate life with dignity and autonomy.

With regard to medical examinations, Foucault says

> "[t]he superimposition of the power relations and knowledge relations assumes in the examination all its visible brilliance . . . People write the history of experiments on those born blind, on wolf-children or under hypnosis. But who will write the more general, more fluid, but also more determinant history of the 'examination'-its rituals, its methods, its characters and their roles, its play of questions and answers, its systems of marking and classification. For in this slender technique are to be found a whole domain of knowledge, a whole type of power". ([15] (p. 184))

This "slender technique" is the genealogical approach, with its ability to examine the medicalized approaches of biopower-so readily apparent in medical examinations and assessment-and reconsider them through the lens of those younger disabled adults in LTC, to look for those discontinuities where disabled voices must be present.

6. Conclusions-Looking Forward

There are many strengths to using Foucault's genealogical approach for research based in institutionalized care, particularly one that explores the emergence of the societal practices that led to younger disabled adults being cared for in LTC facilities. Foucault's genealogical method provides an investigational style that allows a thorough examination of the "how" and "why" rather than merely the "what". It allows for a level of complexity in the discovery of the emergence of societal practices, to look at decisions that were made and hence opportunities that were missed. Most importantly, Foucault's approach to power relations, particularly in the areas of normalization and biopower, provide a bridge to disabled lives and their manipulation by the institution of care.

A Foucauldian genealogical approach can be used to concentrate on three major areas. First, history matters in a values-based investigation of care. A comparison with Paul Hunt's [1] Stigma demonstrates that change is slow, and in creating a history of the present, problematizing the emergence of our current practices concentrates on why they emerged, rather than what practices emerged. Second, power relations matter. The complex web of power relations within any institution are magnified for the younger disabled adults that are the focus of my research, given that these institutions and their practices were not designed with them as in mind. Furthermore, the all-encompassing role of biopower within a medicalized, normalized environment must be dissected to be understood, as it forms the data on which the "rules" are based, creating the apparatus of the institution

of care. Finally, a Critical Disability lens matters. Rosemarie Garland-Thomson [27] looks beyond the exclusion and alienation created by normalization in mainstream society, and sees that "the experience of misfitting can produce subjugated knowledges from which an oppositional consciousness and politicized identity might arise". (p. 597). As someone who researches from the inside, my experience of misfitting is an essential condition of my research creation that not only investigates the emergence of societal practices shaping LTC for young adults, but also produces knowledge generation as a condition of action, so that disabled people will be the main voice in creating the care they want, where they want it, when they want it, and how they want it.

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