

Costly Bodies: An Examination of Long-term Care and COVID-19 using
Autoethnography and Critical Discourse Analysis

by

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A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF SCIENCE

Department of Disability Studies

University of Manitoba

Winnipeg

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Abstract

The COVID-19 pandemic intensifies the challenging realities of institutionalization for many disabled people living in care facilities. This thesis project examines the impact of the COVID-19 pandemic on the lives of disabled people living in institutions from the perspective of a care provider. This project is situated within the theoretical frameworks of the political/relational model of disability, along with Crip theory. Data was collected from personal journal excerpts, as well as from health care protocols released from the Government of Saskatchewan and governing health care bodies. Data analysis through analytic autoethnography and critical discourse analysis revealed themes including isolation and societal understandings of the disposability of disabled individuals. This thesis project looks to communicate the realities of long-term care and highlight the harm health care protocols had for disabled individuals during the COVID-19, from the perspective of a care worker, while challenging ideas of institutionalization and merging thoughts around aging and disability studies.

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Acknowledgments

I would like to thank my loving and supportive family. Mom, Dad, and Regan, you have continually been in my corner, allowed me to change my mind, and stood by me throughout the hardest of times. This thesis is a testament to your grace and love for me.

Thank you endlessly to Dr. Nancy Hansen, you have continually believed in the importance of this project and are forever blowing my mind in lectures and life chats. Thank you for allowing me to grow into the understanding of disability and allyship I have today, and for always making me laugh.

Thank you also to my committee members Dr. Diane Driedger, and Dr. Chrissy Kelly. Your guidance and expertise have helped me immensely.

To Cara, thank you for creating a space where I could heal and encouraging me throughout this process. You have influenced this project more than you could possibly know.

Finally, thank you to my partner in life, John Erik. Thank you for your endless support and encouragement. I am eternally grateful for long chats about theoretical frameworks, your intentional thought process, your strong editing eye, and that you make me coffee in the morning.

Dedication

This project is dedicated to Wilhelmina Jantz. Your name and legacy are remembered here.

Chapter 1: INTRODUCTION AND THEORETICAL FRAMEWORK

Who Am I?

I have been working in long-term care as a recreation worker since 2016. I grew up around long-term care, as my mother has worked at a long-term care home for her entire career. I spent many summers and evenings tagging along with my mom to work, and volunteering for events and excursions. This experience developed into a job working in long-term care throughout my post-secondary education, and I have been working in long-term care in various capacities ever since. I also spent much of my youth volunteering with organizations that support disabled youth in accessing summer camp, and other recreation services such as dance classes. Because of these experiences, I have always thought of disability as a normal part of the life course. My work and volunteer experience were part of what inspired me to pursue a graduate level education in disability studies. I was passionate about working with disabled people living in long-term care and the greater community and felt that a program focused on disability studies would help me grow my skill set.

The COVID-19 pandemic began shortly before beginning my graduate level education and I saw my work change drastically as a result of health care protocols put in place for residents living in long-term care. The changes I saw in long-term care, coupled with my education in disability studies, inspired me to select this topic and write about the ways that COVID-19 has changed long-term care and life in general for disabled people living in institutions. As I learned about the history of institutionalization and the injustices disabled people have and continue to face at the hands of a society that looks to relegate them to residual space, the fringes of society, I began to question how the effects of institutionalization were present in my workplace in long-term care. Another final inspiration for this project, was a recent

discovery I made about my own paternal great-great grandmother. As with many families, disabled, institutionalized relatives are often the best kept secret, and mine is no different. My re-introduction to my own family heritage and personal links to a woman who spent over sixty years of her life, held in an institution, largely forgotten about, pushed me to take a closer look at institutionalization and its' lasting effects in our health care system.

Through my studies, I have been challenged to acknowledge my own ableism, personal biases, and the ways that infantilization and stigmatization of disabled people are present in my own thinking. As a result of my professional and personal relationships with disabled individuals, I entered my graduate studies, thinking that I was an excellent ally to the disability community; instead, I was challenged in my understandings of disability, independence, and the ways I contribute to ableism in society. There have been several "Aha!" moments, that seem glaringly obvious in hindsight, that were most certainly only monumental discoveries for me, because I grew up in, and benefit from an ableist society. I am a product of that society, a society that values knowledge that comes from people who look a certain way, people who can stand at the front of the room, a society that perpetually relegates disabled people to residual spaces.

This thesis is the result of the continued dismantling of ableist understandings of disability. Learning about the history of mass institutionalization of disabled people, eugenic practices, and the remaining influences of these harmful practices in the modern health care system, inspired me to take a critical look at long-term care environments. The COVID-19 pandemic exacerbates issues already present in long-term care such as isolation and problematic understandings of quality of life of people living in long-term care (United Nations, 2020). The themes discussed in this thesis were certainly present before the pandemic, and COVID-19 has only increased issues with long-term care for disabled individuals. It is, however, important for

me to acknowledge that these issues were likely prevalent before the pandemic, and a disability studies lens has simply allowed me to examine the realities of institutional long-term care. This thesis project examines long-term care in the context of institutionalization and the challenges that COVID-19 has presented for people living in long-term care.

Background

Many disabled individuals are not provided the necessary support or opportunities to live independently within their communities and instead, must live in custodial or institutional care facilities (Linton, 2020; People First of Canada, 2010). Custodial care is defined as non-medical care that assists with activities of daily living such as dressing, bathing, eating, and/or toileting (CMS, n.d.). Long-term care provides accommodation, meals, and 24-hour nursing and personal care for people with complex medical needs (Alberta Department of Health, 2021). While long-term care is generally thought of as a service provided to the elderly, it is used by disabled people of all ages who need complex medical care that they are unable to access in the community (Alberta Department of Health, 2021; Petretto et al., 2019). In a news article by Stephen Frost, he states “Those in nursing homes are referred to as elderly, with ‘underlying conditions,’ or ‘vulnerable.’ These are euphemisms that avoid using the word disability” (Frost, 2020, p. 1).

This thesis is contributing to the growing area of study that is connecting aging and disability studies, to decrease the stigmatization of disabilities associated with aging (Priestley & Rabiee, 2002; Petretto et al., 2019). Institutional care for disabled individuals is strongly criticized by disability rights activists (People First of Canada, 2010). These critiques became stronger during the COVID-19 pandemic. Institutional care facilities such as long-term care have seen some of the highest incidence of COVID-19 mortality (Public Health Agency of Canada,

2021). Disabled individuals living in institutions have been subject to strict rules because of public health precautions, such as confinement to personal rooms for prolonged periods of time, and limitations in their ability to see family members or the greater community outside of care facilities (Saskatchewan Health Authority, 2022).

Though there are a wealth of publications about COVID-19, there is a gap in the body of scholarly work that communicates the realities of long-term care and other healthcare institutions during the pandemic (CIHI, 2021a; Clarke, 2021; Akhtar-Danesh, et al., 2022). This project also contributes to research that is exploring both aging and disability related concepts. In *The Aging-Disability Nexus*, authors discuss how most publications in either disability or aging studies do not consider these topics in the context of interdisciplinary and intersectional scholarship (Aubrecht et al., 2020). There are few publications that combine concepts of aging and disability through a critical disability lens, an intersectional view that can be helpful when examining settings such as long-term care where disability and aging often intersect (Chivers, 2020). This thesis project will acknowledge that in instances of long-term care, distinctions between aging and disability do not reflect lived experiences, and that critical perspectives of both aging and disability can contribute to more nuanced care, policy, and understanding that this thesis examines (Barken & Santinele Martino, 2020).

There is published data on mortality rates in long-term care throughout COVID-19 from the Canadian Institute for Health Information (CIHI) showing that long-term care residents account for 3% of all COVID-19 cases in Canada but 43% of the COVID-19 deaths across the country (CIHI, 2021a). Data from Statistics Canada and retrospective cohort studies, reflect these findings, showing “excess mortality due to a positive COVID-19 test” in long-term care settings (Akhtar-Danesh, et al., 2022, p. 2; Clarke, 2021). This thesis reframes long-term care as

institutional health care and draws on ideas that long-term care is that last socially acceptable form of institutional care (Herron et al., 2021). This project aims to convey the harsh realities of institutional living during the COVID-19 pandemic, and some of the challenges that disabled people who are residents in institutional care face during this recent public health crisis. This project examines my experiences working in long-term care and health care throughout the COVID-19 pandemic, and the ways that the pandemic affects the daily life of disabled people living in institutions using both analytic autoethnography and critical discourse analysis. The first-person voices of disabled individuals living in long-term care are not able to be included in this project due to ethical and confidentiality concerns. The following sections will provide a background on, and a brief overview of these concepts, and define them in the context of this thesis.

Purpose of Study and Research Questions

Although there is significant data to show that disabled individuals living in long-term care and other institutions have had negative health and well-being outcomes because of the pandemic, there are few academic resources discussing the challenges of isolation and realities of institutionalization disabled individuals living in these settings during the pandemic. The purpose of this thesis project is to explore the following question: How has the COVID-19 pandemic impacted disabled people living in institutions from a care worker point of view? “Institutions” in this project will include both government and privately run facilities where disabled people may live. The World Health Organization defines an institution as a facility where disabled people, elderly people, or children live in a congregate setting away from their families or communities (WHO, 2011). This project aims to convey the realities of living in medical institutions such as long-term care during the COVID-19 pandemic and the ways that

institutionalization affects the lives of disabled individuals. The following are related questions that address research concerns and that guide and the research process:

- How has COVID-19 changed daily life in care institutions from the perspective of a care worker?
- What elements of COVID-19 and institutionalization are of particular significance for disabled individuals living in institutional care?
- How has COVID-19 highlighted the social positioning of disabled populations living in institutional care?

If this project can establish that there are areas that long-term care institutions and the health authority has failed to meet the needs of disabled people required to utilize institutional care for complex medical needs, then this research could impact future policy regarding long-term care, disability, and management of public health crises. This project stems from ideas in Kafer's political/relational model of disability that environments "stigmatize particular kinds of bodies and minds" (Kafer, 2013, p. 6). The research questions above aim to reveal how institutional environments such as long-term care facilities have further stigmatized disabled people throughout the COVID-19 pandemic. This project establishes the need for a systemic shift in long-term care culture to adequately meet the needs of disabled individuals requiring complex medical care that is not available in the greater community. Finally, this project demonstrates that the protocols enacted throughout the pandemic affecting those living in long-term care were harmful and increased isolation and negative health outcomes for residents of long-term care facilities.

Theoretical Framework

This autoethnography is informed by two theoretical frameworks: the political/relational model of disability, and Crip theory. The following sections will provide an overview of these theoretical frameworks and discuss their contextual relevance with regard to this thesis project.

The Political/Relational Model of Disability

The political/relational model of disability was developed by Alison Kafer in their book *Feminist, Queer, Crip* “as a friendly departure from” two more common models of disability known as the medical model and social model of disability (Kafer, 2013, p.7). Marcia Rioux, the late Canadian disability studies academic and researcher, characterizes the medical model as one that looks to cure and correct disabilities through “biological and/or genetic screening” or “treatment by medical/technological means” (Rioux, 1997, p. 6). The medical model views disability as an anomaly and often portrays disability as a medical and social burden. *Rethinking Normalcy*, Michael Oliver explains that the medical model uses a “personal tragedy” model of disability, which suggests disability is some “terrible chance event that occurs at random to unfortunate individuals” (Oliver, 2009, p. 20). Tanya Titchkosky (2011) discusses the medical model, saying it insists disability is a problem possessed by individuals, and is unrelated to normative order of society.

Because the medical model so often characterizes disability as something to cure, control, and/or correct, “what disability is, can be a representation of our fear” (Titchkosky, 2011, p. 53). An ableist society seeks to control this fear, and the perceived risk of disability by “eliminating the range of unacceptable and devalued bodily forms” (Garland-Thomson, 1997, pp. 14-15). However, disability is everywhere, and ought not be feared. Garland-Thomson (1997) states that “disability is the most human of experiences, touching every family – and if we live long enough

– touching us all” (p. 5). Even if we eliminate congenital disabilities, a process that is extremely ableist, there is no controlling for the environment, for acquired disability. In their essay published in *The Aging-Disability Nexus*, FitzGerald (2020) states that “both aging and disability are normative aspects of being human, albeit complex and varying ones” (p.88). Would it not be easier then, just to make environments more accessible, designing for disability from the outset, and expecting disability to be present?

It is in response to these questions and to critiques of the medical model, that the social model of disability was established. The social model highlights disability as a social pathology that assumes “disability is inherent to the social structure” (Rioux, 1997, p.7; Ladau 2021). The social model focuses on distinguishing between the notions of impairment and disability, with an impairment being defined as a “functional limitation within an individual caused by physical, mental, or sensory impairment” (Runswick-Cole & Goodley, 2013, p.69). Disability, however, is defined as a loss or limitation of opportunities to take part in desired life and/or community on an equal level with others due to physical or attitudinal barriers (Runswick-Cole & Goodley, 2013). The social model, however, is not without its critiques. For example, the social model has been criticized as not connecting the experiences of impairment and disability (Oliver, 2009). Many disabled people feel that their disability is part of their identity and the way the social model “doesn’t connect, with the experience of impairment” (Oliver, 2009, p. 24; Ladau, 2021; Kafer 2013).

Kafer, in their political/relational model of disability, contrasts the medical model that views disability as an individual issue with a relational model that views disability as a reality created by “ideological systems that attribute normalcy and deviance to particular minds and bodies” do not prioritize disability and/or accessibility (Kafer, 2013, p. 6). The

political/relational model of disability also expands on the social model of disability that completely separates the concepts of impairment and disability (Kafer, 2013). Contrarily, the political/relational model suggests that impairments and social factors of disability can exist in tandem (Martin, 2013). Kafer (2013) sees disability as a fluid and complex topic that should be the focus of more “questions, rather than firm definitions” (p. 11).

This model acknowledges the relationship of personal factors, physical, and social context, and that the ‘problem’ with disability is not individual bodies or minds but “built environments and social patterns that exclude or stigmatize particular kinds of bodies and minds” (Kafer, 2013, p. 6). Chouinard et al. (2016) discusses that “rethinking disability as a socially and spatially produced from of exclusion and oppression and recognizing the capacity of disabled people to challenge or transform such disabling social relations and spatial structures” contributes to critiques of an individualized model of disability (pp. 2-3). A strength of the political/relational model is it allows space for medical interventions while remaining critical of the biases towards elimination of disability that are prevalent in the medical industry (Hall, 2019). This model of disability critiques the political nature of the medical view of disability and looks to critique medical approaches rather than rejecting them outright. This political/relational model also creates space for acknowledging the challenges that come with disabilities, while recognizing that these challenges cannot be separated from their social context or causes (Kafer, 2013; Brilmyer, 2018)

The political/relational model of disability is utilized in this thesis project to highlight an oppositional perspective to the medical model that views disability as a medical burden, an idea that has been perpetuated throughout the COVID-19 pandemic. This model of disability also promotes the concept that disability is not a binary idea of impairment and disability or disabled

and non-disabled; it can be a fluid and complex concept. The political/relational model also plays an important role in this project as it examines the multiple factors of disability such as personal, social, and environmental factors. This project utilizes the political/relational model to examine long-term care institutionalization and the policies of health care authorities during the COVID-19 pandemic and their impact on disabled individuals living in institutional care.

Disabled people are not one-faceted individuals, and they live full and complex lives (Berne, 2018). One of the principles of disability justice, outlined by Patty Berne, is that “disabled people are whole people” and within this idea, that “each person is full of history and life experience” (Berne, 2018, p. 27). Disabled people are so often seen as just that, their disability, and while disability may certainly play a role in their lives and the way they interact with the world, “primacy is given to disability over other key elements” (p. 75). A gap in the political/relational model of disability, is that it does not address the intersectionality experienced by many disabled people who also experience discrimination as BIPOC, queer, trans, religiously diverse, and/or femme people (Morris, 1991; Piepzna-Samarasinha, 2018). Goethals et al. (2015) state that “people with disabilities are frequently assumed to share the same views, experiences, and priorities, regardless of gender, age, cultural background, sexual orientation, socio-economic status, religion, and other categories of difference”, when in fact, the disability community is as diverse as the world it occupies (p. 75). As a person who does not experience intersectionality in many of these ways, it is important for me to acknowledge these realities are multiply marginalizing and for this reason I have also chosen to root this project in the theoretical framework of Crip theory.

Crip Theory

Crip theory is a theoretical framework that began to take hold in the early parts of the 21st century (McCruer & Cassabaum, 2021). In *Crip Theory: Cultural Signs of Queerness and Disability*, Robert McCruer discusses the ways that Crip theory can be used to “resist the contemporary spectacle of able-bodied heteronormativity” (McCruer, 2006, p. 3). Essentially Crip theory seeks to challenge heteronormative, ableist expectations placed on humans as they move through the world (Bone, 2017). Crip theory strives to affirm the “embodied experiences of disability and the knowledges that emerge from such experiences”, while remaining critical of restrictive language, neoliberalism, and barriers to accessibility (McCruer & Cassabaum, 2021, p. 1). Neoliberalism is generally associated with privatization of services and governmental deregulation, but it is also strongly linked to a focus on individual responsibility and within this social understanding, disabled people are often viewed as “costly bodies that use up limited healthcare resources” (Sakellariou & Rotarou, 2017, p. 3). Fitzgerald (2020) states that “to have needs or to participate in care is marked as both an unfortunate occurrence and an individual failing” (p. 91). Sally Chivers (2020) discusses how it is therefore beneficial to Crip care and health advice provided to those accessing long-term care that may be needed with disabilities and disabilities associated with aging. A crip perspective on disability, health, and aging, challenges “the misunderstanding that aging with a disability is necessarily negative by asserting disability central to human existence” (Chivers, 2020, p. 53). Disability activist Judy Heumann (2020) discusses how it is important to acknowledge disability as a “natural part of the aging process; thus, the fact that people acquired disabilities as they age should be accommodated, so people can remain active in their community” (p. 72). If we expect and plan for disability, we can ensure that systems are in place to help all individuals access the services and community they desire.

As discussed previously, it is important to include a theoretical understanding of disability in this project that intentionally creates space for multiply marginalized individuals. Hall (2019) explains Crip theory as being a highly inclusive understanding of disability that “invites coalitions among pathologized persons” (p. 1). Hanebutt & Mueller (2021) expand on the potential inclusivity of Crip theory by stating that it “allows for a critical and expansive look at disability as an aspect of identity and culture that holds inherent value” (p. 1). An understanding of disability that is rooted in this inclusivity is an important element of this thesis project. While the political/relational model of disability does acknowledge the societal factors of disability, it is also important to include a theoretical framework that is critical of normative standards of body and mind, and of systems such as institutionalization that look to control the bodies and minds of disabled people.

Crip theory attempts to promote inclusion of individuals who are self-diagnosed or undiagnosed with disabilities including those who lack a “medically acceptable, doctor-provided, and insurer-approved diagnosis” (Kafer, 2013, p. 12). It is important to understand that disability can be seen as a continuum and that certain people may not always have an evident disability or may not always experience symptoms of their disability. Individuals who could be considered disabled may also choose not to identify with these labels due to stereotypes and stigma associated with disability labels (Ladau, 2021). It remains important to include space for such individuals in conversations around access and disability. For example, a study from Bogart et al., (2018) found that experiencing stigma associated with disability was one of the greatest factors in whether a person self-identifies as disabled. It is, however, no less important to provide equitable access to people, whether they feel as though they identify as disabled or not.

The Futurities of Disability

A final important facet of both Crip theory and the political/relational model of disability is a focus on the futurity of disability and disability culture (Hall, 2019; Kafer, 2013). Often, disability is portrayed as a worst-case scenario and that a disabled life is “not worth living” (Titchkosky, 2011, p. 34; Fristch, 2016). Crip theory highlights a resistance to the personal tragedy narrative of disability presented by the medical model. In their book, *Care Work: Dreaming Disability Justice* (2018) Piepzna-Samarasinha, discusses the importance of Crip futurities, and the radical ways that Crip communities, Crip humour, Crip wisdom, and Crip love make futures for themselves. She expands on this point saying that it is “radical to dream a liberated future by and for sick and disabled” people (Piepzna-Samarasinha, 2018, p. 249). Kafer (2013) critiques social norms by asking why a good future is always one without disability?

The political/relational model of disability politicizes the conversation around disabled futures by challenging rhetoric around the quality of life of disabled people (Kafer, 2013). With the political/relational model of disability, Kafer centers conversations about futurity, but also examines the way a future is often portrayed as one that does not include disability by saying that “disability, in other words, becomes the future of no future” (Kafer, 2013, p. 33). Kafer describes a concept also explored in aging studies, one that challenges normative ideas of time and highlights the futurity of disability as not necessarily a future in time, but an “elsewhere – and perhaps, and elsewhen” where disability is valued and understood (Kafer, 2013, p. 3; Aubrecht, Kelly, & Rice, 2020).

During the COVID-19 pandemic, it has become more important than ever to discuss the futures of disabled people. A societal response to this pandemic has been to view disabled people as disposable, and health regions have continued to make decisions that show that society does not believe disabled lives are worth spending medical resources on (Andrews et al., 2021;

Goggin & Ellis, 2020). One may ask why it is important to talk about futurity in a project that examines long-term care, where the average length of stay is approximately two years (Hoben, et al., 2019)? Rice et al., (2017) encompasses the need for futurity by stating that a Crippled future is one built in response to disabled and aging bodies “by imagining a time and place for disability and difference” (p. 217). Disability continually operates outside the normative understandings of space and time, and a disability-focused futurity is one that makes space for these operations and understands that disabled lives hold value in the spaces they are in (Rice et al., 2017). It is important to include theoretical frameworks that account for disabled futures. For this reason, Crip theory and the political/relational model of disability are valuable additions to the theoretical framework of this project, as they are utilized to analyze disabled futures and critique systems of power that result in institutionalization, isolation of disabled individuals, and ableist understandings of disability.

Scope and Limitations of the Study

Individuals living in institutions have been uniquely impacted by the COVID-19 pandemic. The COVID-19 pandemic has shaped the ways that long-term and institutional care are viewed by society. This thesis project attempts to communicate the realities of institutional living during this global pandemic through my experiences of working in long-term care in Canada. The current cultural spotlight on long-term care in Canada provides an opportunity to rethink the way we institutionalize disabled people, and this project will contribute to this body of work. This project will also contribute to the growing body of working that is linking aging and disability studies and working to decrease the stigma around disability identities in aging populations.

This project will include written excerpts from journals and other health care documents starting in March 2020 through January 2022. Autoethnography will be utilized to provide context to institutional practices during the pandemic and how they have affected disabled individuals. Critical discourse analysis will also be used to analyze health care protocols published by the Saskatchewan Health Authority. The personal reflections included in this project are based on my time working in a long-term care facility in Saskatchewan, Canada during the global COVID-19 pandemic. Health care protocols examined for this project were published by the Saskatchewan Health Authority or its affiliate organizations. It is beyond the scope of this project to examine other health care settings or the experiences of disabled people living in the community during the COVID-19 pandemic.

As with all research methods, autoethnography does have limitations; with a limited participant pool, it is important to ensure findings are transferable. Autoethnography can be challenging because the author must ensure to not speak for other's experiences as they cannot quote or breach the confidentiality of others. One of the challenges of autoethnography is maintaining a research focus although there may be other engagements in a research environment (Anderson, 2006). For example, because data is being drawn from experiences at the author's place of work, there are times when a professional responsibility may conflict with a research interest. It is important to balance these research interests to ensure a professional environment is maintained throughout the timeline of the project.

Critical discourse analysis (CDA) is about seeing language, not as some abstract thing, but as something with meaning that may have strong social outcomes. CDA can be carried out on part of a text or on a text as a whole (Patel, 2020). It is beyond the scope of this project to do full document discourse analysis for each excerpt; however, this project will look at the excerpts

of importance in detail to explore any implicit meanings of communication (Mogashoa, 2014). Excerpts were chosen through a targeted search of available publications that met the inclusion criteria for this project. Griffin (2007) states that discourse analysis is about revealing the operations of power, of how knowledge and truth are produced and about the effects that these discourses have. This project will analyze the selected excerpts to reveal this power dynamics and the possible effects of each discourse, whether intended or otherwise.

Chapter 2: REVIEW OF THE LITERATURE

This chapter consists of a literature review focusing on important concepts for this research project including disability, institutionalization, and the effects of the COVID-19 pandemic on the disability community; specifically, individuals who are living in long-term care institutions.

Disability

The definition and understanding of disability can be as unique as each individual disabled person. The *United Nations Convention on the Rights of Persons with Disabilities* defines disability as “long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others” (International Paralympic Committee, 2012). The *Accessible Canada Act* defines disability as “any impairment, including a physical, mental, intellectual, cognitive, learning, communication or sensory impairment — or a functional limitation — whether permanent, temporary or episodic in nature, or evident or not, that, in interaction with a barrier, hinders a person’s full and equal participation in society” (Accessible Canada Act, 2019, p. 1).

However, in writing this project, it has become increasingly apparent how important it is to include the voices of disabled people in defining disability. Disability is a personal experience and therefore personal definitions of disability may reflect a person’s lived experience. For example, Neil Marcus (2008), a disabled actor, artist, writer, and activist states that “disability is art, it is an ingenious way to live”. In her book *Dismantling Disability* (2021), Emily Ladau states that “disability is a state of being, a natural part of the human experience” (p. 9). A person’s interaction with disability or impairment is a deeply personal experience and individuals

may choose to identify with a disability or not depending on their own identity, level of comfort, and their own interaction with the stigma associated with disability (Ladau, 2021).

Throughout history, disability has been defined with different language and understandings. Historically, individuals with disabilities who were likely to be institutionalized were often referred to as “morons”, “idiots”, “feeble-minded”, “mentally delayed”, or “handicapped” (Baynton, 2011). While these terms are highly disrespectful, derogatory, and often considered slurs in modern language, these terms were originally used by medical professionals as a medical diagnosis of disability. These historic uses of language highlight the generalization of disability in the era of popular institutionalization and that the focus was not on specific diagnoses, let alone specific care or nuanced understanding of disability. As society’s understanding of disability has changed, the ways that disability is referred to have changed as well.

It is also important to acknowledge that not all experiences of disability are homogenous. Disability can be congenital, meaning that individuals are born with a physical, intellectual and/or sensory impairment (Bogart, Rosa, & Slepian, 2018). Many instances of disability, however, are acquired, meaning that “a disability that has developed during the person’s lifetime” (Employers for Change, 2022, p. 1). Acquired instances of disability may be caused by an event or incident that causes injury or long-term impairment, or that may produce challenges in “learning to adjust to one’s new reality” (Tallman & Hoffman, 2017, p. 133; Stuntzner & Hartley, 2014). Additionally, individuals with disability may experience increased incidences of possible traumatic events through stigmatization, exclusion, bullying, and/or experiences of chronic pain and medical challenges that can contribute to intersecting disabilities (Tallman & Hoffman, 2017; Piepzna-Samarasinha, 2018). For example, Piepzna-Samarasinha (2018)

theorizes that ableism and “all those systems of oppression are locked up tight” and contribute to intersecting marginalization of disabled people (p. 22). Disability is so often viewed through a binary understanding of either abled or disabled but that viewing disability “through a binary lens can have profound consequences” that exclude potential members of this community and increase societal stigma associated with disability (Jawadi, 2022, p. 1). In situations where stigma, triggers, or medical hurdles are present, intersectionality of disability or other forms of marginalization may be present

In context of this project, the term disability will refer to a set of circumstances, whether invisible or visible, that may impact the ways that a person interacts with the world around them. Disabled people will also refer to any person who self-identifies with a disability, as it is important to acknowledge that every person’s experience of disability varies and that individuals should be allowed to choose how they identify. This thesis project examines populations living in long-term care that may include younger disabled individuals, as well as older people experiencing disabilities associated with aging. Most social theories and research do not address the cumulative experiences of aging and disability over a life course (Putnam, 2002). Older people often think of limitations in function as something that is appropriate or expected for aging, and they are therefore less likely to identify as disabled, even if they have challenges accessing environments or performing tasks (UNRWA, 2017). Kelley-Moore et al. (2007) state that “a high proportion of older adults who are classified as disabled, do not consider themselves disabled” (p. 2). This disconnect in identity can be linked to the stigma associated with ideas of disability (Kelley-Moore et al., 2007). By normalizing the idea that disability can be part of a normal life course, and decreasing the stigma around identifying as disabled, these challenges can begin to be addressed. The residents I was working with throughout the course of this project

would most often describe themselves as disabled. Many of the residents I worked with most closely are under the age of 65 years, with residents' ages ranging from their mid-20s to over the age of 90; however, there is always a variance in age and disability present in long-term care environments.

Naue & Kroll (2010) discuss the importance of bridging knowledge between disability and aging and creating a shift in understanding that decreases the stigma around both these populations, instead of adding to it. Part of this bridging is beginning to acknowledge those with disabilities associated with aging as disabled people. Chechik (2019) acknowledges the complex nature of these labels by quoting Dr. Will Cox who stated that "labels are complicated because on one hand we need words and labels for things to just be able to talk about issues, but then also they can kind of bring with them stigma or stereotypes" (p. 1). Labels are indeed complex, and stigma is real, and yet, by including those who are disabled living in long-term care, including older people, in these definitions, it can reduce the stigma. Chechik (2019) states that "changing language is changing perception" (p. 1). This project is contributing to the movement of changing perceptions about disability, and as a result will include older people with disabilities in the definitions of disabled people.

This project utilizes identity first language that is stated by many in the disability community as preferred language when referring to disability. Identity-first language (IFL) states the disability first in a description of a person and is used to demonstrate that disability is a part of a person's identity (Ladau, 2021). Identity-first language is often adopted with the goal of normalizing disability and to communicate that disability is not a bad word that needs to be separated from a person's identity (Ladau, 2021). Disability advocate Lawrence Carter-Long states that suggesting that "disability is simply a 'difference' and has no impact on a person's life

is a very privileged position to take” (Carter-Long, 2016, p. 1). To acknowledge disability, and name it for what it is, reduces stigma, increases accessibility, and works to “interject a disability consciousness into everyday situations that, thus far, too many have been able to ignore or take for granted” (Carter-Long, 2016, p. 1).

It is important, however, to acknowledge that members of the disability community may feel differently about this topic, and this project will hold space for all views on this topic from those within the disability community. There are cases where individuals prefer person-first language (PFL), that uses the format of ‘people with disabilities’ to separate a disability as a defining characteristic of an individual (Ladau, 2021). A push for person-first language is based on the ideas that society should be “realizing people are so much more than their disabilities and to place disproportionate emphasis on this one characteristic does them a disservice” (Collier, 2012, p. 936). In cases where individuals referred to in this thesis prefer person-first language, this language, and any other preferred language, will be utilized.

Institutionalization

Throughout history, there has been a pattern of maltreatment in social movements such as institutionalization and eugenics and it is important to highlight this disability history to provide context for disability in a modern-day health care context. People First of Canada (2010) defines an institution as any facility where people who are labeled as having a disability are “isolated, segregated and/or congregated” (p. 4). It is also important to acknowledge that People First states that an institution is not defined merely by its size but can be any environment or facility where people do not have or are not allowed to exercise control over their lives and their day-to-day decisions (People First of Canada, 2010). Institutionalization of individuals with disabilities

began in North America during the nineteenth century and these institutions have taken on many names including asylums, institutions, and developmental centers (Dyck, 2014; Linker, 2013). Although these facilities have taken on several different monikers, they have all been used to house individuals seen as deviant, defective, or a burden and have been linked to serious instances of maltreatment (Linker, 2013).

Institutionalization has been seen as a piece of the larger eugenics' movement, which aimed to ameliorate humanity by disposing of members seen as weak or undesirable (Kelves, 1999; Dyck 2014). The theory of eugenics was pioneered by Francis Galton, who first defined the term in 1883 (Ball, 2021). Galton drew on and changed findings of Darwin's theory of evolution and survival of the fittest and created the theory of eugenics to speed up this process by decreasing unwanted genetic traits and "dispensing of the undesirables" in the human population (Kevles, 1999). Eugenics was not only a societal norm, but through the nineteenth century was the "law of the land" throughout the Canadian provinces, as well as in the United States, and Europe (Grenon & Merrick, 2014, p. 2).

The practice of eugenics, and negative attitudes towards disabilities, gave rise to institutionalization throughout much of the Western world as people with disabilities and other 'undesirable' individuals were removed from public society (Brown & Radford, 2015). Radford and Park (1993) state that "the mentally deficient were to be removed from society, where they were seen as inefficient, obtrusive and largely unwelcome". The history of the eugenics and institutionalization movements has pushed disability to the fringes of society, creating an out of sight, out of mind phenomena where society does not see disability visibly in their communities and therefore does not address the support needed to make spaces accessible for all individuals. Chouinard et al. (2016) highlight this idea that if disabled people are kept separate "it reduces the

need to make meaningful change to the physical and social environments beyond the disabled person's home" (p. 11).

Institutions, which have been referred to as asylums, hospitals, sites of incarceration, residential schools, and/or training centers grew in popularity throughout the nineteenth century, largely as a result of the industrial revolution (L'Arche Canada, 2014; Ben-Moshe 2020, Chapman, & Carey, 2014). With the rise of the industrial revolution, individuals with disabilities were seen as less productive or efficient in the workplace using cost-benefits analysis, and therefore less valuable to society (Ben-Moshe, 2020). Because disability was viewed as a problem with the individual, people with disabilities were more commonly seen as a burden on an improving and more efficient society (Ben-Moshe 2020). The practice of institutionalization was portrayed as a solution to the 'social problem' of disability and was communicated as a positive decision by medical professionals to parents who would never have been provided support to raise disabled children in their communities (L'Arche Canada, 2014). These attitudes towards disability were reflected in the conditions of institutions across Canada. Many institutions were often overcrowded, underfunded, and understaffed, and these situations often resulted in "abuse, neglect, and isolation of residents in institutions" (People First of Canada, 2010, p. 4).

In 1876 the Government of Ontario opened what is widely considered one of the first institutions in Canada called the Orillia Asylum for Idiots (Brown & Radford, 2015). The number and popularity of institutions in Canada continued to grow until the mid 1970s, especially in Western Canada, where large rural institutions were established to house people with disabilities (Government of Ontario, 2018). One of the factors that contributed to this growth was the rise of the medical model of disability and the power that medical professionals

such as doctors and social workers held in society (Grekul, Krahn, & Odynak, 2004). Dowbiggen (1997), discusses how medical and scientific knowledge was increasingly viewed as the solution to perceived ‘social issues’ such as disability and therefore the opinions of medical professionals of the time held great influence. As disability was increasingly perceived “as a medical condition...many asylums were re-named hospitals”, a rebranding that made it seem like these institutions were the best option for people with disabilities who were viewed as sick, vulnerable, or unable to contribute to society (Brown & Radford, 2015, p. 19).

Institutions were generally utilized to remove unwanted individuals from society, a population that included criminals, individuals in poverty, people with intellectual and/or physical disabilities, aging people with complex medical needs, and individuals requiring mental health support. It was, however, common for all these people to be housed together in institutions with very little support given (Grekul, Krahn, & Odynak, 2004). People living in institutions were rarely given basic levels of care, let alone individual support systems or care plans that could have been needed. Institutionalization was portrayed as a one-stop solution for ridding society of individuals who may be perceived as a burden and decreasing levels of criminality and poverty, issues that were often linked to disability, whether the correlation was accurate or not.

Although the popularity of historical institutions that housed large numbers of disabled individuals has dwindled with the rise of the disability rights movement, there are remnants of the institutional system apparent in current health care systems. For example, as of 2017 there were still 900 people being held in large institutions in Manitoba, Alberta, and Saskatchewan (Spagnuolo & Earle, 2017). This number has since lowered further with the closure of the Valley View Center in Moose Jaw, Saskatchewan (Neufeld, 2019). The closure of this institution was announced in 2012 and “over the course of seven years...every one of the institutions’ 153

residents” were transitioned into the community (Neufeld, 2019). Valley View Center was permanently closed September 24, 2019, when the last two residents moved into the greater community (Neufeld, 2019; Boulanger et al., 2021). Much of this deinstitutionalization advocacy has been done by groups such as People First of Canada who, through a campaign known as *The Freedom Tour* in 2008, and class-action lawsuits have exposed the harms these institutions (L’Arche, 2014; Remember Every Name, 2022; Boulanger et al., 2021). This continued advocacy by People First of Canada and other survivors of institutionalization has resulted in the closure of institutions across Canada such as The Huronia, Rideau, and Southwestern Regional Centers (Ontario) in 2009, and the Michener Institute (Alberta) in 2013, and the Valley View Center (Saskatchewan) in 2019 (Remember Every Name, 2022; People First of Canada 2010; Neufeld, 2019).

After the closure of institutions in Ontario in 2009, some survivors chose to pursue the route of litigation where “a thirty-five-million-dollar settlement was reached between the Government of Ontario and survivors” (Boulanger et al., 2021, p. 434). Litigation work for survivors of Manitoba institutions is ongoing (Boulanger et al., 2021). Although there have been numerous closures of institutions, people continue to be institutionalized in group homes, long-term care facilities, and nursing homes (Boulanger et al., 2021). Additionally, People First of Canada (2010) states that there are numerous ‘trap-doors’ to institutionalization such as hospitals and group homes where disabled people are ‘warehoused’ because there are no appropriate settings for them to live in their communities. Society is often reluctant to support disabled people living in the greater community and public support is often not available to support disabled people in living independently (Andrews et al., 2020). As a result, disabled individuals often wind-up living in custodial care settings such as long-term care, nursing homes, seniors’

homes, or traditional regional institutions (Spagnuolo & Earle, 2017). It is important to acknowledge the ways that modern health care practices draw from an institutional past in discussions about COVID-19 and institutionalization as the impact of modern institutional practices on disabled people has been concerning throughout this pandemic.

The Government of Canada has signed and ratified documents from the United Nations Convention on the Rights of Persons with Disabilities and has committed to tackling human rights issues for disabled citizens (Boulanger et al., 2021). Upon a visit to Canada, however a Special Rapporteur on Rights of Persons with Disabilities, issued a statement that “access to support is not considered as a right [in Canada], but rather as a social assistance programme dependent on the availability of services” (Devandas-Anguilar, 2019, p. 1). There is continued work to do when it comes to the rights and freedoms of disabled people to receive support while living in their communities and in de-institutionalizing long-term care for disabled individuals. For example, the process of closing and de-institutionalizing the Valley View Centre in Saskatchewan was a “process seven years in the making” (Neufeld, 2019, p. 1). Through this process a transition committee, that included input from Inclusion Saskatchewan, was established that prioritized a person-centered approach where “each Valley View resident was empowered to make choices about where they wanted to live, how they wanted to live, and who they wanted to live with” (Neufeld, 2019, p. 1). The closing of Valley View Centre shows that supporting disabled people living in their communities can be done successfully through collaborative support work.

History of Long-term Care Facilities

The history of long-term care in Canada is challenging to trace because of differences in language and jurisdiction of health care throughout the past. Historically, elderly and disabled

individuals often lived with family, however for individuals without this option, religious or community groups often provided care facilities or other support (Emodi, 1977; Kishchuk, 2010). Disabled and elderly individuals who did not have family to support them, or whose families were unable to support them financially were sent to informal boarding houses or larger regional institutions (Emodi, 1977). Before 1905, when the province of Saskatchewan was formed, individuals with mental, physical, and psychiatric disabilities were deemed to be “dangerous lunatics” and were incarcerated in the Stony Mountain Penitentiary in the neighbouring province of Manitoba (Kishchuk, 2010). The first facility for disabled people in Saskatchewan was the Saskatchewan Provincial Hospital for the Insane in North Battleford that opened in 1914 and to which, patients were then transferred from Stony Mountain Penitentiary (Kishchuk, 2010). There was a discussion at the time whether this facility should use a cottage system, where patients are kept in smaller homes or a pavilion system where large numbers of patients are held in one large building (Wickham, 2012). At the time, the architectural firm hired for the project recommended a pavilion approach with room for over 1000 patients held in four large wards (Kahah, 1965). This decision built a foundation for large institutions for disabled people in the province of Saskatchewan (Kishchuk, 2010).

The *Mental Defectives Act* was then passed in 1930, with the goal of separating individuals with psychiatric and intellectual disabilities and sending those with intellectual disabilities to training schools (Mental Defectives Act, 1931). This legislation was subsequently amended in 1936 to become the *Mental Hygiene Act*, a legislative act that would be amended several times through the coming years (Kishchuk, 2010). The formation of the *Mental Hygiene Act* in Saskatchewan was the first time “approved homes” were established where disabled people could be involuntarily committed, as opposed to being held in large institutions or

penitentiaries (Mental Hygiene Act, 1954; Kishchuk, 2010). In the 1920s and 1930s private hospitals began to form a link between previous large institutions and nursing homes of today (Emodi, 1977). These changes in care for elderly and other disabled individuals aligned with the creation of disability pensions after the end of the First World War and the Old Age Pensions Act in 1927 (National Union Research, 2007)

Nursing homes or long-term care facilities as we know them, were developed as large institutions faced overcrowding and many beds in hospitals were occupied by long-term patients who could not be discharged, due to lack of accommodation that could meet their medical needs (Emodi, 1977; Kishchuk, 2010). The Government of Saskatchewan opened the first long-term care facility in Woseley, Saskatchewan in 1921, however non-profit organizations and religious groups proceeded to open many more long-term care facilities (Kishchuk, 2010). It was these non-profit and religious organizations that formed the Saskatchewan Association of Special Care Homes in 1958 to communicate with the provincial government and coordinate with each other (Kishchuk, 2010). This organization is responsible for the first sets of standards for long-term care facilities developed in 1964 (Kishchuk, 2010). Alongside these standards, the Government of Saskatchewan also developed physical and functional design standards that determined the level of care that could be provided in individual facilities (Kishchuk, 2010; Government of Saskatchewan, 1999). Long-term care facilities are not without their modern critiques however, Tremain (2021) describes long-term care “as carceral environments that enable the segregation and management of certain populations deemed to be unproductive and disposable” (p. 14).

In 1999, the Government of Saskatchewan announced that it would begin implementing Resident Assessment Instrument- Minimum Data Set (RAI-MDS) to electronically classify the care required by individuals in long-term care facilities (Government of Saskatchewan, 1999;

Daly & Armstrong, 2016). Resident information gathered through RAI-MDS contributes, even today, to care planning and long-term care facility placement in the current Saskatchewan health system (Daly & Armstrong, 2016). As the movement of deinstitutionalization began in conjunction with the disability rights movement, long-term care facilities that emphasized less complex care were generally replaced by smaller group homes, or Home Care services that were introduced in the early 1980s (Kishchuk, 2010). As of 2018, there are 8517 long-term care beds available in the province of Saskatchewan (Braedley, et al., 2019). There are currently 161 long-term care facilities operation in Saskatchewan (CIHI, 2021b). Long-term care environments have evolved throughout the years to their modern iterations; however, they still are influenced by the institutional history of Saskatchewan.

COVID-19

The SARS-CoV-2 (COVID-19) virus, first discovered in the final months of 2019, has since spread to become a global pandemic that has dramatically impacted people all around the world (WHO, 2022). However, the COVID-19 pandemic disproportionately impacted disabled people in all aspects of life and health (Andrews et al., 2020). As of January 2022, the World Health Organization has reported over 300 million cases of COVID-19 and over 5.5 million deaths resulting from the virus (WHO, 2022). The United Nations policy brief on a disability-inclusive response to COVID-19 demonstrates that this pandemic has exacerbated pre-existing inequalities in society and has caused adverse effects for disabled individuals including negative impacts on physical, mental, social, and emotional wellbeing (United Nations, 2020). The policy brief states:

The global crisis of COVID-19 is deepening pre-existing inequalities, exposing the extent of exclusion, and highlighting that work on disability inclusion is imperative. People with disabilities—one billion people— are one of the most excluded groups in our society and are among the hardest hit in this crisis in terms of fatalities. (United Nations, 2020, p. 2)

Linton (2020) of the Disability Justice Network of Ontario discusses how disability communities, especially those living in long-term care institutions, have been adversely impacted by the pandemic. Unfortunately, the institutionalization of disabled people has been a tragic reality during the COVID-19 pandemic, resulting in high rates of mortality for those living in long-term care or other facilities (Linton, 2020). Although the COVID-19 pandemic has been challenging for all, it has been particularly challenging for those living in long-term care institutions where disabled people have faced severe isolation and even confinement to their bedrooms (Saskatchewan Health Authority, 2022; Linton, 2020). Disabled individuals living in institutional care settings have consistently been limited in their ability to see their friends and family, participate in greater communities, or participate in activities that may interest them outside of their facilities, or even their rooms for large portions of this pandemic.

Throughout the COVID-19 pandemic there has been a focus from health care professionals on underlying health conditions and how they impact a person's outcomes when diagnosed with COVID-19. Although individuals with physical disabilities are at increased risk of negative outcomes from COVID-19, a study from March of 2021 demonstrated that having an intellectual disability was the strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent factor other than age for COVID-19 mortality (Gleason, et al., 2021). There are also concerns about the role of ableism in accessing treatment and medical services as a result of medical rationing due to COVID-19 (Andrews et al., 2020). If

medical resources are scarce, as has been seen during the COVID-19 pandemic, and disabled people are seen as having poor quality of life by nondisabled society, they may not receive access to medical care, even when they need it (Goggin & Ellis, 2020). The COVID-19 pandemic has illuminated areas of ableism that were already present in health care and greater society. This project will examine how the COVID-19 pandemic has impacted disabled individuals living in institutional care.

There has been scholarly literature published about the COVID-19 pandemic in Canada, as well as Saskatchewan, but no literature that examines the experiences inside long-term care facilities throughout the COVID-19 pandemic. There are several publications that examine the mortality rates experienced by long-term care facilities, such as a study from Thompson et al. (2020) that found that long-term care residents made up 62.5% of total COVID-19 deaths in Canada. Additionally, there are several commentaries published in scholarly journals that examine specific issues for long-term care during COVID-19 in Saskatchewan, such as family presence or using rapid review to identify areas of improvement (Tupper et al., 2020; Petrucha et al., 2022). Although these articles do discuss long-term care and COVID-19, they do not examine the experiences of long-term care for institutionalized disabled people throughout the COVID-19 pandemic, nor do they examine the specific protocols and the way these affected residents of long-term care facilities. Finally, this project also adds to the growing body of literature that is bridging topics of aging and disability studies.

Chapter 3: METHODOLOGY AND PROCEDURES

This project utilizes the qualitative research methods of analytic autoethnography and critical discourse analysis and is informed by the theoretical frameworks of the political/relational model of disability and Crip theory. The methods aim to answer the primary research question: “How has the COVID-19 pandemic impacted disabled people living in institutions?” By answering this question this project also attempts to address the literature gap of projects that discuss the experiences of institutionalized disabled people during the COVID-19 pandemic, while merging the topics of aging and disability studies as highlighted in the literature review. This chapter will review the methodology that will be used for project, data collection, and data analysis.

Methodology

Autoethnography

Autoethnography is a research method that values the researchers own experiences as meaningful data (Ellis, Adams, & Bochner, 2011). This method uses writing as both a research practice and a tool. The term autoethnography is derived from the words *auto*, meaning personal experience, *ethno*, meaning cultural experience, and *graphy* meaning to write, describe, and analyze (Ellis, 2004). Autoethnography, therefore, seeks to “describe and systematically analyze personal experiences” and use this data to understand cultural phenomena and experiences (Holman-Jones, 2008, 210). If ethnography is the researcher immersing themselves in a culture or society and writing about the people and/or sociocultural phenomena, autoethnography is the researcher immersing themselves in an environment and writing about themselves to highlight cultural concepts or phenomena. It provides a deeply personal and, hopefully, relatable analysis

of concepts. Duncan (2004) states that in using autoethnography the researcher is not trying to become an insider in the research setting but that they are, in fact, the insider, and that the context is their own. Chang (2007) describes the methodology of autoethnography as undergoing the typical ethnographic research process, included data collection, data analysis, interpretation, and report writing. Chang (2007) further describes the autoethnographic research process by stating that researchers:

Collect data by means of participation, self-observation, interview, and document review; verify data by triangulating sources and contents; analyze and interpret data to decipher the cultural meanings of events, behaviours, and thoughts; and write autoethnography. (p. 209)

Autoethnography is a deeply self-reflexive method of research. Self-reflexivity is a process gaining traction in research and refers to the process of a researcher considering the ways that they themselves may impact the research through personal experience, biases, interactions, and interpretations (Tracy, 2017). Ethnography is often said to provide ‘thick’ description, meaning it provides context and details of the cultural and social phenomena (Poulos, 2021). Poulos (2021) states that autoethnography develops “richer and thicker” analysis due to its “realist” and personal accounts. Autoethnography is generally grounded in postmodern philosophies. Postmodernism is based on the idea that there are many ways of knowing or types of knowledge and truth that are valid and legitimate (Neuman, 1994; Wall, 2006). Postmodernism operates with an understanding that no way of knowing should be privileged over others and is therefore a good fit for work in disability studies that values the lived experiences of disabled people as valuable knowledge and data (Wall, 2006). Autoethnography seeks to convey the experiences of groups of people, and it is important to understand these lived

experiences as valuable knowledge. In a 2008 publication, Holman-Jones eloquently describes autoethnography by saying that it is:

Setting a scene, telling a story, weaving intricate connections among life and art, experience and theory, evocation, and explanation...and then letting go, hoping for readers who will bring the same careful attention to your words in the context of their own lives". (p. 208)

An inspiration for the use of autoethnography for this project is Paralympian and author Heather Kuttai, who utilized autoethnography for her master's thesis, an autoethnography that became her book *Maternity Rolls: Pregnancy, Childbirth, and Disability* (2010). Kuttai discusses the need for stories about disability and ableism to be told, "and that, in the telling, [these stories] have the ability to bring about change" (Kuttai, 2010, p. 35). The experiences of disabled people and communities have been silenced throughout history and continue to be largely ignored or deprioritized. This pattern has continued during the COVID-19 pandemic as the needs of disabled people have been continuously ignored, even when their real-life experiences could have provided much needed guidance to non-disabled communities. By bringing these stories of long-term care during the COVID-19 pandemic to the forefront, it is my hope that they can highlight the changes that need to take place in institutional care environments. These untold narratives have power to shift societal understandings of disability and long-term care.

Autoethnography can be utilized to share personal experiences that demonstrate societal factors such as ableism. For example, Kuttai states that disability is an "ideology that informs many of our cultural ideas of self and other, as well as what constitutes acceptable and celebratory bodies, political stances, public policy, and language" (Kuttai, 2010, p. 39). In sharing the stories of long-term care during the COVID-19 pandemic, even from my perspective as a care worker, it is

my hope that information about health policy, language, and ideas of disability can be communicated.

There are many factors that drew me to an autoethnographical study. In doing so, I had to examine my own biases towards positivist research. I am, without a doubt, the product of an academic world that prioritizes positivist research. So, while I was consistently drawn to qualitative methods, there was certainly internal conflict of whether it counted as ‘real’ science and research. A respite to this dilemma was the frank and honest instruction of Dr. Christine Kelly. Through in-depth reading, I grew to understand the bias towards positivist research and knowledge, and that, even today, qualitative researchers are often required to defend their research as valid science from critiques saying that qualitative research has “no way of verifying their truth statements” (Denzin & Lincoln, 2005, p. 11).

This bias rears its head in disability studies perhaps more often than we would like to admit. Here is the thing about the academe; for better or for worse, clean, straightforward, positivist research with double-blind randomized control trials thrives in a system that looks to measure output. If the academe is looking for researchers who make money, can secure grants, and publish with regularity, positivist research is the best bet. The problem, however, is that real life does not stop at crisp lines and singular truths. It is messy, confusing, and holds a multitude of viewpoints, personal truths, experiences, and validity. Disability is real life, it is leaky, challenging, personal, and yet it is valid, and true (Santos & Santos, 2017). A framework that understands that disability is part of life, “understands that all bodies are unique and essential, and that all bodies have strengths and needs that must be met” and that disabled bodies and truths are “powerful not despite the complexities of bodies, but because of them” (Piepzna-Samarasinha, 2018, p. 21). Perhaps this is a contributing factor as to why medicalized, positivist,

research has done so much harm in the disability community. When you are looking for singular truth, for clear cut answers, you often gloss over, or intentionally exclude real people and real stories. As an academic, I longed for research and inquiry that connected with real people, their stories, and their issues. However, as Wall (2006) states, this research is often “seen as soft and fluffy and, although nice, not valuable in the scientific community” (pg. 147).

Autoethnography as a research method, is well suited for this project for many reasons, not the least of which were time and resources. Chang (2007) discusses one of the benefits of autoethnography is that “it offers a research method friendly to researchers and readers” (p. 213). This is because the researcher has access to the primary data source from the beginning, the primary data source being themselves (Chang, 2007). As a master’s thesis project being completed during the COVID-19 pandemic, there were time and resource restrictions inherent to this project. Autoethnography provided a pathway to accessible data and a project that could change with the requirements of the pandemic and distance learning, while still providing a research project. Furthermore, utilizing autoethnography allowed me to bypass the need for research ethics board approval, a process that has proven lengthy and challenging for many of my peers in the disability studies program at the University of Manitoba.

Rodriguez & Ryave (2002) present the usefulness of autoethnography by highlighting that it allows access to “covert, elusive, and/or personal experiences like cognitive process, emotions, motives, concealed actions, omitted actions, and socially restricted activities” (p.3). In this project, autoethnography allows me to present information about the realities of long-term care during the COVID-19 pandemic through my own experiences. Within the time and public health restraints of this project, autoethnography allowed a research project, discussing the internal happenings of a long-term care facility during the COVID-19 pandemic, to take place.

Chang (2007) states that another benefit of autoethnography is that it can “transform self and others toward cross-cultural coalition building” (p. 213). The utilization of this method allowed this research project to take place in a way that will hopefully allow an outside reader more perspective into the realities of institutional care during this pandemic. Chang (2007) expands on this point by writing that “the transformation of self and others is not necessarily a primary goal of autoethnography, but a frequently occurring, powerful by-product of this research inquiry” (p. 215). In this same way, transformation of self and others, was not an initial intended goal of this project, however, it has certainly been one such by-product for me. My hope is that utilizing autoethnography within this project will allow for this same learning for others.

Beginning this examination and autoethnography of my immersive experience in long-term care settings throughout the COVID-19 pandemic, I was hesitant to add my perspective to this area in such a personal way. At the time, I was concerned about what another white, physically temporarily abled academic could really convey with an autoethnography that would be able to come across as authentic and valuable. To be honest, I was hesitant about autoethnographies at all. As a student who completed an undergraduate degree in a field that values quantitative research and “hard” science conclusions, qualitative research with a data point of one participant, was a challenge. I have many people to thank for this push into the qualitative scientific realm, both my supervisor Dr. Nancy Hansen, and Dr. Christine Kelly who helped me explore the importance of qualitative research and discover its power in conveying the nuances and idiosyncrasies of disability studies and disability advocacy within research, by examining personal narratives, interviews, and storytelling.

Deborah Reed-Danahey (1997) discusses autoethnography as a tool to write a personal narrative, to communicate a singular story and then situate that story within a social

context. This is how I became drawn to qualitative methods, and particularly autoethnography. Autoethnography provides an avenue to use myself and my own experiences to get to the important ideas that need to be conveyed (Pelias, 2003). (Kafer, 2013) Autoethnography also lends itself well to communicating the knowledge of disabled individuals because they are the experts of their own disabilities and at navigating ableist systems. McCruer & Cassabaum, 2021 This autoethnography seeks to situate my own story within the context of disability studies to examine the realities of institutionalization in the COVID-19 pandemic.

Critical Discourse Analysis

Discourse analysis is a qualitative research method that examines written and/or spoken language with a specific focus on the contextual meaning of language (Mullet, 2018). Discourse is defined as language in the real contexts of its use; it is what happens when language is used in varying political, social, and cultural contexts (Machin & Mayr, 2012). Discourse analysis assumes that it is important to understand and analyze the way that information is communicated (Machin & Mayr, 2012). Critical Discourse Analysis (CDA), therefore, draws from critical linguistics to demonstrate how language can be used as an ideological instrument to construct, maintain, and legitimize social inequalities (Machin & Mayr, 2012; Mullet, 2018). Critical Discourse Analysis assumes that power and social relations are discursive, or communicated in language, and asks how these choices may serve the interests of authorities, ruling groups, or institutions (Machin & Mayr, 2012)?

Critical Discourse Analysis operates on the assumption that there are power dynamics involved in discourse (Machin & Mayr, 2012; Mullet, 2018). Disabled individuals are most often the social actors with the least social power in any given situation. Whether it is a result of

implicit ableism or overt hierarchical power dynamics, disabled individuals are rarely entering into a discursive environment from a position of perceived power. This is equally true in long-term care environments, where rules and protocols are generally created and enforced by Health Authorities, upper-level management, and care staff, and residents are expected to follow these protocols. Tremain (2021) states that:

Institutions where disabled people live should be defined in terms of the power relations that structure them and circulate within them: whether disabled people live in them with or without control of the types of support and care that they receive, whether they live in them with or without control of when these types of support and care are provided, where they are provided, and by whom they are provided. (p. 24)

Health care protocols and publications for long-term care that are examined in this project are developed by the Saskatchewan Health Authority and are to be followed by disabled people living in long-term care. There is clearly a great discrepancy in power dynamics between these two groups that are creating and affected by these protocols, and therefore these discourses should be examined with this power imbalance in mind.

Using CDA as a method involves looking at lexical (word) choices and grammar in written or spoken language to analyze for underlying discourses and ideologies that may highlight social inequalities (Machin & Mayr, 2012). CDA works to reveal social relations that may be implicit or explicit in a discourse (Van Dijk, 1993). Analyzing discourse can involve looking at social participants, behaviours, goals, values, and/or locations involved with the discourse (Sudajit-apa, 2017). Discourse analysis may examine what kind of words are present in a document or speech, who is involved in the situation, and how events are portrayed, and how these communication choices can highlight social relations (Fairclough, 2010). Hyatt (2013) and

Van Aswegen & Shevlin (2019) both discuss how CDA is particularly valuable for critical policy analysis because it allows the researcher to investigate the relationship between “language and other social processes, including power, structures, and institutions” (p. 641).

Critical discourse analysis is used in this thesis to examine protocols published by the Saskatchewan Health Authority affecting long-term care institutions in response to the COVID-19 pandemic. This analysis will help illuminate the protocols that affect people living in long-term care throughout the COVID-19 pandemic and the ways that power or social relations may be involved in these protocols. Critical discourse analysis is a method that contributes to the effectiveness of Crip theory in this project, as Crip theory seeks to challenge ableist systems of power and critical discourse analysis examines the power dynamics involved in discourse (Machin & Mayr, 2012; Bon 2017). Additionally, the political/relational model of disability, a model that critiques binary notions of disability while challenging traditional medicalized power structures, can be easily linked to the method of critical discourse analysis. Barnes, Mercer, & Shakespeare (1999) state that critical analysis of disability discourse can demonstrate the implicit ideologies society may have in connection with disability. By examining these health care protocols and restrictions that impact disabled people living in long-term care institutions, this project highlights discourses that may contribute to disablism in institutions of long-term care throughout the COVID-19 pandemic.

Data Collection

Data from this project was gathered from my time working in long-term care throughout the COVID-19 pandemic. Data was selected from existing journal entries, personal reflections, and health care protocols released from the provincial government and governing health care bodies

between March 2020 and January 2022. Data was selected based on specific inclusion criteria including that the excerpts selected must be: (a) written reflections, journal entries, and/or publications from health care governing bodies, and (b) include discussion of the effects of COVID-19 on disabled people living in institutions and/or other elements of significance for the disability community. Sample size is six written reflections and seven health care protocols. Health care protocols were retrieved through the work standard/protocol archive accessible on the Saskatchewan Health Authority website and media releases from the SHA.

Data collection of health care protocols took place through a targeted literature search at <https://covid19evidencereviews.saskhealthauthority.ca/>, a database of rapid reviews about COVID-19, completed by the Saskatchewan Health Authority. Initial keyword search included the words *COVID-19* and *long-term care*. These search parameters yielded 256 results. A revision of the keyword search then took place with the search parameters using the keywords *COVID-19* and *“long-term care”*. This search yielded 122 records. After elimination of duplicates and initial examination of abstracts, 7 rapid reviews met the inclusion criteria. After full document reading and analysis, 2 rapid reviews fully met the inclusion criteria.

A similar literature search was completed at <https://publications.saskatchewan.ca/#/home>, the publication center of the Government of Saskatchewan. Initial keyword search included the phrase *COVID-19* and *“long-term care”*, and this yielded 129 results. After elimination of duplicates and examination of abstracts or overviews of publications, 10 publications met the inclusion criteria. After full document reading and analysis, 5 publications met the inclusion criteria. These two literature searches of publication databases resulted in 7 publications that were analyzed using critical discourse analysis.

Data collection of personal written reflections took place through a review of my personal journals to find reflections that matched the inclusion criteria established for this project. From 22 months of journal entries, 6 reflections met the inclusion criteria. After data selection, I had 13 excerpts to analyze from published health care documents and journal entries and as I read through them more closely, three themes emerged: Isolation, Daily Life Changes, and the Social Position of Disabled Individuals. As excerpts examined were grouped into these main themes, they became the basis for several chapters of this thesis. A timeline of excerpts has been included in Appendix A to provide clarity of the order and timeline when the excerpts were written within the context of the pandemic.

Figure 1:

Search of SHA Rapid Reviews

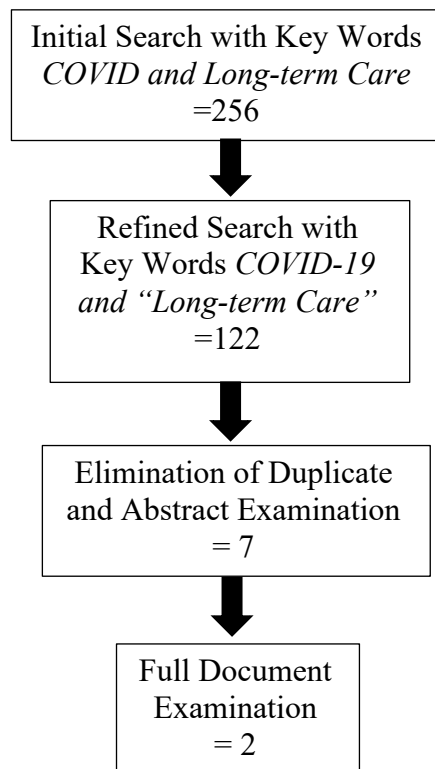
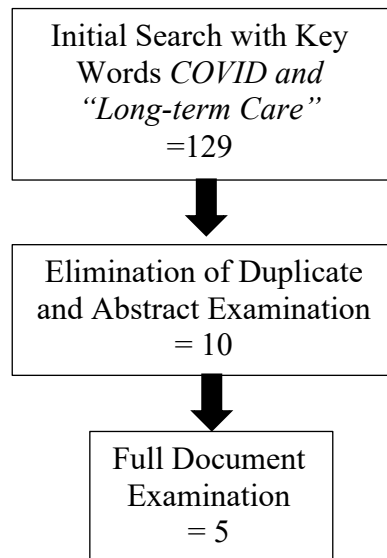


Figure 2:***Search of Government of Saskatchewan Publications*****Data Analysis**

Protocols and excerpts were analyzed to determine the impact of the COVID-19 pandemic on disabled individuals living in custodial institutions from a care worker's perspective. Reflections, journal entries, and health care protocols were analyzed using introspection and cultural analysis, forms of data analysis often used in autoethnography (Hokkanen, 2017). Introspection as a form of data analysis is focused on personal, embodied experiences, whereas cultural analysis focuses on broader cultural concepts and phenomena (Chang, 2008; Hokkanen, 2017). These two methods of data analysis are therefore well-suited for use in autoethnography where the goal is to produce contextual real-world knowledge based on personal experiences (Anderson, 2006).

Data gathered from health care protocols released by the provincial government and long-term care facilities was analyzed using critical discourse analysis. Critical discourse analysis studies written and/or spoken language in relation to social context to examine power inequalities (Fairclough, 2010). Using a critical discourse analysis to examine public health and long-term care protocols published during the COVID-19 pandemic, allows for interpretation of language, power, and social dynamics involved in these documents (Sudajit-apa, 2017). Critical discourse analysis will contribute to this thesis by examining health care protocols as a form of discourse that contributes to the wider social context of institutionalization throughout the COVID-19 pandemic (Burch, 2018).

Using introspection and cultural analysis, several themes emerged from journal entries that could be relegated to three categories: isolation, daily life changes in institutions as a result of COVID-19, and the social positioning of disabled people in institutions throughout the COVID-19 pandemic. In performing critical discourse analysis, several methods were used to organize data. Firstly, a priori coding was applied to the protocols published by the Saskatchewan Health Authority, based on the themes that emerged in analysis of the journal excerpts. A second cycle of coding was then completed where both versus coding and value coding were applied to protocols. Versus coding is utilized with the goal of seeing which groups are in conflict or the power dynamics between groups; it is therefore well suited for a project using critical discourse analysis that seeks to understanding the power dynamics present in discourse (Saldana, 2021). Value coding is utilized to examine the beliefs or attitudes present from individuals and institutions that may reflect world views (Saldana, 2021). Finally, a third level of coding was developed, based on temporal phases of the pandemic, as different phases of the pandemic had different restrictions and factors present. Temporal phase 1 describes the time

between March 1st, 2020, and May 13th, 2020, where the initial public health restrictions were put in place quickly to respond to the unknown of the COVID-19 virus. Phase 2 describes the time between May 14th, 2020, and January 30th, 2021, a time where public health restrictions were lifted for those living in the greater community, but those living in long-term care were still subject to these measures. Temporal phase 2 also takes place before vaccination was available for those living in long-term care. Finally, phase 3 refers to the time after January 30th, 2021. Temporal phase 3 takes place after residents in long-term care and those in the greater public were able to access COVID-19 vaccination and restrictions were lifted for those living in the community.

Figure 3:

Temporal Phases for Data Analysis



I began this project with the intention of using autoethnography as the only method. My intention with this project was to convey what is happening in long-term care during the

COVID-19 pandemic. Through discussions with my supervisor and thesis committee, I realized that a discourse analysis of pandemic related health care protocols affecting residents in long-term care, alongside an analysis of my own reflections would aid in communicating the current situations. I certainly do not think that it is a secret that long-term care institutions have been challenged by the COVID-19 pandemic, however this project aims to take a critical look at policies that are affecting disabled people living in these institutions. Ellis & Bochner (2006) discuss how an analytic autoethnography should develop critical understandings of broader social phenomena and ideas that go beyond the data. This project uses the marriage of autoethnography and critical discourse analysis to highlight the greater implications of institutional living during the COVID-19 pandemic.

Validity

This research project will utilize multiple sources (journal entries and health care protocols) and by using triangulation of the described methods, this increases the validity of this research (Berg, 2004). Triangulation is a process of combining methods, theories, or other variables to eliminate the possibility of bias and increase the validity of a research project (Noble & Heale, 2019). Two methods of data analysis are used in the forms of introspection and cultural analysis and critical discourse analysis. Theory triangulation is used by including both the social model of disability and Crip theory to increase the depth and breadth of the study (Berg, 2004). Because the theoretical frameworks approach data from different backgrounds, it provides greater validity to the information and allows for more in-depth analysis of excerpts that will be presented by this project.

Self-Checks

Writing this thesis and analyzing my own reflections from throughout the pandemic was a challenging process for me. Working through my own journals, while also examining health care policies, brought up complex emotions and sometimes anger for me. This project has had many fits and starts. Occasionally it would take me several weeks to analyze and work through my thoughts on one excerpt, while other times, thoughts seemed to fall into place. I am sure this is not a unique experience for individuals completing a thesis project, but I certainly had work to do sorting through the hard emotions that came with examining this topic.

A challenge of this project is maintaining the utmost care for confidentiality of residents living in long-term care settings. I often felt the need to talk through some of the journal entries I felt met inclusion criteria for this project to ensure that they did not threaten the confidentiality of residents and that they accurately represented the realities of long-term care institutions during the COVID-19 pandemic. I had these conversations with coworkers who I knew were bound by the same levels of confidentiality that I am, and who also worked with residents throughout the pandemic. I also had concerns about confidentiality in the workplace and chose to meet with my human resources representative to discuss the stories I planned to share to ensure that this project would not put myself or any residents at risk. Through these meetings and continual self-checks, I have worked to maintain the confidentiality and uphold the highest level of academic rigour possible for this project.

Ethical Considerations

There are ethical considerations to acknowledge with this autoethnography. Due to the nature of autoethnography there are no direct outside participants involved in the project, and therefore research ethics board approval is not required for this project. It is, however, important

to recognize that there can still be risks to the confidentiality and rights of individuals that may be discussed in this project. The Health Information Protection Act (HIPA) protects the privacy of personal health information (HIPA, 1999). These protections legislate that an employee of a health authority is required by law to protect the privacy of personal health information and respect the rights of patients or clients (HIPA, 1999). The HIPA states that an employee cannot “use personal health information...except with the consent of the subject individual” (HIPA, 1999). This thesis will not name any residents or mention any personal health information that could be used to identify said individuals. To ensure all levels of confidentiality are upheld, specific health care facilities or settings will not be named. Additionally, no names or identifying details of coworkers, individuals living in care settings, or other individuals will be included in this project.

People confined to long-term care are considered vulnerable populations and have not expressed consent to take part in this project and therefore, there will not be any quotes taken from residents living in long-term care and no identifiable information will be present in the data. This thesis project includes my personal reflections of working in long-term care during the COVID-19 pandemic and will not discuss any identifying information of residents. I have completed Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics and PHIA training and pledge of confidentiality through the University of Manitoba. This project will take the utmost care to ensure confidentiality of all parties is maintained throughout.

Chapter 4: ISOLATION

Journal Excerpt- Locking the Gates, March 22, 2020

Today I locked the gates to the patios that allow residents to explore the community and grounds freely. It's my job, and I have to, but restricting these residents' freedoms feels wrong. Everyone is so worried about COVID, and I know it is important to protect residents' health. I know safety is the priority, but this feels like a slippery slope to not allowing this freedom again.

The beginning of the COVID-19 pandemic was a time of great fear and uncertainty for long-term care facilities in Saskatchewan. Everyone had seen the outbreaks spreading like wildfire in New York and closer to home in Canada, and long-term care facilities that had not been so lucky in Ontario and British Columbia had seen outbreaks that had resulted in the deaths of many of their residents. The first weeks felt as though we were waiting for disaster to strike, and rules and restrictions were put in place with haste to protect those who were being defined as the most vulnerable populations, mostly disabled and elderly individuals living in congregate settings like long-term care facilities. There were a lot of unknowns in the first few months of the pandemic, and I had many conversations with residents and their families regarding concerns for resident safety, but also about concerns about what the coming months could look like with rules and restrictions in long-term care.

I have worked in a recreation therapy department in long-term care in Saskatchewan in some capacity since 2016 and have taken great pride in working in a long-term care facility that prioritized resident-oriented care and care plans that optimized freedom of choice and expression whenever possible for residents. While by no means perfect, the standard for long-term care that I understood and worked to preserve, meant that residents were encouraged to have pets, look for

opportunities for employment if they were interested, develop relationships, take part in community organizations, and have family and friends visit them as much as they desired. These realities of living in long-term care changed suddenly with the arrival of COVID-19 in Canada as the priority changed to preservation of life over preservation of freedom.

The first days of COVID-19 prevention measures were filled with many decisions that were quickly enforced and rarely explained. Day programs and excursions were canceled; residents were required to quit jobs and cohort themselves within their areas of the building. It was at this time that I was asked to lock the gates on the patios that extend from each area of the building. This closure of the patios blocked paths that led to residents' garden boxes, the greater property, and to exits off the property. Residents would be required to remain on the small patios, big enough for perhaps 3 or 4 wheelchairs or patio chairs while maintaining 6 feet of social distance. By removing access to the greater property, I was limiting residents' access to being outside, to enjoying sunshine, and the freedoms that I personally enjoy throughout the spring and summer months. Locking these gates felt like a betrayal of trust, a limit on freedoms that would only affect the residents, not myself. I remember calling my mom and discussing how easy it was to take freedoms away even in an organization known for its ability to support residents in their independence. The reality is, there are less variables to deal with and control in long-term care facilities, when residents have less freedoms. Locking these patios felt like a concrete step in the loss of these freedoms that would continue over the coming years of the pandemic.

Chief Medical Health Officer Orders- March 16, 2020

The Chief Medical Health Officer **orders** that visitors to long-term care homes, hospitals, personal care homes, and group homes are **restricted** to essential visitors only. Essential

visitors means immediate family for compassionate reasons.” (Government of Saskatchewan, 2020)

Another significant change caused by COVID-19 prevention measures was the restriction of visitors to those living in congregate health care settings such as hospitals, long-term care facilities, group homes, and personal/custodial care homes (Government of Saskatchewan, 2020). Previously, visitors could come and go at any time that was convenient to the residents living in the long-term care facility where I work, meaning that residents could share meals with their loved ones, spouses could share nights together, and friends could share time with those living in long-term care. A rapid review report from the Saskatchewan Health Authority dated from May 14, 2020, examined the impacts of visitation restrictions on family units and found that literature “reports negative psychosocial, physical, and social or relational impacts of visitation restrictions” (Tupper et al., 2020).

Initially, there was strong support for visitation restrictions to limit deaths from COVID-19 outbreaks, however as the pandemic has progressed and vaccination has become an available option for residents, these increased restrictions have been criticized (Linton, 2020). For example, in their own publication regarding the ways that long-term care facilities can prepare for a pandemic, the Saskatchewan Health Authority states that strategies for infection control “that have a potential negative impact on LTC residents” such as visitor restrictions, need to be handled with flexibility and individual assessment (Tupper et al., 2020, p. 2). However, this flexibility has not been a factor in many visitor restrictions policies, in fact, restrictions have remained largely unchanged for individuals living in institutions throughout the pandemic, even

as health protocols have changed for the general public (Saskatchewan Health Authority, 2022a).

Examining this statement from the Chief Medical Health Officer of Saskatchewan from a critical discourse perspective, reveals some interesting findings. It is important to note the words “order” and “homes are restricted”. These lexical choices, along with the release being titled, as from the office of the Chief Medical Health Officer, show the use of functional honorifics to convey a sense of authority (Machin & Mayr, 2012). These words were coded with versus coding because the statement highlighted the binary between two groups, those creating public health protocols, and those who must follow these protocols. The tone of this document is authoritative, and this is communicated through the discourse choices.

This statement also utilizes impersonalization of social actors as a tool to convey the weight of the press release by representing the Government of Saskatchewan, the Chief Medical Health Officer as the whole institution that is implementing these protocols, as opposed to one specific person (Government of Saskatchewan, 2020; Machin & Mayr, 2012). Finally, this statement was released during what is being coded as temporal phase 1; these are protocols that were released at the beginning of the COVID-19 pandemic in response to the concerns to public health, but before health care systems had strong data on the virus. These communication choices in this document demonstrate that this public health order comes from a place of authority and therefore must be followed, meaning that individuals living in long-term care were facing long periods of isolation with no visitors.

Gao et al., (2020) – Evidence for Fourteen-Day Isolation

New residents who transition to long-term care, from the community or acute care settings during the COVID-19 pandemic are currently required to isolate in their rooms for 14- days.

When protocols for infection control were introduced at the beginning of the COVID-19 pandemic, the Saskatchewan Health Authority announced that all individuals admitted into long-term care institutions would be required to isolate themselves in their rooms for 14 days. In this isolation period, they were only to be seen by staff for essential care and staff were required to wear full personal protective equipment (PPE) including masks, gowns, gloves, and face shields (Saskatchewan Health Authority, 2020). This rapid review of the isolation protocol, conducted in December of 2020 by the Saskatchewan Health Authority found there was “no evidence found as rationale for the fourteen-day isolation period on resident transition” to long-term care (Gao, et al., 2020). Additionally, this review discusses how these isolation periods can be challenging for disabled individuals moving into long-term care, and states that there is limited guidance on how to support disabled individuals in long-term care facing long isolation periods that may have negative effects on their independence, and personal dignity (Gao, et al., 2020).

Although this review conducted by the Saskatchewan Health Authority in December of 2020 states that a fourteen-day isolation period for individuals moving into institutional care such as long-term care is not best practice and can cause harm to disabled individuals facing lengthy isolation, this protocol continued until a change in work standard on January 19, 2022 (Saskatchewan Health Authority, 2022a). Gao et al., 2020 states in this internal protocol review that this practice of isolating residents in rooms for fourteen days is not only impractical, but

unsafe, and yet this practice continued for 13 months after these recommendations were published by the Saskatchewan Health Authority.

Using critical discourse analysis for the Gao et al., 2020 publication highlights that the authors of this document used repeated lexicon such as “the literature in contrast to policies” and “impractical and unsafe”. These phrases indicate a strong critiquing tone of the current policies regarding this prolonged isolation of residents in long-term care. This rapid review compares the protocols in Saskatchewan to other provinces, but in doing so utilizes the technique of collectivisation by communicating that the other Canadian provinces are also using a fourteen-day isolation period by stating that “most jurisdictions across Canada” follow these guidelines (Gao, et al., 2020). The collectivisation of actions in publications can aim to justify certain decisions or protocols (Machin & Mayr, 2012). It is important to note the social context that these policies were created, one where health authorities were concerned with minimizing deaths in long-term care caused by the COVID-19 pandemic. Many of these protocols were created in response to high rates of mortality that were seen in institutional care settings at the onset of the pandemic, however as restrictions were changed for the general public, they remained highly restrictive for people living in institutional care. This protocol was released during temporal phase 1, where there was limited information about the COVID-19 virus, but was enforced well into temporal phase 3, the post-vaccination and reopening phase. The timings of this protocol are significant as this publication demonstrates that there was an understanding that this level of prolonged isolation was harmful and unnecessary based on public health data, and yet the isolation practices continued (Gao et al., 2020).

Even though these isolation protocols were critiqued by this rapid review, they remained in effect for more than 13 months after these findings were published (Saskatchewan Health

Authority, 2022a). Without any evidence of the benefit of this prolonged isolation practice, it brings into question the motivation of keeping disabled individuals moving into long-term care in a fourteen-day isolation period. There is certainly less work for staff when there cannot be any visitors to residents and disabled individuals are confined to their rooms. In discussing critical discourse analysis, Van Dijk (2001), states that texts can reveal implicit meanings that are related to underlying beliefs. Does the fact that data, gathered by the Saskatchewan Health Authority itself, indicating that a fourteen-day isolation was unnecessary and harmful did not inform a policy change for over a year, communicate an implicit desire to ensure disabled people living in institutions can be controlled or at the very least that a situation with more control is worth the cost freedom of residents in long-term care?

Journal Excerpt- Fourteen-Day Isolation Periods, August 5, 2020

These fourteen-day isolation periods for residents coming [to long-term care] are going so poorly. Moving into long-term care is already so difficult, let alone when you can't see family, you can't even see your nurses or CCAs face because we are wearing so much PPE. Recreation staff can't come in to even provide any relief from the boredom because it isn't deemed "essential". So many people have died, maybe it's not more than normal, but it feels like it. The rest of the province has no restrictions, there are no gathering restrictions or masks requirements and yet these residents are so lonely and can't have anyone when they move here.

This reflection was written in August of 2020 when there were no public health orders for the general public relating to COVID-19 in place in the province of Saskatchewan. Isolation requirements, however, were still in place for individuals moving into, or returning to long-term

care. Although I felt it important to protect those moving into our facility, residents were clearly struggling with the intense isolation and loneliness. It seemed so unfair that there were no restrictions for the general public, and I as a staff member, could go to any number of gatherings unmasked, but disabled people requiring care provided by long-term care facilities were forced into these prolonged isolations. Titchkosky (2011) discusses the concept of “those who are essentially excludable”, a term they use to describe those who “we [as an ableist society] can’t, won’t or don’t imagine as potential participants” in greater community (p. 39). During this health care restrictions that only apply to individuals living in long-term care institutions, have made these residents the “essentially excludable” population (Titchkosky, 2011, p. 39).

It felt as though so many residents moved in, and then passed away before their fourteen-day isolation period was over. These residents were confined to their rooms and were not able to meet any neighbours or have any interaction, other than with staff who entered their rooms to provide personal care and deliver meals. Moving into long-term care is challenging as it is, let alone when people cannot have any family or friends with them, and they are not allowed to integrate into their new environment. Systematic reviews of qualitative literature indicate that isolation and loneliness decrease quality of life in long-term care, even prior to pandemic restrictions (Bradshaw, 2012). Loneliness is seen as one of the three plagues of long-term care that impact quality of life, alongside helplessness and boredom (Thomas, 1996; Merastya et al., 2012).

In conversations around isolation, links can be made between the carceral system and the institution of long-term care. In conversations around imprisonment, the John Howard Society of Ontario (2017) states that “prolonged solitary confinement has been called a form of torture” (p.1). Solitary confinement, however, has not only been used in prisons throughout the COVID-

19 pandemic, but it has also been used in long-term care facilities. Bryant (2022) states that “quarantine and medical isolation area necessary to prevent the spread of COVID-19, but the inhumane use of solitary confinement must end” (p.1). It is worth noting the parallels in critiques of isolation in both prisons and long-term care facilities throughout the COVID-19 pandemic and that these critiques are a result of the institutional nature of both systems. The John Howard Society of Ontario states that “regardless of the reason cited for its use, or the nomenclature, segregation is an inherently punishing experience” (p.3).

Throughout the entirety of this pandemic, I have noticed the loneliness normally associated with moving into long-term care, was only amplified by these required isolations, where residents were not permitted to see family, friends, or even a smiling face during the turbulent time of moving into long-term care. There were so many residents who would move in, that I would not even have the chance to meet before they passed away. These residents often felt like the forgotten casualties of the COVID-19 pandemic. They were not counted, rarely were able to have memorial services, and unfortunately were not often able to have any relationship with staff due to their isolation requirements. These residents are mourned however, by their families and friends. They were spouses, parents, friends, and members of chosen families. They had exciting careers, told funny stories, and were imperfect and were all that the rest of us are. Reaume (2018) states disabled people “are just like everyone else, with the positive attributes, faults, and grey areas that make up most of what it means to be human” (p. 31).

Tupper et al., (2020) – Impact of Visitation Restrictions

Visitation restrictions that prohibit all family members from being physically present in hospitals or long-term care homes have negative physical and psychological impacts on patients/residents, families, and staff.

This excerpt is taken from another rapid review report completed by the Saskatchewan Health Authority in May of 2020. This report examines the impacts of family unit visitations restrictions during infectious disease outbreaks, such as COVID-19 (Tupper et al., 2020). This document examined data that demonstrated the psychosocial impacts of visitation restrictions that include increased anxiety, depressions, loss of dignity and loss of control, as well as physical impacts such as health deterioration, increased confusion, and reduced mobility (Tupper et al., 2020). Additionally, this report acknowledges that visitor restrictions in place at the time of the review that categorize family members as non-essential visitors is in conflict with the Saskatchewan Health Authority's family-centered care and open family presence policies in long-term care (Tupper, et al., 2020).

The rapid literature review also found that limitations in visitation to individuals living in long-term care result in increased medical errors and inconsistencies in resident care, as family and/or friends are not present to alert staff to issues (Bélanger, et al., 2017). Data shows that although difficult, families and residents are generally accepting of visitation restrictions to protect the health of those living in long-term care (Tupper, et al., 2020). This data regarding acceptance of restrictions reflects my own experiences of working with residents and families. Families and residents that I worked with, especially at the beginning of the pandemic, were very supportive of visitor restrictions to ensure the reduction in spread of COVID-19. The challenge with visitor restrictions has been their prolonged usage when there are little to no restrictions for individuals in the general public.

This report acknowledges that safety throughout this pandemic has generally been seen as minimizing infection transmission, however it is also important to acknowledge that inflexible

limitations to visitation can also affect the psychological safety and emotional well-being of residents (Tupper, et al., 2020). Heumann (2020) discusses that “when institutions don’t want to do something, to claim that something is a ‘safety’ issue is an easy argument to fall back on” (p. 59). While the safety of residents in long-term care institutions is clearly important, it is worth examining those restrictions on residents to provide more control and less unpredictability for staff working in these facilities. It is easier to complete the checklist of things required for care when residents must remain in their rooms and do not have visitors.

By examining this publication using critical discourse analysis, there are several interesting themes that emerge. When analyzing a document, it is just as important to examine what is included as what is not; this omission of information is called suppression or lexical absence (Machin & Mayr, 2012). Although created in response to COVID-19 protocols, this publication does not specifically mention COVID-19 at all, and instead refers to any infectious disease outbreak. This lexical choice may have been made to increase the transferability of the review findings to other outbreak scenarios, however the COVID-19 pandemic has seen unprecedented and unique public health responses, and therefore is a unique situation with visitor restrictions. Additionally, this document does not specify the social context or circumstances at the time of publication, an important element of discourse analysis (Machin & Mayr, 2012; Tupper et al., 2020).

This statement was coded using versus coding that examines which groups’ interests conflict with each other. This statement highlights conflicting needs, the residents’ needs for social contact with loved ones, and the institutions needs to minimize COVID-19 transmission. It is important to acknowledge the power imbalance between these two groups, one who is enforcing protocols, and one who must follow them. This protocol was released during temporal

phase 2, a time when restrictions were easing for those living in the greater community but there was not yet access to vaccination. This document is important because it discusses visitor restrictions in long-term care institutions at the time that public health restrictions were being lifted for the general public in the province of Saskatchewan. Not providing the social context that mask usage and gathering restrictions were lifted for the public, while visitor restriction remained in place in long-term care institutions, does not demonstrate all the information required to understand the social context of this publication.

Chapter 5: DAILY LIFE CHANGES IN INSTITUTIONS

Journal Entry- Outbreak and No Baths, January 25th, 2021

We are currently in an outbreak, and it is so difficult. Staff have been doing their best and residents have been patient with us, but there is no way this is going to go well. A new protocol that we must enforce is that residents living in outbreak units are not allowed to have showers or baths, only bed/sponge baths because they are considered close contacts. I guess the rationale is that it's an infection control issue, but who knows how long this outbreak could go for? It's awful to be stuck without a shower or bath for so long, there is no way this is fair.

Throughout the first year of the COVID-19 pandemic there were protocols in place limiting access to showers and baths for residents living in areas of the building considered to be in outbreak (Saskatchewan Health Authority, 2022b). A long-term care COVID-19 outbreak in the Saskatchewan Health Authority is defined as “one or more residents or staff of a long-term care facility has a lab-confirmed COVID-19 diagnosis” (Danielson et al., 2020). It is also important to highlight that a concluded outbreak can only be declared by 28 days have passed with no new cases after the last date of exposure to a positive COVID-19 case at the long-term care facility, including staff and residents (Danielson et al., 2020). This protocol is different from the health order for individuals of the public where the longest time required for isolation was 14 days after an exposure to a positive COVID-19 case (Danielson et al., 2020). Outbreak control measures in long-term care facilities include temporarily keeping residents in their room, limiting visitors to end-of-life situations only, and canceling group activities (Saskatchewan Health Authority, professional communication, January 6, 2021).

At the time of this journal entry, we were told that residents could only receive bed (sponge) baths for the duration of the outbreak. The duration of outbreaks, however, are defined differently in long-term care facilities than they are for the public (Danielson, et al., 2020). As stated earlier, an outbreak can only be deemed over, 28 days after the last day of exposure to a COVID-19 positive resident or staff (Danielson, et al., 2020). These definitions mean that an outbreak can last much longer and affect many residents throughout a facility. The longest outbreak that took place at the time of this journal entry lasted more than 50 days. Residents who endured this outbreak, not only had to experience over 50 days of isolation in their rooms as a result of continual outbreak status but had to do so without access to regular bathing or showering.

I cannot imagine going more than 50 days without a proper bath or shower and this is yet another example of how COVID-19 health care protocols adversely impacted disabled people living in institutional long-term care. Not only were residents facing a COVID-19 outbreak and worried about their health and safety, but they were also having to do so with no access to proper bathing. What makes this protocol so dehumanizing, is that the use of sponge baths was not medically necessary; there was no scientific evidence or justification provided as to why the shower and tub room could not be disinfected between each resident. Andrews et al., (2021) discuss that “whether explicit or implicit, the message that some lives are more worthy than others can be transformed into policy and practice where disability is concerned” (p. 452). This inequitable measure of the worth of disabled quality of life, is seen in protocols such as this, that do not account for the harms a policy such as an extended ban on showering and bathing may have. For individuals living in their communities, requiring to self-isolate, can certainly be a nuisance but they are able to access regular bathing, and moderate freedom to move around their

homes. For disabled people living in long-term care, COVID-19 outbreaks have resulted in residents being confined to their rooms, lack of access to proper bathing, and complete isolation from those around them.

SHA COVID-19 Outbreak Guidance Protocol – No Baths and Showers

Residents who are close contacts, COVID-19 positive, or who have symptoms should be **bed bathed until additional precautions are discontinued**, at which time they may resume use of the communal tub/shower.

This excerpt is taken from the outbreak guidelines for long-term care homes from the Saskatchewan Health Authority and communicates the protocol suspending tub and shower usage for residents during COVID-19 outbreaks. This statement does specify that these restrictions are only in place if communal tub and shower rooms are used, however there are few long-term care facilities with private tubs and showers due to the medical needs of individuals usually living in long-term care that often require accessible bathing rooms. These guidelines were enacted in temporal phase 2, where residents were facing even more restrictions and losses of freedoms, and the general public was experiencing more freedoms and restrictions began to relax for the public.

The social actors in this statement are the residents who are close contacts, are diagnosed with COVID-19, and/or have symptoms of COVID-19 and those creating outbreak guidance protocols. This statement seems as though these protocols would only affect a few residents, however, due to the congregate living settings of long-term care, all residents living in an area of outbreak are considered close contacts (Danielson, et al., 2020). The statement uses the collectivisation of participants by communicating residents in long-term care as a unified group,

instead of showing that these protocols are affecting real individual people. This technique of collectivisation, groups similar categories of people to develop a collective identity, and while this may sometimes be used to unify a group, it also makes it more challenging for a reader to understand that this collective is made up of individuals who have diverse and unique needs (Statham, 2021).

This guidance from the Saskatchewan Health Authority does not mention that these protocols could last for lengthy periods of time. For example, in my workplace this protocol was in place for residents for over 50 days. It is important to acknowledge that this protocol guidance affects real people and holds real consequences for these individuals. The document also pulls the focus to when precautions are discontinued, stating clearly when they may resume the use of baths and showers. These lexical choices seem to change the focus from a challenging situation to the fact that these precautions will be discontinued but do not mention how long these protocols could be in place. This omission of mentioning how long these protocols could really be in place for, keeps the reader's focus off how physically challenging a protocol like this can be for residents living in long-term care.

SHA COVID-19 Outbreak Guidance Protocol – Cancelling Group Activities

All group activities should be suspended for the duration of the outbreak...all previously scheduled residents' special events/activities (e.g., special holiday meal celebrations, birthday parties, entertainers) **must be cancelled/postponed**.

This protocol is published in a document entitled *Saskatchewan Health Authority COVID-19 Outbreak Guidance for Long Term Care Homes* and is currently in its 9th version that was published March 24, 2022. This document aims to provide guidance for staff and

management of long-term care facilities to limit the spread of COVID-19 to residents and staff. This protocol was enforced during temporal phase 3, the outbreak stage. A challenge for residents living in long-term care facilities has been that daily events are continually changing due to numerous COVID-19 outbreaks that severely affect the daily activities taking place in their lives. This excerpt shows that each time there is an outbreak declared in an institutional setting, all activities that may bring fulfillment and joy such as special events or excursions must be canceled or postponed (Saskatchewan Health Authority, 2022b). Although a certain level of unpredictability has been present for everyone throughout the COVID-19 pandemic, for those living in institutional care, an outbreak or positive case of COVID-19, results in severe restrictions for unforeseeable amounts of time including isolation to personal rooms, restrictions on baths and showers, and an inability to see loved ones.

In examining this statement, a technique of over-lexicalization, through repetition of the words and concepts, by naming the many possible special events and gatherings that must be canceled, is present (Machin & Mayr, 2012). This focus on the many extra events, pulls focus from the other activities that must be canceled that fall under group activities which include any kind of recreational programming or even basic social situations between residents. The cancellation of all group activities means that residents have virtually no social contact for the duration of the outbreak. Although the use of these protocols results in residents living in long-term care institutions having almost no ability to socialize and access the associated benefits of emotional connection, this detail is only mentioned briefly, in comparison to the discussion of the large parties or events that would need to be cancelled.

This protocol is stated in the outbreak guidance for long-term care homes by the Saskatchewan Health Authority that can be accessed by the public, however, it is not easy to find

this document and the document is not written in plain language that would be more accessible for the greater public. This document does provide step by step protocols for outbreaks that take place in long-term care facilities, and therefore it brings into question why this document is not more readily accessible for the public, or even those living in these long-term care settings. As this document is not readily available on many public platforms and is only available on a website that is not easy to navigate for the greater public, there are certainly concerns with how available this information is to the public.

Journal Entry- Social Toll of Cancelled Social Events, July 12, 2021

It is so difficult to continue to try and keep residents engaged and plan interesting activities because every time we go into an outbreak, we have to cancel events and plans that we've made. I can see how frustrating it's becoming, because every time we get our hopes up for something fun, it seems we head back into outbreak, and we have to cancel. It feels like there are so many increased freedoms for the general population, but that means less freedoms for people in long-term care facilities because the restrictions have remained in place for them and so many immunocompromised residents are having to make decisions to isolate themselves further to keep themselves safe. I just feel as though we went from a building that focused so much on resident freedom to a building that was scared to even allow moderate freedoms because we did not want to be the long-term care facility that's in the news for a big outbreak.

This journal entry was written as we entered the second summer of the COVID-19 pandemic in my place of work. The first summer of the pandemic, while certainly challenging, felt as though there was a certain newness, excitement, and sense of teamwork for us in long-

term care. Residents were happy about the nicer weather and the ability to be outside, even if that was limited by our ability to maintain social distancing on patios. We were able to set up outside visits for family members to meet with residents through patio fences. Additionally, in that first summer, there seemed to be a sense of the general public rallying to protect disabled populations living in long-term care that were deemed to be the most vulnerable. All these factors helped a challenging first summer of the pandemic have some moments of relief and joy for residents.

The second summer of the pandemic, however, when this journal excerpt was written felt as though the momentum was lost. The Government of Saskatchewan launched their “reopening roadmap” stating that it was time to get back to normal for a “great Saskatchewan summer” (Quenneville, 2021). These reopening plans did not extend to long-term care facilities that would still face fourteen-day isolation restrictions, masking, social distancing, and outbreak protocols (Gao et al., 2020). These decisions were cited as being for the protection of the most vulnerable, but it ended up resulting in a rather out of sight, out of mind attitude for many in the general public. As the province “got back to normal” with no mask requirements, no isolation requirements, and few public health measures, those living in long-term care were no longer prioritized. A few residents expressed as though it felt everyone got tired of caring and that as soon as they were ready to get back to normal, supporting disabled people became less of a priority.

This consistent theme of disabled people being forced out of sight and out of mind as the pandemic has continued, has continually come to the fore throughout this project. It can be seen in policy decisions as the province of Saskatchewan makes efforts to “get back to normal” (Quenneville, 2021, p. 1). It can also be seen through medical rationing and the ease with which restrictive protocols were put in place and how difficult it has been to remove these same

policies. Titchkosky (2011) examines how an “accommodation is not regarded as reasonable if it costs an organization too much” (p. 36). This assessment holds true for greater social situations that professional organizations. The cost in this situation is the freedom of those not living in long-term care, and eventually this accommodation of reasonable remaining restrictions to protect disabled people was perceived as too great. At this time, restrictions remained for residents living in institutional care, as the rest of the province moved on to getting “back to normal” (Quenneville, 2021, p. 1). There can be parallels drawn between the isolation of today’s residents institutionalized in long-term care facilities, and disabled individuals kept in large institutions away from the rest of society (Brown & Radford, 2015). As families were told to forget about loved ones who were institutionalized in the past, perhaps we are drawing closer to forgetting about disabled people in long-term care still facing the challenges of isolation due to COVID-19. Dr. Martin Ginis (2021), the director of the Centre for Chronic Disease Prevention and Management, states that “As the pandemic continues to draw on, we need to prevent more individuals from slipping further through the cracks (p. 1). It is important for us to remember those that are continually relegated to residual spaces as the world tries to get back to normal without them.

Chapter 6: SOCIAL POSITIONING OF DISABLED PEOPLE IN INSTITUTIONS**MAID*****Journal Entry- MAID, March 15, 2021***

Residents have started to access MAID. Residents who prior to the pandemic, had full and abundant lives filled with family and friends. Perhaps they would have made the same decisions about their end-of-life care anyways, but I can't help but think that the isolation and loneliness is a motivator. The other thing that is concerning is that as soon as someone wants to access MAID, they have access to a psychologist and social workers, but other residents who are seeking these services are having to stay on waitlists for so long. It is so sad that disabled people may feel like it is an easier option to access MAID than other services that may improve their well-being.

Medical Assistance in Dying (MAID) became legal in Canada in 2016 and is governed under federal jurisdiction through Bill C-14 and Bill C-7 (An Act to Amend the Criminal Code (medical assistance in dying), 2021). To be eligible to access MAID you must be 18 years of age or older, provide a voluntary request and informed consent for MAID, and must have a "serious and incurable disease, illness, and/or disability" (Saskatchewan Health Authority, 2022c). Once eligibility criteria have been met through assessments by MAID practitioners, a death is deemed as foreseeable can be processed and scheduled within two business days of deemed eligibility (Saskatchewan Health Authority, 2022c). If an individual's death that is deemed non-foreseeable, defined as a person's "natural death that being anticipated in the near future due to their medical conditions", there must be a 90-day waiting period between when a person is deemed eligible and when MAID occurs (Saskatchewan Health Authority, 2022d).

Many major disability rights organizations critique MAID and the risks this legislation poses to disabled people (Stainton, 2019) There are concerns regarding lack of compassionate care and adequate support for disabled people as well as a devaluation of disabled lives playing a role in people accessing MAID (Downie & Schuklenk, 2021). If there is not adequate support for disabled people to live, or they feel their lives are a burden to others and MAID is easier to access than necessary services, disabled individuals may feel as though there are no other options. In 2020, the United Nations Human Rights Council presented the findings of a Special Rapporteur regarding the rights of disabled people, with a particular focus on medical assisted death (Devandas-Anguilar, 2019). This report discusses that disabled people are often viewed as having very low quality of life and that these assumptions and ableism can contribute to prejudice, discrimination, and oppression of disabled people (Devandas-Anguilar, 2019). The Special Rapporteur states:

Despite the significant advances in the recognition of the rights of persons with disabilities at international and national levels, the deeply rooted negative perceptions about the value of their lives continue to be a prevalent obstacle in all societies. Those perceptions are ingrained in ableism—a value system that considers certain typical characteristics of body and mind as essential for living a life of value. Based on strict standards of appearance, function, and behaviour, ableist ways of thinking consider the disability experience as a misfortune that leads to suffering and disadvantage, and invariably devalues human life. As a result, it is generally assumed that the quality of life of persons with disabilities is very low, that they have no future to look forward to and that they will never live happy and fulfilling lives. (Devandas-Anguilar, 2019, p.3)

As Hansen & Janz (2009) state “there is often a tendency to conflate quality of life with worthiness to live” (p. 30). This report regarding MAID and the rights of disabled people also demonstrates that this ableism can inform policy, practice, and legislation (Devandas-Angular, 2019). As neoliberalism becomes ever more present, in society there are increased pressures for disabled people living in long-term care to refuse costing the system money by opting out entirely via assisted death (Kim, 2017; Goodley et al., 2014).

When restrictions were first brought in for residents and the long-term care facility, it felt as though the building banded together. There were certainly high levels of stress and concern, but residents and staff seemed to work together to come up with creative solutions for social distancing, masking, and recreation activities that could be performed safely. As restrictions pressed on, it felt as though the momentum of the beginning of the pandemic waned. Residents were now facing extended months without seeing family or friends in person and this seemed to have a real toll on the mental health of our residents. As the pandemic continued and restrictions were lifted for the public, this feeling of comradery faded. Residents were still required to respond to outbreaks with mandatory lockdowns. Residents who had I watched fulfilling lives with jobs and community before the pandemic, began to explore the options of medically assisted death. One resident stated to me that they had no desire to live in continued isolation when their friends and family in the community did not, and that was the reason they were accessing MAID services

Residents began accessing MAID resources and several residents who prior to the pandemic had not discussed MAID as a desire, chose to complete their end-of-life journeys as the severe isolation dragged on. These situations were not only incredibly sad because of the death of disabled leaders and friends but were accentuated by how quickly these resources were

available. I watched with great sadness as so many residents struggled with loneliness and depression throughout this pandemic, as they remained on waiting lists to access counselors, psychiatrists, and social workers. As soon as residents chose to access MAID, however, they were generally able to access a psychiatrist and other mental health and assessment resources within a week's time.

There is a great discrepancy between the resources disabled people living in long-term care can access prior to and after they choose to access MAID. I cannot help but wonder if we failed residents living in long-term care institutions during this time. Perhaps, they would have chosen to access MAID regardless of the current global health situation, as is their right, however, it cannot have been easy to watch the rest of your province lift restrictions, be able to gather, and hug their loved ones, and have to remain in isolation because your medical needs are deemed too complex to live in the community. MAID is often explained as a service people access to end their suffering. A statement from Inclusion Canada regarding MAID says:

It is not disability that causes people's suffering, just like it is not a person's indignity or sexual orientation that causes suffering in Canadian society, though there are higher than average suicide rates for Indigenous persons and the LGBTQ2S community. Suffering comes from living in a society where the conditions of your inclusion and dignity are denied because of your personal characteristics. (Inclusion Canada, 2020, p.1)

As other disability rights activists have stated, it is certainly concerning the ease with which disabled individuals can access MAID, when accessing other support services is such a challenge (Duong, 2021). I cannot help but wonder if this discrepancy is present because a disabled life, especially one living in long-term care, is not seen as valuable enough to spend our resources on. In her book, Piepzna-Samarasinha (2018) includes a quote for disabled activist and collective

care pioneer, Loree Erickson where she states, “it’s too bad taking care of each other has to be so radical” (p. 44). My question is why does it have to be so ground-breaking to provide adequate, supportive care before someone wants to access medical assistance in death?

Medical Rationing

Journal Entry- Medical Rationing, April 18th, 2020

With COVID raging through other regions in Italy and the United States, there has been more and more discussion about the possibility of medical rationing. If cases get bad enough, there will need to be decisions made about ventilators and who is given medical priority. There has started to be discussions at work about how that will affect the care residents receive. Residents themselves have acknowledged in conversations with me that they will likely be passed over in cases of medical scarcity.

This journal entry was written in the first few months of the COVID-19 pandemic when we still knew very little about this virus and regions of the world were struggling to keep control of outbreaks and seeing high mortality rates. In this state of panic, we all started talking about the possible implications of this new virus if we were to have an outbreak situation in Saskatchewan. Among these concerns were ideas that there would likely not be enough ventilators for people who may need them if cases of COVID-19 were to get out of control. Conversations in long-term care turned to what that shortage might mean for residents living in these care institutions. In my heart, I easily knew that disabled people living in long-term care would be the first to be passed over in a situation of medical scarcity. Lund & Ayers (2020) discuss how disabled people hold valid fears that they will be deprioritized for medical interventions or possibly disqualified altogether because they are often perceived as being lower priority than non-disabled individuals.

It is in situations such as these, that a concept known as the disability paradox is prevalent (Ubel et al., 2005; Andrews et al., 2020; Goggin & Ellis, 2020). The disability paradox is a discrepancy that exists between self-reports of quality of life from disabled people and how greater society or health care providers see disabled quality of life (Ubel et al., 2005). For example, disabled individuals general report high quality of life levels when surveyed, but non-disabled society assumes that disabled people have a low quality of life due to their impairments (Ubel et al., 2005). In examining the disability paradox, I think it is helpful to look at the ideas of disability advocate and author Alice Wong. Wong (2020) states that if a doctor were to look at her, a disabled woman who uses a wheelchair and ventilator and make assumptions about her quality of life, they may think she is a waste of their efforts and resources. She goes on to discuss that judgements around quality of life are typically made by someone with no lived experience of disability (Wong, 2020). The idea that some lives are more worthy than others can affect policy and practice that has real life consequences for individuals with disability (Goggin & Ellis, 2020).

These concerns that residents may not be able to access medical care should they need it, were not only being discussed by staff members. At this time, I was having many conversations with residents about whether the health authority would make decisions about their ability to access ventilators or intensive care beds. There were mixed responses and opinions to these realities. Some residents expressed their fears to me, some felt that some sort of medical rationing would be necessary, but consistently there was a feeling of unease at what was to come. As Andrews et al., 2021 states there is a real risk “that the medical diagnosis [of an individual] is more of a threat and factor in life-or-death decisions than COVID-19 complications and current medical status” (p. 457)

Titchkosky (2011) discusses in a chapter written nine years prior to the COVID-19 pandemic how “in the aftermath of disasters or epidemic preparedness programs, disability is collapsed into the category of vulnerable” (p. 52). This analysis held true during a worldwide pandemic, where disabled people were excluded through medical triaging from accessing the same levels of care as those who were not deemed to be vulnerable (Valiani et al., 2020). The policy brief from the United Nations in May 2020 about a disability inclusive response to the COVID-19 pandemic examines the reality of medical rationing by stating:

Persons with disabilities are at greater risk of discrimination in accessing healthcare and life-saving procedures during the COVID- 19 outbreak. In some countries, health care rationing decisions, including triage protocols (e.g. intensive care beds, ventilators), are not being based on an individual prognosis, but rather on discriminatory criteria, such as age or assumptions about quality or value of life based on disability. Moreover, access to healthcare, rehabilitation, and assistive technologies for persons with disabilities, including with respect to accessibility and affordability, can also be curtailed due to the increased pressure on the healthcare systems. (pp. 5-6)

Titchkosky (2011) also states that what is “more disturbing than the quantification of human life and limb, is the social fact that this repetitive, routine practice [of devaluing disabled lives] can remain unquestioned and can continue to produce the differential value of people” (p. 33). Once again, this is what happened with the COVID-19 pandemic, where it became an unquestioned norm that disabled people in long-term care would face different restrictions and expectations, when the rest of the population faced no restrictions whatsoever. Hansen & Sampert state “In the

two years we've been dealing with the COVID-19 pandemic, it's become clear just how precarious the social positioning of disabled people really is" (p. 1).

Saskatchewan Critical Care Resource Allocation Framework

It is patients with end-stage, progressive, and incurable illness who are less likely to be admitted to ICU in situations of scarcity. Patients with progressive conditions will be assessed based on current condition and likelihood of survival. In contrast, those with stable, non-progressive conditions will not be excluded [from care] on the basis of having these condition, though **associated factors may be considered if they are clinically relevant to treatment and its effectiveness.**

As COVID-19 cases developed in Saskatchewan, the Saskatchewan Health Authority developed a critical care resource allocation framework that would be applied to all individuals eighteen years or older requiring intensive care unit (ICU) care (Saskatchewan Health Authority, 2020; Saskatchewan Health Authority, 2021). The resource allocation framework outlines four stages that become increasingly selective as ICU capacity is increasingly exceeded (Saskatchewan Health Authority, 2020; Valiani et al., 2020). The resource allocation process has been in place throughout all temporal phases of this project, as it has been continually in place, should the need arise. This resource allocation framework does state that discussions of quality of life and/or disability do not factor into these medical rationing discussions (Saskatchewan Health Authority, 2020). Patient case presentation, however, plays a key role in being referred to this critical care triage team that makes decisions on resource allocation. Factors that can contribute to a patient's case include past medical history, history of presenting illness, vital signs, relevant physical examination, and the consultant intensivists' impression (Saskatchewan

Health Authority, 2020). Based on these criteria it is possible that disability could play a role in resource allocation discussions, as disability could potentially affect factors such as medical history, physical examination, and the ICU doctor's impressions.

It is important to analyze the excerpt included above to discover possible interpretations of the critical care resource allocation framework that may impact disabled people living in institutional care throughout the COVID-19 pandemic. The social actors in the excerpt are the patients requiring critical care and the doctors making decisions about these patient's care. There is a significant power dynamic at play between doctors making triage decisions about patients accessing critical care and the patients who may be disabled requiring that care. Additionally, there is use of overlexicalization, through repetition of synonymous terms such as 'end-stage', 'progressive', and 'incurable' illness. Overlexicalization provides a sense of over-completeness or over-persuasion and is often seen when a text is trying to convince the reader of something that can be seen as problematic (Machin & Mayr, 2012). Immediately after, the technique of structural opposition, that compares opposing binary understandings of a concept, is used to compare those with "end-stage, progressive, incurable illness" against those with "stable, non-progressive conditions" (Saskatchewan Health Authority, 2020; Machin & Mayr, 2012). Because of this examination of the binary groups conflicting interests' apparent in this protocol, it was coded using versus coding.

Society's understanding of disability is often organized according to the binary of normal and abnormal and disability is perceived as being "outside the standard view of the life course (Grenier et al., 2020, p. 22). It is interesting to see how those who are less likely to receive critical care are described as having 'illnesses', whereas those who will most likely be provided care are described as having 'conditions'. This is a subtle change in language that shifts how we

see each group of individuals accessing care. A similar concept is explored by Grenier et al., 2022 in separations between aging and disability where they demonstrate that “nearly all references to disability among older people use the word ‘impairment’ rather than ‘disability’” (p. 23). This shift in language is important to acknowledge in concepts around disability. I cannot help but wonder, if during the COVID-19 pandemic, where those with pre-existing disability have been seen as less deserving of medical intervention, if that has pushed individuals to avoid identifying with disability even further. Previously there has been levels of stigma associated with a disability diagnosis, but throughout the COVID-19 pandemic, a disability diagnosis could mean you are ineligible for life-saving care.

Most relevant to disabled individuals in institutions who may need access to critical care, whether they are diagnosed with COVID-19 or not, is the last detail in this excerpt. Although this resource allocation framework states that those with ‘stable conditions’ will not be excluded from critical care because of these conditions, it states that associated health factors “may be considered if they are clinically relevant” (Saskatchewan Health Authority, 2020). This small lexical detail is of great importance in clinical decisions about rationing critical care for disabled individuals. Medical professionals who have the power to make these resource allocation decisions may see factors associated with a person’s disability as clinically relevant to the effectiveness of their treatment and this can disqualify them from accessing critical care resources in the case of a patient overload in critical care units.

These issues with ambiguity regarding medical rationing experienced by disabled people during COVID-19 must also be examined in the social context that they are published. A 2020 global report on disability rights during the COVID-19 pandemic received more than 550 testimonies of disabled people who were denied medical care on the basis of having a disability

during COVID-19 (Brennan, 2020). This report highlights numerous incidences of disabled people living in institutions who did not receive adequate medical care for COVID-19 or who were denied access to treatment at hospitals due to resource allocation (Brennan, 2020). There is, therefore, a precedent for denial of medical care due to disability during the COVID-19 pandemic and the statement from the Saskatchewan Critical Care Resource Allocation Framework should be interpreted in this context. Disabled individuals, especially those living in institutional care have expressed fear in needing greater medical care, should they be denied access or seen as low priority due to ‘pre-existing conditions’ (Brennan, 2020; Linton, 2020; Saskatchewan Health Authority, 2020).

Valiani et al., (2020) – Development of Critical Care Resource Allocation Framework

The [resource allocation] protocol seeks to find patients for whom a **substantial “incremental” survival benefit** would be derived by admission to ICU.

This excerpt is taken from an academic article published by Saskatchewan ICU physicians regarding the development of the framework for critical care resource allocation in Saskatchewan because of the COVID-19 pandemic. This rationale for critical care admittance states they are looking to admit patients to ICU that have the highest rates of survival should they be provided this care. This publication also discusses the ‘tie-breaker’ criteria that would be instituted should there be patients with identical clinical situations (Valiani et al., 2020). These include life-cycle criteria, and instrumental value criteria. Life-cycle criteria prioritizes patients who have not had the opportunity to live through stages such as having children or a career (Valiani et al., 2020). This prioritization could be problematic for disabled individuals because there is an incorrect societal assumption that many disabled individuals will be unable to have

careers, have fulfilling relationships, or start families if they desire to do so (Ubel et al., 2005; Andrews et al, 2020). Disability is often seen as outside of the ‘normal’ life cycle and therefore they may be disqualified based on life-cycle criteria. The criterion of instrumental value prioritizes individuals who have a particular value to society, for example health care workers in a pandemic (Valiani, et al., 2020). These criteria may also disadvantage disabled individuals who in the medical model are portrayed as a medical burden and may not be seen to have instrumental value to society (Titchkosky, 2011).

This explanation of resource allocation protocols from Saskatchewan ICU physicians was published in the *Canadian Medical Association Journal*, a peer-reviewed, academic journal. The only other official publication of these protocols was in a Saskatchewan Health Authority protocol document. Both documents are written in academic language and the framework is not provided in a plain language description that would be more accessible to a lay reader. The lexical choice in this resource allocation framework that states a focus on “substantial survival benefit” is worth noting because it communicates that a triage team is looking for individuals who will not only survive based on ICU admission, but will have a substantial survival (Valiani et al., 2020; Saskatchewan Health Authority, 2021). This phrase was coded using values coding, meaning that it communicates and inferred values or ideology. The idea of substantial survival benefit is one that can be influenced by one’s ableist understanding of quality of life. If an ICU team does not see disabled lives as ones that will benefit from survival through medical intervention, they may reallocate these lifesaving resources elsewhere. Decisions of resource allocation based on this language may impact disabled people accessing this care, especially those with medical needs complex enough to be living in long-term care because their outcomes

and quality of life may be seen as not meeting a survival benefit or being worth the use of medical resources.

Chapter 7: DISCUSSION

Discussion

Although this thesis uses critical methods of data analysis with analytic autoethnography and critical discourse analysis, the goal of this thesis is not to simply point out everything that has been wrong with long-term care over the course of the COVID-19 pandemic. As Aubrecht et al., (2020) discuss, even the best policy frameworks informed by “nuanced understandings and positive intentions” will not solve all issues and harms that take place in institutional care (p. 10). The COVID-19 pandemic has exacerbated issues already present in long-term care (Linton 2020; United Nations, 2020). Loneliness has only increased, as residents of long-term care institutions have continually been locked down and kept in isolation, even when those policies do not reflect what is required of the general public (Quenneville, 2021). Residents living in long-term care facilities have been labeled as being the most vulnerable of populations and largely relegated to residual space and forgotten as we get back to ‘normal’ in surrounding communities.

The reality is, “long-term care policies fail to identify and address the unique experiences, desires, and needs that arise as people with disability age and as people age into disability” (FitzGerald, 2020, p. 93). This means that long-term care is currently not meeting the individual needs of disabled people who cannot access the care they need in their communities. This can clearly be seen in the policies enacted throughout the COVID-19 pandemic that have restricted the personal freedoms of residents living in long-term care far beyond what has been required of those not needing that level of care. It is important to acknowledge that perceptions, and conceptualizations of disability and care strongly affect policy frameworks that come into place (Aubrecht et al., 2020). If society approaches disability with ableist assumptions, including

false ideas that disabled people have a lower quality of life, this can reflect in policy that is enacted about resources and care that disabled people may need to use.

An area where this lack of individualized approach is evident, is the use of long-term care as one of the only housing solutions for disabled people with complex medical needs of any age. For example, an article from Gillmore (2021) discusses how young people are stuck living in long-term care due to a lack of accessible options in their communities. Hewitt (2020), a disabled academic, also examines the challenges of accessing age-appropriate care by saying that young people in long-term care are expected “to be content to fit into a life of an 85-year-old” (p.117). In my experiences working in long-term care, younger residents seemed to show more discontentment with experiencing the forced isolation.

There is a strong “devaluation of lives at the intersection of age and impairment”, an intersection of people who are often required to utilize the services that long-term care provides (Greiner et al., 2020, p. 24). We have seen this as a reality in long-term care throughout the pandemic, as those with “pre-existing conditions” have been seen as necessary casualties of this pandemic (Linton, 2020). Additionally, those with disability living in long-term care have largely been forgotten or deprioritized as society tries to “get back to normal” (Quenneville, 2021, p. 1). As FitzGerald (2020) discusses, when the “human norm is complete independence, those who need [complex care] will be seen as lacking, and as a burden on the system” (p. 91). This has been highlighted clearly as provincial governments have made decisions, reinforced by ableist ideals, that the rest of society can return to normal, while those with disabilities should just continue to isolate, during a mass-disabling event (Stead Sellers, 2022).

A challenge issued by Aubrecht et al., (2020) about long-term care regardless of a pandemic, is to continuously improve the experiences of residents and long-term care conditions

while accepting that there are perpetual and irresolvable issues of care that will arise in tandem with solutions. It is important, therefore, to listen to the disabled voices in our communities that are continuously saying that the COVID-19 pandemic has been and will continue to be a mass-disabling event, and that disabled people in institutional care have faced some of the greatest challenges throughout this pandemic (Stead Sellers, 2022; Linton 2020). Piepzna-Samarasinha (2018) asks a question in her book that I think is valuable to examine here, she states:

What does it mean to shift our ideas of access and care (whether its disability, childcare, economic access, or many more) from an individual chore, an unfortunate cost of having an unfortunate body, to a collective responsibility that's maybe in joyful? (p. 33)

By centering the voices of disabled people in conversations about disability care networks, we create a system more likely to meet the needs of the community it serves. Are there ways that we can center the voices of disabled people and shift traditional ideas of care to change long-term care in ways that improve outcomes for residents living in institutional care?

De-institutionalization of long-term care

A podcast episode of *Invisible Institutions*, supported by People First of Canada, meets with three disabled people living in long-term care and highlights their thoughts on institutionalization and long-term care. Essentially, their message is this, institutions are not the best answer. They state that institutions rarely work for anybody, “for the disabled, for the mentally challenged, for people with developmental disabilities, for people with chronic illness, for seniors” and that institutions are not suited for individuals; however, they do align with bureaucracies (Linton, 2020b). Marcie Roth, the chief executive officer of World Institute of Disability is quoted as saying “You don’t go into a nursing home because you are old. It’s not about age, you go because of stigma and because your community has failed to assist people

with disabilities to live independently with adequate support” (Frost, 2020, p. 1). As stated previously in this thesis, there is a strong link between current long-term care and the problematic history of large institutions in Canada. For example, the Huronia Regional Center, a large institution previously mentioned in this project, closed in 2009 and survivors of this institution have made their wishes clear that this site should be demolished (People First of Canada, 2010; Taylor, 2021). Instead, this building is being considered for conversion to a long-term care facility, a move that is being strongly critiqued by institution survivors who have cited concerns about ended up being cared for in long-term care in the same building where they faced years of abuse (Taylor, 2021). This is just one example of the ways that long-term care is continuing the legacy of institutionalization of disabled people.

Deinstitutionalization is most simply, moving disabled people from care institutions into more community-based care alternatives that prioritize autonomy of value of disabled persons (McCarron, et al., 2019). Although long-term care facilities do encompass the ideas of institutionalization, long term care is often viewed as a necessary space and therefore there are few academic critiques that have examined long-term care structure (Herron et al., 2021). For example, a common critique can be the size of long-term care facilities in institutional issues; the idea is, as there are more residents to care for, the care will become less personalized and more institutional, perpetuating problems that have existed in care facilities throughout history. Instead, a “household model” has been proposed because it has been found that residents are more successful in smaller, homelike environments (Wickham, 2012). These findings, among others, suggest that community living models, care collectives, and intentional care communities do not seem to have the same poor reputation or as many negative outcomes in care partnerships (Wickham, 2012).

The idea of small homes for congregate or supported living already has a history in Saskatchewan health care from when the province was establishing its health care plans during the 1940s. As examined earlier in the history of long-term care facilities, this idea for a smaller cottage system was bypassed in Saskatchewan due to concerns about economic efficiency (Wickham 2012). It is interesting how the critiques of larger institutions are still prevalent in modern long-term care, as they were in the 1940s when this system began in Canada. It has been established those large institutions have a history of physical, social, and emotional harms (Rossiter & Clarkson, 2013; Malacrida, 2015; Abbas & Voronka, 2014). Long-term care institutions have only aggravated these issues throughout the COVID-19 pandemic (Linton, 2020). So, the question becomes, how can we deinstitutionalize long-term care? Are there ways that we can support disabled individuals in having their care needs met while supporting autonomy and community care, especially during a global pandemic?

The largest challenge is that the “landscape of care” is underdeveloped (Milligan & Wiles, 2010, p. 736). This means that networks of relationships, settings, services, and broader care structures are not in place to support disabled people living in communities or non-institutional care (Herron et al., 2021). In the current institutional model, disabled people are seen as “objects of care” and this contributes to ableist and binary understandings of normal and abnormal that look to cure and correct disability (Piepzna-Samarasinha, 2018; Ben-Moshe, 2020). Piepzna-Samarasinha (2018) states that “when disabled people get free, everyone gets free. More access makes everything more accessible for everybody” (p. 78). By dismantling ideas that reduce disabled people living in long-term care as vulnerable, helpless, recipients of care, it not only improves care for those currently living in long-term care but improves quality of care for all those interacting with health care in any capacity.

Long-term care in Saskatchewan and across Canada is under great levels of strain and this has only been made worse by the pressures of the COVID-19 pandemic. There have been many critiques of current long-term care institutions as well as many suggestions from researchers based on academic findings of how to improve long-term care settings. Yet, “the structures of long-term care seem to be too embedded, and we lack alternatives”, that are required for the needed culture change to meet recommendations (Herron et al., 2021, p. 195). The work of deinstitutionalization does not mean simply offloading necessary care onto family members to avoid admission into long-term care (Herron et al., 2021). It is also not just making new, smaller care institutions. The process of deinstitutionalization involves continually dismantling ableism and systems of power in care settings. Most importantly, deinstitutionalization starts with recognizing the personhood and inherent value of disabled persons. Perhaps it is time to change or challenge long-term care in a more fundamental way.

Deinstitutionalization practices only work if there are adequate supports in place both in terms of infrastructure and societal understanding (Fulone, et al., 2021; de Bruijn-Wezeman, 2020). Heumman (2020) states that “curb cuts and ramps are essential, but if you put in a ramp and nothing else happens, then no one will go up the ramp” (p. 200). This point speaks to deeper culture change, then simply ramps into a building. If we only do the work of shutting down institutions, and none of the associated and necessary work of building community supports, of creating “landscapes of care”, and dismantling societal ableism, the true work of deinstitutionalization will not be successful (Milligan & Wiles, 2010, p. 736). We do not want to do all the work of transitioning out of institutional care, just to have people re-institutionalized in different ways such as in the carceral or hospital systems. A 2021 project from Fulone et al., examined systematic reviews using knowledge translation tools and found several strategies that

can aid in deinstitutionalization. The findings suggest that anti-stigma community education, integrated health models that are flexible, community health teams, and assisted living opportunities may help in establishing successful de-institutional practices.

In an examination of home and disability (Imnie, 2010) states that “disabled people often experience the home as a series of ‘disembodied spaces’, or places that are designed in ways that are rarely attentive to their psychological and bodily needs and functions” (p. 26). I believe that this analysis of home environments can be extended to long-term care environments. In discussing long-term care homes, Tremain (2020) states that “these places are neither ‘homes’ nor sites of ‘care’” (p. 1). Long-term care should be reframed in ideas home, ideas of safe and belonging, instead of as care institution. In this way, we can address the ways that homes are disembodied spaces for disabled people and make homes where disabled people live a place where they can have their needs met, as opposed to impersonal, institutional environments. Long-term care should be reframed in a way that allows it to fulfill the needs of a home environment for those living there.

Another systematic review of thirteen qualitative and quantitative studies presented many facets of quality of life associated with deinstitutionalization (McCarron, et al., 2019). This publication found that a greater sense of freedom and living in community was associated with better quality of life outcomes. This project also gave suggestions of de-institutional practices that could be implemented in care institutions that have been shown to increase quality of life. These include access to increased privacy and financial independence for residents, greater compatibility between housemates, increased family contact and social integration (McCarron et al., 2019). There were also recommendations provided for the care workers role in de-institutional practices, including trying to maintain permanent staff that are familiar with

individuals to develop relationships and increase community participation (McCarron et al., 2019). When I see this list of practices that are seen as de-institutional, I cannot help but see that these are situations that would be desirable for any person. Access to reasonable privacy, loved ones, community, and independence are general tenets that I would consider desirable for most individuals.

While completing data collection for this thesis project, I read the book *Care Work: Dreaming Disability Justice*, where Piepzna-Samarasinha (2018) examines disability justice and the possibilities of care webs or collectives. She includes a list entitled “Questions to Ask Yourself as you Start a Care Web or Collective and Keep Asking” and although long-term care is not necessarily the same as community care, perhaps some of these ideas could contribute to deinstitutionalization in care spaces (Piepzna-Samarasinha, 2018, p. 67). Piepzna-Samarasinha asks:

- What is the goal of your care web? Who needs care? What kind?
- What are best practices that allow the people receiving care to receive care well?
- What are best practices that allow the people offering care to offer care well?
- How will you celebrate and make it fun?
- Are you building in ways for disabled folks to offer care, instead of assuming that only able-bodied people are the “care-ers”?
- What meeting structure do you need to check in, talk through issues, and keep things on track? (pp. 67-68)

These questions, although asked for a community care context, have a validity in long-term care settings. How are we building in ways for mutual care between residents and staff and challenging the inherent power dynamics in care situations? How can we make care fun and

celebratory? Additionally, how are we checking in with residents, are we giving them autonomy in their care and letting them talk through issues of care when they arise? These are all questions that I think serve to dismantle power dynamics in long-term care and perhaps can start us on the process of deinstitutionalizing care as we come through this COVID-19 pandemic.

Through the process of completing this thesis and thinking about de-institutionalization in long-term care environments I have had to reflect on the ways long-term care facilities fail to reject institutional practices. I do think this system requires more than just a few recommendations made by academics after systematic reviews of the data. There is a deep and tangible cultural change of care that is needed to adequately meet the needs of disabled people requiring more complex medical care. Prior to the pandemic, the facility where I worked was known for working toward deinstitutionalization and implementing practices in long-term care that created choice and places that were like home (The Eden Alternative, 2016). Responses to the COVID-19 pandemic have changed this focus on freedom to a focus on keeping virus transmission as low as possible, an important focus. It is also important however, to acknowledge the ways that residents in long-term care have been held to standards well and above the greater population. The response to take away freedoms was swift, but a response to restore those freedoms for residents in long-term care has yet to be seen.

Limitations

With any type of research there are certain limitations that are a factor in a research project. A limitation commonly associated with autoethnography is that there is only one participant. Autoethnography is not a representative sample of every like situation, and I can only speak from my experiences, however autoethnography's goal is to reveal bigger truths from personal narratives. This project has highlighted some of the challenges that have been present in

long-term care during the COVID-19 pandemic and I certainly do not believe that these experiences are unique or insular. Institutional care has been the source of critiques prior to the pandemic, and I believe that the COVID-19 pandemic has further demonstrated some of these issues.

A limitation of critical discourse analysis is that it may allow a researcher to too easily uncover findings that they expect to find (Frantz, 2003). In other words, it holds the possibility for bias in interpretation. The analysis in this project, however, has simply worked to highlight the information presented, the social actors involved, and the social context, in which these documents are published and then present possible conclusions. Performing this critical discourse analysis has shown me that it is important to examine how a document can be perceived by its reader, as systemic and implicit social factors and power dynamics can affect the way information is communicated. Another challenge of this project is that it does not directly include the voices of disabled people living in long-term care. This was certainly a limitation of this project that was impacted by time constraints, as well as constraints due to ethical concerns. I do think it is incredibly important to include the voices of disabled people to tell their own stories, I also believe it is important to share the realities of long-term care situations throughout the pandemic in this capacity. I would also like to acknowledge my own privilege as a weakness in this project. As a white person in a temporarily abled body who holds a paid position in a health care environment, I enter relationships with residents in long-term care with a great deal of privilege and power. I have done my best throughout my work and this project to be aware of this privilege and counter act it through actively decentering myself as much as possible in situations where residents are feeling their needs and rights are not being met.

Although there are certainly limitations of this project, this thesis project contributes to academic work in two important ways. This project adds valuable insight to the challenges in long-term care for disabled people throughout the COVID-19 pandemic by including personal accounts of a care worker. This thesis also contributes to the emerging fields of academic work that is linking aging and disability studies, areas of study that should draw from linked theoretical understandings and previous research because aging and disability are not somehow mutually exclusive life courses. Finally, this project works to redefine long-term care as institutional care. I do not shy away from acknowledging the eugenic and institutional past of disability care in the province of Saskatchewan, and across Canada. Long-term care should be recognized as the last socially acceptable form of institutionalization (Herron et al., 2021). By doing so, we can continue the work of providing health care that promotes autonomy and competent, desired care work. Hansen & Philo (2009) state, “there is no magic solution, but we must confront the question about how much more could be accomplished if disabled people were better able to make their way in the world on their own terms” (p. 263). This project has tried to highlight the importance of this idea, that disabled people have the right to make a better world, on their own terms; a world where they are not kept in institutions and forgotten. It is our job to be receptive to these changes.

Future Research Questions

This project has revealed the need for future research that could cover several topics. Through my work experiences I noticed a possible increase in access to MAID services by residents living in the long-term care institutions during the COVID-19 pandemic. There is potential for a future research project that analyzes data for a correlation between disabled individuals both living in long-term care institutions, and in the greater community and the rate

of accessing MAID services during the COVID-19 pandemic. Future research projects could also expand on this thesis by doing more in-depth data collection and including the voices of disabled people living in long-term care. Centering disabled voices in academic research is more important than ever, and I believe that academic work about in this area should continue to strive to do this. As disabled people have continually been pushed out of sight throughout this pandemic, it is more important than ever to allow disabled people to tell their own stories. Future research should stive to do what this project was unable to, by including these voices.

Chapter 8: CONCLUSIONS

Conclusion

This project set out to answer the question of how disabled people living in institutional care have been impacted by the COVID-19 pandemic from my perspective as a care worker. Through analysis of my journal entries and excerpts from protocol documents published by the Saskatchewan Health Authority, this project has shown that protocols enacted throughout the pandemic were harmful for individuals living in long-term care. Hopefully this project has communicated with some clarity, the challenges for those living in long-term care during this pandemic from my own perspectives as a care worker. The challenging thing for me to accept working in long-term care is the fact that I get to go home at the end of the day. As a care worker, I can complain about, and critique ableist health care protocols as much as I want, but at the end of the day throughout this whole process, I have been able to go home and hug my family. I have never needed to face 55 days of bed baths because my area of the building is in outbreak. I have not had to say good-bye to my spouse over video call, not knowing when I will see them again. I have not had my value and worth questioned because my “pre-existing conditions”. I have not faced extended isolations upon moving into an unfamiliar place. It is important that the focus stays here, with disabled people who are facing the real, everyday challenges of institutional care, challenges that have only grown during the COVID-19 pandemic.

Through this process, I have discovered things about both institutions of long-term care and myself, that I am not particularly fond of. I have grown to understand the ways that infantilization and ableist biases in care negatively impact residents living in institutions and I have explored the critiques of disabled individuals about institutional care. Now, I understand

how bad we are at planning for disability, and how poorly we treat disabled people. I have a greater appreciation for the ways that disabled individuals are so often kept out of the spotlight, and relegated to residual spaces, an afterthought. As these realities of mistreatment became more apparent to me throughout my graduate studies and completing this thesis project, it became harder for me to work in long-term care. The links between institutionalization, once pointed out, were harder to ignore. For these reasons, I have stepped away from my role working in long-term care. I plan to use my learning in this project to better myself and my hope is that some prospective reader will do the same. It is my hope in writing this project that it may draw some connection to others striving to make the world a more liveable place for disabled people. Foucault (1984) states that “singular forms of experience may perfectly well harbour universal structures” (p. 335). Autoethnography is meant to encourage some societal understanding and it is my hope that alongside this critical discourse analysis, a fuller picture of the social power dynamics during COVID-19 in long-term care is presented.

In her own thesis and subsequent book, Heather Kuttai (2010) discusses how disability has historically been an “added on” on subject in most research and curriculum areas. This has been a consistent theme throughout this project as well, where disabled people are continually pushed to residual space, and I believe this theme holds true for health care environments. Disabled individuals are consistently seen as the other, the “add-on”. I believe our health care protocols during this pandemic have reflected that. We have insisted that if the only people who die are those with “pre-existing conditions”, then we can consider our pandemic response a success. Hansen & Sampert (2022) state that “when announcements were made that a disabled individual died of COVID, those who tried to downplay the pandemic as nothing worse than a flu pointed to those deaths as another example of Darwinism. It was fine if a disabled person

died of this disease, they suggested. Somehow, our lives were worth less” (p. 1). How disheartening that we do not view the loss of disabled lives as a loss at all.

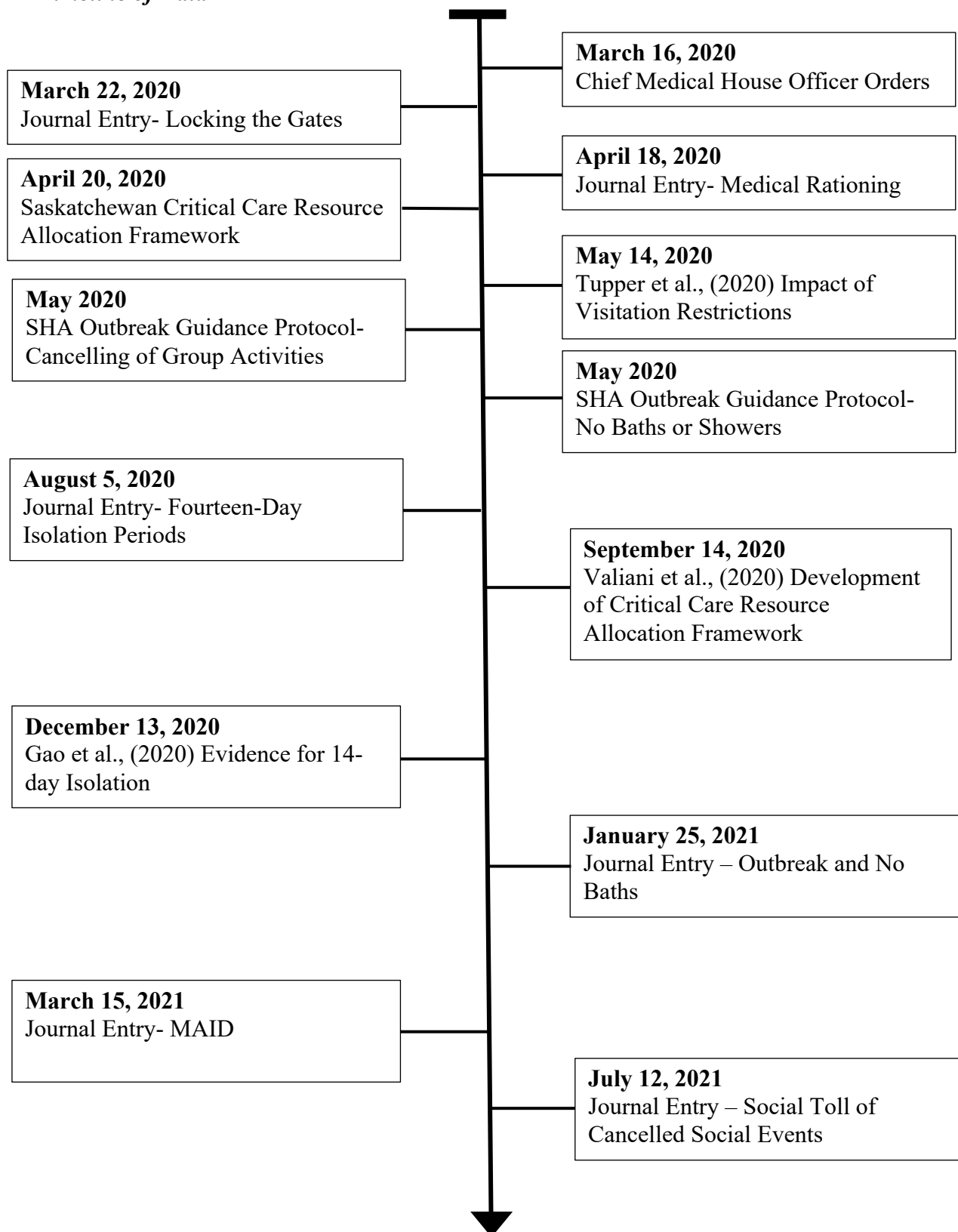
Perhaps most importantly, this project aims to leave some evidence of the realities of long-term care during COVID-19 and the challenges that this time has highlighted. Mia Mingus (n.d.), a disability educator and activist states on a page of her disability justice blog:

We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached. Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other. Evidence of who we were, who we thought we were, who we never should have been. Evidence of each other that there are other ways to live – past survival; past isolation. (p. 1)

This project aims to leave evidence that disability and aging are intertwined in important and tangible ways in long-term care, and that we need to be having conversations that link the critical theories in both aging and disability studies. Lastly, it aims to tell the stories, even if just from the perspective a caregiver, that challenge the ideas that the loss of disabled lives, of costly bodies, is somehow less of a tragedy than losing any other human being.

This thesis project has critically examined the protocols in place in long-term care throughout the COVID-19 pandemic and the ways that these protocols may be informed by ableist understandings of disability. Working through this project has shown me that viewing disability as something that lowers quality of life, something that makes you vulnerable, incompetent, and expendable, reflects in protocols we make that directly affect the lives of disabled people. If there is one takeaway from this project, it should likely be that disability exists, it exists in long-term care, in your community, in your workplace, and in your home. Perhaps if we could acknowledge this, we could make decisions that center disabled voices,

disabled people. After all, if you, reader, are not disabled now, you likely will be one day, as will I, and what a beautiful and ordinary existence it will be.

Appendix A:***Timeline of Data***

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