FALLING THROUGH THE CRACKS?

AN EXPLORATION OF THE CONDITIONS OF CARE EXPERIENCED BY YOUNGER RESIDENTS LIVING IN LONG-TERM CARE FACILITIES

MORGAN A. R. SEELEY

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Abstract

This dissertation examines the situation of younger residents living in long-term care facilities (LTCFs) in Ontario in the decades leading up to the COVID-19 pandemic. Adults under the age of 65 with disabilities and chronic health conditions were impacted by neoliberal processes of long-term care (LTC) reform and the closure of provincial residential institutions for people with disabilities. Gaps in public health and social care associated with these changes led some non-senior adults to turn to LTCFs when their needs were not being met. Very little is known about the situation of younger residents, who comprise less than eight percent of the total resident population in Ontario's LTCFs. I address this gap by exploring non-senior residents' "conditions of care"—the practices, interactions, relationships, and structures that make up their everyday experiences living in a LTCF. My study asks: What are the conditions of care for younger residents, do they align with their needs and preferences, and what factors account for the value of and problems with these conditions? Guided by a relational feminist disability perspective, I address these questions by drawing on data from semi-structured interviews with younger residents, direct care workers, and administrators, as well as from a focus group with family members, field notes, and facility-specific documents. I analyze the data as informed by intersecting relations of difference and inequality associated with gender, disability and age, and as situated within a particular set of contexts. My findings demonstrate that for non-senior residents, the promise of LTCFs lies in relational care—the presence of favourable interpersonal care relationships and the practice of care in relational ways. However, relational care is often prevented by the structures of LTC, particularly those associated with public funding inadequacies and the application of strategies associated with new public management (NPM). Addressing these barriers is key to transforming LTCFs into places that are better for younger

residents. But LTCFs will not be appropriate until a range of accessible, high quality, public LTC and social services are also made available.

Dedication

This dissertation is dedicated to the 18 non-senior residents who so generously and openly shared their experiences of and knowledge about long-term care with me. This project would have little meaning without you. I also dedicate it to the family members, direct care workers and administrators who inspired me with their commitment to better understanding and improving the conditions of care for younger residents.

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List of Abbreviations

ABI — Acquired Brain Injury

ADLs — Activities of Daily Living

ALC — Alternate Level of Care

CAP — Canada Assistance Plan

CCC — Complex Continuing Care

CCACs — Community Care Access Centres

CCRS — Continuing Care Reporting System

CDS — Critical Disability Studies

CHA — Canada Health Act

CIHI — Canadian Institute for Health Information

CMI — Case Mix Index

DS — Disability Studies

EBM — Evidence-based Medicine

FDS — Feminist Disability Studies

FPE — Feminist Political Economy

HCC — Home and Community Care

IDD — Intellectual/Developmental Disability

LOS — Length-of-stay

LTC — Long-Term Care

LTCF — Long-Term Care Facility

LTCHA — Long-Term Care Homes Act

LTRC — Long-Term Residential Care

MOHLTC — Ministry of Health and Long-Term Care

MS — Multiple Sclerosis

NPM — New Public Management

ODSP — Ontario Disability Support Program

PSW — Personal Support Worker

RAI-MDS — Resident Assessment Instrument Minimum Data Set

RCC — Resident-Centred Care

RN — Registered Nurse

RPN — Registered Practical Nurse

UPIAS — Union of Physically Impaired Against Segregation

Introduction

Non-Senior Adults with Disabilities: Falling Through the Cracks in Long-Term Care?

The title of this dissertation, “Falling through the cracks?” was initially conceptualized in the form of a statement rather than a question about adults under the age of 65 living in long-term care facilities (LTCFs) in Ontario, Canada, in the two decades prior to the COVID-19 pandemic. From the start, I assumed this situation was a striking example of cracks in the province’s public health and social service systems. The movement towards public home and community-based disability and health care services was in contrast with the growing presence of non-senior residents[1] in Ontario’s LTCFs. When I began to search for and collect any information I could about this issue, an overall absence of scholarly research and policy on the topic became apparent. The small body of research I did uncover was limited both by a tendency to adhere to narrow, discipline-specific perspectives on long-term care (LTC), and by approaches that did not attend well to the complex, contested and relational nature of care (Banerjee & Armstrong, 2015; Kelly, 2013).

This dissertation attends to these gaps by examining the situation of non-senior residents living in LTCFs in Ontario through an exploration of their conditions of care. This opportunity led me to engage with broader questions about the state of feminist and disability scholarship on long-term residential care (LTRC), and to consider the impacts of contemporary[2] changes to the public LTC system on non-senior adults with disabilities, particularly those with chronic health conditions and more “complex” health and social support needs[3].

Defining Long-Term Residential Care

The focus is on LTCFs, which in Ontario are primarily funded and regulated by the provincial government. While there are many similarities, each province and territory has its own system and history (Banerjee, 2009). In Ontario, LTC involves a range of institutional or facility-based health and social care services, policies and programs aimed at individuals who require on-going care for indefinite lengths of time (Banerjee, 2009). LTRC is one piece of Ontario's LTC system, which also includes public home and community care (HCC) services such as home care (e.g. nursing, paraprofessional personal support work, rehabilitation and other therapies, and social work), home support services (e.g., homemaking, transportation, Meals-On-Wheels, visiting), and other community-based services (e.g., adult day, respite and congregate dining programs (Cloutier-Fisher & Joseph, 2000; Daly, 2007; Government of Ontario, 2022).

LTCFs are intended to serve people whose care needs cannot be met through a combination of HCC and informal supports, but who are also considered not to need hospital-based care (Canadian Institute for Health Information [CIHI], n.d.). LTCFs offer residents 24-hour access to on-site skilled nursing, personal care and supervision in a secure setting (Auditor General, 2012). They differ from other non-hospital based care facilities such as retirement homes in that most of the costs of care are publicly-funded (Roblin et al., 2019).

All of Ontario's LTCFs are licensed and regulated by Ontario's Ministry of Health and Long-Term Care (MOHLTC). They are operated, however, by a mix of private for-profit, private not-for-profit (charitable/religious), and public (municipal) owners (Roblin et al., 2019). Private, for-profit facilities comprise the majority of LTCFs—close to 60 percent of all facilities (CIHI, 2021a; Wilkinson et al., 2019). Regardless of ownership, LTCFs are funded by the province to cover the costs of nursing and personal care, programming and support services, raw food, and other accommodations (e.g., housekeeping, building operation and maintenance, laundry, dietary services and administration; Damji, 2015). The amount of funding is based on the facility's case mix index (CMI)—a measure of residents' relative care needs. Residents themselves pay a monthly copayment, with maximum fees set by the province and varying with the type of accommodation (e.g., private, regular semi-private, basic). Low-income residents may also be eligible for a reduced co-payment fee for basic accommodation.

A Changing Resident Population

Senior adults comprise the majority of residents in Ontario’s LTCFs. Statistics indicate an average resident age of between 83 years (CIHI, 2012) and 84 years (CIHI, 2021b). The literature also indicates that the resident population is not the same group it was in earlier decades (Marrocco et al., 2021). Residents entering LTCFs are doing so with more extensive and complex medical and social support needs (Marrocco et al., 2021; Ontario Long-Term Care Association [OLTCA], 2014; 2019). They are more likely to experience dementia, most have some form of cognitive impairment, and almost all have been diagnosed with two or more forms of chronic illness. It is also clear that since more residents are entering care at the later stages of their lives, LTCFs are increasingly being required to provide palliative and end-of-life care (Long-Term Care Staffing Study Advisory Group [LTCSSAG], 2020; Marrocco et al., 2021; Quality Palliative Care in Long-term Care Alliance, 2011).

At the same time, LTCFs are reporting a growing number of younger adult residents. By 2010, non-senior residents between the ages of 18 and 65 consistently made up a small but significant sub-population hovering between six and seven percent of the total resident population in Ontario (CIHI, 2012; 2020; 2021b). Gaps, methodological, and definitional inconsistencies in survey data—particularly in data collected prior to 2013—have made it difficult to generate an accurate profile of this group over time, but there are several indications that the younger resident population differs from the overall resident population. Where females comprise the majority of residents in Ontario’s LTCFs, younger male and female residents are present in relatively equal numbers (CIHI, 2012; CIHI, 2021b). There are also indications that the types and degrees of impairment and chronic illness that younger residents experience differ from the average resident population (Barber et al., 2021; Fries et al., 2005; Hewitt, 2022; Oliver et al., 2022). While information regarding the average length-of-stay (LOS) among Ontario's under 65 residents is not readily available, age at entrance also appears to matter—residents under the age of 65 are more likely to live in a LTCF for longer than the two to three year average reported in the literature (Damji, 2015; Lievesley et al., 2011). This difference may be related to the fact that some impairment-types more commonly experienced by younger residents are associated with life expectancies similar to that of the population without disabilities (Kelly & Winkler, 2007).

Younger Residents Living in Ontario's Long-Term Care Facilities

The presence of non-senior adults in Ontario's LTCFs in the time leading up to the COVID-19 pandemic requires greater attention. Awareness of their presence in Canada and elsewhere largely emerged through media depictions and disability justice campaigns emphasizing both the inappropriateness of and risks accompanying the integration of this diverse resident population into these sites. Over the past two decades, a wealth of television documentaries, newspaper articles, opinion-pieces, radio shows, podcasts, and articles in professional magazines emerged to describe a "crisis" in Ontario's facilities whereby non-senior adults are being "marooned" and left to "languish" in LTCFs given the absence of accessible, integrated, HCC and disability services and supports (see Crawford, 2007; Goffin, 2017; Lacey, 2007; Punch, 2015; Tremonti, 2014). While this coverage troubles the general assumption that only seniors reside in LTCFs, when metaphors of crisis and catastrophe are perpetuated in the absence of a scholarly knowledge-base, the situation of non-senior residents becomes oversimplified, and information about why this situation exists and what LTRC of the sort younger residents want and need might look like remains elusive (Muenchberger et al., 2011).

At the same time that popular depictions of the experiences of non-senior residents dominated the public imagination, analyses and discussions in academic literature tended to focus narrowly on what is problematic about LTCFs for non-senior residents. A proportion of this small body of literature described LTCFs as the *worst* option for young people, while positive and/or valuable experiences and understandings of LTRC were discussed as indicative of non-senior residents' inclinations not to criticize their care (e.g. Smith, 2004). This approach is understandable, particularly in reference to the oppressive, exclusionary, and violent history of the placement of people with disabilities in Canada (and elsewhere) in large-scale public institutions (Kelly, 2011). It is also connected to evidence of the on-going ways in which smaller-scale facilities and/or "community-based" sites of public care have sustained institutionalizing conditions (Leblanc Haley & Temple Jones, 2020; Spagnuolo, 2016).

A lack of focus on the experiences of non-senior adults living in LTCFs also reflects the dominance of what Asch and colleagues (2008) call "abolitionist" perspectives held by some Disability Studies (DS) scholars and disability justice activists for whom anything short of the complete abolishment of segregated, congregate "care" arrangements aimed at people with disabilities is considered a regressive and disablist undertaking—one that is certainly incompatible with efforts towards disability justice and citizenship. There are, however, limitations to this perspective. While LTCFs may not be ideal nor age-appropriate environments for non-senior adults, we actually know very little about the experiences of those living in them. An abolitionist stance may deter social researchers from engaging in such work—a response that means contemporary institutionalizing conditions, practices and experiences will continue to remain hidden. Without empirical research, there is no evidence-base to drive change (Oliver et al., 2022). It is also a problem if, in an attempt to make visible the negative impacts of LTCFs, it positions non-senior residents as passive victims of the system and its structures.

There has been a rapid growth in empirical research from Australia and the United Kingdom on this topic over the past two decades, but in Canada researchers have only just begun to explore the situation of non-seniors living in LTCFs. Some projects have begun to identify differences in quality of life among residents over and under the age of 65 (Watt & Konnert, 2007). Others have employed qualitative methods to explore the lived experiences and perspectives of non-senior residents (Aubrecht et al., 2021; Barber et al., 2021; Hay & Chaudhury, 2015). Together, this work highlights the need for LTC policy and practices that are better attuned to the social, emotional, and physical needs of non-senior residents (Barber et al., 2021). It also makes apparent the need for more empirical research on this topic.

Multi-level analyses of the factors that influence non-senior residents' experiences and understandings of LTCFs are especially rare. Research on this topic has tended to remain at the level of individual and interpersonal (micro-level) experiences. This work makes an important contribution to the field given the overall paucity of information available, but such approaches tend to miss the contexts, ideas and structures within which experiences of LTCFs are situated. This is a particular problem when considering the situation of non-senior residents living in LTCFs in Ontario in the 2000s and 2010s, as this phenomenon—while not entirely new (see Chapter 4)—is tied to major transformations in public health care and social services and programs including health care reform and the downsizing and closure of public residential institutions[4] and hospitals for people with disabilities. These processes meant a shift in the delivery of public care from hospitals and institutions to other institutions (including LTCFs) and to households and “community-based” health and social care settings. This change has been supported by developments in technologies and pharmaceuticals (Armstrong & Armstrong, 2003b), by notions of “care closer to home” (Armstrong et al., 2000, p.40), by recognition of abuse and neglect of people with disabilities in the residential institutions (Linton, 2021), and by changes in ideas about the rights of people with disabilities. But occurring in the context of neoliberalism, these processes are also about cutting public spending and relatedly, the implementation of a model of public service reform based on techniques developed by the for-profit sector (see Armstrong, 2000; Linton, 2021).

For some, these changes have meant deinstitutionalization and/or the movement of care to home. But given these processes has not been coupled with the development and implementation of a diverse, comprehensive set of adequate, timely, affordable public residential and non-residential health and social services and supports (Fast, 2020; Gibson et al., 2012; Harris & Scarfone, 2014; Linton, 2021; Wilton, 2004), they have also meant the (trans-) institutionalization of people with disabilities in other public institutions or institution-like forms of health and social care (Dube, 2016, cited in Verseghy et al., 2019; Leblanc Haley, 2017; Linton, 2021; Morrow et. al., 2008; Spindel, 2013). Other individuals have gone without or waited years to obtain appropriate services (Gibson et al., 2012). Some non-senior adults turn to LTCFs when their need for health and social services are not being met elsewhere.

The Conditions of Care for Non-Senior Residents Living in Long-Term Care Facilities

The purpose of this project was to examine the situation of non-senior residents living in Ontario’s LTCFs from the early 2000s up until the emergence of the COVID-19 pandemic. I chose this time frame because it followed the closure of residential institutions for people with disabilities, the emergence of contemporary health care reform and relatedly, because it involved changes to the way in which care is funded, regulated, organized, and delivered in Ontario’s LTCFs. I did this through an exploration of younger residents’ “conditions of care”—the practices, interactions, relationships, and structures that make up their everyday experiences living in a LTCF. I wanted to know: What are the conditions of care for non-senior residents living in LTCFs? Do these conditions align with the needs and preferences of younger residents? If so, how and why? Are there gaps and failures in terms of the ways in which LTCFs address the needs and preferences of younger residents? If so, what are they and why do they exist?

Employing a qualitative case study, I adopted an approach to capturing non-senior residents’ conditions of care, relying most on what younger residents reveal to me about their everyday experiences and understandings of living in a LTCF. In order to extend prior research on this topic, I attended to the conditions of work in LTCFs. Research has indicated the conditions of care and work in LTCFs are closely connected (Armstrong et al., 2009; Daly & Szebehely, 2012). As such, I also involved those with particular knowledge of the conditions of work—direct care workers in particular, but also younger residents’ family members and facility-administrators. This decision also reflects my approach to care as a relationship (see Chapter 1). Further, I took seriously the contexts within which younger residents' conditions of care are situated. Drawing on field notes, facility-specific documents and a broader literature examining contemporary issues in Ontario’s LTCFs, I considered the ways in which the organizational (or meso-level) and broader (macro-level) contexts shape the conditions of care for non-senior residents. This necessarily involved considering the role of social relations of difference and inequality.

A Relational Feminist Disability Approach to Long-Term Residential Care

While the primary goal of this dissertation was to uncover and analyze the conditions of care for non-senior residents living in LTCFs, my background research revealed a number of theoretical tensions and methodological gaps in previous work on this topic. I felt a moral and ethical responsibility to approach the issue of LTRC in a way that recognized the institutional history of people with disabilities in Ontario as one characterized by segregation, isolation, pathologization, and violence (see Burghardt, 2018; Simmons, 1982). I also understood institutional violence as an ongoing issue for some people with disabilities in Canada (Leblanc Haley & Temple Jones, 2020), and that LTCFs could be experienced by residents as such.

At the same time, having had the opportunity to hold a research assistantship with the Women and Health Care Reform Group (see Chapter 3) at the time that I was developing this project, I was cognizant of the differential impact that ongoing health and social service reforms could have on women and other marginalized populations. I wondered what this could mean for non-senior adults with disabilities who use public LTC services. I recognized that while not all non-senior adults with disabilities need or want access to LTC, public funding cutbacks, health care restructuring, institutional closure, and an array of gaps in public services necessary to support people at home or in community-based support arrangements meant demand for access to LTCFs among the younger adults with chronic illness and more complex health and social care needs was unlikely to decline in the near future.

Together, these realizations attuned me to the importance of doing research on the topic of LTRC from a perspective that makes room for the possibility of transformation in addition to revolution—even if this approach sits uneasily with some DS scholars and disability justice activists. Feminist disability theories and methodologies, which have long challenged DS scholarship from within and grappled with the tensions associated with “care”, seemed an appropriate choice. However, this perspective tends not to be applied to the practice of social research in LTCFs. This was a particular problem for me as a “novice” researcher in this area (see MacLeod et al., 2018) because this literature contained little practical guidance. Inspired by the emerging work of feminist political economists in Canada who develop innovative approaches to social research in LTCFs (i.e., Armstrong et al., 2009a; see also, Armstrong & Lowndes, 2018), I engaged in a secondary project: the development of a theoretical and methodological perspective that integrates the insights of feminist disability studies (FDS) and Canadian feminist political economy (FPE) to enhance understandings and analyses of LTRC. The resulting relational feminist disability approach to LTRC guided my empirical exploration of non-senior residents’ conditions of care.

Chapter Descriptions

In the next three chapters, I lay the groundwork for this study. In *Chapter One*, I outline the key concepts, assumptions, and debates that comprise the theoretical and methodological approach that guided this project. What I call a *relational feminist disability approach to LTRC* both inspired and was a response to my question about the possibility of a FDS perspective that can grapple with the complexity of guide social research in LTRC. It is an explicitly political approach to the topic of LTRC that assumes the situation of non-senior residents exists within the historical and ongoing violences associated with institutional and institution-like forms of public “care” aimed at people with disabilities (Burghardt, 2018; Kelly, 2011; Leblanc Haley & Temple Jones, 2020; Spagnuolo, 2016). It also makes room for ideas and research aimed at “re-imagining” LTRC in ways that challenge health and health care inequities and prompts greater recognition of care as a collective rather than individual issue and responsibility (Banerjee et al., 2011).

A relational feminist disability approach draws on definitions of disability, impairment, chronic illness, and disablism developed by FDS scholars and is inspired by the ways in which they understand the intersection of gender, disability and other forms of difference and relations of social inequality. It also integrates ideas from FPE that have been developed and utilized by researchers examining LTRC in Canada. This perspective assumes care as relational. Care relationships are recognized as central to the conditions of care and the conditions of care are closely related to the conditions of work (Armstrong et al., 2009a). Further, these relationships are situated within and shaped by historical, social, political and economic contexts and commitments, by ideas about care and those who need it and/or provide it, by policies, models of care, and the ways in which care (work) is organized (Banerjee et al., 2011; Daly, 2013; Day, 2014).

As a methodology, a relational feminist disability perspective it is a framework that centers on the experiences and perspectives of non-senior residents—an approach that is reflected in the extent to which non-senior residents' narratives comprise the central data set for the project. At the same time, because this approach assumes the relational character of care, it is a perspective that necessarily involves the perspectives of others involved in care relationships (e.g., care workers, family members, administrators). It is a "flexible" research approach that assumes the partial, changing and ambiguous nature of social research processes and practices (Waggoner & Mog, 2020). It is committed to fostering greater inclusion, being more responsive to the needs and preferences of participants and reflecting on if not challenging conventional dynamic of power throughout the research process (Danieli & Woodhams, 2005; Kwiotek & McDonnell, 2003; Lunn & Munford, 2007; Owens, 2007).

A relational feminist disability perspective does not establish a specific research design, but it does guide decision-making throughout the research process. In *Chapter Two*, I present a detailed outline of the research methods I used to explore the situation of younger residents living in LTCFs. This project was designed in the form of a qualitative case study of the conditions of care experienced by 18 non-senior residents living in five private, for-profit LTCFs in the Greater Toronto and surrounding areas. I explain the methods that were chosen with a particular emphasis on their coherence to the theoretical/ methodological approach and in terms of addressing the research questions and overall purpose of the study.

Reflecting my methodological assumptions about the importance of attending to power relations and contexts in the development of "evidence" about issues of LTRC, in *Chapter Three*, I draw on participants' narratives, my field notes, data analysis journal, and feedback from my PhD supervisor, to consider a number of tensions that arose as I designed and carried out this project. I provide an account of my motivations behind and interest in the topic of younger residents living in LTCFs and my "situatedness" as a non-disabled researcher new to research involving LTCFs. I also discuss some of the limitations of my methods and the challenges, discomforts, and what I learned from my experiences accessing sites, recruiting participants, gaining informed consent, collecting data, engaging in data analysis, and reporting research findings.

Chapter Four begins my exploration of the situation of younger residents living in LTCFs in Ontario in the two decades leading up to the COVID-19 pandemic by describing the context from which this issue emerged. I focus on two key processes: First, the development of public residential institutions aimed at people with particular forms of disability in Ontario and their subsequent downsizing and/or closure; second, the process of contemporary health care reform, by which I refer to a set of changes to the public health care system in Ontario (including in LTCFs) that began in the 1990s in response to federal austerity measures, and that, following the logic of neoliberalism, meant the adoption of practices associated with new public management (NPM). Given the topic of this dissertation, in the second half of this chapter, I identify key changes and challenges associated with LTCFs in Ontario in light of these processes. I then consider their particular impact on non-senior residents.

In Chapters Five, Six, Seven, and Eight, I draw on data that I gathered for this project to identify and analyze younger residents' conditions of care. *Chapter Five* begins with the narratives of non-senior residents, and a key tension revealed in my analysis of that data—the tendency of these individuals to construct LTCFs as less than ideal but necessary sites for living. In this chapter, I consider the conditions that foster life for younger residents by focusing on what they experience and understand as valuable and/or positive about LTCFs. Notable in this chapter is both the extent to which the relational aspects of care feature in participants' stories, as well as the extent to which they are individually involved in securing access to care of this sort and in working around the barriers. I conclude the chapter with a discussion of a number of structures that appear promising in terms of fostering more consistent and equitable access to relational care for non-senior residents.

The central role played by direct care workers and the presence of conditions that support care relationships and relational care practices in younger residents' positive experiences and understandings of LTCFs provide a point of departure for my exploration of the conditions in which relational care provision can flourish. In *Chapter Six,* I draw on data from interviews with eight female personal support workers (PSWs), seven female nurses, and three female recreation staff to explore these conditions from the perspectives of direct care workers by uncovering what they experience as satisfying when it comes to care provision. The findings suggest that care relationships and providing care in relational ways are key. This chapter concludes with a discussion of the structures that support direct care workers in terms of their efforts and desire to provide relational care to younger residents.

In order to move towards relational care, in *Chapter Seven*, I draw on the narratives of younger residents, direct care workers, and residents' family members to identify factors associated with the organization and delivery of care that appear to prevent these conditions. Four key barriers emerge from the data: staffing level inadequacies; rigid care routines; discontinuity of care; and insufficient equipment. While many of the issues described are likely impact residents negatively regardless of their age, it is clear that the conditions of care (work) are fraught with social meanings about and inequities associated with gender, disability, and age, such that these problems they have particular impacts on younger residents and the ways in which they experience care.

While changing how care is organized and delivered within LTCFs is an important step to fostering the conditions that younger residents experience and understand in positive ways, I argue that this is not enough. LTCFs must also be places that go beyond their role in sustaining life to places within which younger residents can live well and flourish. In *Chapter Eight*, I question the appropriateness and capacity of LTCFs to serve this function by drawing on the entirety of the data collected for this project to identify and explore what aspects of living in a LTCF participants perceive as inappropriate or a problem for younger residents. The findings suggest that age-insensitive programs and services; alienating social environments; a culture of discrimination and violence; rigid safety protocols; deficiencies in the physical care environment; and issues in accessing public LTC services are key issues. Examining these issues within the context of neoliberalism (see Chapter 1), I argue that while these problems impact those who live, work, visit and want access to care, they have particular impacts on and have produced particular tensions for non-senior residents.

I conclude this dissertation by summarizing the main findings of the project and then situating them within the small body qualitative research literature that has focused on the experiences of younger residents living in LTCFs in Canada. I describe the contribution of this dissertation to feminist scholarship, and to understanding the lives of younger residents and those who support their care.

Notes

1. Throughout this dissertation, I use the terms “younger” and “non-senior” residents interchangeably to refer to people between the ages of 18 and 65 who are living in LTCFs. Given the average age of residents in Ontario’s LTCFs is over 83 years (see above) and this age-category has been used in statistical data and research on this topic in Canada, I believe this to be an appropriate characterization. I acknowledge, however, that these terms are socially constructed, and that resident-participants involved in this project may not identify with these categories.
2. Throughout this dissertation, I use the term “contemporary” to denote the period of time between the early 1990s up until 2020, where changes in public LTC and social services for people with disabilities were highly influenced by neoliberalism and the adoption of NPM discourses and techniques as well as by the social and political push away from residential institutions for people with disabilities.

3. The literature often refers to younger adults who access LTRC services as experiencing “complex”, “medically-complex”, “severe”, or “profound” impairments, and/or as having greater, more complex or intense support needs. This terminology is sometimes indicative of a bio-medical, social-deviance or other “individual” approaches to disability whereby the “problems” associated with disability are located in the individual body. This categorization, however, can also be useful when it aims to acknowledge the diversity of impairment-types and effects (including chronic illness) experienced by people with disabilities. I find notions of more “complex” impairments or health and social care needs particularly useful when it leads researchers to take greater account of the disablism experienced by people with disabilities who are in regular contact with the health care system in order to access desired services. See Chapter One for a discussion of my conceptual approach to disability, impairment, chronic illness, and disablism.
4. Two different types of public residential institutions for people with IDD were in operation in Ontario. Schedule 1 facilities were large-scale institutions funded *and* operated by the provincial government (Brown & Radford, 2015). Schedule 2 institutions tended to be smaller facilities that were funded by but operated at arms-length from the provincial government.
5. Drawing on Burghardt (2018), I use the term “intellectual/ developmental disability” (IDD) as a descriptor for individuals and groups of people who experience, have been labeled, diagnosed, or claim particular forms of cognitive impairment that often occurs in combination with other forms of impairment (e.g., physical).

Chapter One: Theoretical and Methodological Framework

A Relational Feminist Disability Perspective on Long-Term Residential Care

In this chapter, I outline the theoretical and methodological perspective I use to explore the situation of non-senior residents living in LTCFs. This development of this framework was an iterative process. It began as an effort to figure out how might I conceptualize a feminist disability perspective on LTRC and was continually refined as I engaged in and learned from the research process. The resulting *relational feminist disability approach* is a perspective that aligns with FDS scholarship—a body of work interested in transforming feminism *and* DS by bringing together concepts, theories, analytic approaches and methods to re-think ideas about and develop research on issues where disability and gender are at the forefront (Hall, 2011). It is also an approach that integrates the concepts and tools of FPE into FDS scholarship. A relational feminist disability perspective is influenced by the ways in which feminist health researchers in Canada have used FPE to uncover and understand contemporary issues of LTRC. Such an integration is warranted given the lack of social research in LTCFs that is explicitly guided by a FDS perspective.

In the first section of this chapter, I examine the underpinnings of feminist disability scholarship, focusing in particular, on the ways in which FDS scholars have challenged the more dominant social model of disability to develop politicized approaches to issues of disability and disability research that are more inclusive and nuanced than more paradigmatic approaches. The second part of this chapter is devoted to FPE, particularly as it has been developed and used by feminist researchers to examine issues of LTRC in Canada (e.g., Armstrong & Armstrong, 2020; 2003b; Armstrong & Braedley, 2013; Armstrong et al., 2019; 2012; 2001a; 2001b; 2000; Browne, 2003; Daly, 2015). I discuss the ideas and critiques that underlie feminist political economy more broadly before discussing the assumptions and analytic lenses that feminist political economists have developed and used to explore issues in LTRC. I conclude this chapter by bringing FDS and FPE together defining the key orientations and assumptions of a relational feminist disability approach to LTRC.

Feminist Disability Studies

It is an increasingly accepted notion in mainstream feminism and DS[1] alike that disability is a feminist issue and gender an issue for the critical study of disability. Feminist and DS paradigms have much in common. They stem from social movements aimed at the eradication of social oppression (Piepmeier et al., 2014). Both have rapidly expanded into academic disciplines offering broad and often disparate analyses of the institutions, relations, processes and ideas that perpetuate and maintain various forms of social inequity. As an iteration of Critical Disability Studies[2] (CDS), FDS represents a diverse scholarship within which various feminist and disability perspectives are drawn and often integrated to encourage new ideas, concepts, and approaches to research (Garland-Thomson, 2001; 2005; 2011; 2020; Kelly, 2013; Thomas, 2007; Waggoner & Mog, 2020; Wendell, 1996).

Four areas of FDS inform my relational feminist disability approach to LTRC. First, I draw on definitions and debates over concepts of disability, impairment and chronic illness developed by FDS scholars. The ideas on which I draw tend to respond to some of the shortcomings of the social model of disability—an approach to disability that is generally regarded as the theoretical or “intellectual” underpinning of mainstream DS scholarship (Mertens et al., 2011). Second, I consider how feminist disability scholars have analyzed the interaction of disability, gender and other forms of social difference and systems of inequity. Third, I discuss ideas about “care” and “support” developed by FDS scholars that move beyond disciplinary divisions that I suggest have much to do with gaps in scholarship on the issue of younger residents living in LTCFs. Finally, I describe a number of the methodological principles associated with FDS researchers that inform my approach to doing research on the topic of LTRC.

Definitional Dilemmas

Historically, FDS has been critical of both DS and mainstream feminism. By drawing on their own experiences of disability as well as the experiences of women with disabilities who are featured in their research, feminists from within DS were some of the first to reveal the multiplicity of ways in which the experiences and concerns of women with disabilities differ from and are marginalized within DS and Women and Gender Studies (Bê, 2012). FDS has been particularly critical of the social model of disability. While this model has, at times, been unfairly constructed as a theory of disability, despite the variety of approaches subsumed under this term (Fawcett, 2000; Thomas, 2007), particular characteristics of what might be called the more paradigmatic or “strong” version of the social model have been identified.

The social model is an approach to disability that emerged in the 1970s in Britain and is rooted in the work of activists in the Union of the Physically Impaired Against Segregation (UPIAS; Shakespeare & Watson, 2001). Key to its development in academia was the conceptualization of *disability* as resulting from economic, environmental, cultural, and other social barriers imposed on people with impairments (Thomas, 2007), and that it is the consequence of a society that excludes and/or takes little account of people with impairments (Shakespeare & Watson, 2001). This conceptualization challenged historically dominant understandings of disability in western culture that tended to locate disability solely in the body. Often referred to as “individual” “medical”, or “personal tragedy” models of disability, these approaches view disability as an individual problem, deficiency or abnormality located in the body and best responded to by medical intervention (“cure”) and/or charity (Barnes, 2012; Shakespeare & Watson, 2001). In contrast, the social model redefines disability as a social creation. It is about the disadvantages and barriers to social participation imposed on people with impairments. The social model thereby reconstructs the “problems” of disability as ones of social justice (Garland-Thomson, 2011).

Disability and Impairment

Notwithstanding its political importance, feminist disability and other CDS scholars have long taken issue with some of the taken-for-granted underpinnings of the social model of disability. Of primary concern is the rigid distinction made between disability and impairment. “Impairment” is a concept used by social modelists to refer to restrictions or losses associated with the structure or functioning of the body. “Disability” is used to describe a variety of material, structural and cultural barriers that are imposed upon and disadvantage or restrict people with impairments within a particular society (Goering, 2015; Thomas, 2007). For some feminist disability scholars, the separation of impairment and disability is a problem.

Similarly to the ways in which feminists (particularly those influenced by postmodernism and social constructionism) discuss the limitations of the sex/gender binary (see Butler, 1990; Fausto-Sterling, 1993; 2000; Oakley; 1972), it is argued that defining impairment solely in terms of nature/biology and disability in terms of social and cultural barriers, the social model perpetuates a binary, reductionist logic akin to Cartesian mind/body and biology/society dualisms that characterize much of medical and scientific discourse (Corker & Shakespeare, 2002). For Wendell (1996), such a separation ignores the ways in which impairment is socially constructed. Not only do a variety of social conditions and structures create impairment—for example, when illness and injury are caused by war—but also, what “counts” as impairment is determined by socially, culturally, and historically-specific standards of (ab)normality and categorizations of what is considered “average” bodily functioning. Further, as Shakespeare (2013) has argued, while the separation of disability and impairment may be politically useful to DS scholars, where impairment ends and disability begins is not always clear in the everyday experiences of people with disabilities. Finally, feminists from within DS have insisted that DS include the “realities” of living with impaired bodies, of pain, physical and cognitive changes, fatigue, illness, and other issues that are a part of many disabled women’s experiences, including their experiences of social oppression (Thomas, 2007; Wendell, 1996).

This debate also includes concerns that, in equating disability with “social barriers”, the social model denies the possibility that impairment could be responsible for *some* of the difficulties people with disabilities experience (Thomas, 2004). In response, Thomas (1999; 2004; 2007) develops the concept of “impairment effects” as a means of acknowledging the “material reality” of bodies with impairments while simultaneously acknowledging their social character and socially constructed nature. Thomas defines impairment effects as “those restrictions of bodily activity and behaviour that are *directly attributable* to bodily variations designated ‘impairments’ rather than those *imposed upon* people *because* they have designated impairments” (2007, p. 136). In doing so, Thomas endeavors to make room for theorizations of impairment and impairment effects within DS, particularly as experiences and understandings of these relate to if not intersect with the structures and relations of disability-based social oppression.

Including Chronic Illness

By challenging the separation of disability and impairment within the social model of disability (and the marginalization of the latter), FDS makes room for chronic illness. This approach contrasts with social modelists who have conventionally distinguished between people with disabilities from those who are ill as a means of rejecting medical approaches to disability that define people with disabilities in terms of illness, sickness and/or disease (Wendell, 2017). For some social modellists, chronic illness is not disability. By constructing disability in this way, however, the experiences and perspectives of those people who claim a disability identity and who want to challenge disablism *and* express and address "troubling" bodily experiences such as fatigue, pain, depression, or chronic illness are marginalized.

FDS scholars (and others) have long sought to bring chronic illness into the social model of disability, arguing that the distinction between disability and chronic illness is not analytically sustainable (Shakespeare & Watson, 2001). Many forms of impairment are not permanent nor predictable (Wendell, 2017), they cannot be neatly defined as stable or non-chronic. Some forms of impairment are marked by episodes of illness, and some chronic illnesses remain relatively stable for indeterminate periods of time (Goering, 2015). Further, it is recognized that many people with disabilities *will* experience chronic illness at some point over their life course. This is a particular issue for women with disabilities who are more likely than men with disabilities to experience chronic illness (Wendell, 2017), and also because some forms of chronic illness (e.g., fibromyalgia) have in particular cultures at particular times, been constructed in highly gendered ways (Jones, 2016).

For FDS scholars, the incorporation of chronic illness into the social model of disability fosters different ideas about chronic illness that will help challenge narrower and/or oppressive (medicalized) conceptualizations. It may encourage, for example, analyses of chronic illness experiences that are also disabling such as “the ugly and unwelcoming attitudes of others, the strict insistence on standard modes and levels of functioning, and the physical impediments to access [that] make people [with chronic illness] suffer” (Goering, 2015, p. 137). It also encourages a re-thinking of chronic illness in ways that allow for considerations of its value. As Goering (2015) explains:

> Some conditions of the body may be inseparable from physiological suffering (e.g., living with chronic pain or nausea), but the ways of life that people form within them may be quite valuable, and the suffering they experience may play some significant constituent role in what brings the value. Perhaps, not all who live with such conditions long to be rid of them given the chance; others would welcome the opportunity to eliminate the suffering, but might still value the perspective they have gained through it (p. 137).

Bringing in chronic illness to the social model also prompts DS to engage with the work of medical and health sociologists. Including chronic illness means making room for the experiences and concerns of those who tend to be in regular contact with the “biomedical world” in order to access necessary treatments for indefinite periods of time (Scambler, 2019; Wendell, 2017). For Thomas (2007), this practice is of great value to both DS and medical and health sociology. Not only does this integration act as a challenge to dominant medical, individual and ‘personal tragedy’ depictions of disability that have historically dominated research in the medical and social sciences (C. Thomas, 2007; G. Thomas, 2022) , it also moves DS away from “the fringes” by positioning it as a topic of value to the social sciences at large rather than a “niche subject” (Thomas, 2022).

Integrating chronic illness into the social model is also appropriate for FDS, as doing so prompts greater attention to issues of health and health care within DS. These are all issues for women with disabilities. As Thomas' (2001) research on disabled women's health care encounters demonstrates, gender and disability often intersect to inform disabled women's interactions with doctors and other health care practitioners. Research also indicates that women with disabilities experience greater barriers to accessing and having their health care needs met than both non-disabled women and men with disabilities (Pinto, 2015).

Theoretical Diversity and Difference

It is not only in critiquing definitions central to the social model of disability that FDS has made important contributions to this field. Feminists from within DS have drawn on a variety of theoretical perspectives to explore issues of disability and gender and expand understandings of disablism (Bê, 2012). Historically, DS—particularly in Britain—has approached disability from a (historical) materialist perspective. This approach is characterized by the notion that the social oppression of people with impairments is tied to the social relations of production associated with capitalism (Thomas, 2004). It is an understanding that has prompted DS scholars to identify, publicize, and challenge the variety of social structures and relations bound up in various systems and structures that disadvantage, exclude, and devalue people with impairments.

Many FDS scholars have found this approach to disability useful. Focusing on the social conditions and mechanisms that give rise to and (continue to) shape the oppression of people with impairments, the social model of disability has provided the underpinning for exploration and analyses of "disablism"—a form of social oppression imposed on people categorized or labeled with impairment that works alongside and intersects with other forms of oppression such as (hetero)sexism, racism and ageism (Thomas, 2010).

At the same time, FDS has been greatly influenced by DS in the United States, where it has been more closely connected to the humanities and cultural studies (Bê, 2012). Garland-Thomson's (2005) oft-cited piece "Feminist Disability Studies" is an oft-cited example. Drawing on examples from western literature of women who defy racialized gender and/or sexual norms and are represented as castrated, hysterical, and "masculine-looking", Garland-Thomson explores the ways in which cultural representations of femaleness and disability in western society are conflated as systems that similarly assume some underlying bodily or cognitive "norm" from which women and people with disabilities deviate. In so doing, Garland-Thomson develops a more "complex" analysis of gender and disability that views the "ability/disability system" and other systems of representation (race, ethnicity, sexuality, and class) as "mutually construct[ed]...to produce and sustain ascribed, achieved, and acquired identities—both those that claim us and those that we claim for ourselves" (p. 3). In other words, she reveals the ways in which cultural constructions of the disabled, female and other bodies mark them as inferior and lacking in parallel and intersecting ways. This and similar scholarship have opened DS up to greater theoretical diversity. Many FDS scholars continue to develop materialist and similar approaches to studies of disability and gender, but there is also a tendency to pay some attention to the role of culture, language, and discourse in the construction and perpetuation of gendered disablism (see Erevelles, 2011).

A critical contribution of FDS to DS scholarship has been its insistence on recognizing if not centering differences in identity and social location. Influenced by second wave feminist scholarship that questioned the race, class, and heteronormative biases of mainstream western feminist theory (e.g. Collins, 1991; Rich, 1980; Spelman, 1988), FDS take seriously differences in the experiences of people with disabilities who are recognized as multiply located within a variety of social divisions and hierarchies (Meekosha, 2006). They do this by developing and putting into practice analytic processes that attend to the "internal diversity" of disability (Bê, 2012).

Focusing on the differences among people with disabilities makes sense for FDS given that historically, the experiences and concerns of women with disabilities have been marginalized within both mainstream feminism and DS. However, this approach is not without its critics—particularly from scholars within DS. Feminist disability scholars have critiqued the tendency of some writers to simply "add" gender to their analyses of disability, impairment and disablism, or add disability to their analyses of gender and gender-based oppression (Bê, 2012). It has also been argued that such approaches may challenge the development of a common political goal or understanding that unites people with disabilities in their struggle against disablism. The challenge for FDS then, has been to develop analytic approaches to disability, gender and other forms of difference that both resist approaching disability in ways that are exclusionary and/or homogenizing, and also support the articulation of common or unifying experiences, concerns and goals (Bê, 2012). And while FDS scholars do this in a variety of ways, the tendency has been to examine the intersection of disability, gender and other relations of difference and inequality.

Disability and Masculinity

In encouraging DS to attend to issues of difference, FDS has inspired disability scholarship focused on issues of masculinity. The concerns and goals of this body of work are diverse, but they are often tied together by what Shuttleworth and colleagues call the "dilemma of disabled masculinity" (2012, p. 175). This dilemma refers to the conflict created by the construction of a dominant or hegemonic form of masculinity in western societies in terms of independence, power, autonomy, and virility in relation to the construction of disability in terms of (childlike) dependence and helplessness. Applied research in this area has often focused on exploring the various ways in which and sites where men with disabilities manage this dilemma. Care or support relationships (see below) is one of these sites. Wilson and colleagues (2010), for example, discuss issues of masculinity within the context of paid support provision. This work reveals that disabled men's masculinity is often experienced or understood as "diminished" within this context. Further, this and similar research (see Barrett, 2014) indicates that men with disabilities often experience feelings of emasculation, concerns over being a burden to others, and frustrations over perceptions of dependency and powerlessness within the context of care relationships.

Feminist Intersectionality

Feminist intersectional analyses appear to offer a way forward in terms of addressing the tensions and limitations associated with the increasing diversification of FDS and other strands of CDS. It is clear that FDS scholars are increasingly drawing on the ideas and tools of feminist intersectionality to develop more nuanced analyses of gender and disability (Bê, 2012). Feminist intersectionality is a widely contested term that is conceptualized differently among feminists including in FDS. However, it often refers to a range of perspectives, analytic approaches and/or practices that according to Hankivski and colleagues,

> Move beyond single or typically favoured categories of analysis (e.g., sex, gender, race, and class) to consider simultaneous interactions between different aspects of social identity (e.g., race, ethnicity, Indigeneity, gender, class, sexuality, geography, age, ability, immigration status, religion), as well as the impact of systems and processes of

> oppression and domination (e.g., racism, classism, sexism, ableism, homophobia; 2009, p. 3).

In contrast to "additive" approaches to gender and disability then, feminist intersectionality assumes that these systems and processes are not only connected, but also, mutually constituted (Bê, 2012).

Drawing on Glenn (2002), Bê (2012) suggests that revealing the "relationality" of social categories—that is, the ways in which disability, gender, age, race/ethnicity, and other social categories are established as interconnected systems or relations constructed around identified differences—is a promising way forward for intersectionality within FDS. Key to this relational approach is the concept of "anchor point", which as Bê suggests, is a tool that may address tensions around attending to difference and focusing on political unity. This concept is a nuanced way of suggesting that FDS scholars temporarily highlight certain forms of difference (such as disability, gender, and age) in their work, recognizing that some relations may be more significant in particular contexts or when it comes to researching particular topics or experiences. This idea of focusing on certain relations of difference without negating recognition of others nor ignoring articulations of commonality, is also a useful analytic approach long used by FPE scholars in Canada (see Armstrong & Connelly, 1999).

Considering "Care"

Although FDS scholars draw heavily on the ideas and tools of both feminism and DS, when it comes to the topic of "care", significant tensions exist. Many of them are rooted in historical differences of emphasis or focus between paradigms when it comes to approaching the concept of care (Hughes et al., 2005). Beginning in the early 1980s, mainstream feminists in the Global North began writing about care in a variety of ways, conceptualizing it as a form of labour or work (caring for), as an emotion or feeling towards others (caring about), and as a complex, asymmetrical relationship (Kröger, 2009; Rummery & Fine, 2012; Winnace, 2010). This work revealed the gendered nature of care—that care is overwhelmingly performed by women and is accorded low status and pay because of its construction as the "natural" work of women (Kröger, 2009). Often focusing on women as informal care providers and/or as paid care workers, feminists revealed care as a potentially stressful and demanding form of emotional and physical labour (Rummery & Fine, 2012). They also made links between women's role as care providers and their lower economic and social status (Fine & Glendinning, 2005).

Feminists have accommodated multiple perspectives on care over time (some of which are in conflict). Feminist "ethic of care" perspectives, however, stand out in terms of the central role this body of literature has played in politicizing issues of care. Gilligan's (1982) work on the ethic of care challenged the low value accorded to care and care providers by presuming and celebrating care as a (seemingly natural) set of feminine moral principles (cited in Fine & Glendinning, 2005). This work aimed to distinguish (feminine) care and caring from the (masculinist) ethic of individualism—a concept associated with theories of liberal justice and rationality, characterized, among other things, by competitive self-centeredness and narrow understandings of independence and autonomy (Daly, 2013; Rummery & Fine, 2012).

Recognizing the ways in which people are interdependent (Winnace, 2010), early feminist ethics of care scholarship focused instead on the relationship between care providers and recipients of care (Daly, 2013). Much of this work focused on care provision in the private sphere, and analysis tended to remain at the interpersonal level (Daly, 2013; Rummery & Fine, 2012). Articulating the value, legitimacy and necessity of care (Rummery, 2011; Rummery & Fine 2012), this work viewed care as an "activity of relationships", an outcome of which was moral growth (Gilligan, 1984, cited in Fine & Glendinning, 2005, p. 604). However, this work was also criticized—often from within feminism—for naturalizing the link between femininity and care and reinforcing an understanding of care as a private concern (Fine & Glendinning, 2005).

Feminist scholars responded to these issues by developing a more nuanced account of care as situated within systems of inequality and oppression. In other words, they politicized care. "Political ethics of care" perspectives emerged from within feminism as an approach to care that presented it as an issue of social justice. As Williams (2001) explained it, "the right to care—to give care, receive care and the right to care for oneself…[need] be seen as the most fundamental of the struggles for justice" (p. 326). Moving beyond the private sphere and beyond analyses of care relationships at the interpersonal level, feminists began to explore the "different experiences, different meanings, different contexts and multiple relations of power" imbued in care (Williams, 2001, p. 468). Such an approach has been used to explore care as an often coercive form of unpaid work that women are obliged to do based on their gendered and sometimes race/class status. This approach has also encouraged discussions of care as a form of gendered and racially divided paid labour that is organized around inequitable power relationships and social processes both locally and transnationally (Erevelles, 2011).

DS scholars are critical of feminist ethics of care scholarship. They argue that feminist care work tends to focus on the perspectives of care workers or informal providers to the exclusion of the recipients of care (Kröger, 2009; Morris, 2001). It often fails to recognize the ways in which people with disabilities who receive care are also care providers, and there has been a tendency for feminists to romanticize care relationships without attending to the ways in which they can be oppressive and/or cause harm to people with disabilities (Barnes, 2012;

Beckett, 2007; Kelly, 2013; 2017; Kröger, 2009; Morris, 1993). Further, despite the politicization of care within feminist ethics of care scholarship, some DS scholars argue that feminist approaches to care ultimately minimize or dismiss DS critiques of care (Kelly, 2013).

DS scholars discuss care in very different if not oppositional ways to that of (mainstream) feminists. Influenced by disability rights activism—Independent Living (IL) movements in particular—DS scholars have tended to "remove care", replacing it with notions of "support", "assistance", or "help" (Kelly, 2016). In DS, care represents the historical and continued oppression of people with disabilities. As Kröger explains it, "care as a concept has symbolized a century-long confinement of disabled people into institutions and of lives controlled and colonized by others, by professional social workers and by care providers as well as by other family members, who are defined as 'informal carers" (2009, p. 403).

In reaction to the problems with care, DS scholars have developed notions of support/assistance. This approach is about advocating for the rights of people with disabilities as citizens to choose and control the services they require to meet their everyday needs (Beckett, 2007). Notions of support moves "care" away from its affective and emotional dimensions, replacing these components with more formal, contractual support services and relationships. In this context, the person receiving support is constructed as the employer relative to the provider or "personal assistant". In doing so, "the disabled person is said to acquire power over her/his [sic] own life and become 'protected from the pejorative, symbolic and practical elements of caring relationships'" (Kröger, 2009, p. 405).

Feminists (including FDS scholars) have critiqued the ways in which DS scholars approach care/support. They argue that constructing care as a commodity and associating it with liberal notions of independence, self-determination, autonomy, and competitive individualism marginalizes many people with disabilities, such as those who require assistance in directing their support services (Rummery & Fine, 2012). This approach leaves little room for acknowledgements of care relationships as a "precondition for autonomy" (Clement, 1996 cited in Kelly, 2013, p. 793), nor does it account for the value of care relationships characterized by interdependence, reciprocity, and/or emotional or affective components. Feminists ask if this "solution" to the problem of care translates into "bad" support practices—care that is instrumental, mechanical, and narcissistic (Rummery & Fine, 2012).

Feminist have also argued that moving away from care towards support/assistance does not dissolve power inequities in provider/recipient relationships. As Glenn (2000) argues, when people with disabilities employ support workers via the market, this support is most likely to be relegated to marginalized (racialized, migrant, and poor) women who perform it for low wages under poor working conditions. For Rummery and Fine (2012), this is a problem for both those who provide and who rely on this form of labour:

> [When] people working in under-valued conditions for low pay are likely to be under significant pressure and be less supported to provide ethical care which is 'responsive' and 'attentive' (Tronto, 1998), those being cared-for by such carers are likely to be at significant risk of exploitative, low-quality care that fails to meet their needs at best and is abusive at worst. (p. 337)

An "Accessible" Approach to Care

FDS scholars complicate care/support debates and divisions between feminist and DS by seeking to both critically engage with DS critiques of care, and resist understandings of feminist care research as necessarily oppressive (Kelly, 2013). Kelly (2013), for example argues for an approach that "builds bridges" between feminism and disability perspectives. She develops the concept of “accessible care” (2011; 2013) as one that does so by conceptualizing care as a complex, often contradictory category, as a process and/or set of practices and living relationships that often involves oppression, exploitation, and/or abuse against those who provide *and* rely on it, and as a “civic value” or important component of healthy, prosperous, and just societies.

For Kelly, making care accessible is also about approaching it as “an unstable tension among emotions, actions, and values, simultaneously pulled toward both empowerment and coercion” (2013, p. 790). This formulation is about making room for a multiplicity of potentially contradictory understandings and applications of care. It means care can be:

> [A representation of] the failure of medical cure and neoliberal progress;... a deep compassion and empathy; a highly intimate relationship; an institutionalized approach to disability; a transnational supply and demand of feminized labor; [and] a dependency on state-funded programs (2013, p. 790).

Making care accessible, however, is not only about finding commonality or shared commitment across feminist care research and disability perspectives. For Kelly (2013), the fact that feminist notions of care are not entirely incompatible with disability perspectives produces a tension that is productive because it prompts critical reflection on, discussions of, and debates over issues of care.

Feminist Disability Methodologies

In addition to providing a number of theoretical ideas about disability, gender and care/support, FDS scholars offer methodological principles and tools to help guide the practice of social research on topics where disability and gender are viewed as playing an important role. Like FDS more generally, feminist disability methodologies are politically situated and theoretically diverse, often drawing on ideas and tools of DS and feminism to develop research that is concerned with the conditions, structures and ideas that marginalized individuals and groups “bear, experience, and resist” (Waggoner & Mog, 2020, p. 2). Like feminist methodologies more generally, feminist disability methodologies engage with questions of power and authority throughout the research process—from developing their topics of study, research questions and approaches, to carrying out data collection, analyses, and writing up the findings (Doucet & Mauthner 2006; Hesse-Biber, 2007). FDS researchers often attend to power dynamics associated with more conventional research relationships. They develop, reflect on, and modify their practices in order to challenge the subjugation of particular forms of knowledge and ways of knowing (Hesse-Biber, 2007; Lunn & Munford, 2007). As such, their research methods are often particularly adept at recognizing and responding to difference, diversity, inclusion, accessibility, and inequality.

FDS methodologies are often influenced by DS methodologies, and more specifically, principles associated with the “emancipatory research” methodology, which is perhaps the most paradigmatic approach to social research involving people with disabilities that is based on the social model of disability (Danieli & Woodhams, 2005). Initially developed and popularized by British DS scholars and disability rights activists, this approach aims to challenge the ways in which (non-disabled) researchers—particularly those in the social and medical sciences—have historically theorized disability and involved people with disabilities in their research projects. DS scholars have argued that much of mainstream disability research has served the professional and economic interests of non-disabled researchers while doing little to support disabled people’s struggles for social and material change (Danieli & Woodhams, 2005; Hunt, 1981; Watson, 2019). Significantly for the topic of this project, some of the most infamous accounts of “parasitic” disability research have been conducted by non-disabled researchers doing research in “care” settings within which people with disabilities have been institutionalized (see Hunt, 1981).

Emancipatory research aims to “empower” people with disabilities throughout the research process (Watson, 2019). Often, there is a focus on researcher accountability, and more specifically, the expectation that researchers devolve control over the production of research to people with disabilities and their organizations. Such research tends to privilege the perspectives and experiences of people with disabilities, and it often aims to uncover (collective) experiences of disablism. Further, emancipatory research tends to employ research methods that facilitate the inclusion of people with disabilities in research, that foster trust and demonstrate respect, and that are flexible enough to respond to differences in understanding and to maximize participant engagement (Dee-Price, 2020).

While “strong forms” of emancipatory research continue to be practiced, FDS and other CDS scholars often draw on but do not strictly conform to this methodological approach. “Participatory” or “inclusive” disability methodologies, for example, make room for research topics and approaches that may not fit well with the social model of disability (e.g., personal experiences of impairment and/or health care services). Arguing against the development of a hegemonic set of disability research principles, FDS researchers nonetheless develop approaches that challenge conventional power dynamics in research relationships involving participants with disabilities, “whereby the researcher is the ‘expert’ and the researched merely the object of investigation” (Stalker, 1998, cited in Watson, 2019, p. 131). They also tend to recognize that “people have the right to be consulted about and involved in research which is concerned with issues affecting their lives”, and they often assume that “the quality and relevance of research is improved when disabled people are closely involved in the [research] process" (Stalker, 1998, cited in Watson, 2019, p. 131). Thus, FDS methodologies are marked by the efforts of researchers to do research that is not only accessible in the sense that research methods assume and respond to the diversity of those involved in the project, but also, accessible in the sense that their projects aim "to transform the conditions that created that inaccessibility in the first place….[and] make sure that the inaccessibility doesn't happen again" (Mingus, 2018, cited in Waggoner & Mog, 2020, p. 2-3).

Personal Experience Matters

In contrast to more paradigmatic DS approaches, FDS researchers have long asserted that attending to "personal" experiences of disability (including impairment) can result in highly "political" ideas. Influenced by notions of feminist "standpoint", or what Garland-Thomson (2020) refers to as "sitpoint" theories as "a place to begin inquiry" (Smith, 1992, p. 91), empirical, qualitative feminist disability research has historically centered on capturing the everyday "lived experiences" and perspectives of people (often women and other socially marginalized people) with disabilities. At the same time (and as feminists have long argued), "merely focusing on experience [is not enough, because it] does not account for how that experience emerged (Olesen, 2011, p. 135). Being committed to "giving voice" to one's participants should not preclude analyses of the ways in which various social and cultural ideas and structures influence these experiences and understandings. Further, uncritically presenting participants' narratives as "the truth" obscures and over-simplifies the processes through which researchers "make choices about how to interpret the voices [of participants] and…present [data] as evidence" (Mauthner & Doucet, 2003, p. 418).

Kelly (2013) attends to this issue in her work on public disability support provision by developing a relational approach through which everyday "care" experiences and arrangements can be explored. While beginning with the "daily, intersectional experiences of support provision" (2013, p. 790). She also attends to the processes and structures in which everyday experiences are embedded. Inspired by William's (2001) account of the political ethic of care, Kelly (2013) emphasizes that "accessible" care research involves explorations and analyses of care experiences, arrangements and issues as situated within historically specific local and global socio-economic and political systems.

Flexibility in the Practice of Social Research

FDS methodologies resist prescriptive social research practices associated with the uncritical adoption of normative qualitative research methods and quality criteria. It is argued that conventional practices and expectations can limit what is recognized as research evidence, and who and what is considered a legitimate source of knowledge (Waggoner & Mog, 2020). FDS scholars encourage disability researchers to be flexible in their research practices. Challenging more prescribed, standardized research processes, practices and assumptions, it is assumed that flexibility is imperative if research is to be more inclusive, accessible and respectful (Mietola et al., 2017).

FDS researchers often critique hegemonic social research practices as unsuited to experiences of disability, as these experiences and the processes of gathering and analyzing them are often fragmented and nonlinear (Waggoner & Mog, 2020). Similarly, Garland-Thomson insists that FDS methodologies should be characterized by "intellectual tolerance…. [They] espouse the partial, the provisional, the particular…, [and they demonstrate] the normalizing phallic fantasies of wholeness, unity, coherence, and completeness" associated with more conventional practices (2011, p. 28). Price and Kerschbaum differentiate their approach to doing disability research from more conventional forms by characterizing their process as “sideways, crooked, and crip” and the issues and gaps they come across to be without “a neat resolution” (2016, p. 22).

Flexible research methods are also necessary if research is to maximize understanding and be accessible to participants with a variety of disabilities in a variety of research settings. For example, Owens (2007) criticizes the tendency of conventional qualitative interviewing practices to be oralist/auralist in the sense that the techniques used tend to privilege particular ways of communicating over others. Similarly, DeVault and Gross acknowledge the limitations of and ableist assumptions behind the tendency of in-depth qualitative interviewing techniques to assume a “relatively easy back and forth” verbal exchange (2012, p. 214). Instead, Owens (2007) suggests that when it comes to doing narrative research with people with IDD, researchers are often required to act as their “own methodologists”. They do this in order to develop techniques aimed at building trust and understanding, that show respect for participants, and that support cognitive accessibility and address communication differences among participants (McDonald et al., 2022; Owens, 2007).

Feminist Political Economy

Thus far, I have explored FDS as a body of scholarship that provides a number of concepts, ideas and tools useful to thinking about and engaging in social research where questions of gender, disability and “care” are at the forefront. However, FDS perspectives have rarely been used to guide social research in contemporary LTCFs, particularly in Canada. This gap in scholarship makes approaching LTRC from a feminist disability perspective a challenge. In contrast, a rapidly growing body of research in Canada has emerged over the past two decades that uses FPE to engage in research on issues of LTRC. Below, I identify and discuss the theoretical underpinnings, key concepts, and methodological lenses of FPE that feminist health care researchers in Canada have developed and used for this purpose. I first provide an overview of the underlying assumptions and orientations of a "Canadian" FPE approach. Second, I discuss how feminists have prompted the theoretical diversification of political economy and approached issues of difference. I then explore how FPE scholars have conceptualized health care, including some of their key methodological contributions to researching and analyzing issues of LTRC, particularly in the Canadian context.

Canadian Feminist Political Economy

The version of FPE on which I draw inspiration is rooted in Canadian political economy. Canadian political economists tend to be influenced by historical materialism and as such, assume a "real material world" (Armstrong & Armstrong, 1983, p. 7). Social issues are analyzed within the historically and spatially-specific social, economic, political and cultural/ideological contexts within which they are situated. Canadian political economy is an approach to the study of society that is explicitly holistic and interdisciplinary (Clement, 2001; Luxton, 2006). It assumes established social relations and practices are characterized by inequality and that establishments will seek to maintain and conceal that which keeps inequalities in place (Clement, 2001). As such, Canadian political economists seek to uncover and understand the potential for and effects of human struggle and resistance, and assume the possibility of change.

Canadian FPE emerges as a critique of conventional political economy as being overly functionalist, and often, sex/gender-blind (Armstrong & Armstrong, 2003a; Vosko, 2002). While political economy tends to focus on the relationships between production, the distribution of wealth, paid labour, and government policies and legislation related to these, FPE recognizes that such analyses often overlook the ways in which the “formal” economy is connected to and relies on “social reproduction”—the often unpaid practices, beliefs and relationships that maintain life “on a daily basis and intergenerationally” (Laslett & Brenner, 1989, cited in Luxton, 2006, p. 35). Instead, FPE includes examinations of the work involved in maintaining labourers, in raising and caring for children, and in supporting older people and those with illnesses and/or disabilities.

FPE scholars also ask critical questions about the gendered and inequitable nature of political-economic and other social structures, aiming to uncover the ways in which work is divided between and within the sexes and how these types of work are differently valued (Jackson, 2012). Not only does FPE consider the role of the state (and its institutions) in perpetuating patriarchal capitalism, it also examines the relationships between the public and private spheres and the ways in which these are constructed in gendered ways.

Women’s struggle both individually and collectively to disrupt existing relations of inequality is also of interest to FPE scholars (Armstrong & Connelly, 1989; Armstrong et al., 2001b). But while understanding that change is possible, it is also assumed that people do not act “under conditions of their own choosing or simply as a result of ideas that spring independently to their minds” (Armstrong et al., 2001b, p. viii). Instead, everyday experiences are viewed as situated within global and local historial, economic, political, social and cultural forces, ideas and relations.

Theoretical Diversity and Difference

In ways that parallel FDS, FPE is continually challenged and enhanced by on-going (often internal) critique and debates. Vosko’s examination of the historical development of FPE in Canada suggests that while FPE scholars were once largely divided by those who view the material relations and conditions of patriarchal capitalism as “the driving force” (2002, p. 60) behind women’s oppression, and those who focus on ideology and culture—the ideas, subjectivities, discourses and associated practices that impact relations of ruling and inequality, such tensions also spurred more integrative, multi-disciplinary, and multi-scalar analyses of women’s social oppression under (global) capitalism (see also Daly, 2013).

Similarly, in the process of critiquing mainstream political economy for (over)emphasizing economic relations of production to the exclusion of considerations of other relations of difference (Vosko, 2002), FPE has become increasingly characterized by approaches in which gender, “race”, ethnicity and other social relations of difference and inequity are examined in terms of the ways in which they shape class relations (Jackson, 2012). As such, FPE scholars have increasingly engaged in intersectional analyses. They ask questions about the ways in which the reigning socio-political-economic approach perpetuates and sustains intersecting inequalities, and they seek to transform these relations in ways that are more equitable (Armstrong et al., 2001b; Jackson, 2012).

Conceptualizing Health Care

While theoretical debate continues amongst FPE scholars in Canada, much attention has turned to the development of theoretically grounded, applied social research (Laxer, 2014; Vosko, 2002). A rich body of scholarship on health care has emerged from this re-orientation. FPE scholars view health care as a complex social system that is shaped by the political, economic, social and cultural institutions, relations, and ideas that exist within a particular historical and spatial context. It is also assumed that health care is characterized by tensions—that is, by “ideas, approaches, practices, programs, interests and communities that have conflicting demands and/or consequences” (Armstrong, 2018, p. 11). The ways in which these systems are arranged will benefit certain individuals and groups while disadvantaging others (Armstrong & Braedley, 2013). The resulting tensions are not only “between classes, regions, sexes, cultural groups, and races…, [but also] within and among aspects of the system…, [and] between public and private interests” (Armstrong & Armstrong, 2003b, p. 6).

As such, FPE scholars take a politicized approach to health care systems. They recognize that in Canada (and elsewhere), gendered relations are central to issues associated with contemporary public health care systems. Not only are dominant ideas about health care highly gendered, but also, health care is a women’s issue and an issue for women because women are more likely to need and use the public health care systems, to do paid care work within them, and to fill the gaps with informal (unpaid) care (Armstrong, 2012).

Examinations of the division of health care labour by sex/gender, race and other forms of difference has therefore been a topic of interest among FPE scholars in Canada, as has the relationship between paid and unpaid care labour in the public and private spheres, and the changing role of the state and market in terms of its responsibility for health care (Jackson, 2012). FPE scholars also explore the undervaluing of health care work, linking this issue to its feminization, and revealing and challenging the over-representation of women, and in recent decades, racialized and migrant women, as care workers in the lowest paid, precarious health care occupations and positions (Armstrong & Laxer, 2006; Laxer, 2014; Smith et al., 2021).

Issues of gender within health care systems are also linked to gender issues outside of them. For example, Aronson and Neysmith (1997) examined the impact of government attempts to contain the costs of public LTC through policies that, since the 1970s, have aimed at shifting LTC from institutions to communities/private households. Arguing that these policies have redistributed the costs of and work involved in LTC from the public to the private sphere, Aronson and Neysmith (1997) trace the particular impact on women not only as paid home care workers, but also as those most likely to provide unpaid care to family members. FPE scholars have also considered linkages between gender issues within and outside the health care system in Canada by discussing the relationship between the over-representation of women in poorly paid, precarious health care jobs (where women "choose" to engage in part-time health care work so they can provide informal care to family members), the inequitable, gendered distribution of informal care work within private households, and a lack of accessible, affordable childcare and public HCC supports (Armstrong & Armstrong, 2009).

Neoliberalism and Health Care Reform

In the decades leading up to the COVID-19 pandemic, FPE researchers in Canada developed a rich body of scholarship aimed at uncovering the mechanisms and impacts of a major set of changes occurring in Canada's health care systems often referred to as contemporary "health care reform"(Armstrong, 2012; see also Chapter 4). These changes, while multiple, are driven by the logic of neoliberalism and the associated rise and adoption of NPM. Neoliberalism is a term that has been variously defined as a logic, ideology, rationality, and/or system of governance (Armstrong, 2013) that emerged in the context of global capitalism. Key to this logic is the assumption that markets are "the most efficient and effective producer of goods and services" (Armstrong et al., 2001c, p. 3) as well as "a source of wealth and justice" (Coburn, 2001, p. 46). The focus of neoliberalism is a smaller role for government and a larger role for the market (Armstrong et al., 2016). It also assumes an individualistic approach to human beings, defining equity in terms of "treating everyone the same regardless of circumstance or gender" (Armstrong, 2001, p. 128). Pritlove expands on these principles, summarizing the assumptions behind a neoliberal approach to or "agenda" in the following way:

> Free markets without government interference provide the most efficient and socially optimal allocation of resources and thus states should provide a minimum of public goods (e.g., public education and social welfare programs); privatization removes inefficiencies of the public sector and improves consumer choice; and individualism, individual responsibility, and entrepreneurial initiative are necessary to protect the 'natural order' of the market (2016, p. 13).

NPM is an approach to managing public services associated with neoliberalism. Drawing on Bach and Bordogna (2011), Cunningham and colleagues define NPM as characterized by "removing differences between private and other sectors, the use of market-orientated mechanisms and private sector management techniques in delivering services, and the principles of efficiency, value for money and greater service user choice" (2014, p. 583).

Through investigations of the changing relations between the state and the market, and of the implications of health care reform in Canada (Mykhalovskiy, 2001), Canadian political economists implicate neoliberalism in rising health and health care inequities, and to a variety of (other) issues with public health care systems and services across Canada that have emerged in recent decades. FPE scholars also recognize the direction of health care reform as "gender-biased" (Armstrong, 2001). The data on which policy decisions are made does not recognize the ways in which health and health care are impacted by gender-based and other social inequities, nor does it make room for analyses of the particular impacts of health care reform on women and other socially marginalized groups (Armstrong, 2001). From a DS perspective, Linton (2021) has made similar arguments about data gaps that may contribute to the marginalization of people with disabilities when it comes to public service provision in the context of NPM.

Re-thinking Health Care Evidence

Responding to the logic of neoliberalism driving contemporary health care in Canada, feminist health care researchers have drawn on FPE to develop and implement a number of methodological concepts, lenses, and tools to guide their research into issues of health care reform (Jackson, 2012). As mentioned, feminists have raised issue with gender-insensitive health care reform. They similarly critique the privileging of particular forms of evidence within conventional health care research and policy. For example, it has been argued that the research behind “evidence-based medicine” (EBM) or “evidence-based decision making” that drives contemporary health care reform relies almost exclusively on quantitative, clinical data and tends not to consider the role that sex, gender and other forms of difference might make in the production of evidence (Armstrong et al., 2016; Hankivsky & Friesen, 2007; Jackson, 2012). In fact, the data behind EBM is also assumed to be neutral, objective, and a direct reflection of “reality” (Armstrong et al., 2016).

FPE scholars have argued that EBM is an overly narrow, biomedical approach to health care reform that privileges economic evaluations of the system over evaluations focused on health and health care equity. The research behind EBM is often decontextualized—removed from real world settings and circumstances (Morrow & Hankivsky, 2007), and it tends to overlook issues of power and privilege, making it particularly unsuited to projects that aim to capture marginalized experiences and perspectives (Laxer, 2014). In fact, Armstrong and colleagues (2016) argue that the “reductionist forms of knowledge” that has tended to form the evidence-base on which decisions about health care are made are especially inappropriate when it comes to issues of LTRC. This “knowledge base” is one that has rarely included the perspectives of residents, family members, or paid care providers—a gap that feminist FPE scholars tie to the devaluation and gendering of LTC in comparison to “cure-oriented, masculine-attributed activities of [acute] medical care” (Armstrong et al., 2016, p. 352).

Like feminist researchers more generally (see above), FPE researchers assume that power dynamics and social relations are central to the production of knowledge. It is recognized that the choices researchers make throughout the research process and the ways in which they interpret data and produce evidence are shaped by their subjectivities and the contexts in which they are situated. Further, while they often value “women’s [and other marginalized] voices and experiences as authoritative and credible sources of knowledge” (Jackson, 2012, p. 18), it is assumed that these perspectives are informed by a variety of contexts and power relations.

A “Relational” Approach to Long-Term Residential Care

FPE researchers in Canada have challenged more conventional forms of health care evidence on LTRC by developing and implementing a variety of lenses through which they approach and analyze issues of LTRC. While diverse, these approaches are based on understandings of LTRC as complex, messy and gendered (Banerjee & Armstrong, 2015). In order to capture the issues in LTRC, FPE researchers have developed and applied multi-scalar analytic lenses (see Daly, 2013; Day, 2014). These are approaches to analysis that may begin with the interpersonal, but move beyond this level to explore the organizational contexts and broader policies, structures, ideas, and forces that shape everyday experiences and understandings of LTRC. Daly (2013) and Braedley (2013) both argue for the importance of multi-scalar analytic approaches to LTRC. Daly, however, argues that such an approach should also consider the ways in which these levels interact, while Braedley argues for an intersectional analytic framework that begins by uncovering gender relations as they operate within and are perpetuated through ideas and practices of LTRC.

“Relational care” is a concept and analytic approach to LTRC that can capture many of these ideas. When Banerjee and Rewegan (2017) conceptualize LTRC as relational at an “ontological” level, relational care becomes a framework prompting multi-scalar analysis. They explain:

> Ontological relationality recognizes that all interpersonal relationships in LTRC are situated within broader socio-cultural, political, economic, organizational, and policy contexts (Martin, Myers, and Viseu 2015). These contexts shape the types of relationships that are possible (Banerjee & Rewegan, 2017, p. 401).

Not only does approaching LTRC as relational mean uncovering the relationships between the interpersonal (micro), organizational (meso) and broader social, political, economic and cultural (macro) contexts, but relational care has also been constructed as key to or the equivalent of “good” or “high quality” care provision. Viewed as a relationship, care becomes about interpersonal connections and “treating people as human beings” (Banerjee et al., 2015, p. 32). Care relationships are assumed to be “central to determining what good care looks like for any particular [resident]…, [and necessary to] delivering good care and doing so safely” (Banerjee & Armstrong, 2015, p. 11). Research has shown that relationships between residents and providers are both the outcome of positive care interactions and necessary to the practice of good care, and it is the relational aspects of care work that care workers often experience as especially rewarding (Banerjee et al., 2015).

At the same time that relational care is the promise or goal, it is also assumed that relationships in LTRC are relationships of inequality. Armstrong and Braedley (2013) argue that the ways in which LTRC is arranged benefits certain individuals and groups and disadvantages others. It is characterized by tensions—tensions in “ideas, approaches, practices, programs, interests and communities that have conflicting demands and/or consequences" (Armstrong, 2018, p. 11). It is not assumed that all of the tensions in LTRC can or should be resolved—although FPE scholars certainly make room for considerations of how they may be negotiated and balanced (Armstrong, 2018). Instead, tensions in LTRC are viewed as instructive. Uncovering them, and identifying the practices, processes and structures that construct, maintain, and challenge them is key to the development of critical conversations and debate about LTRC that are necessary if change is to occur, particularly in terms of moving toward greater health and health care equity.

The Conditions of Care are the Conditions of Work

In order to draw attention to the relationships between everyday interpersonal experiences of LTRC and the organizational context that shapes them, Armstrong and colleagues assume that "the conditions of work [in LTCFs] establish the conditions of care" (2009a, p. 13). It is argued that workplace conditions associated with LTRC—the ways in which employees are treated and compensated, the nature of physical and social environment within care work is done, the care work itself, how it is organized, and staff members' influence over this process—are central determinants of the conditions of care for residents. For example, when the conditions of work in LTCFs are characterized by staffing shortages, this not only results in excessive workloads for care workers, often leading to physical and mental exhaustion, but also, it greatly impacts the conditions experienced by residents as it means there is not enough time for workers to complete (even essential) care tasks, and even less time for them to provide residents with the more social aspects of care.

At the same time, understanding the conditions of work as a means of understanding the conditions of care is about more than uncovering the organizational/workplace structures that shape these conditions. It also involves attending to the ways in which individuals resist, or "work around" the organizational constraints that shape their conditions of work and care (DeForge et al., 2011, cited in Day, 2014, p. 246). This means that analytic approaches must not only identify the structures of care work but tie them to the everyday experiences and practices of those involved in the conditions of care and work

The Lens of Privatization

FPE researchers in Canada have also developed and applied the concept of privatization as means of guiding their analysis of issues in LTRC—particularly in terms of the tensions that have emerged in the context of contemporary health care reform (see Chapter 4). The lens of privatization has been used to uncover and better understand issues in health care as situated within the context of neoliberalism and the adoption of NPM. To do this, FPE scholars develop a broad conceptualization of privatization that makes room for analyses of the forces, policies and other factors involved in health care reform and that together, are indicative of a "process of moving away from [public care]" conceptualized as "public delivery and payment for health services" and also, "a commitment to shared decision-making, and the ideas that the public sector operates according to a logic of service for all." (Armstrong & Armstrong, 2020, p. 17). While recognizing that the specific mechanisms involved in the privatization of LTC services in Ontario are numerous, diverse, and sometimes contradictory (see Chapter 4), FPE researchers identify six key components of this process: the privatization of delivery, the privatization of health care organization and management, the privatization of care work, the privatization of costs, the privatization of responsibility for care, and the privatization of decision-making (Armstrong, 2012; Armstrong et al., 2020). Uncovering these processes within public LTC services means making links between contemporary issues in LTC at the interpersonal and organizational levels, and the broader contexts with which they are situated.

The lens of privatization is also intended to prompt analyses of the impacts of health care reform in ways that attended to gender and other social locations and relations It is a frame that FPE researchers have applied to consider how ideas about gender, race, and class are embedded in and perpetuated by processes of privatization (Armstrong, 2012). For example, the particular vulnerability of LTRC to privatization may be understood in connection to its inferior status within the public health care system, as a sector that provides a great deal of social (as opposed to acute, medical) care. This lower status is connected to gendered ideas about social care as the natural work of women and as unskilled work (Braedley, 2013). Further, the privatization of LTRC is understood as a women's issue and an issue for women given that women comprise the majority of residents and direct care providers within this sector, and because it is most often women who provide informal care to make up for inadequacies in the public system (Armstrong & Banerjee, 2009, see also, Seeley, 2012).

Exploring the Situation of Younger Residents Living in Long-Term Care Facilities from a Relational Feminist Disability Perspective

Throughout this chapter, I have described the theoretical and methodological concepts and lenses that define a relational feminist disability approach to LTRC. This framework draws heavily on concepts and ideas central to FDS scholarship and research. However, FDS frameworks have rarely been applied to contemporary social research in LTCFs, particularly research carried out in Ontario. This is an absence that may be linked to the negative history of residential health and custodial care institutions (including hospitals) aimed at people with disabilities in Ontario and elsewhere, and relatedly, to disciplinary tensions in approaches to care/support. A relational feminist disability perspective addresses this gap by integrating a number of insights from scholarship developed by FPE researchers in Canada who are engaged in issues of LTRC int the context of neoliberal health care reform.

The integration of FDS and FPE leads to a particular set of assumptions upon which my examination of the situation of younger residents living in LTCFs in Ontario in the two decades prior to COVID-19 is based. First, a relational feminist disability perspective takes a critical, politicized approach to LTRC that aims to uncover and challenge social, health and health care inequities associated with the public LTRC system. Central to this goal is approaching the notion of care cautiously or “carefully” (Kelly, 2013). Care is understood as a historically and contextually-situated complex, multiply-defined concept and tension. Understanding it as such makes room for research that attends to its negative aspects *and* considers its promise or best potential (Banerjee et al., 2011; Kelly, 2013).

A relational feminist disability approach also conceptualizes LTRC as relational at multiple levels of abstraction. LTRC is understood as an activity of relationships and as relational in an ontological sense (Banerjee & Rewegan, 2017). This means that context matters in explorations of issues in LTRC. When it comes to the contemporary situation of younger residents living in LTCFs in Ontario, this context is one that includes the history of public residential institutions for adults with disabilities as places of violence, neglect and abuse, as well as a recognition of the ongoingness of institutionalization (Leblanc Haley & Temple Jones, 2020; Linton, 2021; Spindel, 2013) or institution-like care arrangements. This context is also one in which gender and disability matter not only because neoliberal approaches to LTC reform have particular impacts on women and people with disabilities as individuals and groups who are more likely to use and provide care in Ontario’s LTCFs, but also because the ways in which LTC services are provided reflects particular ideas about gender, disability, age and about the value and worth of those who provide and require it (Armstrong & Armstrong, 2020). As such, a relational feminist disability approach prompts analyses of the role of social relations and social location in the situation of younger residents living in LTCFs in Ontario. This can be done by "anchoring" (see Bê, 2012) gender, disability and age in analysis as well as being open to recognizing others.

Formulating LTRC as relational means attending to a multiplicity of experiences and perspectives. It is an approach that assumes the ideas, structures, approaches, relationships, practices and programs that characterize LTRC will benefit certain individuals and groups while disadvantaging others (Armstrong & Bradeley, 2013). The success of research in this area is not, however, defined by the resolution of tensions. While many could be better balanced (Armstrong & Bradeley, 2013), the tensions that characterize LTRC are assumed to be instructive—they are a constant reminder of the need for critical reflection on and debate over issues of LTRC.

Like FPE and FDS perspectives, a relational feminist disability perspective does not prescribe a rigid set of methodological principles or methods for examining issues in LTRC. It assumes that doing so may contribute to the marginalization of particular forms of knowledge. This perspective does, however, assume that the production of evidence about LTRC is not an objective or neutral process. Subjectivity, power relations, and context are viewed as impacting all aspects of the research process including the questions that are asked, what counts as data, how data are collected and interpreted, and how evidence is presented. It is also assumed that power inequities can be challenged (though not resolved) and the quality of research improved when researchers reflect on and are transparent about their research process (see Chapter 3).

As a methodology, this approach is mindful of the ways in which people with disabilities have historically been involved in (or marginalized from) disability research (Watson, 2019), and of the tendency for evidence-based decision-making in LTRC to rely on research that rarely includes the perspectives of residents, family members, and paid care workers (Armstrong et al., 2016). A relational feminist disability perspective encourages researchers to respond to these issues by beginning with marginalized experiences—an approach that necessarily assumes the political value of the personal or experiential. It also recognizes the value of including multiple and potentially conflicting perspectives on issues of LTRC as a means of uncovering the tensions and understanding the relationships of care. However, while committed to uncovering and fairly representing personal experiences and perspectives, a relational feminist disability perspective does not assume an unproblematic relationship between personal experiences of, evidence on, and knowledge about LTRC. Instead, it understands them as situated—influenced by a number of social, cultural and other structures, ideas and contexts. As such, a relational feminist disability approach to issues in LTRC encourages researchers to use multi-scalar analytic frameworks and related lenses to connect the experiential to the organizational context, and the broader policies, structures, ideas, and forces within which they are are situated. Assuming the conditions of care are the conditions of work assists with such an analysis, and so does approaching issues of contemporary LTRC from the lens privatization. This is a tool that over the past two decades, has assisted feminist researchers in Canada to better understand contemporary issues in LTRC within the broader context of neoliberalism.

Finally, it is assumed that a flexible approach to “doing” social research in LTCFs supports the goal of attending to and including multiple (marginalized) perspectives. While designing research to foster inclusion matters, so too does reflecting on and making changes to various aspects of the research process as a means of responding to differences among people with disabilities. A flexible research approach is also more likely to respond to challenges associated with the partiality, provisionality, complexity, messiness, and relationality of social research that centers the perspectives of people with disabilities and takes place in a LTRC setting (see Chapter 4).

Notes

1. Recognizing the heterogeneity of feminisms and DS approaches alike, I use the term "mainstream" to distinguish more paradigmatic versions of these paradigms and perspectives from more marginalized contributions including FDS.
2. The term "critical disability studies" (CDS) refers to a body of social inquiry that encompasses more diverse theoretical and multi-disciplinary approaches to DS (Meekosha & Shuttleworth, 2009). CDS often challenges various aspects of a more paradigmatic version of DS including the social model of disability. I understand much of FDS scholarship as a form of CDS.

Chapter Two: Methods

A Study of Younger Residents' Conditions of Care

In the previous chapter, I described the relational feminist disability approach to LTRC that framed my exploration of the situation of younger residents living in LTCFs. This perspective involves a number of concepts, assumptions and lenses on which social researchers can draw to examine issues of LTRC. This perspective does not, however, dictate a particular research design nor set of data collection procedures or techniques. Instead, it emphasizes a flexible approach that privileges marginalized experiences, fits with the complexity and relationality of LTRC, employs a multi-scalar analytic lens that attends to gender, disability and other social relations and locations, and reflects on issues of power, subjectivity and inclusion throughout the research process.

Applying this approach to my exploration of the situation of younger residents living in LTCFs in Ontario in the decades following contemporary health care reform and leading up to the emergence of the COVID-19 pandemic, in this chapter, I provide a detailed outline of the research methods I used for this project. I justify my design decisions by referring back to the key assumptions of a relational feminist disability approach to LTRC, and by considering their appropriateness in terms of addressing the purpose of this dissertation and its research questions.

Purpose and Research Questions

The overall purpose of this dissertation was to explore the situation of non-senior adults living in LTCFs. I was particularly interested in the situation in Ontario given that very little empirical research has focused on this topic in this location. I viewed this oversight as a major gap in scholarship and policy. At the time I was developing and carrying out data collection for this project (2009-2011), Ontario had undergone over a decade of health care reform and reached significant milestones in processes of deinstitutionalization/dehospitalization (see Chapter 4). I assumed these changes were impacting younger adults with disabilities who relied on public LTC services. While media reports were emerging at this time, framing the issue in terms of a crisis (see Introduction), there was a clear paucity of empirical research. What I was most interested in uncovering and understanding was the everyday experiences and perspectives of younger adults with disabilities who were living in LTCFs. As such, I aimed to generate a rich, detailed exploratory account of this situation by uncovering non-senior residents' "conditions of care". These conditions of care are the practices, interactions, relationships, and structures that make up younger residents' everyday experiences living in a LTCF. I asked: What are the conditions of care experienced by non-senior adults residing in LTCFs? I also wanted to know: Do these conditions align with the needs and preferences of younger residents and those who provide them with care, if they do, how and why? Are there gaps and failures in meeting these needs and preferences, if so, what are they and what factors account for them?

Drawing on a relational feminist disability perspective (see Chapter 1), I assumed non-senior residents' conditions of care are shaped by a variety of personal, organizational, policy, social, political-economic and cultural contexts. This meant it was not enough to uncover the conditions of care, their value, and the problems with them. I also sought to identify and understand the variety of factors influencing these experiences and how younger residents themselves may contribute to or struggle against particular conditions.

This project also offered me an opportunity to contribute theoretically and methodologically to existing literature on LTRC. As described in the Introduction, I recognized that existing research on this topic in Canada is characterized not only by its scantiness, but by limitations in the theoretical and methodological approaches being used. Existing research on the situation of younger residents has not attended to the complexity of care and care relationships, and it rarely goes beyond a description of the issues for younger residents (Hewitt, 2022). I began to understand these gaps as indicative of larger disciplinary divisions and tensions over the topic of LTRC. These tensions are maintained by the tendency of feminist researchers to gloss over DS perspectives (Kelly, 2013) as well as by DS scholars who take narrow, abolitionist approaches to the issue (Asch et al., 2008). These limitations prompted me to ask how might I conceptualize a feminist disability perspective on LTRC, and what would it mean to approach research in LTCFs from this perspective?

A Qualitative Research Design

Given the purpose and research questions guiding this dissertation, I chose a qualitative research design aimed at examining non-senior residents' conditions of care. Qualitative methods are designed to explore social phenomena or behaviours in their natural setting (Avis, 2005; Creswell, 1998). They are also "flexible plans of inquiry" (Avis, 2005, p. 6), making them well suited to the complexity of and potential challenges involved in doing research in LTCFs (see Chapter 4), and to the methodological ideas guiding this project (see Chapter 1). Feminist disability and feminist health researchers have long used qualitative research methods to explore the lived experiences of marginalized individuals and groups, and to generate accounts of these experiences in ways that attend to sex/gender, disability and other differences and relations of inequality (Mactavish et al., 2000; Morrow & Hankivsky, 2007). DS researchers in particular note the value of qualitative methods in terms of supporting the inclusion of those who have historically been excluded from and are often viewed as unable to tell their own stories (Booth & Booth, 1996; McDonald et al., 2022; Owens, 2007; Phillipson & Hammond, 2018).

The “Case” of Younger Residents Living in Long-Term Care Facilities

The situation of non-senior residents living in LTCFs in Ontario in the 2000s and 2010s is situated within the context of neoliberal health care reform and the closure of many public residential institutions and hospitals for people with disabilities. Little is known about this phenomenon. As such, I chose an in-depth, exploratory qualitative research design framed as a case study. The qualitative case study is an approach used to conduct detailed investigations of specific social phenomena about which little research exists (Yin, 2009). As a method of empirical inquiry, qualitative case studies are well suited to “in-depth” investigations and analyses of the processes and contexts involved in the phenomenon being examined (Meyer, 2001). I was also drawn to the qualitative case study approach because it has been used feminist researchers to tell the story of marginalized women and groups (Reinhartz & Davidman, 1992). Case studies have also been used in “parasitic” ways, for example, to objectify people with disabilities living in institutional settings (see Hunt, 1998), but they have also been used by FDS scholars to uncover experiences of disability and to demonstrate the gendered dimensions of these experiences (Deegan, 1985; Frank, 1988).

At the same time, conventional assessments and narrow conceptualizations of case studies (particularly among those who take a postpositivist approach) indicate that case studies tend not to fit with feminist and other critical, interpretive perspectives (White et al., 2009). Further, misunderstandings, or what Gerring refers to as the “quasi-mystical qualities associated with the case study” (2007, p. 7) have at times undermined the value of the case study. When it comes to qualitative case studies, design decisions are diverse, flexible, and often left to the researcher. As such, case studies are sometimes considered “soft research” or research that lacks rigor (Yin, 2009). In contrast to these views, Willis (2007) argues that researchers from critical and interpretive paradigms often use case studies because it permits the gathering of rich data in a real life setting and because it is a holistic approach to examining a particular social phenomenon, person, process, institution, or group. At the same time, however, Gerring (2007) suggests that some assumptions about case studies thrive in part because many case study researchers do not clearly detail their methodological considerations nor design decisions. This is an issue I have tried to address by developing a detailed and transparent account of my research methods within this chapter as well as by reflecting on some of the limitations of my design and challenges that I arose as I conducted the research (see Chapter 3).

Following Willis (2007), I define the qualitative case study as a research approach focused on a specific phenomenon that aims at developing a full, "rich understanding (*verstehen*)" by gathering "rich, detailed data" about it in a "naturalistic" or "authentic" setting (p. 240). Ethnographic and interpretive case study approaches are particularly appropriate for research concerned with a particular socio-cultural phenomenon that aims to gather and analyze descriptive data in order to develop new understandings and to relate these to prevailing theories (Willis, 2007).

Guided by this conceptualization, I developed and employed a design whereby the "case" or specific phenomenon of interest—younger residents living in LTCFs in Ontario in the two decades leading up to the COVID-19 pandemic—was examined through an exploration of the conditions of care for non-senior residents living in five private for-profit LTCFs in the Greater Toronto and surrounding areas. Following Mukhijia (2010), my aim was not to use the qualitative case study design to yield a representative or generalizable account of this phenomenon. Instead, my focus was on generating a thick description of the conditions of care experienced by these non-senior residents. The richness, depth and details of the results and the ways in which they link back to theory and advance understanding are what determine the credibility, resonance and significance of this study.

I chose to define each of the five sites involved in the research as a “sub-unit of analysis”. I used a combination of data collection methods (Meyer, 2007), recognizing the value of this approach in terms of crystallization and triangulation—the use of multiple kinds of data, perspectives and/or theoretical concepts to enhance the complexity and in-depth nature of the analysis and to solidify the findings (Tracy & Henrichs, 2007). This strategy also seemed to align with my understanding of care as relational and relatedly, my interest in focusing on both the conditions of care and the conditions of work in LTCFs. Defining the “site” as the sub-unit of analysis prompted me to focus on similarities and differences between the structures at particular sites that might illuminate the factors underlying the conditions that meet and/or fail to meet the needs and preferences of younger residents. At many times throughout this study, however, I paused to reconsider why I framed the “sites” as sub-units of analysis rather than each non-senior resident. I reflect on this decision and its outcome further in Chapter Three.

Ethics and Access Procedures

Data collection for this project took place between October 2010 to November 2011. It was preceded by a lengthy process of gaining ethics approval for the project, identifying potential research sites, gaining access to these sites, and recruiting potential participants.

Ethics Approval

To start, this project was evaluated and approved by York University’s Research Ethics Committee and complies with the 2010 Tri-Council policy statement for the “Ethical Conduct of Research Involving Humans”. Following ethics approval, I completed an application to the applied research committee of a major association of providers in Ontario. This committee provides assistance to academic researchers in terms of gaining access to LTCFs with whom they are associated for the purpose of conducting research. Following approval of my application, I was invited to make a presentation about the research project to their research board. Following my presentation, several directors offered me assistance by putting me in contact with administrators at various LTCFs. I was also provided with some information about facilities that might be particularly appropriate for the project. For example, it was suggested that I contact a facility where residents under the age of 65 were described as a particularly distinct group given several had moved into this facility at the same time, coinciding with the closure of a complex continuing care (CCC) unit at a nearby hospital.

Based on this initial contact, I developed a site selection strategy aimed at recruiting for-profit facilities in the Greater Toronto and surrounding areas. My choice of for-profit facilities was purposive, reflective of the fact that almost 60 percent of LTCFs in Ontario were, at the time of data collection, proprietary facilities (Berta et al., 2014). Since the Greater Toronto and surrounding areas boast large numbers of for-profit LTCFs, I assumed this was a particularly good region in which to engage in this project. Given my assumption that a multiplicity of contexts impact younger residents' conditions of care, this decision was also pragmatic because it offered me a greater chance of gaining access to five diverse facilities in which small numbers of non-senior residents were likely to reside. Facilities could be chosen that differed from one another in terms of their ownership group (i.e., facilities owned and operated by different companies), if younger residents were living in integrated units and/or a unit dedicated to younger adults, and in terms of their location within the defined geographic area.

Access to potential sites relied on members of the applied research committee connecting me to gatekeepers at the facility level. In some situations, I was put in contact with an administrator, while in others, access was facilitated by a university-based research institute that had an existing research relationship with a number of LTCFs. Each facility had its own ethics approval process that variously occurred at the level of the owner-operator organization, or the research committee/board of the ownership group. At one facility, approval was also required from the Resident and Family Councils. I was also required to gain ethics approval from the university-based research institute that assisted me in accessing some of the facilities.

The Consent Process

I began the process of recruiting potential participants with the assistance of an administrator or a research coordinator associated with the facility. During my initial meetings with and in some situations, presentations to these “gatekeepers”, I indicated my goals for recruitment and criteria for participant inclusion in the project. Given my focus on centering the perspectives of non-senior residents (see Chapter 1), I aimed to include *at leas*t four resident-participants at each site involved. I aimed to involve residents between the ages of 18 and 64. I chose this age range to define “younger” or “non-senior” residents because it meant this group would be at least twenty years younger than the average age of a resident in Ontario’s LTCFs (see Introduction). Further, it corresponded with the notion that the term “senior” tends to be defined in national census classifications and other forms of research to include adults 65 years of age and older. I also emphasized a desire to include both male and female residents, residents experiencing different forms of disability, and residents who had been living in the facility for different lengths of time. Since only small numbers of non-senior residents were present at any one facility involved in the project, these efforts towards representation were often difficult to meet (see Chapter 3).

Potential resident-participants were identified by gatekeepers and provided with information about the nature of the project with the assistance of administrators, staff members, or research coordinators. At one facility, I was also invited to make a brief presentation to potential resident-participants. Here, I described the purpose of the study, outlined the details of involvement, and answered any questions.

Understanding care as a relationship and the conditions of care as closely linked to the conditions of work (see Chapter 1), I also sought to include a number of direct care providers working in these facilities to participate in the project. I assumed that their knowledge of and perspectives on working in a LTCF and providing support to younger residents would enhance my understanding of non-senior residents' conditions of care. Drawing on Berta and colleagues (2006) definitions of the different types of "direct care" staff in LTCFs, I defined this group to include staff most likely to be involved in the formal provision of nursing, personal, and/or social care—that is, providing care of this sort is a central component of their job responsibilities. Since the overwhelming majority of direct care workers in Ontario's LTCFs are female (Laxer, 2013), I chose to include only women workers. I aimed to recruit two nurses (RNs or RPNs), two PSWs, and a recreation staff at each research site. The recruitment of staff members relied on the assistance of an administrator or nurse supervisor who introduced the study to potential participants, distributed consent forms, and often, put up a "sign up" sheet for interested staff.

Understanding the conditions of care as situated within a number of personal, organizational, policy, and other contexts (see Chapter 1), I also sought the involvement of others who would have insight into the factors shaping younger residents' conditions of care. I requested the involvement of an administrator at each facility. Administrators who had acted as gatekeepers, all of whom were female, agreed to participate in the project, although only four ultimately did. I also attempted to recruit family members of non-senior residents at each facility to participate in a focus group interview. I assumed some family members would be involved in the provision of informal care and that in some situations, younger residents might request their support in order to facilitate involvement in the study.

An administrator or a research coordinator played a key role in gaining access to younger residents' family members. They contacted family members on my behalf either in-person, by phone, or by (e-)mail. At one site, I was invited to make a presentation about the project at a Family Council meeting, where I described the study and answered questions.

Initial Interactions

At each of the five facilities involved in the project, various staff members were asked by administrators to distribute consent forms to potential resident-participants (see Appendix A). Sometimes, the staff member also assisted the resident in reading and interpreting the form. With the exception of residents who I had met at earlier presentations, my first meeting with those who had indicated interest in participating was also facilitated by a staff member, most commonly, a recreation staff or PSW. When I first met a resident-participant, I provided a brief overview of the goals of the project, discussed the consent procedures, asked them about their availability, answered questions, and spent some time getting to know the participant if they were willing. Although some of these interactions were brief, the informal conversations that occurred between the resident-participant and I were vital in terms of beginning a process of establishing rapport and trust.

Initial meetings with interested direct care workers often occurred at the time of data collection. Prior to this time, administrators had distributed consent forms to interested staff and organized an interview schedule. Given the intense workloads of most direct care workers, there was little time for me to get to know worker-participants prior to the start of the interview, although I did ensure ample time to go over the consent form and answer any of their questions. In some situations, I had informally met a worker-participant as a result of spending time at their workplace or with a younger resident to whom they provided care. Such opportunities were especially valuable in terms of gaining their trust (see Chapter 3).

Having met all five administrators during the process of gaining access to facilities and recruiting potential participants, I had already established some degree of rapport with these women prior to data collection. I had also met a small number of family members via the process of spending time at facilities and obtaining informed consent for some younger residents' "guardians" or powers-of-attorney. It was these individuals who ultimately agreed to participate in the project despite my other efforts at recruitment. This outcome reflects some of the challenges and limitations of my chosen recruitment methods—an issue I discuss further in Chapter Three.

Informed Consent

Gaining informed consent from participants was an on-going process. For the majority of resident-participants, the resident consent form (see Appendix A) was initially introduced by a staff member at their facility. This form had to be signed by the participant prior to my meeting with them one-on-one. This decision helped maintain the privacy of those younger residents who were not interested in participating in the project. For some resident-participants, I was informed by the facility that a guardian consent form was also required (see Appendix B). In such situations, I also insisted on the voluntary consent of the resident. At some facilities administrators handed out consent forms to potential direct care workers (see Appendix C) prior to my meeting with them. In other situations, worker-participant consent forms were distributed, discussed and signed at the start of their interview. This was also the situation for family members (see Appendix D) and administrators (see Appendix C).

Given my reliance on administrators and staff members to distribute, and in some situations, read and/or explain the consent forms to resident-participants, I began each interaction with a resident-participant by discussing the nature of the study using simple and concise language and offering multiple opportunities for them to ask questions. Drawing on the information in the consent forms, I explained what was being asked of the participant and emphasized how confidentiality would be protected. Furthermore, I stressed the voluntary nature of participation, indicating that the participant could withdraw at any time and/or request that I omit sections of their narrative without penalty. I encouraged interaction throughout this process, asking participants if and what they understood from each section of the consent form, and I clarified any questions they might have.

Research Sites and Participants

The Facilities

Data collection for this project took place at five LTCFs. Major characteristics of each site are listed in Table 1. To help ensure confidentiality, I gave each site a pseudonym. In addition, more specific, potentially identifying characteristics of each site were left out of the chart and other results collapsed into more generalized categories/ranges. The five facilities were in diverse locations throughout the Greater Toronto and surrounding areas and were operated by four different ownership groups. They were all large facilities, ranging in size from approximately 120 to 220 beds. In general, senior and non-senior residents were integrated throughout these facilities. While separate units aimed at particular resident sub-groups existed

Table 1

Characteristics of Research Sites

Pseudonym	# Residents Under 65	# Beds	Other Characteristics
Eastern Sunrise	Under 10	150-200	Located near shops and public transportation Effort to place younger residents in one unit
Northern Willow	10-15	100-150	Smallest participating facility Intended to open with separate younger resident unit
Sherwood West	Under 10	150-200	Farthest location from urban center Pre-existing younger resident group
South River	10-15	150-200	Newest participating facility Attached to Assisted Living and Retirement Facilities
Spruce Hollow Central	10-15	Over 200	Largest participating facility Oldest participating facility Located near shops and public transportation Includes ward-style rooms Large population of residents belonging to a particular faith group

in most facilities, these were not organized around age. Instead, they tended to be arranged for residents with advanced Alzheimer's disease and other forms of dementia.

I was informed that at one of the sites involved in this project, there had been a plan to create a separate unit for younger residents upon the opening of the facility. According to the administrator, however, low numbers of younger residents, pressures to maximize occupancy rates, and concerns over the equal distribution of work across units prevented the establishment of such an arrangement. Administrators at three other participating facilities told me informal efforts were made to place younger residents in rooms in close proximity to one another, but this was only possible once appropriate beds opened up.

The Participants

43 individuals participated in the project. They included 18 non-senior residents, 18 female direct care workers, four administrators, and three family members of resident-participants. Resident-participants ranged in age from 31 to 64, but the majority were over 45. All were residing at one of the five sites involved in the project during the period of data collection for their site. In order to gain access to a LTCF, each resident would have had to go through a process of being diagnosed with and/or classified as having (multiple) conditions and/or impairments, and/or as having high or very high care needs. However, resident-participants did not necessarily understand or identify themselves as having or being a person with "a disability". Most did, however, indicate that they were experiencing chronic illnesses and/or impairments and linked this to the types of assistance they required while living in a LTCF. The socially constructed nature of age categories also meant that some resident-participants did not agree with me categorizing them as "younger" or "non-senior". However,

with one exception, resident-participants all indicated that they perceive themselves as significantly younger than the majority of residents living at their facility.

Table 2 provides demographic information about the resident-participants involved in the study. I gave each resident a pseudonym to protect their identity. I also collapsed some demographic details (e.g., an age range rather than the resident's precise age is provided) and removed others throughout the dissertation, as a means of better protecting their identities.

Of the 18 residents who agreed to participate, ten identified as female and eight identified as male. Only two resident-participants were racialized minorities. The vast majority of residents described residing at home either alone or with family members for the majority of their lives. Prior to coming to live in a LTCF, some had spent time living in hospital, chronic care or rehabilitation facilities, or other LTCFs. Others came to live in a LTCF directly from their own or their family household. The period of time for which resident-participants had been living at the facility where data collection took place ranged from a few months to over 15 years. All but four residents had been living at their facility for three or more years, and about half of the residents had lived at their facility for five or more years—although not all could recall precisely how long it had been.

Resident-participants described experiencing a variety of impairments such as acquired brain injury, multiple sclerosis, stroke, cerebral palsy, early onset Alzheimer's, and Parkinson's disease. The vast majority had acquired impairment/chronic illness as an adult. Two participants indicated they were born with a disability. All of the residents involved experienced mobility-related impairments/chronic illness, and most also described difficulties with short-term memory or other cognitive activities. All residents required assistance with some of the activities of daily living (ADLs). Most often, residents described needing assistance with transferring in and out of

Table 2

Characteristics of Resident-Participants

Pseudonym	Gender	Age (Years)	Length of Stay (Years)
Andor	M	46-64	3-8
Catherine	F	46-64	> 3
Celene	F	46-64	> 3
Elton	M	46-64	< 8
Freeman	M	46-64	> 3
George	M	46-64	< 8
Jackson	M	31-45	3-8
Janet	F	46-64	3-8
Joan	F	46-64	< 8
Julie	F	46-64	3-8
Mallory	F	31-45	< 8
Marnie	F	46-64	3-8
Matthew	M	45-64	< 8
Norah	F	46-64	> 3
Shannon	F	31-45	< 8
Steve	M	46-64	3-8
William	M	46-64	< 8

bed to a wheelchair, dressing, bathing, and toileting.

In some ways, the demographic characteristics of the resident-participants well-represent the non-senior resident population living in LTCFs in Ontario at time of data collection. In particular, I was successful in terms of involving similar numbers of male and female resident-participants. Further, there were more resident-participants who were in the 46- to 64-year-old range than those in the 31- to- 45-year-old range. This fits with statistical data on the resident population in Ontario (see CIHI, 2020; 2021b). As well, most resident-participants were living at their facility for a longer length of time than the reported resident average of two to three years (Damji, 2015).

18 female direct care workers (worker-participants) were also involved in this project. Eight were PSWs, seven were nurses (RNs and RPNs), and three were recreation workers. PSWs provide residents with assistance with the ADLs such as washing, bathing, eating, dressing, toileting, and transferring. Recreation staff organize and run a wide variety of group and individual social and recreational activities for residents. Both groups indicated they provide various levels and types of social, emotional, and/or spiritual support to residents. I included both RNs and RPNs under the category of registered nursing staff. This was a practical decision associated with challenges I experienced recruiting them (see Chapter 3). Nurse-participants described being responsible for the management of medications, changing dressings on wounds, and setting up feeding tubes. Most indicated that much of their time is spent on administrative tasks particularly in terms of regulatory compliance, and that the extent to which they provide direct care to residents is limited. This information is similar to that reported in Ontario’s Long-Term Care Staffing Study (LTCSSAG, 2020).

Participant-workers were a diverse group in terms of age, racial/ethnic background, years of experience working in a LTCF, and employment status (e.g., full-time, part-time, permanent, temporary). The majority of PSW-participants were visible minority and/or immigrant women who identified as coming from a variety of geographic areas such as the West Indies, the Philippines, the South Pacific, and Latin America. However, this was not the situation at Sherwood West—the facility located furthest from a major urban center—where both PSWs involved in this study were white and did not identify as migrant women. In terms of experience, PSW-participants had been working at their respective LTCF from between 18 months and eleven years. Half had been working at their respective LTCF for over five years. The employment status of PSWs also varied. While most had full-time, permanent contracts, two participants were part-time workers, and one participant had a full-time, temporary contract which she explained to me as working full-time hours without the security or benefits offered to full-time employees.

All three recreation staff were white women. One identified as a migrant. Two of these women were the youngest staff-participants in the project—they were both in their twenties. All three had full-time, permanent contracts, although this was a recent development for one of them.

Just under half of the nurses involved in the project identified as immigrant and/or racialized women. There was great disparity in terms of their age and number of years of experience they had working in a LTCF. For example, one participant who was under 30, had been working at her facility for under three years. This was her first formal job after completing her nursing degree. A second nurse, who was in her mid-50s, had been working in her facility for over five years and health care for over 20 years—first as a nurse in a hospital in her country of origin, then, as a PSW when she first came to Canada, and now, as an RPN in a LTCF.

Four administrators, all of whom were women, also participated in the study. They included three General Managers and one Director of Programs. A fifth administrator who had originally shown interest in participation could not be contacted for an interview. Finally, three family members of non-senior residents, all of whom were affiliated with younger residents at the same facility, agreed to participate. They included two parents of younger residents and the spouse of a younger resident.

Data Collection Procedures

The data collection techniques used for this qualitative case study included individual open-ended interviews with non-senior residents, direct care staff, and administrators, a group interview with family members, field notes, and collecting and reviewing documents available in the information packages of the facilities involved in the project or located on their websites. I used multiple data collection techniques not only because this is a common feature of qualitative case study research that supports the triangulation of the data (see above), but also because each of these techniques aimed at capturing a potentially different perspective on or information about younger residents' conditions of care and the contexts within which they are situated.

Participant Interviews

Centering non-senior residents in an exploration of their conditions of care meant starting with their personal experiences (see Chapter 1). Over a period of 13 months, I engaged in open-ended, semi-structured interviews with non-senior residents, direct care staff, administrators, and family members. While I drew on interview guides (see Appendices F-I) to facilitate our discussions, in the interest of destabilizing more conventional researcher- respondent power relations and in order to develop a good rapport with respondents, most interviews were practiced in the style of a conversation. Participants were encouraged to speak openly and freely about their experiences and understandings of LTRC, to take some control over the focus and pace of our conversations, and to raise topics and issues beyond those covered in the interview guide.

I approached my conversations with resident-participants assuming that it may take some time for me to develop enough rapport for them to speak openly about their experiences and perceptions. I also assumed that it may take time for me to understand and adapt to residents' preferred and most effective ways of communicating their stories. My previous experiences interviewing youth with disabilities as part of my Master's thesis made me aware that it was my job as a researcher to maximize the quality of our interactions by assuming a flexible, dynamic and inclusive approach to interviewing. In practice, this often meant moving away from the style of interview I had originally envisioned. For example, I utilized both open-ended and more closed and leading questions (including "Yes" and "No" questions) in situations where this supported verbal articulacy. Some methods, including offering resident-participants the opportunity to write and/or draw in a personal journal, and taking extensive field notes during my interactions with resident-participants as a means of recording their non-verbal communication practices (e.g., pointing, showing, making sounds, facial expressions), were tools I added to the project reflexively as I learned more about how different resident-participants (prefer to) express their thoughts.

18 non-senior residents were involved in the project. Most resident-participants chose to meet in their bedrooms, but some interviews occurred in more public areas of facilities such as meeting rooms or dining areas. Residents were welcomed to invite a confidant or support person

to accompany them during the interview if they so desired. I presented this option based on my assumption that for some residents, the inclusion of a support person of their own choosing may increase the likelihood of their participation. I interviewed all but two participants alone. An additional participant was interviewed with the assistance of a family member. The remaining participant was interviewed both with a family member present and without.

Drawing on the Resident Interview Guide (see Appendix E), resident-participants were encouraged to describe their typical day, to define care and their individual care needs, and to describe the care practices and relationships in which they are involved. Participants were also asked to discuss the ways in which they contribute to the care environment and how they care for themselves. Further, I asked residents to comment on the quality of the care they experience in their LTCF and to discuss any factors they perceive as having a particularly positive and/or negative influence on it. I asked questions that prompted residents to consider the impact that differences related to social location may have on their experiences and understandings of care and care-relationships. I also prompted them to discuss anything they would change about the care they experience.

These conversations were audio-taped using a small digital recording device. They lasted between 15 minutes and two and a half hours. In some situations, interviews took place over multiple sessions, particularly where residents indicated experiencing fatigue, where they explicitly asked me to return to discuss a topic further, and/or where, upon my initial review of the interview recording, I recognized a need for greater clarification.

I also spent time with two residents with whom I did not conduct oral interviews. Instead, I took extensive field notes in my research journal both during and after spending time with them. These residents—one with the assistance of a family member—offered insights into their conditions of care by showing me their rooms and parts of the facility where they spend time. I also used this method with a third resident to complement the more formal interview. One resident chose to write and draw about his conditions of care in a personal journal, guided by the Resident Personal Journal Guide (see Appendix F).

I also conducted individual interviews with the seven nurses, eight PSWs and three recreation workers. These single-session conversations took place in a variety of spaces within each LTCF such as in small offices, nursing stations, rooms used for computer charting, recreation rooms, training rooms, dining areas, and at one facility, a board room. The variance can be accounted for in terms of some of the challenges I experienced securing a degree of privacy while conversing with staff members (see Chapter 3). Interviews with direct care workers lasted an average of 40 minutes. The shortest interview (nine minutes) involved a PWS who was paged shortly after our conversation began, and who declined to finish the interview at a later time. The longest interview took place over a period of two hours.

Drawing on the Direct Care Worker Interview Guide (see Appendix G), I encouraged direct care workers to talk both generally about their experiences working at their LTCF and more specifically, about the care they provide for and relationships they have with younger residents. Direct care workers were prompted to describe a “typical” day at work including their daily work practices and responsibilities. They also discussed their definitions of care and how care is organized and delivered at their facility. I asked them to talk about their relationships at work, the ways in which they contribute to them (particularly when they involve younger residents), and if/how they perceived differences in social location to impact care work and care relationships. Direct care workers also discussed their understandings of appropriate care for non-senior residents, told stories about any issues they had experienced caring for younger residents, and described the factors they perceive to influence the quality of care they provide, and what (if anything) they would change about their conditions of work.

Recognizing that some family members play important roles in the younger residents' conditions of care (see above), I also conducted an in-depth group interview with two family members of non-senior residents. This took place in a common room at the LTCF and lasted two hours and 25 minutes. This conversation was guided by the Family Member Interview Guide (see Appendix H). A third family member of a non-senior resident was interviewed individually in a somewhat unplanned manner, and in conjunction with the first session of a resident-participant’s interview. Many of the same topics addressed in the resident-interviews were discussed with family members. I asked them about what care looks like for non-senior residents, and how younger residents and family members contribute to the care environment. Family members were also prompted to discuss the quality of care they perceived their family member to be experiencing, to describe the factors they view as necessary for high quality care, and to tell me about any concerns over the quality of care and to consider factors they perceive as negatively impacting it. Family members were also asked to tell me about the facility’s Family Council and their involvement in it (or not).

Finally, assuming administrators could also share valuable information about the organizational, regulatory and policy contexts within which younger residents’ conditions of care are situated, I also conducted single-session, individual, semi-structured interviews with four administrators. Each of these interviews was conducted in the participant’s office. These conversations lasted between 39 and 49 minutes. Drawing on the Administrator Interview Guide (see Appendix I), administrators were prompted to discuss many of the same topics as direct care worker-participants. I also prompted administrators to provide more general information about the facility including resident demographics, as well as to discuss their roles as administrators, and if they were aware of programming aimed at or staff training focused on the provision of care to non-senior residents.

Field Notes and Facility Document Review

A relational feminist disability perspective views the conditions of care as situated within a number meso- and macro-level contexts (see Chapter 1). In order to assist me in identifying such factors, I made field notes in a research journal. I also collected a number of documents in the form of either "information packs" the facility offered to prospective residents and/or their family members or printed from facilities' websites.

I approached writing field notes as a process of recording what I was hearing, seeing, thinking, and experiencing during the process of accessing sites, collecting data, and reflecting on the research process. I aimed to capture both descriptive and reflective information that would provide more context than what I assumed could be captured in the interviews. Guided by Muhall (2003), I took an unstructured approach to writing field notes. Muhall suggests that this decision is appropriate for situations where a researcher is first entering a site with little predetermined notion of what they will see, hear, or think.

While unstructured, I did follow a general process for writing field notes. I spend a bit of time writing notes when I first arrived at each facility in order to capture some key descriptive information such as its location, size and physical layout (e.g., how many floors and units and how these were divided, the layout of bedrooms, common, and outdoor areas and what these looked like, where areas of the facility were busy/quiet). During the time I spent interacting with participants, I only had time to jot down quick notes about what I was seeing, hearing, experiencing and thinking. I tried to expand on these "jottings" when there were breaks between interviews, and once I left each facility. I focused on recording physical descriptions of the places where the interviews were taking place. I also wrote down demographic and other forms of information that I gained about participants through our informal conversations and the time we spent together. I also wrote notes about my experience interacting with participants and noted particularly challenging and/or rewarding aspects of these interactions.

As mentioned, the jottings I made throughout the interviews were extremely limited. Similarly to Muhall (2003), I found that writing in my journal distracted me from focusing on the conversation I was having with the participant. I did, however, take more careful notes in situations where I had modified my interview methods to make them more accessible such as when I asked residents to spend some time “showing me” their lives and experiences residing in a LTCF, and/or when I recognized that a participant used a lot of non-verbal auditory sounds and/or physical cues to convey their stories. I also wrote down some overall impressions of my experience at a given facility after I had left the research site for the day. I analyzed these notes as part of my overall data set, and they played a particularly central role in helping me reflect on the research process (see Chapter 3).

The facility documents I reviewed tended to outline the corporate care philosophies and/or standards of care. They provided both general and more specific information about available accommodations and the services that would be provided at the facility. In most cases, sample meals and recreation plans were also included. The site-specific information I attained by reviewing these documents helped me identify some key similarities and differences between the five facilities involved in the project, which supported my analysis of the larger data set.

The Data Analysis Process

Data analysis was a process that started early in the project and continued throughout the writing up of the dissertation. It included an ongoing exploration of the sociological and historical literature on public residential institutions for people with disabilities in Ontario and on key issues in Ontario's LTCFs in the 2000s and 2010s. This work was valuable in terms of helping me identify and understand key components of contexts within which younger residents' conditions of care are situated (see Chapter 4).

A more explicit or formal period of data analysis occurred throughout and following 14-months of empirical data collection. I transcribed the interview data from the first research sites and engaged in preliminary examinations of participants' narratives while I was still collecting data at other facilities. To begin, I transcribed audio-recorded interview material. While there is always a degree of interpretation that occurs during transcription, my approach to transcribing the interview material was to do this as closely to verbatim as possible, focusing on words and other vocalizations. As much as possible, I also noted body language, particularly in situations where this comprised a key way in which the participant communicated with me. I drew heavily on my field notes to assist me with this practice. I also chose not to "edit" participants' voices by removing words, vocalizations, or solecisms. This decision reflects my recognition that participants each had their own ways of communicating their stories. I assumed that modifying transcriptions in this way would silence some participants, thus contributing to rather than resisting research practices that marginalize. Since not all resident-participants' narratives were captured through more formal oral interviews, I constructed a "narrative" for these individuals by transcribing the field notes I had taken during our interactions as well as transcribing any information they had provided me via the participant journal.

A Voice-Centered Relational Approach

Once I had collected data at a given facility, I began a process of interpreting and analyzing participants' narratives using a framework inspired by the voice-centered relational method of data analysis (Bright et al., 2018; Doucet & Mauthner, 2008; Fairtlough, 2007; Mauthner & Doucet, 1998; 2003; Paliadelis & Cruikshank, 2008). While originally developed by feminist psychologists (Gilligan, 1982; Brown & Gilligan, 1991; 1992), this approach has been adapted by a number of feminist sociologists (Fairtlough, 2007; Mauthner & Doucet, 1998), including those doing qualitative research in health care settings (Bright et al., 2018; Paliadelis & Cruikshank, 2008). It has also been used in research involving people with communication disabilities (Bright et al., 2018).

I chose this tool because of its coherence with a relational feminist disability approach. It aims to "uncover the layers within [participants'] narratives" (Paliadelis & Cruikshank, 2008, p. 1444) through the successive reading of transcripts three or more times (Fairtlough, 2007; Mauthner & Doucet, 1998). These readings begin (as a relational feminist disability methodology does) with the participant's "voice" or stories/perspective (Bright et al., 2018). However, it is assumed that this perspective is "necessarily situated within a wider network of personal social relationships and cultural and social structures" (Fairtlough, 2007, p. 6). Subsequent readings therefore involve the researcher attending to different aspects of the narrative.

A voice centered relational approach also encourages researchers to engage in a process of reflexivity while analyzing the data. Researchers are prompted to consider their own (personal) response to a participant's story (Mauthner & Doucet, 1998). Mauthner and Doucet describe this as the researcher "'*read[ing] for herself'* in the text. She places herself, her background, history and experiences in relation to the respondent. She reads the narrative *'on her own terms'*" (2003, p. 419).

I engaged in a five-stage analysis or reading of resident-participants' narratives. Inspired by the process described by Paliadelis and Cruikshank (2008), during the first reading of a given narrative, I also listened to the accompanying audio recording, where this existed. During this reading/listening, I focused on capturing the participants' story as a whole, attending to the overall "plot" of the narrative. I searched for and highlighted text that gave a general picture of the participant's conditions of care (or work), and how the participant perceived (e.g., valued and/or devalued) the conditions they describe. I also made notes in the margins of transcripts to indicate significant and/or recurrent ideas.

The first reading/listening was also an opportunity for me to reflect on my own intellectual and emotional reactions to the participant's narrative. For example, I indicated in the margins of the transcript where I was having a particularly strong emotional reaction to what was being said, when what was being said did not fit with my assumptions, or when I was reminded of something I had read about or heard before. As these notations became more extensive, and I moved from reflecting on the stories in the narrative to the thoughts I was having about my interactions with participants and the time I spent at their facilities, I decided to create a data analysis journal, where I could write down my reflections in greater detail.

The second reading consisted of what Fairtlough (2007) describes as reading for "the voice of 'I'" (p. 6). The purpose of this reading is to attend to how participants present themselves. In this reading, I looked for the ways in which participants talk about themselves, their identity, their history, their feelings, their views and opinions. The idea was to better understand the participant and how their understanding of themselves impacts their narrative.

In the third stage, I was “reading for relationships” (Fairtlough, 2007, p. 6). Here, I attended to the interpersonal relationships being discussed in the narrative. I focused on what participants were saying about individuals and groups of people involved in their conditions of care. I focused on periods where participants talked about the people with whom they live and/or work, and about who provides them with and/or receives their care. I considered who was and who was not being mentioned in participants’ narratives. I also focused on what participants were conveying about the qualities of the relationships they value/enjoy, and on identifying key tensions within these relationships.

In the fourth and fifth stages, I modified the voice-centred relational framework to better fit my specific research questions and theoretical/methodological approach. Bright and colleagues view such modifications as appropriate given this model “functions as a research framework informed by the epistemological and ontological assumptions of the researcher rather than being a fixed prescription for how research must occur” (2018, p. 36). I began this process by transcribing and examining my field notes as well as reading through the informational documents I had obtained for each participating facility. I then conducted a fourth reading of participants’ narratives. This reading aimed at revealing the organizational structures, delivery practices and conditions of care work within which participants' experiences were occurring. I looked for moments where participants talked about how care (work) was being organized and delivered at their facility. I attended to problems and tensions associated with how care work was being done and how it was being delivered. I also noted situations where the ways in which care was being organized and delivered at the facility-level seemed to be impacting participants' sense of self or their relationships with others.

Finally, I engaged in a fifth reading of the data. At this stage, I aimed to locate participants' narratives within a larger set of contexts—to make links between "micro-narratives and macro-level structures and processes" (Doucet & Mauthner, 2008, p. 406). This reading was largely an opportunity for me to think about how participants' narratives might be shaped by the history of public residential institutions for people with disabilities, by ideas about deinstitutionalization, and by contemporary changes in LTC associated with neoliberal health care reform in Ontario. This macro-level analytic reading also meant attending to social location and social relations within participants' narratives. I looked for diversity and difference, attending to stories where disability, gender, age and other relations of difference and inequality are featured.

All of the narrative-data I gathered from my interactions with resident-participants (i.e., interviews, field notes and participant journals) were fully analyzed according to the five-level voice-centered relational method. In accordance with my theoretical/methodological perspective, I wanted to prioritize the narratives of non-senior residents. I also recognized that committing to five-levels of data analysis for the entire body of data collected for this project was an unmanageable task. I decided that not all interviews would undergo the same analytic process. I chose only to analyze a selection of the remaining interviews: one PSW, one nurse, one recreation provider, the family group interview, and one administrator, using the five-step process. I purposely selected "robust" transcripts to undergo this process. I did this by systematically searching through the transcripts of a given group of participants to find one that closely addressed a range of topics associated with the interview guide, and where the participant regularly provided examples or told stories to illustrate their points. The remaining transcripts of direct care workers, the family member, and administrators underwent a more limited analysis, where my main focus was reading/listening until I understood the “plot” of the narrative as a whole and could identify key themes, topics, or perspectives that reinforced, differed or were absent from the data that had already undergone the more thorough analytic process.

At this point, I began to engage in what Mauthner and Doucet describe as a “thematic ‘breaking down’ of the data” (1998, p. 20). Here, my focus of analysis moved from individual narratives and texts to dealing with the data set as a whole. However, the existing literature provided very little instruction on how exactly to complete this process, apart from indicating that the relational “filter” through which this stage was to be completed involved what Bright characterizes as attending to “multiple forms of relationship: those within the data; between the voices in the data; between the participant and those around them; and within the contexts in which they live” (2016, p. 3). This suggested to me that the process of thematic analysis would be an iterative one whereby I would explore similarities, differences and tensions within and across participant groups and within and across data collected at the five research sites.

To begin this process, I imported the transcripts (interview, participant journal, and field notes) into a software program for organizing and managing qualitative data (NVivo). I had used this program before and found it can simplify the physical process of fragmenting and reassembling pieces of narratives by category or theme (or “nodes” in NVivo). I formulated some initial themes based on the highlighted sections of transcripts and notes I had written in the margins while engaging in the five-level analytic process. I added to and refined them as I went through the data set—collapsing some similar categories into larger themes and differentiating others.

I followed a particular strategy in terms of the order in which I coded the data. I started with the resident-participant data at the first research site. I then went through the other data for that site that had undergone the five-level process. I then moved on to the data from a different facility. Once all the data had been categorized in this way, I went back to examine the data by code for a particular participant group (i.e., resident, nurse, PSW, recreation worker, family member, administrator) across research sites. Finally, I revisited the transcripts as a whole and re-read my data analysis notes and journal. This summative step was important in terms of re-orienting me to the overall themes driving participants' narratives as well as the (different) contexts within which these stories were being told.

Writing Up the Findings

Returning to my original research questions, I began formally writing up my findings by constructing outlines of "data chapters" (see Chapters 5-8). For each key theme or argument, I drew heavily on quotations from participants' narratives to illustrate the finding. I looked for quotations that well represented common or shared experiences/perceptions. But I also looked for "outliers", assuming that these exceptions might point to particular contextual factors that were shaping that experience or understanding. This strategy of drawing heavily on participants' narratives not only fits with my goal of "giving voice" to participants, it is also a technique that supports the credibility of the findings. Through the use of multiple (and sometimes longer) quotations, I provided the reader with more concrete detail and thicker description. It helped me "show" rather than "tell" readers what to think (Tracy, 2010).

While writing up my findings into chapters that reflected key themes in the data, I also organized them in a way that reflected multiple assumptions within my theoretical approach. For example, I chose to write two chapters with a focus on the promising aspects of or value of LTRC, while the other two emphasized the problems and tensions. I also positioned my chapters in a way that reflected my progression from an interpersonal/experiential or micro-level of analysis, to the meso- and macro-levels. Finally, my decision to deal separately with the data of some participant-groups (non-senior residents and direct care workers) and then bring the data together as a whole was about making room for different perspectives and demonstrating common experiences, understandings and issues.

Conclusion

In this chapter, I have discussed the research methods I chose for this project and explained why I chose them particularly in relation to the relational feminist disability perspective that framed this project, but also in terms of its fit with the research questions and overall aim of the research. My interest in providing this detailed description is largely about being transparent about my research design decisions and the ways in which they are linked to if not driven by the theoretical and methodological assumptions that frame this project. Being transparent about the research process, how data was collected and who was involved, and how data was analyzed and written up also allows readers to more accurately assess the quality of this project. In Chapter Three, I continue my efforts towards producing transparent and credible research by discussing some of the limitations of my methods, reflecting on some of the challenges I experienced carrying out the project, and describing how I responded to and what I learned from them.

Chapter Three: Methodological Reflections

Reflecting on the Research Process from a Relational Feminist Disability Perspective

In this chapter, I draw on the narratives of resident-participants, my field notes, data analysis journal, and feedback offered by my PhD supervisor, to reflect on a number of methodological, ethical, and practical issues, concerns and limitations that emerged as I carried out this project. This practice follows the relational feminist disability approach I described in Chapter One. I assume that research practices and the production of evidence are neither objective nor neutral processes. Reflexive practice in a way in which I aim to make the power relations, exercises of power, and the contexts within which the research process is situated, more explicit.

While reflexivity is often about sincerity, this practice can also strengthen the quality of their research and provide practical guidance to others. Detailing one's personal, professional and theoretical influences in the process of data analysis and interpretation, may, for example, enhance the trustworthiness of the research by providing the reader with more information about how the data was approached, analyzed and transformed into findings (Tracy, 2010). Further, when reflexivity involves providing a transparent account of the research process—when it involves noting the challenges, shortcomings, and tensions involved in "doing" the research—this information becomes a pedagogical tool that may be useful to others engaged in similar projects.

I begin my reflexive practice by accounting for my motivations behind and interest in the topic of younger adults with disabilities living in LTCFs. I also describe why I was drawn to the theoretical and methodological ideas that informed this project. I then discuss the challenges I experienced designing this study, and the tensions and discomforts I experienced accessing research sites, recruiting participants, and gaining informed consent. Next, I reflect on some of the issues I experienced while collecting data and engaging in the process of data analysis and interpretation. Finally, I consider some of the tensions related to reporting the research findings and my on-going struggles with respect to researcher accountability.

Choosing a Topic and Developing a Theoretical and Methodological Approach

Given that reflexivity often involves considerations of how the situatedness of the researcher, their personal biography, academic and political commitments, ethical judgements, and the contexts within which they are doing the research shapes the project and its outcomes (Mauthner & Doucet, 2003; Ramazanoğlu & Holland, 2002; Tracy, 2010), I begin with an account of how my personal and academic subjectivity drew me to develop a research project focused on the situation of younger adults residing in LTCFs in Ontario. At the time I was developing this project, I identified as a non-disabled, female doctoral student in Women's Studies. I also considered myself a novice in terms of doing empirical research involving LTCFs. I came to work on my PhD shortly after completing a Master's thesis that explored how youth with mobility impairments construct notions of health and fitness (Seeley, 2005). As part of this experience, I spent time both doing volunteer work at a children's rehabilitation hospital and interviewing a variety of youth with disabilities about what health and fitness means to them.

One issue that often arose as I spent time with some of those adolescents was a concern with the future and in particular, what becoming an "adult" would mean to them and their families in terms of the nature, availability, and quality of public services to which they would have access. As other researchers have described, the transition to adult health care services can be extremely difficult for people with disabilities and their families (Lindsay & Hoffman, 2015; Young et al., 2009). Aware of some of the gaps in appropriate housing and the financial and social inequities experienced by many adults with disabilities in Canada, I wondered what would happen to these young people if and when they wanted to live independently or when their aging parents could no longer provide enough care at home to meet their needs.

These concerns re-emerged when during my first years as a doctoral student, I gained a research assistantship with the Women and Health Care Reform group (originally called the National Coordinating Group on Health Care Reform and Women). This was a federally funded feminist research group whose mandate, as part of the Women's Health Contribution Program, was to coordinate research on health care reform (see Armstrong, 2012). During my time with this group, LTC reform emerged as a central topic of interest. We understood this as a women's issue and an issue for (different groups of) women (see Seeley, 2012), and while we often thought about the problems associated with the direction the LTC system was taking, we also thought about how it could be different and better (see Armstrong et al., 2009b; 2012).

I recognized at this time that LTC reform was also a particular issue for (some) younger people with disabilities. While in Ontario many public disability supports and benefits fall under community and social services, gaps and inadequacies in these services in combination with the restructuring of LTC meant that some (younger) adults with disabilities would have few options but to rely on LTCFs to meet their health and social care needs (see Chapter 4). It was also clear that this group was largely missing from policy and research regarding LTC reform and its consequences. LTRC in particular, was consistently being constructed as an issue for seniors.

While motivated to pursue research exploring the situation of younger people living in LTCFs, I was much less confident about how best to approach such a project. I had entered my PhD program somewhat disillusioned with my previous attempts at conceptualizing an appropriate feminist framework for exploring issues where disability and disablism appeared to play a central role. In my Master's thesis, I had used what I described at the time as a perspective inspired by feminist poststructuralist and DS perspectives. However, my previous mentors and colleagues had very little background in FDS, and the theoretical perspective that ultimately framed my Master's research was much more a reflection of my thesis supervisor's theoretical leanings than my own.

The misfit between the focus of my Master's thesis and the theoretical approach I had taken became especially clear to me after having submitted a journal article to a prominent DS journal. I received (valuable) feedback from a reviewer that helped me recognize major issues with respect to the limitations of the feminist poststructural framework I was using to explore issues that (in hindsight) would have also greatly benefited from a materialist analysis.

As I engaged in coursework for my PhD and began working with my supervisor and Women and Health Care Reform, I was exposed to the ideas and tools of FPE. I recognized that issues of disability rarely played a central role in much of the literature I was reading, but the parallels between this perspective and many of the concepts and debates within FDS were clear—albeit so were the disciplinary tensions and gaps (see Chapter 1). FPE made me think of FDS writers who recognize the value of analyses of disability and gender that focus on the material relations, social structures, and interrelated systems of power and inequality that establish and perpetuate disablism without precluding the role of culture and discourse (see Chapter 1). Like FDS, FPE researchers are drawn to intersectional analyses, and to research methodologies that center on and make room for marginalized experiences within health care evidence.

My theoretical approach was also shaped by the academic context within which I completed data collection for this project and began engaging in a process of data analysis and reflection. I was fortunate enough to be included in some of the initial meetings and background work of a research study entitled, “Re-imagining Long-Term Residential Care: An International Study of Promising Practices” (see Armstrong, 2010). This project brought together scholars from different geographic regions and diverse academic disciplines, competing perspectives and interests, to conduct interdisciplinary, multi-method research on LTRC (Banerjee et al., 2011). Many of the researchers involved were drawing on FPE as a framework that is well suited to exploring LTRC. Given my involvement in this project, the fact that my dissertation supervisor was the Principle Investigator, and that my dissertation committee members were members of this research team, my analytic framework was certainly influenced by this project.

At the same time, and despite recognizing the fit between FDS and FPE, I felt intellectually (and perhaps morally) caught between two paradigms. This tension largely played out in terms of the struggles I experienced developing and refining a methodological framework. This was a tension that continued to impact my practice years after completing data collection for this project. My biggest concern was that as a non-disabled person engaging in research on the issue of younger residents living in LTCFs, I was complicit in the production of knowledge about a disability issue that was much more likely to benefit me professionally than those whose experiences I was exploring. I also recognized that I was approaching the issue of LTRC somewhat differently from those DS scholars and disability justice activists who take an abolitionist stance (see Introduction). This made me wonder if I could engage in this research without feeling like and being regarded by others as a “parasite person” (terminology adapted from Hunt, 1981).

My initial response to these concerns was to immerse myself in the DS methodology literature. I was inspired by the emancipatory paradigm, as a methodological approach that set out a list of principles that, if adhered to, would help ensure the production of disability research that is less exploitative and more closely aligned with the social model of disability (see Chapter 1). I raise this issue here because (as will become clear) many of the challenges described in this chapter are linked to my efforts to adhere to emancipatory research principles under a particular set of institutional and personal contexts within which I was carrying out the project.

Designing the Research, Accessing Sites, Recruiting Participants, and Gaining Consent

The Case of Case Studies

My efforts to solidify a research design, gain access to sites, recruit participants, and get their informed consent, were characterized by several challenges and dilemmas but also, many successes. Several of these issues arose after I chose to make contact with and present my research proposal to the research board of a provider association whose members were in a position to assist me with identifying and accessing potential research sites (see Chapter 2). At the time, I had proposed to carry out a qualitative single case study approach (Yin, 2009). I argued that this was an appropriate design for this dissertation given that I aimed to conduct a deep, rich, exploratory investigation of the situation of younger residents living in LTCFs. Members of the research board, however, expressed to me their concern that my methods were not those of a conventional case study, and that the single case in particular was a limited approach. They argued that this design would mean the inclusion of only one facility and relatedly, that I would only be able to involve a very small number of younger residents in the project.

I perceived this critique as related to common misunderstandings and assumptions about the usefulness of qualitative research that does not aim for generalizability as well as about the case study research approach itself. I also had my own concerns and assumptions. First, I was concerned that a single case study design would place too much “burden” on the facility and participants who would be involved. Generating in-depth data is time intensive and I recognized that “time” was not something some potential participants would have the capacity or be willing to give me. Indeed, researchers warn that the complexities of LTCFs can mean that researchers face significant obstacles in the process of data collection such as obtaining and maintaining participants (Maas et al., 2002). I was worried this would compromise the amount of data I would generate, which was an issue given my focus on generating a thick and nuanced account of the case via an exploration of the conditions of care.

I also recognized the challenge presented to me by members of the research board as an opportunity to gain greater access to research sites and potential younger-resident participants. I initially responded to their concerns by agreeing to modify my design from a single case study to a one involving multiple units of analysis (i.e., the five LTCFs). I believed that examining the conditions of care among younger residents at five different sites could deepen my understanding of the case by allowing comparison across sites. However, after spending time collecting data at the first site, I quickly realized that it was unlikely that I would generate complete data sets for all five.

Doing qualitative research in LTCFs is a much more complicated practice than I had initially assumed. Despite the extensive time I had spent on a recruiting process—a process that involved the assistance of members of a research board, various administrators, staff members, and a research coordinator associated with some of the sites (see Chapter 2), I was not able to meet my recruitment goals at any one site. Similar issues have been noted in the LTRC literature (e.g., Decker & Ademek, 2004; Mass et al., 2002). I especially struggled because the overall number of younger residents living at any one facility was low. I was also frustrated when potential resident-participants left their facilities, or when changes in their health status led them to withdraw their initial interest. At some facilities, direct care staff were difficult to recruit. The nature of their jobs meant they were often overburdened with work, and they did not have time to get involved. Sometimes their schedules or duties would change, or they would forget about agreeing to meet with me. Some were extremely distrustful, assuming that their participation could be used against them in the future (see below).

I was concerned that the unevenness of participation levels at various sites would compromise the development of a thorough cross-comparison of the data by sub-unit. This is a technique I knew was common in conventional multiple case study approaches. Searching for an alternative approach, I came across the work of Mukhija (2010) who challenges conventional divisions between single and multiple qualitative case study designs. Mukhija "blur[s] the conventional boundary between single and multiple case studies" by engaging in research whereby a primary case or cases are identified and developed by drawing on secondary cases (2010, p. 419). In other words, it is not necessary for each site to generate the same data set in order for the data to be useful.

In the end, I recognized that involving five sites would be a challenge particularly as it would decrease the amount of time I could dedicate to any single site or group of participants, but moving away from a more conventional case study design had many benefits. It meant I gained access to and was able to include a larger number of younger residents and other participants than I originally anticipated. This was particularly important to me given my commitment to centering marginalized experiences and perspectives. Including multiple sites also allowed me to consider differences in the conditions of care for younger residents between facilities. It meant access to a larger set of experiences and perspectives, and this made it easier for me to identify a broad range of factors impacting and issues associated with younger residents' conditions of care.

Overall, this design played a key role in the development of a detailed account of the conditions of care among non-senior residents—not for the purpose of generalizability, but in terms of generating findings characterized by complexity, depth and nuance. At the same time, I recognize in hindsight that my case study design and redesign were influenced by my own assumptions about what "counts" as a unit of analysis. Assuming the site should be the sub-unit, I did not consider defining a younger resident as a unit of analysis. Doing so may have prevented some of the dilemmas I experienced with respect to the generation of "complete" data sets at each site. At the same time, this approach may not have fit well with my theoretical/ methodological perspective. It seems to me that defining a resident as a "unit of analysis" has the potential to be experienced or understood as objectifying. I am also not convinced that this approach would have led to different findings. While I should have defined the boundaries of the case more clearly, releasing the boundaries associated with the site by defining the unit of analysis as the non-senior resident may have made drawing cross-case conclusions a much more daunting task.

Power Dilemmas in Accessing Sites

Reflecting on the process of gaining access to facilities made me aware of the ways that the research setting and academic contexts within which a researcher is situated shapes their methodological "choices", sometimes in ways that complicate if not conflict with their methodological principles. As mentioned, I was very much a novice to doing research in LTCFs. I did not have a personal or professional connection to this setting prior to engaging in the project. I assumed it was imperative that I establish relationships with a number of gatekeepers to the facilities themselves. I was in fact, able to easily connect with and gain the support of members of a research board of a large provider association (see Chapter 2). But this meant I came to rely on members of this board and through them, the administrators of facilities to act as primary gatekeepers to potential participants. I was concerned about this "way into" the lives of potential participants. Even at the earliest stages of the project, I was relinquishing control over the process to a group of people who have a great deal more social power than the non-senior residents and direct care workers whose experiences and perspectives I was committed to uncovering. I was further concerned that these gatekeepers represented the leaders of a profession that has been especially complicit in the oppression of people with disabilities both historically and in contemporary times (see Thomas, 2007). What did it mean that they were playing such a central role in a project that hoped to challenge conventional (ableist) exercises of power throughout the research process?

I also recognized that my dissatisfaction with this way of gaining access to sites and potential participants was linked to my assumption of an "oppressive dualism" (McColl et al., 2013) between potential resident-participants and this group of gatekeepers. Since this research project was an opportunity to (re)consider the nature of various care relationships that comprise younger residents' conditions of care—relationships that are clearly much more complicated and nuanced than the often polarizing "them versus us" binary apparent in some of the DS and feminist care literature—I tried to challenge this assumption while also continuing to reflect on the power dynamics involved in both the research process and the conditions of care in LTCFs.

I also developed a few strategies that I believed would help ensure the expectations (and ideally practices) of primary gatekeepers aligned with my relational feminist disability perspective. My presentations to and initial communications with gatekeepers made clear my ontological, political and methodological position. I emphasized that this project was focused on facilitating changes to LTCFs in ways that support the concerns of younger residents. I made it clear that the narratives of younger residents would guide data analysis for this project, but also that the narratives of direct care workers would play a central role given my assertion that the conditions of care are the conditions of work (see Chapter 1).

My experiences with board members and administrators were mostly positive. Many expressed a great deal of interest in the topic, noting that the project was timely given their perception that the number of younger residents living in LTCFs was growing. Many believed that the non-senior residents at their facilities had important stories to be told, and they hoped these narratives would assist them in their role as directors and administrators to ensure LTCFs were meeting the needs of this group.

Some administrators seemed to gain inspiration from this project. At one facility, an administrator who was particularly interested in the focus of this project, began creating her own survey aimed specifically at residents under the age of 65. The survey focused on learning more about the social needs of younger residents, their recreational interests, and their concerns over existing programs.

In terms of challenging the exclusive gatekeeping role played by both members of the research board and facility administrators, I was inspired by the ethics procedures of one facility whereby the Residents' Council was asked to approve the project before I was permitted access to the facility for the purpose of data collection. This process permitted greater resident involvement at the earlier stages of the research process. This is an important goal and a good model for future LTRC research, but this strategy may not have worked at other sites. My experiences doing research in five facilities made me aware that some Residents' Councils are not regularly active, are not well attended, and in many situations, younger residents are infrequently involved.

I would also advocate for a similar process in terms of gaining the support of potential worker-participants. While I initially approached this project from a FDS lens that prompted me to play particularly close attention to disability-related power inequities, it was not until I spent some time with direct care workers at the LTCFs that I became aware of the ways in which power imbalances between gatekeepers and direct care staff were greatly impacting the participation of workers (see below). Bringing direct care workers together as a collective at the early stages of the project would have provided me with more information about these dynamics and helped me recognize from earlier on, the necessity of negotiating support for the inclusion of direct care workers. This would mean, for example, ensuring that supervisors permitted workers sufficient break times to participate and had their positions covered during this time. I would also mean securing physical spaces and access to privacy in order to conduct interviews.

This project also made me more aware of the existence of resident and other advocacy groups who I might have contacted for assistance in facilitating my access to potential participants (residents and direct care workers in particular) without the direct involvement of the provider group and/or administrators. However, given that this project involved younger residents, direct care providers, family members and administrators (see Chapter 2), gaining access through a director or administrator would have been necessary regardless of the involvement of, for example, a resident-advocacy group. Further, I cannot assume that advocacy groups themselves would constitute a form of gatekeeping that challenged inequalities in power relations between members of these groups and younger residents living in LTCFs.

Issues of Inclusion in the Recruitment of Participants

The process of recruiting participants to take part in this project raised additional tensions with respect to the research context and the principles of a relational feminist disability perspective. When it came to doing research in a LTCF, a number of safeguards to confidentiality and privacy associated with the various ethics processes and institutional policies impacted my access to potential resident-participants. Because of these rules, I relied heavily on staff members to identify potential resident-participants, to recruit them, and to introduce the project and get the consent of residents (and in some situations, a guardian) to participate. I was aware of the ethical value of relying on staff members throughout this process. Such practices would help "protect" residents by ensuring their privacy. It also seemed to be about maintaining confidentiality related to the release of personal information about them (such as name, age, and health information). I also recognized, however, the paternalistic aspects of this process—these rules seemed to reinforce problematic notions of people with disabilities as "vulnerable". This construction is one that signals the potential for exclusion (see below).

However, reflecting on my experiences of recruiting potential participants, I recognized that there were some benefits to relying on staff members as gatekeepers. My initial interactions with resident-participants, for example, were often positive because the gatekeepers on whom I had relied had introduced the project in especially favourable terms. Further, because these workers tended to have positive relationships with the younger residents at their facility, the non-senior residents who agreed to participate seemed to trust that their participation in the project was in their best interest. Indeed, building trust with resident-participants was rarely a difficult component of the research process. This was not always the situation, and it is notable that as a researcher, spending as much time at a facility as possible, participating in recreational activities or joining residents for a snack when invited, are invaluable practices in terms of building rapport with resident-participants and attracting additional participants. Indeed, some younger residents who initially expressed no interest in participating in the project when approached by a gatekeeper, changed their minds once they had seen me around their facility.

On the other hand, my reliance on gatekeepers to recruit resident-participants led to some tensions in terms of inclusion. While I was committed to ensuring that every opportunity was given to younger residents with a diversity of impairments to participate in this project, from early on in the project, I noticed that residents with more complex impairments, those who were residing on “secure” areas of facilities, and those for whom guardian consent to participate was required by the facility, were not always being recruited. I was particularly wary of this issue given my previous experiences doing research involving youth with disabilities (see above). During this experience, I had to rely on various disability and health care service providers to gain access to potential participants. On several occasions, I became aware of instances of overt paternalism and disablism from service providers who were acting as gatekeepers. Gatekeepers' beliefs about the capacity of some youth with disabilities to participate in a social research, paired with the requirement that I gain consent from a guardian meant some youth were excluded from the recruitment process—often without their knowledge.

In this project, it became clear that during the process of recruiting resident-participants, some younger residents were initially being excluded because of assumptions on the part of gatekeepers that those with varying communication-based impairments and/or who experienced significant cognitive impairment-effects were ineligible or would be unable to participate in this project, particularly because it was interview-based. Further, I came to learn that some potential resident-participants were being excluded because of administrators’ and staff-members' concerns about my comfort and safety if I was to spend time alone with a resident who sometimes displayed aggression or other “behaviours”.

Tensions around inclusion were not always about administrators’ and/or staff members’ (mis)understandings of who was a good “fit” for the project. Sometimes, the exclusion of potential participants was related to structural factors—of staff and administrators who did not have the time required to clearly communicate information about the project to non-senior residents with particular forms of impairment. Further, some younger residents were not in regular contact with family members and if gatekeepers indicated a need for consent from a guardian, this could exclude them (see below).

Power relations between administrators/supervisors and potential worker-participants also impacted the recruitment process. At one facility in particular, it became clear that I was viewed as in allegiance with a distrusted figure of authority. Here, it appeared that worker-participants were being compelled to meet with me as a part of their job rather than volunteering their time out of interest. These workers came to meet with me with little understanding of the project, who I was, and what they were “agreeing” to participate in. This contrasted with my understanding of informed consent. I found myself continually reiterating my status as a student researcher, explaining to these women that I had no previous or other connection to the facility, the residents, or their families, and that their participation in the project was completely voluntary and could be withdrawn at any time without the knowledge of their superior.

Other challenges may have been related to limitations in recruitment methods. For example, I tried out a number of strategies for recruiting family-members including presenting to a Family Council, asking administrators to contact family members of younger residents, and relying on a research coordinator to send out letters to potential family-member-participants.

Relying on “arm's-length” recruitment strategies was unsuccessful. In the end, only three family-members agreed to participate. There were some similarities between these family members. Each acted as a gatekeeper to a resident-participant who required their consent to participate. This situation resulted in my having more direct contact with the family member. Further, each of these family members were highly involved in the facility as volunteers, visitors, and/or through their involvement in the Family Council. They each expressed a great deal of enthusiasm for the project and very much desired to share their experiences and concerns with me. Two of the three participants were also regularly present in the facility, meaning I had the opportunity to meet with them informally and establish a degree of rapport. I associate this situation with the richness of the focus-group interview data.

Together, these challenges make apparent some of the difficulties social researchers may experience when doing research in LTCFs from a relational feminist disability perspective. While potentially discouraging, reflecting on these issues early on in the process is necessary because it allows researchers to make changes and improve their future research practices. These experiences prompt me to be much more forthcoming with gatekeepers about the ways in which I want potential resident-participants to be recruited. In comparison to my practice at the first two research sites, I was clearer in my presentations to and on-going communications with administrators at later sites that I wanted to include younger residents who experience a variety of impairments, and was happy to modify the way in which the “interview” was being conducted to facilitate inclusion. I also asked more explicit questions about what younger residents had and had not been contacted. A number of direct care workers were especially supportive of my commitment to greater inclusion, and in some situations, they offered to talk to non-senior residents about participating in the research.

Thinking back on the group of younger residents who agreed to participate in the project, I also recognize instances where specific residents were identified by staff members as a particularly good “fit” for engagement in this project. Staff members sometimes encouraged me to speak to include particular non-senior residents because they perceived this individual as having greater cognitive capacity than their co-residents. The participation of certain younger residents in this project was constructed as being “good for them”. It meant they would have someone to talk to, to tell their stories to. Some staff members also seemed to assume that these younger residents would provide me with “better” data given they are more verbally articulate than other non-senior residents.

In relying on staff members to facilitate recruitment, I found it extremely challenging to ensure a balance between residents being given ample information about the study and full opportunity to participate, and ensuring specific residents not being pressured by staff members (or in one situation a family member) to be involved in the project because they were constructed as a particularly ideal participant. In hindsight, I would have spent more time going over recruitment protocols and discussing issues of power and coercion with all potential gatekeepers. I came to understand that often the work of recruitment was being downloaded to supervisors and staff members whom I had not met, who had little understanding of the project, and/or little experience with social research and research ethics. I also know that education would not have been enough to overcome some of these issues. The structure of the working conditions within LTCFs and the barriers gatekeepers face when they do not have the time nor support necessary to engage in more ethical, inclusive and informed recruitment practices impacts the “choices” they make during this process.

Questions of and Questioning Informed Consent

For me, being conscientious of the multiple power relationships that exist within the research process meant recognizing that in an institutional setting such as a LTCF, notions of participant autonomy are complicated by the structures and relationships of care. Madjar and Higgins (1996) argue that in LTCFs, long-standing relationships between residents and care providers may limit the exercise of choice when it comes to residents who agree to participate in a given research study. Notions of consent are also complicated by the interaction of impairment and disability. Impairment-effects such as frailty and memory challenges combine with disabling assumptions and inaccessible consent procedures to make it difficult for researchers to recognize if a given participant understands the implications (risks/benefits) of participation and is “freely” giving their informed consent (Mass et al., 2002; Tinney, 2008).

In this project, resident-participants’ relationships with staff members appeared to influence the willingness of younger residents to consent to participate even when staff did little more than read the resident the information on the consent form. One example involved a resident with whom I tried to discuss the particularities of the consent form that he had signed prior to meeting me. Uninterested in going over the form again, he told me he would willingly sign *anything* the recreation worker gave to him because he was so fond of her (she reminded him of a girlfriend he had during his youth). While an extreme example, this resident’s willingness to consent to participate because of his positive relationship with a given care worker was not an uncommon situation. It became especially important in such instances for me to re-address the particularities of the consent form even if I anticipated this process to be uncomfortable and/or time intensive.

Reflecting on my methods of gaining informed consent from resident-participants, I was again reminded of the ways in which notions of vulnerability have historically limited the participation of people with disabilities (especially those residing in institutions) in social research. While the overwhelming majority of resident-participants involved in this project gave their own consent to participation, at one facility, I was informed that almost all of the residents under 65 would require consent from a guardian in order to participate. In several situations, the research coordinator who assisted me in contacting guardians had difficulty gaining their consent. Some did not reply to emails or phone calls. Others indicated a lack of interest in the project. It is likely that some non-senior residents who would have liked to participate were excluded because of these barriers.

Maintaining informed and voluntary consent over the course of data collection was sometimes a challenge. Some resident-participants with cognitive impairments had no recollection of completing the informed consent form, and/or they indicated having no knowledge of the research project prior to my interviewing them despite having signed the form. A few times, resident-participants did not remember who I was nor why I was meeting with them when I came back to their facility following our initial interview session to complete it or to ask follow-up questions. One participant admitted she was unsure of who I was and why I was interviewing her in the middle of our interview session.

Adopting an understanding of informed consent as an on-going process was helpful. As Swain and colleagues write in the context of doing open-ended interviews with people with IDD, “In this form of research, informed consent is not simply contracted at the outset, but is a continuous process to be reaffirmed as the research progresses” (1998, p. 28). I decided that at each meeting with, and sometimes at the midpoint or end of a long interview, I would ask the participant about their understanding of the project and its purpose. I often reiterated the risks and benefits associated with participation and went over issues of confidentiality. Most importantly, I made it clear that they had a right to withdraw their consent to participation and gave them the opportunity to do so. While this approach cannot completely ensure voluntary informed consent, it does ensure participants' greater involvement in and control over the consent process.

Tensions around consent were not limited to my interactions with resident-participants. Power relations also figure into the process of gaining informed consent from worker-participants. For example, late in the process of data collection, I came to realize that at one facility, my reliance on a particular supervisor to recruit staff-participants was ethically problematic. In my research journal, I described a specific instance where the "consent" of a PSW-participant appeared not to be voluntary, but the result of pressure she felt from her supervisor to participate in the project. I wrote:

> I have concerns over following up and finishing the half-done interview with [Tamika, a PSW], despite her supervisor ensuring me that she had agreed to have me come speak with her today. She was on the "dementia unit" today, but when I got there, she was behind in charting, hadn't had a break, and her shift was ending in one hour…. Her supervisor had organized to have someone help her out, but she really didn't want to participate. He [the supervisor] ignored her resistance probably because he knew I had come a long way on his assurance that it was ok. After sending me to sit in the charting room and wait for her while she finished up, I left, after waiting 45 minutes for her. I checked around the floor and the staff room before I decided to leave…. I didn't tell her supervisor about this. I am concerned that he will give her a hard time. I think the

> situation [Tamika] has been put in is very unfair. This is supposed to be "volunteer" participation.

I raise this issue to suggest that power dynamics among workers within LTCFs matter when it comes to doing social research. Certainly, direct care workers are not powerless within their work environments. As my notes about Tamika demonstrate, they find ways to resist. But there are ways in which researchers can better support direct care workers. For example, Clement and Bigby (2013) not only provide participants with an informed consent form, but they also give them a withdrawal of consent form. The purpose of the latter tool is to "allow [participants] to withdraw consent to participate at any time without any consequences" (2013, p. 489). In terms of this project, direct care workers may have benefitted from this way of withdrawing consent without their supervisors' awareness.

There were also multiple situations where administrators and other staff in positions of authority supported staff involvement in the project in respectful ways. Some provided comfortable and private locations for interviewing, some rearranged schedules and provided coverage so worker-participants did not have to use their break times or remain after their shifts to participate in the project. I also became aware of some of the ways direct care workers act to secure their participation in research. Some sought me out after learning about the study through co-workers, some took me to areas of the facility where we would not be disturbed by others. Some worker-participants handed their pagers to co-workers so they could tell their stories without interruption, and some staff members recruited additional participants for me, and helped to assure their co-workers that my intentions were good.

The Data Collection Process

Establishing Rapport

My first few experiences collecting data for this project made me aware of a number of challenges of doing social research in LTCFs. When I entered a facility, I was especially focused on establishing positive relationships with the younger residents and direct care workers who had agreed to participate. However, time often became an issue with respect to this process. In most situations, I had limited access to facilities. Usually, I negotiated a certain set of days where data collection would be carried out. I also faced barriers in terms of the location of different facilities from my place of residence because of transportation challenges. This meant that frequently, the time I spent establishing rapport with a participant was also connected to the “interview time”.

When it came to my interactions with resident-participants, time was less of a barrier to establishing rapport. While some resident-participants had very full schedules (and some had very little planned during the times I was at their facility), most welcomed the opportunity to spend time conversing with me even if this meant cancelling their other plans. I made deliberate efforts to establish some degree of comfort with residents by asking them to tell me about themselves. I then drew on this initial information to begin an informal conversation about their conditions of care. I was also open to and indeed expected resident-participants to engage me in conversation about my own life and interests, professional and otherwise. Perhaps the most unusual way in which I developed rapport with a resident-participant occurred during the time I spent with George. Our mutual enjoyment of playing cards influenced me to conduct the interview while we played. Although engaging in card games while asking questions and following up on answers was difficult at times, it was also a great way to develop trust and comfort. I credit this practice as part of the reason George’s narrative was characterized by personal and in-depth responses.

My informal attempts to establish rapport with resident-participants also became unexpected sources of data. For example, taking note of stories and bits of personal information shared when the audio-recorder was “off” in my field journal provided me with a great deal of contextual information useful in data analysis. It allowed me, for example, access to demographic and other types of information that was not captured in the interview guide, but which became important when I began to look for factors that might account for differences in the experiences and perspectives of resident-participants.

Gaining the confidence of worker-participants, PSWs in particular, was more of a challenge. Some PSWs were hesitant to participate in an interview, and when they did agree, appeared cautious in providing detailed responses. With some notable exceptions, PSWs were less likely than other participant groups to take control over the direction of the interview, and many limited their answers to a description of their duties and related practices. Differences in social location (while complex, multiple and shifting) in combination with time constraints may have acted as barriers to the establishment of trust. The overwhelming majority of PSW-participants were racialized and/or immigrant women with varying amounts of formal education. As a white, middle class, highly formally educated woman, I may have appeared to be more similar to the nurse supervisors and female administrators to whom PSWs report. Assumptions of my authority may have been reinforced by the fact that often, I was introduced to staff by an administrator or supervisor. In this context, it is not surprising that some workers were distrustful of my intentions and assurances of confidentiality.

Building rapport was also difficult with direct care workers—nurses and PSWs in particular—given the intensity of their workloads. In most situations, 30 minutes of time was about all they could commit to. This meant there was little time for the type of informal interactions and discussions that eased tensions and generated trust between me and resident-participants. Madjar and Higgins (1996) describe similar challenges in their interactions with nurses in LTCFs, attributing suspiciousness of researchers to the demands of care work. As they explain, "practices and responsibilities that "do not stop because a couple of researchers are present" (p. 135). However, I also found that overtly recognizing direct care workers' intense commitment to their jobs and acknowledging that I was aware of and concerned about the physically and emotionally challenging nature of care work helped worker-participants view me as an advocate rather than an evaluator.

I also drew on the fact that I was, at the time of data collection, a relatively young female student and an outsider to LTCFs. I presented myself as someone who required experienced and knowledgeable care workers to guide me through the LTC environment and make me aware of the issues and tensions associated with the situation of younger residents living in LTCFs. I also realized that direct care workers were often much more comfortable discussing topics that emphasize the more relational components of their work such as their concerns over the well-being of younger residents. Beginning with these topics rather than eliciting job descriptions and responsibilities was a helpful strategy.

Despite my efforts to generate positive relationships with participants, I also became concerned about the potential consequences of my efforts to establish a positive rapport with residents, especially when this seemed to result in their sharing more personal, emotionally-charged information or perceptions. Multiple resident-participants told me stories about the emotional difficulties they experience when co-residents die, or preferred care workers leave their position (see Chapter 8). Others spoke about feeling lonely, and of the challenges they experience building and maintaining friendships while living in a LTCF. The personal nature of these conversations and my efforts to "be a good listener" sometimes had results that I was not prepared for. For example, while indicating that she rarely interacts socially with the direct care staff at her facility, Norah, a resident, tells me, "See, I love you because I chat with you." Similarly, at the end of our interview, Mallory, a resident, "hugged me" and "I wonder[ed] how long it [had] been since someone at this home spent this much time with her trying to communicate with her about her life?"

I experienced similar discomforts in situations where the direction of an interview with a resident-participant led to the discussion of a more personal or sensitive issue than I had anticipated. This excerpt from my field notes, which I wrote following my interview with a resident named Marnie, is an example:

> We chatted for a while before we started the interview…. /She told me a great deal about her life…. /She spoke a bit about her family—a niece she was sending a birthday present to…./ The tears were tough. I didn't realize I was leading us into something that was so difficult for her to talk/think about. It is so hard when people open up to you when you are really a stranger in their home. And I wasn't sure if I should comfort her or if that would make things more uncomfortable. So when she said "ask me something different", I just moved right along, as if people cry in front of me all the time.

These types of more challenging interactions also occurred during interviews with worker-participants, although much less often. One PSW described at great length (and at her request, with the audio-recorder turned "off") the "emotional breakdown" she was experiencing as a result of a recent change in her job responsibilities. Following our interaction, I wondered if she was reaching out to me because she simply needed someone to confide in, or because she needed advice.

Recognizing the potential for exploitation in any research relationship, I had tried to maintain clear boundaries between myself and the research participants using several strategies: reminding them of my purpose in spending time with them and my role as a researcher, by being upfront about the limited time I would be spending at the facility, by describing my intentions share my my findings in a way that made clear the fact that this could be a lengthy process, and by sending each participant a thank-you note. But given these experiences, I was also prompted to ask myself questions about who benefits most from these relationships, and who stands to get hurt. At the same time, I recognized that these were not one-sided relationships, and the participants involved in this study were certainly not the passive victims of my exploits. Many participants benefited in the short term, enjoying the social engagement, and my sympathetic ear. Others appreciated the opportunity to tell their stories and share their knowledge or expertise.

Securing Privacy and Confidentiality

Ethical issues related to privacy and confidentiality also arose early in the process of data collection. Securing privacy for participants was often thwarted by the communal nature of LTCFs and the central role played by care relationships within these spaces. Staff and residents regularly utilize common spaces and are continually aware of each other’s daily activities and whereabouts. While none of the resident-participants I interviewed expressed overt concerns over staff members and co-residents being aware of their involvement in the project, some direct care workers certainly did.

Finding a location suitable for audio-recording, where we would not be interrupted, and have some amount of privacy was an on-going challenge. Even in rare cases where administrators had “reserved” a space for me to conduct interviews, it quickly became clear that my presence in these spaces either prevented residents and their guests from accessing a quiet and more private place to spend time together, or prevented staff members from accessing charts, computers, or a place to have their break.

Conducting interviews with resident-participants in their rooms came with its own set of challenges. Residents often shared their rooms with one or more roommates, and care workers regularly came in and out of residents’ rooms while interviews were going on. Like Decker and Adamek (2004), I found that in some facilities, staff were very respectful of our privacy—offering to come back later. In other facilities, however, privacy was constantly in jeopardy. This problem was reflected in the findings of this project, as privacy arose from participants' narratives as a key barrier to relational care (see Chapter 8).

Finding a private space in which to interview direct care workers—PSWs in particular—was extremely difficult to achieve. While administrators and nurses often had access to offices and training rooms, and recreation workers had access to gyms and other communal areas that at the time of the interview, were not being used for programs, in many cases, PSWs did not have access to similar spaces because they did not exist, or because using them would take PSWs away from being easily available to residents and co-workers. For example, in one facility, I interviewed PSWs in the “charting room”—a very small room that contained a chair, a set of hooks where staff could hang their personal items, and the computer where all their charting was done. One PSW indicated that this was the only private space away from residents available to her on their floor. Doing the interview in the dining room or staff lunchroom meant we would have to travel to another floor, which would take this woman too far away from the residents. However, using this charting room was a poor decision as I quickly learned that it was a hub for PSWs. At times, this participant's co-workers were very generous in allowing us some privacy for the interview. However, the necessity of charting on the computer in this room meant we were limiting others in doing their jobs, preventing the completion of a task necessary to allow PSWs to go on break, go for lunch, or go home at the end of their shift. While I could not come up with a solution at the time, this experience, particularly in comparison to my experiences at other facilities, attuned me to the importance of the physical environment in terms of shaping the conditions of care work.

Modifying Methods

My experiences of gathering interview data from resident-participants were characterized by a number of challenges. Relying on open-ended interviewing techniques to elicit the experiences and perspectives of residents was one of them. While this method offered highly articulate participants the opportunity to exercise control over the content and direction of the interview, the use of open-ended questions did not support all participants in telling their stories. I realized early on that I would need to continually modify my style of interviewing to fit the participant. In some instances, my style became much more direct; where I would encourage participants to reply with one word, a short phrase, and/or a yes or no answer.

I also relied on non-verbal methods of communication. For example, I modified my approach to a more direct "yes and no" style when interviewing Mallory, a resident, who communicated her agreement and/or disagreement with my questions through vocal noises. She showed delight and embarrassment through laughter, and also communicated through facial expressions and physical gestures. I audio recorded our interactions which largely consisted of me offering Mallory various response options and guessing and checking with her to come up with a clear understanding of her intentions. Consider this example from her transcript:

Morgan: How long have you lived here?

Mallory: Oh. Uh hum. (Draws [a number] with her finger)

Morgan: Really?

Mallory: Uh hum.

Morgan: So you are an expert on this place?

Mallory: Ah.

Morgan: Has it changed a lot?

Mallory: Uh hum.

Morgan: Are there—

Mallory: (Wrinkles her forehead and makes a face indicating disgust)

Morgan: Bad? Oh, it's gotten worse?

Mallory: Uh hum.

Morgan: So how has it changed? Is it the people who live here that's changed?

Mallory: Uh huh.

Morgan: And it's worse with them?

Mallory: (Nods).

Morgan: Yeah. Is that because— I'm trying to think how you can tell me why?

Mallory: Uh uh. Uh uh. Uh uh.

Morgan: Oh, they talk a lot?

Mallory: Uh.

Morgan: Is it [bothering you] because they don't really know what they are saying?

Mallory: (Nods, laughs).

Additional techniques of non-verbal communication emerged as Mallory and I developed greater rapport. During our interview in her room, Mallory began collecting a wide range of personal items that allowed her to “show me” instead of “tell me” about herself and her daily life, and we used pictures in a book that she would point to in order to indicate she liked to do and eat.

Modifying data collection methods can result in some practical challenges for researchers. I recognized a need for additional tools and techniques in order to respond to communication differences and preferences among resident-participants. For example, during my interactions with Jackson—a resident who was fond of drawing but who seemed to experience our verbal interactions as somewhat frustrating if not exhausting—I wondered if a journal might be a better or additional method of communicating with him. Jackson demonstrated a great deal of excitement when I made this suggestion. In response, I created a journal with a set of open-ended questions printed on the inside cover (see Chapter 2). I assumed this journal would be beneficial to other resident-participants, so I went through an ethics review process to have this tool approved.

Despite my excitement over the potential of this tool, I experienced challenges when I attempted to use it. Some residents indicated that they disliked writing. For others, this tool was inaccessible as it required reading and manual writing. Even Jackson, for whom I initially developed the journal, required some assistance to complete it. While I could offer some degree of help, he asked me to leave the journal with him because he had a lot more to share with me. When I returned, Jackson explained that the PSW who usually agrees to assist him with writing was too busy, so he had added very little to the journal despite his desire to do so. While we were both a bit disappointed, the journaling Jackson did complete served as a useful complement to our verbal interview sessions. I also asked Jackson to show me his daily routine by taking me to different areas of his facility. I used the latter technique successfully with other resident-participants at other facilities.

My experiences with Mallory, Jackson and other resident-participants demonstrates the importance of flexibility. It was only through the on-going modification and addition of tools and techniques that I had some success in terms of accessing their experiences and opinions. Interestingly, these strategies tended to develop “organically” and were almost always inspired by participants themselves. Jackson wanted to draw and write, and Mallory wanted to show me her personal possessions.

Flexibility helped me ensure greater inclusivity and it allowed me to acknowledge and demonstrate my respect for individual participants' communication styles and preferences and to act on their suggestions for improvement. This process of change requires corresponding flexibility when it comes to ethics processes. What constitutes a significant change in protocol requiring an amendment to the ethics process if not always clear. I had originally received ethics approval for interviewing. I then submitted an amendment and received a second approval for the journaling and more extensive taking of field notes. But I was also engaged to some degree in observation—particularly in situations where residents were showing me their personal possessions and touring me around their facilities.

Novice researchers doing work in LTCFs would greatly benefit from an exploration of the variety of strategies and tools used by people who do research with individuals with a variety of disabilities as part of the development of their research designs. Stalker (1998) highlights several “aids to communication” in her research with people with “profound” impairment. Such tools include having residents take her on a tour of the hospital where they were residing and supplementing semi-structured questionnaires with photographs and drawings related to the topic of the research. In more recent years, social researchers doing work in LTCFs have also developed a number of valuable techniques and tools. Barber and colleagues (2021) use “photovoice” in combination with interview methods to capture younger residents' experiences of health and aging in a LTCF in Nova Scotia. Armstrong and colleagues describe and reflect on a wide range of techniques in the development of a “rapid, site-switching ethnography” that they use in an international study that examines “promising practices” in LTRC (see Armstrong & Lowndes, 2018). Of course, having the expertise, time, resources and opportunity to be trained in the use of a wide variety of tools might be a significant challenge for some graduate students. Additionally, I maintain that pre-planned tools are never enough to ensure good communication practices. They should not and cannot replace the need for flexibility.

The Data Analysis Process

“Choosing” Narratives for Analysis

My experiences grappling with how to make sense of the large quantity of data I collected throughout the research process involved a number of challenges and decisions. At the outset of this process, I was committed to an approach that reflected the relational feminist disability perspective I was developing. It was not until I had collected most of the data from my first research site and was struggling with the question of “what next?” that I came across the voice-centered relational approach to data analysis. As discussed in Chapter Two, this method fit well with my research questions, was useful for analyzing multiple sources and types of data, and echoed many of the principles espoused in my theoretical/ methodological approach to LTRC.

Despite its “fit”, I recognized some potential challenges. In a practical sense and as Mauthner and Docuet (1998) and Byrne and colleagues (2009) have noted, the voice-centred method is extremely time consuming. This is not only because it involves extensive analysis and interpretation of the data, but also because the researcher is prompted to reflect on and document the analysis process along the way. The case study design I employed resulted in extensive field notes, a participant journal, informational documents for each facility, and over 33 hours of audio recordings. It became clear following my first reading of transcriptions and field notes from the first research site in which I completed data collection, that I would have too massive and potentially diverse a data set to systematically complete the voice-relational method in a conventional way.

I have already described the strategy I developed to select and analyze the transcripts of different participant groups (see Chapter 2). Ethically, however, this was a very difficult decision to make. While I was committed to centering the experiences and perspectives of the younger residents whose conditions of care I was exploring. I had also approached this project with a relational understanding of care that included recognizing the link between the conditions of care and the conditions of work for direct care providers (see Chapter 1). My choice to privilege resident-participants’ narratives in the first stage of data analysis seemed to challenge the spirit behind this approach to care. I was also concerned that in the more selecting “robust” interviews among those conducted with direct care staff and administrators to undergo the full five-stage analytic process, I was privileging those narratives I found particularly exciting, controversial, or articulate.

Upon reflection, my decision was somewhat balanced by my recognition that in selecting a more manageable number of transcripts to undergo the multi-stage analysis process, I was helping ensure sufficient time, effort and care necessary to the development of in-depth and nuanced findings. Further, undertaking a second stage of data analysis, where I focused more on themes and on comparing sites and participant-groups, provided me with many opportunities to attend to the range of experiences and perspectives encompassed in the data.

Issues of Credibility

Key to a relational feminist disability methodology is the privileging of marginalized experiences, viewing these as “authoritative and credible sources of knowledge” (Jackson, 2012, p. 18). For me, this meant centering on the narratives of resident-participants. However, I was sometimes challenged by narratives that I knew contained accounts that were fabricated or confused. For example, I struggled to accept some portions of Norah’s narrative while she was providing it. In the following excerpt, Norah, a resident who experiences memory-related impairment-effects, tells me she has never had a bath or a shower in all the time she had lived at her facility:

Morgan: What about when you need a shower or a bath? Where does that get done?

Norah: I haven’t had a shower or a bath.

Morgan: Never?

Norah: Never.

Morgan: Really?... So you mean, not today, I guess?

Norah: No. I haven’t had one since I got here.

Morgan: Really?

Norah: Yeah.

Morgan: Okay. How long did you say you have lived here for?

Norah: I’m not sure. Couple of months, I think.

Norah was not the only resident-participant who provided questionable information about the conditions of care. My conversation with Janet, a resident whom I interviewed with the support of a family member, is another example. In the portion of the interview I have transcribed below, I am trying to encourage Janet to tell me about the direct care workers who provide her with care on a regular basis:

Morgan: Who wakes you up in the morning?

Janet: Nobody.

Morgan: You just wake up?

Janet: [Nods].

Morgan: Ok. What time do you like to get up at?

Janet: After nine.

Morgan: Oh, you like to sleep in? I'm the same [laughs].

Family Member: You're an early-riser hon. You are probably up somewhere between six and seven o'clock. Is that right, hon?

Janet: No.

Family Member: Well, how come you have breakfast at eight then?

Morgan: That's ok…. Do they treat you nicely, the people who work here?

Janet: Yes.

Morgan: Do they come and chat with you?

Janet: Yes.

Morgan: And do you like that?

Family Member: And also hon, tell her about Erin (pseudonym).

Janet: Erin was the biggest mistake this company ever made.

Morgan: How come?

Janet: Well, they hired her and they shouldn’t have.

Family Member: Now hon, what are we talking about now? Are we talking about here or are we talking about your previous working career?

Janet: I don’t know…. / This is very hard for me.

The above pieces of data are important illustrations of some of the ethical and intellectual dilemmas that may arise when doing research in LTCFs. Researchers who involve residents with dementia and other forms of cognitive and/or psychiatric disability in their research have also encountered such tensions. Swain and colleagues, for example, advocate for what they describe as “respect expressed as acceptance” (1998, p. 27). This refers to the importance of researchers showing respect for participants by allowing them to provide their narratives without challenging its validity or terminating the conversation.

I followed this suggestion, maintaining respect for residents during the interview process by allowing participants to provide their narratives without challenging their credibility. However, the interview with Janet and her family member made this practice much more complicated. I believe the family member’s concern over the validity of the information Janet was providing was about him wanting to support Janet by ensuring I had an accurate account of her conditions of care (as opposed to an account that reflected the confusion she was experiencing at the time of our interview). However, his actions felt paternalistic if not disrespectful. This family member’s approach to respecting Janet’s “voice” clearly contrasted with mine. His actions made it more difficult for me to foster open communication with Janet and to demonstrate to her that I valued what she was sharing with me. At the same time, this family members' long-standing relationship with Janet greatly facilitated our communication, and, at the beginning of our interaction, made the interview process more comfortable for her.

It was more challenging to figure out how to approach this type of data when it came to the process of data analysis. I experienced a tension between maintaining the academic integrity of the research and being accountable to the participants. Similarly to Swain and colleagues (1998) who note that there can be significant conflict between demonstrating respect in the form of accepting participants' stories as "truth", and respect in terms of researcher honesty and integrity, I realized I was not willing to uncritically accept Norah and Janet's descriptions of their conditions of care. To suggest that Norah was never given the opportunity to have a bath or shower, or that Janet disliked the PSW who regularly provided her with care conflicted with the corroborating information I had gained spending time with their co-residents, staff, and family members, not to mention my broader understanding and observation of care practices and policies at each of the LTCFs involved in the project. At the same time, I recognized that impairment-effects such as Norah's inability to remember bathing or Janet's confusion about her relationship with a PSW, are part of how some residents understand their conditions of care. As such, these understandings are important and "valid" in their own right. They are perceptions that should not be disregarded.

In the end, I aimed to maintain the overall integrity of my participants' narratives by drawing as much as possible on the primary data and making clear whose voice (mine, the resident's, or the family member's) was being represented. I also made an effort to uncover meaning in all accounts. Sometimes this meant drawing on information gleaned from care workers, family members and co-residents. For example, Norah's concern that she was not being given the opportunity to have a bath or shower took on new meaning when I understood it alongside the comments of a co-resident, who suggested that the direct care staff do not understand the complex nature of Norah's disability and tend to become frustrated with her when she demands more support than they perceive her to need.

Similarly, the details of Janet's narrative helped me recognize some of the tensions that can characterize care relationships. Her comments also reminded me not to ignore the larger context of residents' lives beyond that of the LTCF—such as a participants' personal history and the wider social and familial networks of which they are apart— because these too have a significant impact on non-senior residents' experiences and understandings of their conditions of care. Finally, drawing on feminist methodological writings about the production of knowledge and the situatedness of women's experiences (see Chapter 1), I came to understand that my role, and perhaps responsibility as a researcher, was to recognize that it is fruitful rather than unethical to draw on all of my experiences, knowledge, and expertise to interpret the data and produce the findings even if this means challenging some narrative accounts.

Reporting Findings and Researcher Accountability

Towards Confidentiality

My efforts to ensure the production of high-quality research continued beyond formal ethics approval and data collection procedures to how I reported my findings. Given that LTCFs tend to be structured in ways that make it difficult to support the privacy of participants (see above), it was especially important that I engaged practices that help ensure confidentiality. While I followed the requirements for confidentiality commonly ensured through a number of formal ethics requirements (e.g., the removal of names and personal identifying information from transcripts, the use of pseudonyms, and processes related to the secure storage of data), this did not seem like enough.

Since care relationships within LTCFs are characterized by the regular exchange of personal information, I was concerned that including biographical details in the research results would lead to some participants being recognized. I was particularly concerned with resident-participants given how numerically small the under 65 resident population was at the five LTCFs where I collected data. Providing specific information such as age, gender, and impairment-type, descriptions of residents' rooms, discussions of their previous employment or their partners and children could (particularly in combination) make them easily identifiable to people involved in their conditions of care. But I was also concerned about direct care workers, especially because several expressed concerns to me about the potential consequences of their narratives becoming "public". Expressing concerns over the conditions of care (work) was risky to them as was sharing information about residents whose privacy was taken very seriously by some workers.

As such, I was careful with both the type of potential identifiers I collected and how I reported them. I relied on participants themselves to provide the personal information they were comfortable sharing. Most participants did this without direct prompting. It was woven into their narratives.

Residents-participants' narratives in particular were saturated with biographical information. It became clear from early on in the data collection process that in many ways, their understandings of the conditions of care were situated in their life histories. So while I could have removed and/or altered all biographical information, I did not want to undermine the importance of this context and of supporting participants in telling their stories. I was also concerned that in my efforts to "protect" resident-participants, I was falling into the sort of paternalism that has long been challenged by DS researchers.

My approach to altering and removing biographical information was therefore a "juggling act". I worked to ensure more than one potential identifier was not presented together—particularly in situations where I was drawing on extensive quotations in the reporting of findings. I also tried to identify and alter biographical details that had little relevance to the issues being discussed, while I maintained biographical information common to multiple participants. I recognized that the potential benefits of participation in research to the participant could not be realized if the revelation of their identities led to adverse consequences. As a researcher, I was guided by the notion that it was my responsibility to safeguard their identities.

The Ethics of Exiting

It was several years after the completion of data collection at each of the facilities involved in this project that I completed the bulk of the writing up process for this project. It is with this phase of the research that I struggled with most in terms of its ethics. I made the decision more than a year after I had completed data collection to discard my intentions of returning to these facilities to share some initial findings with participants and to gain their feedback and approval. For many social researchers—DS researchers in particular—this is a particularly important practice when doing qualitative research with people with IDD and communication-related disabilities because often, these participants have little power to redress how their stories are being told and used in social research (Nind, 2008).

I did not come by this decision lightly. This was a clear instance of where the personal, academic, and institutional contexts within which I was situated conflicted with the ideals of the relational feminist disability methodology I was developing. Several factors led me to change my plans. First, the challenges I experienced gaining access to the sites as well as going through various levels of ethics approval meant that data collection was an extremely lengthy process. In fact, a year passed between my access to the first and fifth research sites. This put me under a great deal of pressure in terms of finishing my degree in a timely manner. This was further complicated when I began a one-year maternity leave a few months after completing data collection, and my decision a semester later, to formally withdraw from my PhD program.

If regaining access to the facilities, travelling to the facilities, going over the transcripts with participants, and writing up and presenting my preliminary results to the participants involved in the study was a requirement of completing the study, I would not have been able to finish it. I struggled to maintain connection to the participants involved in the project. Several resident-participants had passed away or become ill even before I withdrew from my program. A change in administration combined with poor recordkeeping meant that at the one facility where I did try to regain entry, I was informed that I would have to go through another ethics process just to gain access to the site.

Although far from ideal, it is my hope that in completing this dissertation despite the time that has lapsed, I might have an impact on younger residents living in LTCFs in Ontario, if not on those individuals who participated in this project. I have yet to develop and realize a data translation and dissemination strategy beyond that of the dissertation itself. At this time, the personal and academic context in which I am situated has led me to make the choice to focus on completion. But I also hope that making this original contribution to academia will lead to more opportunities for me to disseminate my research findings in multiple and more accessible formats, perhaps as a separate future project.

Conclusion

My aim in writing this chapter was to make transparent the subjectivities, contexts, power relations, and practical concerns that shaped my decisions and practice throughout the research process. Many of the challenges I have described above are strong demonstrations of the non-linear, partial, and provisional characteristics of research discussed by FDS scholars. They also reflect what FPE researchers have written about research in LTCFs (see MacLeod et al., 2018).

I learned that the contexts within which we do research can make it difficult to align the principles we associate with our chosen theoretical and methodological perspective with our practice. For example, I did not perceive myself as having much autonomy over many aspects of the access, recruitment, and ethics process. This made it difficult for me to challenge some of the more normative power dynamics associated with more “parasitic” research approaches (see Chapter 1). I recognize that since the time of data collection for this project, researchers in the area of LTRC have made important advancements in the development of research approaches that challenge more conventional (disablist) research relationships and power dynamics (see Aubrecht et al., 2021). However, I have also come to understand that the challenges and limitations should not be understood as failures. For me, the ways in which I responded to some of these challenges led to improvements in my methodological approach and research methods. I am confident that this practice will help me develop better research in the future, and I am also hopeful that it will benefit others who are similarly engaged in research in LTCFs and/or who are drawn to FDS and FPE research methodologies.

Chapter Four: Contextual Overview

The Situation of Non-Senior Adults Living in Long-term Care Facilities in Ontario

Thus far, I have described the relational feminist disability perspective that framed this project, outlined my research methods, and reflected on my research practice. In this chapter, I begin the process of exploring non-senior residents’ conditions of care by developing an overview of the contexts within which the situation of younger adults living in LTCFs in Ontario in the two decades leading up to the COVID-19 pandemic emerged. My focus on context fits with a relational feminist disability perspective. This practice can help reveal the ideas, processes, structures and other forces shaping this phenomenon. It also assists in the development of “responsible” research evidence (Jackson, 2012, p. 21). Contexts, and the complex (inequitable) power relations related to disability, gender, age, and other forms of social diversity that imbue them, shape participants' experiences, perceptions, and understandings of the conditions of care for non-senior residents. Similarly, these forces impact my own approach to this issue and how I analyze the data.

The presence of younger adults in Ontario’s LTCFs in the 2000s and 2010s was not an entirely new phenomenon. Non-senior adults with disabilities have, throughout Ontario’s history, lived in a variety of public institutional settings alongside seniors and other groups of people who require or are deemed in need of “care”. However, the phenomenon on which this dissertation focuses emerges from a particular set of social, political-economic, historical and cultural circumstances that both connect it to and distinguish it from other (historic) situations. It is this set of contexts on which this chapter is focused.

Drawing on social, historical, and legal scholarship focused on Ontario’s residential institutions aimed at people disabilities, as well as a body of sociological literature examining public LTC services in Ontario from the early 1990s until 2020, I discuss two key processes shaping the situation of non-senior residents living in Ontario's LTCFs and relatedly, the conditions of care younger residents' experience. First, I discuss the development and expansion of the province's asylum system, and the subsequent deinstitutionalization[1] of people with disabilities from the provincial residential institutions and psychiatric hospitals that developed from this system. Second, I consider the process of contemporary health care reform and more specifically, changes to the public LTC sector that emerged within the context of public funding cuts. It included a number of changes to the ways in which LTCFs in Ontario are funded and regulated and care is organized and delivered within them that reflected the adoption of for-profit management techniques associated with NPM.

Finally, drawing on sociological research, I summarize key changes to and issues in Ontario's LTCFs in the wake of these processes. These issues have increasingly become a topic of research and debate—particularly among FPE scholars who asked questions about the impact on women as the majority of those living and providing care in LTCFs. However, very little attention has been paid to non-senior adults who require residential LTC services and who, during this time period represented a small but significant sub-population of residents within Ontario's LTCFs. In the final section of this chapter, I discuss why these issues should be recognized as issues for non-seniors with disabilities and an issue for younger residents.

Residential Institutions for People with Disabilities

The situation of younger adults living in LTCFs in Ontario is shaped by the history of disability policy that, starting in the early to mid-1800s, was characterized by the placement of some people with disabilities against their will into provincial residential institutions (see Simmons, 1982). Often referred to as "institutionalization", scholars of sociology, history, DS, feminist, and legal studies have provided various and oft-competing understandings of the aims and functions of this approach. Some scholars have characterized the development of these and similar public institutional systems in Canada and elsewhere in terms of social control—as "total" and "all-powerful" structures that imposed social order (Oliver, 1990) by separating "deviants" from society indefinitely (Chupik & Wright, 2006) and controlling opportunities for people with disabilities to reproduce (de la Cour, 2013). For others, these institutions were "porous and reactive welfare institution[s]…responsive to broader social, economic, political and cultural trends" (Chupik & Wright, 2006, p.78). From this latter perspective, the development and acceptance of institutions aimed at people with disabilities in Ontario may be variously understood as driven by paternalistic, humanitarian, educational, or health-related goals.

Notwithstanding these debates, the history of institutional care for people with disabilities in Ontario is one of oppression, marginalization and violence. It is also a history that involves more than the group of people who might, in contemporary times, be categorized as having a disability. As Burghardt (2018) and Leblanc Haley and Temple Jones (2020) discuss, the institutional history of people with disabilities in Ontario is also one of the confinement and regulation of aging, racialized, gendered, classed, queer, and colonized lives. Indeed, there are clear indications that since the mid-1800s when the first provincial "insane asylum" was established, these sites and their successors were "catch all" institutions for people who were viewed as dangerous, disruptive, or whose behaviours challenged moral codes of the time (Sussman, 1998). They were populated by those who deviated from the educated, middle-upper class of European descent (Burghardt, 2018), who were experiencing poverty and/or various forms of illness, and/or whose families and/or communities could not support them (Sussman, 1998).

The development of the asylum system in Ontario was significant because it marked the first formal involvement of the House of Assembly of Upper Canada (i.e., the provincial government) in the provision of public care. At this time, most people with disabilities who received care, received it at home (Joffe, 2010). Some individuals accessed "relief" through local charities, religious groups or private philanthropists (DesRoches, 2004), while others received some financial aid from local councils (Joffe, 2010). Some people with disabilities also ended up in prisons where the conditions were dangerous, crowded, and unsanitary (Joffe, 2010). Others were placed in charitably-run general hospitals primarily occupied by unemployed, indigent, and otherwise poor populations (Gagan & Gagan, 2002). These were also considered dangerous places, owing not only to high mortality rates associated with hospital-based illnesses, lack of sanitation, and medical ineffectiveness, but also because of the population they served (Gagan & Gagan, 2002).

Historians point to the rise of capitalism, rapid urbanization, migration and accompanying ideas about work and moral worth as contributing to the expansion of, ongoing demand for, and general acceptance of the provincial asylum system (see Burghart, 2018; Joffe, 2010; Libbiter, 1994; Simmons, 1982). Capitalist owners required a "stable" and "compliant" workforce to ensure production and the accumulation of wealth (Libbiter, 1994). Those who did not fit well into an "urban, factory-based… [labor market] organized around the individual wage labourer" were greatly disadvantaged (Oliver, 1990, p. 28). As Oliver (1990) argues, the rigidity of paid work excluded many people with disabilities from the workforce and rendered them "shamefully dependent". More generally, people who did not or were not able to comply with the new "social order" were viewed as a social problem (Oliver, 1990).

At the same time, the move to an industrial economy increased rates of impairment and illness among the population. This was largely the result of “unsafe working conditions, child labour, poor sanitation, lack of public health, and poverty” (Hanes, 2004, np). According to Hanes (2004), the shift to a wage-based industrial economy left working class families poor (due to poor pay), such that fewer could afford to care for family members with disabilities at home. Given these pressures, the House of Assembly of Upper Canada was called on by local governments to provide assistance (Simmons, 1984). The provincial insane asylums that were built as part of the government's response, were constructed, owned and operated by the House of Assembly (i.e., the provincial government).

The insane asylums, or what came to be known as the provincial “mental hospitals” and eventually, the provincial psychiatric hospitals (PPHs), tended to operate under the scope of science and medicine (Joffe, 2010). Run by “alienists”—medical men who claimed authority over issues of insanity—these institutions aimed to treat and “cure” the (acute) insane. However, given the absence of a public health and social welfare system, the asylums also commonly contained seniors, people with physical disabilities and IDD, and other populations who alienists often classified as “chronic” or “incurable” (Rossiter & Clarkson, 2013; Simmons, 1982).

Within these facilities, inmates were provided with “moral treatment”—a scientific philosophy that stressed the “self-curative” properties of nutrition, fresh air, exercise, kindness, minimum restraint, structure, routine and hard work (Mitchinson, 1987; Terbenche, 2005). As part of their treatment, inmates were required to participate in highly gendered forms of unpaid labour that acted to support the internal economy of the asylum.

In the context of inadequate public funding, overcrowding, and a growing population of chronic inmates, the provincial insane asylums transformed into what Libbiter calls “mammoth warehouses of abject human misery" (1994, p. 94). The conditions were characterized by strict routinization, staffing levels were inadequate, and inmates received little more than basic custodial care. These institutions also became notorious for conducting violent gynecological "therapies", experimental somatic surgeries, and the testing of psychoactive drugs on patients who had not consented to nor had any knowledge of taking them (Mitchinson, 1980; Niles, 2013).

"Idiot asylums", or what came to be known as the "hospital schools" emerged from the insane asylum system. Aimed at "idiots" and later, "the feebleminded", these provincial institutions often acted as dumping grounds for people in need of ongoing health and social care—those "fobbed off" (Simmons, 1982) by the insane asylum and the general hospitals because they were considered incurable, and from houses of industry/refuge, because they were unable to cover the costs of their relief through labour (Rossiter & Clarkson, 2013; Simmons, 1982). While often framed as places where people with IDD could go to be educated and taught skills that would allow them to return to communities and be "productive" (Joffe, 2010), the conditions in these institutions were abysmal. As Joffe describes it,

> 'Inmates' lived in dormitories with tens of hundreds of others, with no curtains on the window and no privacy between the beds. The doors were locked from the outside, and abuse among the inmates themselves was not uncommon…. [Inmates] were often forced to work without pay…even performing the same kinds of jobs that staff members were paid to do…. Sexual, physical and emotional abuse of people with disabilities by staff were rampant in institutions. (2010, p. 15)

Despite significant changes to the social, political, and economic circumstances that gave rise to the first provincial institutions for people with disabilities, this system continued to grow for many decades, spurred on by new discourses about disability, and as new social and economic concerns arose (Burghardt, 2018). These institutions also became increasingly differentiated. For example, in the first half of the twentieth century, the development of "scientific" techniques of intelligence testing and taxonomies of "idiocy" in combination with the rise of eugenics discourses contributed to the identification and segregation of large numbers of "defective" children and women of child-bearing age who were poor and/or defied gender or sexual norms into the hospital schools and similar, smaller institutions (Burghardt, 2018; de la Cour, 2013; Rossiter & Clarkson, 2013).

A number of stand-alone chronic care hospitals and smaller health care facilities aimed at the "cure" and/or rehabilitation of people with physical disabilities were also built following WWII (Jongbloed, 2003). As well, within general hospitals, separate units aimed at more specific groups of patients including people with mental illness, people with IDD, and those in need of chronic/convalescent care were developed (Gagan & Gagan, 2002). This model served to reinforce an institutional, segregated, and increasingly, medicalized approach to public health care services for people with disabilities.

Towards the Closure of Institutions

The number and size of provincial residential institutions for people with disabilities continued to grow in the decades following WWII (Brown & Radford, 2015; Simmons, 1990). What came to be known as the "mental health system"—an institutional system aimed at people with mental illness and IDD (Simmons, 1990, p. 158), reached its peak in the mid-1960s in terms of the number of patients with mental illness living in the provinces' mental hospitals and psychiatric units within general hospitals, and the early 1970s in terms of the number of people living in the hospital schools, smaller (Schedule 2) institutions, and designated hospital-units for people with IDD (Brown & Radford, 2015; Hartford et al. 2003; Joffe, 2010).

At this time, however, there was some evidence of a movement away from the institutional model of public care aimed at people with disabilities. For example, in 1964, the province set regulations for the placement of people living in the provincial mental hospitals and, four years later, people living in the institutions for people with IDD, into publicly funded but privately run "residential" and "nursing homes" via the *Homes for Special Care Act* (Simmons, 1982). This program was not an entirely new idea. More modest efforts to discharge "chronic" hospital patients into designated residential units or other private facilities via the *Approved Homes Program* had, since the 1930s, been ongoing (Sylph et al., 1976). The *Homes for Special Care* program was a larger effort premised on the notion that these facilities would offer patients who were no longer benefiting from "active" hospital treatment, a more "homelike" care setting within the community (Simmons, 1982). Further, discharge to these facilities also meant the legal reinstatement of patients placed in psychiatric hospitals who would, at the time of discharge, become a "person" or "resident" (Sylph et al., 1976).

There were some significant differences between the two-types of facilities that developed under this program. According to Sylph and colleagues (1976):

> Residential homes [were] intended to provide a good homelike atmosphere and regulations [were] few…. Requirements for nursing homes [were] more stringent, according to The Nursing Homes Act. Two levels of nursing care, intermediate and extended, with different staff/patient ratios and costs, were provided [in nursing homes] according to the needs of individual patients (p. 233).

Patients with physical disabilities living in the PPHs and who required nursing care were prioritized and placed in existing nursing homes (Simmons, 1982). “Ambulant” and “socially competent” patients were placed in residential homes (Sylph et al., 1976, p. 233). Most of these residents were seniors (Simmons, 1982). Later, patients of the institutions for people with IDD including non-senior residents were included in the program.

Notwithstanding these differences, it has been suggested that the *Homes for Special Care* program was of very little benefit to residents. Discharge from the provincial hospitals and institutions meant residents received much less (if any) medical treatment (Simmons, 1982; Sylph et al., 1976). Particularly in the situation of those people placed in residential homes, custodial care and supervision was provided by unregulated and untrained workers (Sylph et al., 1976). Government funding was not provided for social and recreational programming at either type of facility. Instead, any programming relied on volunteers. Many nursing homes had financial problems, and inadequate provincial funding meant that most facilities could not afford to offer much more than basic custodial care (Simmons, 1982).

Financial motivations drove this program and were linked to the development of federal hospital insurance and social assistance programs. For example, the 1957 *Hospital Insurance and Diagnostic Services Act* meant federal-provincial cost-sharing for hospital services, but it did not cover the province’s mental hospitals and institutions for people with IDD (Simmons, 1982). The cost of care per diem paid by the province to a nursing home was significantly less than the cost associated with the psychiatric hospital, and it was even less for residential homes. Further, the introduction of Old Age Security, Old Age Assistance, and later, the Canada Assistance Plan (CAP), meant the provincial government could better ensure residents paid a portion of the costs of their care. Simmons (1982) argues that despite the existence of legislation that charged patients a per diem for hospital care, this contribution was rarely paid by patients living in the provincial psychiatric hospitals. Patients of the institutional mental health system were not eligible for the CAP until they were discharged.

Deinstitutionalization

By the 1970s, a number of social and cultural factors and forces came together against the growth of the existing system. What Simmons calls a “fortuitous linkage” of efforts involving a variety of groups and individuals emerged to reveal the limitations and failures of the province’s long-established institutional system of mental health care (1990, p. 158). These factors, combined with political-economic pressures to reduce health care spending, paved the way for the wide-spread downsizing and closure of the PPHs and residential institutions for people with IDD.

“Deinstitutionalization”, a philosophical, theoretical, or morally-based reaction to the negative components of institutional care (Sussman, 1998) is a term commonly used to refer to the movement of large numbers of people with disabilities out of (large-scale) residential institutions and hospitals into “community-based” care[1] (Niles, 2013). Support for deinstitutionalization grew in the years following WWII as the consequences of eugenics policies were revealed (Rossiter & Clarkson, 2013). The emergence of Egalitarian ideologies and the 1948 adoption of the United Nations *Universal Declaration of Human Rights* that entitled all persons to be free from “cruel, inhumane or degrading treatment or punishment” (United Nations, 2013, cited in Rossiter & Clarkson, 2013, p. 13) helped challenge public and professional acceptance of the institutionalization of people with disabilities.

The humaneness of the psychiatric hospital had increasingly come into question given reports of the poor conditions of care within them and involuntary treatments being used to control patients (Nile, 2013; Simmons, 1990). Further, in 1967, the *Mental Health Act* was introduced, leading to the protection of some people with mental illness from involuntary hospitalization (Hartford et al., 2003). A critical body of literature developed by anti-psychiatrists and other academics emerged at this time, making apparent the counter-therapeutic effects of long-term institutionalization in the psychiatric hospitals and questioning the political and professional motivations behind them (Libbiter, 1994; see also Foucault, 1965; Goffman, 1961; Scull, 1977).

Support for deinstitutionalization was further solidified by the emergence of disability rights activism in North America (Jongbloed, 2003), the development of the social model of disability in Britain (see Chapter 1), and the human rights perspectives on disability (Burghardt, 2018). The formation of disability justice groups including those organized by ex-psychiatric patients (Jongbloed, 2003), and parent advocacy groups (Burghart, 2018; Simmons, 1982) also made an impact. For example, parent groups that lobbied the provincial government for the inclusion of people with IDD in public education challenged the need for some of the province's largest hospital schools (where children and youth were most often placed) if educational support was available in communities (Rossiter & Clarkson, 2013; Simmons, 1990).

Academics, sometimes working in association with parent advocacy and disability rights groups also played a key role in garnering support for deinstitutionalization (Simmons, 1982). The development of the theory of "normalization", which argued that people with IDD should be involved in work, education, recreation, and housing, and have opportunities to develop relationships with people in their community (Brown & Radford, 2015, p. 23) paved the way for a movement away from residential institutions for people with IDD. The principle of "social inclusion" was developed and demonstrated, offering evidence that people with IDD could reside and participate in community-life when appropriate public community-based supports were made available (Joffe, 2010).

Dehospitalization

What Simmons (1990) describes as a “hidden revolution” in mental health policy occurred in Ontario in the 1970s. It was characterized by the movement away from the use of large-scale standalone PPHs to mental health care provided in general hospitals and clinics (Simmons, 1990). It also involved the transfer of responsibility for residential institutions for people with IDD from the Ministry of Health to the Ministry of Community and Social Services in accordance with the *Developmental Services Act*, 1974 (Rossiter & Clarkson, 2013).[2] While increasing acceptance of notions of deinstitutionalization played an important role in the movement away from the use of residential institutions and hospitals for people with disabilities, in Ontario, deinstitutionalization also took the form of “dehospitalization”— a policy approach to deinstitutionalization driven by a focus on cost containment (Niles, 2013).

In the late 1950s and 1960s, cost-sharing associated with hospital insurance (see above) prompted the province to move away from providing services in psychiatric hospitals to general hospital psychiatric units (Mulvale, 2007). Pressure increased to control the costs of hospital care in light of federal funding cuts associated with Establish Program Financing in 1977 (see Armstrong & Armstrong, 2008) and the introduction of the *Canada Health Act* [CHA] in 1984, which required the province to cover all insured health care services provided in hospitals (Armstrong & Armstrong, 2008). A number of “chronic” patients were shifted from psychiatric units to other non-hospital-based facilities such as nursing homes (Mulvale, 2007). Others were discharged into the community where an absence of community services and supports meant many were readmitted to hospital. Others were reinstitutionalized in jails or experienced homelessness (Hartford et al., 2003).

The deinstitutionalization of residential institutions for people with IDD underwent a somewhat different process. Following a provincial inquiry into these facilities following allegations of abuse and the death of a man with IDD, a series of reports set the stage for the *Developmental Services Act* (Linton, 2021). The Act meant a shift in responsibility for these institutions from the Ministry of Health to the Ministry of Community and Social Services. It also provided for the public funding of a range of home and community-based services and supports that would make it possible for people with IDD to live with their families, in group homes, or independently (Rossiter & Clarkson, 2013). This eventually led to a multi-staged, multi-year initiative characterized by the downsizing and closure of these institutions. The last large-scale provincially operated residential institution for people with ID closed in 2009 (Rossiter & Clarkson, 2013). However, it is well recognized that public services for people with IDD have been characterized by a wide range of issues including the existence of a number of barriers with respect to accessing the program funds for caregiver respite and person-directed planning (Linton, 2021). Inadequacies in residential services such as long-wait lists for and staffing deficiencies in group homes and other settings are also a problem.

Contemporary Health Care Reform

The situation of younger residents living in LTCFs in Ontario is also situated within the context of contemporary health care reform. I use the term “contemporary health care reform” to refer to a diverse set of changes to the public health care system that in Ontario, began in the early 1990s as a response to federal austerity measures (Armstrong & Armstrong, 2003b). Beginning in the 1970s, Canada’s health care systems were increasingly being discussed as “in crisis" (Armstrong & Armstrong, 2003b). Economic pressures on governments in the Global North associated with globalization, the rising cost of health care associated with population demographic and technology changes, a recognition of good health as not primarily determined by health care, and mounting criticisms of the efficiency and effectiveness of Canada's health care systems came together to provide the justification for health care reform (Armstrong et al., 2000). The set of changes that ensued, although diverse and sometimes contradictory, were highly influenced by neoliberalism, NPM, and relatedly, the adoption of a model for health care reform that meant the use of business- orientated strategies and the application of management techniques associated with the private sector (Armstrong et al., 2000).

Drawing from this paradigm, changes to the health care sector were driven by both a medical and business approach. First, the medical model of health and health care assumes a biological understanding of health, illness and disability, as primarily determined by the body (Armstrong & Armstrong, 2003b). The body is viewed very much like a machine with component parts that could be separated and "fixed". Following this model, it is assumed that the role and goal of health care is to cure or "fix" the body when things go wrong. It is also assumed that these outcomes are made possible by scientific medicine. Through science and scientific "evidence" the causes of illness and/or disability can be determined, treated, and cured. Second, the business model of health care assumes an understanding of health as a market good (Armstrong et al., 2000). While it is also recognized (particularly in Canada) that governments should play some role in health care—particularly in terms of its funding and regulation—it is also assumed that when it comes to the delivery of health care, "the private sector is better; better at creating choice, delivering service, reducing costs, and organizing work." (Armstrong, 1997, p. 19).

Basing health and health care on the medical model meant focusing on acute medical care provision and the downsizing and delisting of those services outside this definition (Armstrong & Armstrong, 2003b). It also meant less attention to the social and psychological aspects of health care, to considerations of the individual as a whole, and to the social context from which experiences and understandings of illness and disability emerge. Notions of the body as a machine capable of being divided into component parts helped frame the reorganization of care work, and (uncritical) acceptance of the science on which medicine is based formed the "evidence-base" on which changes were made and evaluated (Armstrong & Armstrong, 2003b).

Aligned with NPM, a business model of health care drove cost-containment strategies and promoted (where possible) a privatization of the delivery of health care (Armstrong & Armstrong, 2003b). It meant the deregulation of some aspects of the public system, and the increased regulation of others, and involved the adoption of business practices in the organization and delivery of care. As much as possible, health care was moved out of hospitals to other facilities and households where the costs to the province were far less (Aronson & Neysmith, 1997). Aspects of the health care system not covered by the CHA were increasingly marketized, and private sector strategies and for-profit management techniques were adopted with the aim of minimizing costs and maximizing efficiency (Armstrong & Armstrong, 2003b). The deregulation of particular components of the health care system further enabled private sector delivery (McGregor, 2001). However, this change meant increasing and sometimes rigid government regulation of other aspects of health care.

Hospital-Based Long-Term Care Reform

Changes to the LTC system associated with neoliberal health care reform impacted non-senior adults with disabilities who required access to public LTC services. In-hospital LTC was a target of health care reform because when based in hospital, the costs to the province were much more than when provided in LTCFs or private households (Williams et al., 2016). As health care reform meant redefining hospitals to focus almost exclusively on acute medical care and "only the most severe diseases and injuries" (Armstrong et al., 2000, p. 40), LTC was largely moved out of this setting. The *Health Services Restructuring Commission* (1996-2000) was established by the province to drive hospital restructuring (see Health Services Restructuring Commission (HSRC), 2000). It spurred the widespread closure and amalgamation of CCC and rehabilitation hospitals, as well as of designated chronic care units within acute hospitals (CCCRPLC, 2006). As a result of this reform, in-hospital LOS for LTC beds were significantly reduced, and hospital admission procedures to access these services became more restrictive (Armstrong, 1997). The Commission also led to a second wave of dehospitalization of people living in PPHs and long-term mental health care beds within general hospitals. Wiktorowicz (2005) reports that hospital reform meant the elimination of fifty percent of in-hospital psychiatric beds. But Little and colleagues (2018) indicate that even more beds were closed post-Commission.

Home and Community Care Reform

Given that health care reform involved the movement of public care away from hospitals, HCC services experienced considerable pressures (England et al. 2007). In the context of hospital bed closures, shortened hospital stays and the move to more out-patient services, HCC was redefined as "an extension of hospital care" (Daly, 2007, p. 69). The HCC sector itself underwent a number of changes that were shaped by neoliberalism and the adoption of NMP. As demand for HCC increased, and acuity levels of HCC "clients" rose in accordance with hospital restructuring, eligibility requirements for HCC were tightened (Daly 2007; England et al., 2007). Further, in the mid-1990s, the Conservative provincial government of the time merged funding streams for health care services provided via home care (e.g., professional nursing, rehabilitation and other therapeutic services, and paraprofessional personal support work), and the social care aspects of home care or what was referred to as "home support services" (e.g., homemaking, transportation, Meals-On-Wheels). It gave responsibility for both components of HCC to the Ministry of Health (Daly, 2007). The implication of this development was a "privileging" of the health care aspects of home care, and the cutting of social care services. Homemaking in particular was largely delisted, made available only to veterans. However, in medicalizing HCC, what Daly (2007) describes as a gap in "preventative" support services was created. Without social care, some long-term users of HCC could no longer live in their homes and communities. Access to these public services was preventing them from requiring more institutional forms of LTC.

Changes to the HCC sector also involved the introduction of "managed competition". This was a provincial policy whereby Ontario's Community Care Access Centres (CCACs)[2] were prompted to develop a competitive bidding process that had home care service providers develop proposals to win a multi-year service delivery (Daly, 2007; England et al., 2007). The result was a major change in which organizations were delivering public HCC services. Until this time, for-profit organizations had played a relatively minor role in HCC provision (Daly, 2007). However, the introduction of competitive bidding supported the growth of for-profit HCC provision by disfavouring not-for-profit groups who were less likely to have the experience or resources necessary to be successful in the bidding process.

Changes to Ontario's Long-Term Care Facilities

Ontario's LTCFs also underwent significant changes that revolved around the application of policies associated with NPM to the funding, regulation, organization and delivery of care in

LTCFs. Together, these changes were shaped by the assumption that changes to the LTCF sector driven by a medical model and business model of care would mean cost-savings to governments and more effective, efficient, and accountable care (Armstrong et al., 2020).

Private for-profit groups had, at the time of contemporary health care reform, long played a role in the public LTRC system. Beginning in the 1940s, hospitals in Toronto began discharging “bed-blocking” convalescent patients from “indigent” wards (for non-paying patients) to small, proprietary nursing homes, to whom hospitals paid a subsidy much lower than the costs of in-hospital care (Struthers, 2017, p. 292). Nursing homes also played a key role in the province’s *Homes for Special Care* program (see above). In both situations, nursing homes were being used to relieve the “burden” of LTRC from the hospital system and the public purse. However, as the role of nursing homes in the provision of LTRC grew, so too did the province’s role in funding and regulating this sector (Daly, 2015).

Since the early 1990s, changes to Ontario’s LTCF sector have solidified the role of for-profit organizations in the delivery of care, and since 2007, has meant commercial consolidation amongst a few large chain corporations (Daly, 2015; Ontario Health Coalition [OHC], 2019). A variety of neoliberal policies drove this change. In the mid 1990s, the province introduced a competitive bidding process for access to enhanced public operating funds aimed at infrastructure development. The goal was to create new LTC beds and renovate existing beds that failed to meet new regulations regarding physical structure (i.e. fire, safety, and privacy standards; Daly, 2015). This process supported the expansion of for-profit LTCFs. As Armstrong and colleagues (2016) explain, bidders for these funds had to have sufficient capital to invest in construction costs. Smaller, family-owned facilities and not-for-profits were less likely to have such funds. This process also disfavoured not-for-profit and public facilities by removing the funding privileges they had previously enjoyed (Daly, 2015).

Some aspects of the sector also underwent deregulation, the effects of which favoured for-profit ownership. For example, in 1993, when for-profit, not-for-profit and public LTCFs achieved provincial funding parity, changes to the public payment system removed requirements that any profits accumulated from accommodation fees paid by residents be returned to the government (Harrington et al., 2017). Further, no rules were established around the reinvestment of such profits into services and programs.

The deregulation of staffing standards also supported the commercial consolidation of LTCFs in Ontario. In 1993, the introduction of Bill 101 eliminated minimum standards from existing legislation (Harrington et al., 2017). The 2007 *Long-Term Care Homes Act* (LTCHA) failed to (re)establish standards for staffing levels, apart from the requirement that one Registered Nurse be present in each facility at all times, regardless of the number of residents (Badone, 2021). This meant staff-to-resident ratios were left largely up to the discretion of each facility operator. Low staffing levels meant cost-savings for providers.

With the passage of the LTCHA, other aspects of care provided in LTCFs became more heavily regulated. This change aligned with NMP discourse and the related efforts of government to implement management strategies that made possible “governing from a distance” (Armstrong et al., 2016). When the LTCHA came into effect in 2010, the overall number of regulations to which providers had to adhere to maintain their license and receive provincial funding were greatly increased. Reporting practices became much more rigid and complex (Daly, 2015), and they were tied to the implementation of new technologies—the Resident Assessment Instrument Minimum Data Set [RAI-MDS] in particular. This tool has been used in care planning and management in LTCFs as well as in the development of quality indicators used to demonstrate accountability (Armstrong et al., 2016). These changes significantly increased documentation and technology requirements. Daly (2015) suggests that such increases in the “regulatory burden” had a negative impact on smaller and not-for-profit providers. While the large for-profits could reap the benefits of economies of scale, other providers were less likely to have the capacity to manage data and reporting requirements. The implementation of the RAI-MDS also medicalized the delivery of care in LTCFs by relying on clinical indicators of need and quality. Such measures were favoured because of being countable and easier to count. The RAI-MDS data was also linked to provincial funding. As such, more medical care practices became prioritized over social care (Armstrong et al., 2016).

Not all changes to LTCFs are so overtly about the models of marketization and medicalization that were driving them. On the surface, some appeared to be driven by a focus on quality. For example, the LTCHA was clearly influenced by Resident-Centered Care (RCC). Not only did the preamble of the LTCHA included “an overarching “[belief] in resident-centred care” (Long-Term Care Homes Act [LTCHA], 2007), a number of regulations reflected this approach—the mandatory development of Residents’ Councils, the imposition of restorative care programs guided by a philosophy of maximizing independence, the implementation of individual care plans, and the requirement that a resident and/or their substitute decision-maker be given full opportunity to participate in its development. RCC is an approach to care that “centers” on the resident as an individual (Morgan & Yoder, 2012). It emphasizes giving residents greater choice and respecting their values and preferences (Eales et al., 2001). It also promotes resident involvement in, if not enhanced control over, decision-making processes (Morgan & Yoder, 2012). Often drawing on language associated with IL movements (see Chapter 1), RCC is frequently understood as challenging power inequities within resident-provider relationships by constructing the resident as individuals with the right to make choices about and control their care (Smele & Seeley, 2013).

Ontario's efforts to regulate access to care also suggested that equality was a concern. When the LTCHA came into effect, it replaced the *Nursing Homes Act,* the *Charitable Institutions Act,* and the *Rest Homes Act*, which had separately governed the province's facilities based on ownership type (for-profit, not-for-profit and municipal; Auditor General, 2012). As part of this, maximum rates for accommodation fees that residents could be charged based on the type of accommodation they sought (private, semi-private, basic) were set by the province to help ensure access to a LTCF was not about money. The placement process for access to all LTCFs in Ontario—the process for determining eligibility and prioritization for placement—was also standardized to help ensure access to care was tied to need, and that "crisis" cases were consistently prioritized.

The Privatization of Long-Term Care in Ontario

Research examining Ontario's LTC system in the decades following the wide-scale deinstitutionalization of the province's residential institutions for people with IDD, the implementation of health care reform including changes to the LTC sector driven by neoliberal discourses and policies and associated with NPM suggest that these processes had significant limitations and challenges. While deinstitutionalization represented a movement away from a long history of public institutional care characterized by isolation, maltreatment, and often, abuse, as indicated previously, the form it took suggests that it was also about cost-cutting. It has been argued that the closure of many of the province's PPHs and beds made room for the redistribution of money to community-based mental health supports and services, this transfer never fully occurred (Niles, 2013). This gap has left many former patients living in poor quality, unregulated housing, and struggling with insufficient income (Hartford et al., 2003). Others have been re-institutionalized in hospitals and other institutions, while others have experienced homelessness. Rossiter and Clarkson (2013) similarly argue that the closure of the largest provincial residential institutions for people with DD (a.k.a. the “Regional Centres”) was not accompanied by the provision of an adequate range of publicly funded high quality developmental services and other supports. This meant “people who were vulnerable within institutions remain vulnerable within the context of community care” (Rossiter & Clarkson, 2013, np).

A number of problems associated with contemporary changes to the public HCC system associated with neoliberal NPM policies and strategies also emerged. For example, during periods of time when government funding levels have been frozen, the CCACs were forced to cut services to users in order to match their budgets and offset rate increases associated with contracts with providers (England et al., 2007). In order to win contracts, provider organizations (both for-profit and not-for-profit) had to minimize pay and reduce benefits to care workers. This change has led to increased workloads and stress among HCC workers. Not surprisingly, staff retention became a major issue in this sector, as nurses and PSWs left HCC to work in hospitals and LTCFs where pay and job security are better (England et al., 2007). Further, research suggests that changes in HCC policies meant eligible clients were no longer receiving the amount of services they were assessed to need (Daly, 2007). Not enough time, not enough providers, and the prioritization of health care services over social care also meant that family and friends (most often women) became increasingly responsible for filling in the gaps in HCC.

Drawing on the lens of privatization (see Chapter 1), feminist health researchers have argued that changes in public LTC and social services have, since before the 1990s, been driven by neoliberalism in the forms of funding cuts and the adoption of a NPM discourses and techniques (see Armstrong & Armstrong, 2020; Armstrong et al., 2020; 2016b; 2001a; Aronson & Neysmith, 1997). The outcome has been a privatization of LTC. LTC has become privatized in the sense that these strategies have meant a movement away from the LTC as a public responsibility. It has meant a shift in the costs of, work of, responsibility for, and decision-making around LTC to the private sector and to individuals and families (Armstrong, 2012; Armstrong et al., 2020). It has been recognized that the public LTC system in Ontario is especially vulnerable to these forms of privatization, because as an "extended" health care service, it is not (unlike the acute, hospital-based health care system) subject to the principles upheld by the CHA (i.e., public administration, universality, comprehensiveness, portability and accessibility; Armstrong et al., 2012; Estabrooks et al., 2020).

The privatization of LTC and the processes involved in this shift have disparate effects on particular individuals and groups. For example, feminist health researchers have argued that the privatization of LTC care is a problem for women who are more likely to need public LTC as a result of sex and gender-based differences and social inequalities related their lower relative income in comparison to men and lesser access to private health insurance, as well as their higher morbidity rates and tendency to live longer (Armstrong et al., 2001a; 2013; Seeley, 2012). It is also an issue for women (racialized and migrant women in particular) who are the majority of direct care providers within the LTC system, and also, the poorest paid and least likely to be regulated. And it is an issue for women who are most likely to fill gaps in public LTC services via informal care provision (Barken & Armstrong, 2020).

Changes in and Issues with Ontario's Long-Term Care Facilities

These changes in Ontario's LTC system have impacted key aspects of Ontario's LTCFs. I have already provided an overview of major changes in the resident population in the Introduction Chapter, but to summarize, one outcome of these changes is that residents enter Ontario's LTCFs with more extensive and complex medical and social support needs (Marrocco et al., 2001). They are more likely to experience cognitive impairment, especially advanced Alzheimer's and other forms of dementia, and to be diagnosed with multiple impairments and/or chronic illnesses. The resident population is also a much older population and overall demand for beds has grown (Marrocco et al., 2021; OLTCA, 2014; 2019).

Reports indicate that LTCFs are not well equipped for and have failed to evolve to keep up with these changes (Marrocco et al., 2021). The COVID-19 pandemic brought to light numerous issues in LTCFs, but it is also clear that they existed in the decade leading up to the pandemic. Central issues include gaps in and poor quality of care, staffing issues, deficiencies in the physical care environment, a "crisis" in staffing, and violence in LTCFs (see Badone, 2021; Estabrooks et al., 2020; Marrocco et al., 2021; Ontario Health Coalition [OHC], 2019).

Researchers are increasingly linking these issues to underinvestment in and poor funding of the system—a system where funding is not enough to keep up with demand nor keep up with the changing needs of residents (Armstrong et al., 2019). They are also shaped by adoption of management strategies and techniques associated with NPM. For example, issues in quality have been linked to the commercialization of LTCFs. Research indicates, for example, that compared to non-profit LTCFs, on average, for-profit chains have more deficiencies, higher rates of resident complaints, and provide significantly fewer hours of nursing care (Harrington et al., 2017). Staffing levels, recognized as key to quality of care (see Estabrooks et al., 2020;

Marrocco et al., 2021), are lower in Ontario's for-profit chain facilities than not-for-profit or public ones (Armstrong et al., 2019).

Further, it has become clear that the adoption of NPM practices are not resolving issues that existed in prior eras. For example, while the enhanced funding policy aimed at resolving infrastructure issues led to an increase in the overall number of beds, this growth was insufficient and waitlists for beds have continued to increase into 2020 (OLTCA, 2020). Similarly, large numbers of beds continue to be located in facilities that do not meet contemporary structural design standards (Marrocco et al. 2021). Old facilities containing "ward style" rooms shared by up to four residents continue to exist, and most of these are owned by the for-profits (Badone, 2021). Not only does these mean barriers to privacy, physical accessibility, and safety, as the emergence of COVID-19 demonstrated, it also puts residents at greater risk of infection (Marrocco et al., 2021).

Studies have also connected the adoption of for-profit business practices to the emergence of a staffing crisis in Ontario's LTCFs (see LTCSSAG, 2020). PSWs and other unregulated workers (particularly those working in private for-profit facilities) are some of the poorest paid in all of Ontario's health care sector. In many facilities (for-profits in particular), PSWs are paid just above minimum wage (Stevens, 2020 cited in Badone, 2021). Nurses wages in Ontario's LTCFs lag behind those of hospital sector nurses, and over-reliance on part-time, casual and agency workers in order to minimize staffing costs mean worker retention issues, regular staffing shortages, and economic insecurity among workers who are "forced to piece together a number of part-time and casual jobs to make a living wage and support their families" (Marrocco et al., 2021, p. 53).

The adoption of for-profit managerial strategies in Ontario’s LTCFs also has a number of serious consequences in terms of the health, safety, and wellbeing of residents and formal and informal care providers. While focused on maximizing efficiency and demonstrating accountability, these strategies and their related technologies have been associated with the provision of care in highly task-oriented, medically-focused, standardized, and routinized ways (Banerjee et al. 2015; Daly & Szebehely 2012). These practices also undermine many of the more positive aspects of legislative changes to LTCFs. For example, in opposition to the RCC philosophy espoused in the LTCHA, the organization of care work around complex, fragmented regulations and onerous accountability practices that favour medical care is incompatible with social care provision and the provision of care in relational ways (Armstrong et al., 2016; Banerjee et al. 2015; Siegel et al. 2012). Evidence also suggests that workers in LTCFs experience a great deal of stress and other psychosocial consequences that are linked to highly task-oriented care work and strict divisions of labour (Syed et al., 2016). And while research makes it clear that causes of violence in LTCFs are multifaceted, there are strong links between the adoption of for-profit delivery methods and high incidence of violence against care workers and residents (OHC, 2019).

The Issue of Younger Residents and Issues for Younger Residents

The situation of younger residents living in LTCFs in Ontario in the twenty years leading up to the COVID-19 pandemic emerges from and exists within the processes described throughout this chapter. As a whole, however, relatively little attention has been paid to their impact on non-senior adults with disabilities, and on non-senior adults living in LTCFs more specifically. Certainly, some CDS scholars linked and problematized a growth in the number of younger adults with IDD living in Ontario’s LTCFs to the closure of the Regional Centers (see

Crawford, 1996; Spindel, 2013). Further, and as described in the Introductory chapter, a number of media sources published stories about younger residents living in Ontario's LTCFs during this time period. With some exception (see Tapley, 2018), the situation has been constructed as a "crisis" reflective of a "neo-asylum" era whereby people with disabilities are being (re)institutionalized, this time, in smaller facilities that while typically associated with "community", maintained "institution-like conditions" (Leblanc Haley & Temple Jones, 2020, p. 2).

Contributing to this gap is the construction of public LTC services as "senior's care". This association is notable in a list of "Public Information" posted about LTC programs and services on the Ontario MOHLTC website (2020) that places them under the heading "Senior's Care" despite the fact that not all people who use LTC services are seniors. Reports and policy documents concerning the province's LTCFs also commonly describe them as services for seniors and fail to identify the existence of younger residents within these facilities.

Although the literature produced towards the end of the time period on which this dissertation is focused indicates a need for Ontario's LTCFs to recognize the increasing diversity of the resident population, diversity usually means linguistic, sexual orientation, religious, spiritual, racial and ethnic, not age (see Marrocco et al., 2021). Yet there is reason to believe that age matters when it comes to issues in LTCFs. For example, reports have called for changes to LTCFs that align with the fact that residents are entering LTCFs in Ontario later in life than in previous eras, and that increasingly, LTCFs are becoming sites for palliative and end-of-life care (Marrocco et al., 2021). What does this mean for residents who live in LTCFs for much longer periods of time (longer than the two year average), and who are (potentially) "growing old" in a

LTCF? What does this mean for residents who do not view themselves as being at the end of their lives?

As mentioned, a multiplicity of reports and policy documents have indicated that as a group, Ontario’s residents enter LTCFs with more medically complex needs and/or higher levels of acuity than in previous eras. Younger residents are certainly part of this group, but it also appears that the types of impairments they experience differs from those commonly associated with old age (see Colantonio et al., 2010; Fries et al., 2005). What does this mean for younger residents in terms of having their needs met, and for the direct care workers whose jobs it is to meet these needs?

A gap in age-sensitive LTC research and policy may also be accounted for by the historical tendency of disability and seniors’ issues to be treated as separate concerns. For example, the situation of younger residents living in LTCFs tends to be approached from a perspective where the solution is deinstitutionalization—the removal of people with disabilities from LTCFs and the development of improved community-based services (see Herron et al., 2021). In contrast, it has been argued that the placement of older people in LTCFs is rarely framed as “institutionalization”. Herron and colleagues (2021) wonder if ageism is playing a role in the marginalization of older people within such discussions, and they suggest that broader societal attitudes to older people—particularly those living with advanced Alzheimer’s and other forms of dementia—have led to “softer” responses to their segregation from society within LTCFs.

Notwithstanding the reasons for the overall gap in LTC research and policy that attends to the non-senior adult population living in LTCFs in Ontario, as summarized in the Introduction chapter, there does exist a small body of qualitative social research developed in Canada focused on the experiences of younger residents living in LTCFs. Some of this scholarship has suggested that younger residents experience particular issues while living in a LTCF. Key issues include a lack of community engagement and social interaction, limited choice over everyday activities, and difficulties with mental health (Barber et al., 2021; Hay & Chaudhury, 2015; Oliver et al., 2022). As a whole this research argues that LTCFs in Canada do not meet the physical, social, sexual, nutritional and emotional needs of younger residents, nor their desires for independence and self-determination (Barber et al., 2021). This work does not, however, consider the larger contexts within which these issues are situated. Most research does not make links between the structural conditions of LTCFs (e.g., how care is funded, regulated, organized, and delivered, and what the physical environment consists of) and the concerns of non-senior residents.

In terms of understanding the situation of younger residents living in LTCFs in Ontario, this analytic oversight limits understandings of this issue particularly given that there are several reasons to believe major changes to health care and social services in Ontario had a particular impact on non-senior with disabilities—especially those with more complex health and social care needs. For example, for younger adults living in CCC and other long-term hospital beds, health care reform often meant being “transitioned” out of facilities where they had access to intense active rehabilitation and specialized supports and programs, the costs for which are covered under the CHA. In the 2000s, CCC hospitals and units were also locations where a greater proportion of the patient population was younger compared to numbers in Ontario’s LTCFs (CIHI, 2007). These were also locations within which some younger adults resided for extensive periods of time.

There is also reason to believe that changes to LTCFs associated with underinvestment and the adoption of NPM strategies have particular impacts on younger residents. Ongoing infrastructure issues in the form of outdated physical structures compromise the accessibility of LTCFs for all residents, but given differences in the clinical profiles of younger and older residents, there is reason to believe that small elevators, narrow hallways and ward style rooms are a particular issue for non-seniors because these structures are unlikely to accommodate more complex mobility technologies and the equipment necessary for the provision of more complex medical care (Armstrong et al., 2009a). Further, the implementation of for-profit management strategies in the organization and provision of care in LTCFs meant its standardization and medicalization (see Banerjee et al. 2015; Daly & Szebehely 2012). Again, these factors have negative consequences for residents of all ages, but when examined alongside literature that indicates younger residents experience particular difficulties having their social and emotional needs met in LTCFs (see Oliver et al., 2022), it can be assumed that these changes are being experienced in particular ways by non-senior residents.

Conclusion

In this chapter, I sought to describe the context within which the contemporary situation of younger residents living in LTCFs in Ontario is situated. I did this to better understand the broader ideas and processes that frame the experiences of non-senior residents. The context I have described is one characterized by a history of the institutionalization of people with disabilities in provincial residential institutions and hospitals, which, regardless of the intention (and perhaps because of them), were places where large numbers of people with disabilities were subject to a variety of abuses, isolation, marginalization, and segregation from society at large. This context also involves processes of deinstitutionalization and the efforts of patient, family and disability justice advocates, groups, and scholars to develop new understandings of disability and challenge the (dominant) institutional approach to public care. However, the timing of deinstitutionalization coincided with the emergence of neoliberalism, leading to the dismantlement of institutions in ways that focused on cost-cutting rather than on the development of a robust community-based system of public health and social services and programs.

This context is also one in which neoliberalism and NPM as the driving forces behind health care reform meant major changes to the public health care system in Ontario including the LTC sector. Characterized by a business model and reinforcing a medical model approach to LTC, since the 1990s, LTCFs have experienced underinvestment and the implementation of management strategies that have changed how they are funded and how care is organized and delivered within them. Some aspects of care have become more highly regulated (e.g., reporting requirements, accommodation fees, and the placement process for access to a LTCF), and other aspects deregulated (e.g., staffing levels and rules preventing profit-making in LTCFs). Yet, in contrast to promises of a system that is more efficient, effective, accountable, and offer residents more choice and involvement in decision-making, evidence drawn from research developed in the twenty years following the onset of these changes indicates a number of serious issues in the sector—long wait times for access, staffing crises, poor quality of care, and escalating incidents of violence among them.

Notes

1. It is often recognized that public residential institutions and hospitals historically associated with the province's asylum system were places of isolation, exclusion and violence for people with disabilities. However, it has also been argued that the placement of people with disabilities in "community-based" residential care settings and LTCFs represent the "ongoingness" of the institutionalization of people with disabilities in

Ontario (see Leblanc Haley & Temple Jones, 2020; Spindel, 2013). Notions of "community" have also been challenged by scholars who recognize the shift to community care usually means the private household not "local ties and readily available support networks" (Aronson & Neysmith, 1997, p. 42).

2. Services for people with mental illness remained the responsibility of the Ministry of Health, a decision reflecting the persistence of the medical model in the provision of mental health services (Simmons, 1990). The transfer of the residential institutions for people with IDD has been characterized as a movement towards a social model approach to policies and services regarding people with developmental disabilities. However, as Linton (2021) argues, services and supports for people with IDD in Ontario continue to be influenced by understandings of disability associated with the medical model.
3. During this time period, Ontario's CCACs were not-for-profit provincial government organizations funded and overseen by the Local Health Integration Networks (LHINs). The CCACs were responsible for determining eligibility for and placement in LTCFs as well as determining eligibility for and assisting people to access HCC services (Auditor General, 2017). In 2017, the CCACs were absorbed by the province's Local Health Integration Networks. However, they maintained their role in terms of determining and facilitating access to public LTC services including LTCFs.

Chapter Five

Valuing and Securing the Conditions of Relational Care from the Perspectives of Non-Senior Residents

Introduction

This chapter begins the process of uncovering younger residents' conditions of care by drawing exclusively on the narratives of 18 non-senior resident-participants living in five private, for-profit LTCFs in the Greater Toronto and surrounding areas. These narratives are a collection of diverse, periodically conflicting, often highly personal, and sometimes pain-filled accounts of how and why younger adults come to live in LTCFs, and how they experience and understand the conditions that characterize their situation. For most resident-participants, living in a LTCF is not considered an ideal situation nor one they anticipated at earlier points in their lives. Regardless, they consistently acknowledge LTCFs as places where the complexity and intensity of their medical and personal care needs are most likely to be addressed at this time in their lives. As such, LTCFs are simply but significantly understood as necessary to sustain life. Marnie, a resident-participant, captures this core value when she tells me: “Without [it] we can’t live—or, *I* can’t live” (emphasis added).

While recognizing that LTCFs are necessary for life, it is also crucial to uncover the conditions of care that foster living—that go beyond life sustaining care to care that supports good, high quality everyday experiences and a more fulfilling life. I address this issue by providing an account of what resident-participants experience and understand as valuable and/or positive about their conditions of care. Drawing on the relational feminist disability perspective described in Chapter 1, five key features of positive care experiences emerge from the data: It recognizes and supports autonomy; it is respectful of one’s personhood; it aligns with one’s individual needs and preferences; it involves meaningful experiences; and it is care in which younger residents are active contributors.

Despite differences in younger residents' positive accounts of care, their narratives have one remarkably similar characteristic. They overwhelmingly demonstrate that favourable *interpersonal care relationships*—that is, the presence of positive, quality relationships of care formed and maintained with others—and everyday r*elational care practices*—that is, care-related activities that feature interpersonal relationship-building and/or maintenance—are key to these experiences and understandings. Many of the ways in which younger residents contribute positively to the conditions of care are also relational in character. Further, access to relational care is often secured through their individual efforts to get the care they want and need and resist the more negative conditions. Often, this means drawing on a number of personal resources and capacities. At the same time, the data also indicates the presence of a number of structural conditions within LTCF that appear to facilitate non-senior residents' access to positive, relational care experiences in more consistent and equitable ways.

The Relational Characteristics of Positive Experiences of Care

For non-senior residents, living well in a LTCF means much more than accessing skilled nursing care, shelter and basic personal care. In this study, resident-participants emphasize that the conditions of care they need, prefer, and value supports their autonomy, reinforces their personhood, is individualized to their needs and preferences, and fosters meaningful experiences. Further, most younger residents stress that they are and want to be actively involved in securing the conditions that amount to these qualities of care.

Resident Autonomy and Relational Care

A key component to non-senior residents' positive and/or valuable experiences of LTCFs is resident autonomy. I use the term autonomy referring to the emphasis that non-senior residents place on controlling and directing care practices, as well as having some degree of choice over their everyday activities including the reception of care including its timing, location, quantity, and the type of care being received. In many situations, autonomy in care is about maintaining some semblance of the lifestyle, everyday practices, and structure of these, as enjoyed by the resident-participant prior to living in a LTCF.

Non-senior residents' narratives suggest that developing and maintaining positive care relationships with care providers is key to autonomy-supporting care. Their descriptions of interacting with preferred or "favourite" direct care workers is illustrative of this finding. Jackson indicates that his "favourite" care worker supports his goals concerning rehabilitation. She assists him in reaching his aspirations of using a walker instead of a wheelchair for mobility, in gaining greater functionality in his hand and fingers so he can write and draw more easily, and in improving his verbal communication skills. Through these practices, Jackson develops a particularly close bond with this worker, one that may be characterized as respectful and affectionate. He describes her in the following conversation:

> Jackson: This um, um, this one (Name of PSW). But is gone.
>
> Morgan: Oh, she doesn't work here anymore?
>
> Jackson: Oh my God, oh my God.
>
> Morgan: You like her?
>
> Jackson: Oh my God. Oooh. I don't know man. She's um, "Ok, ok, good, good."…"Ok, ok. This, that, that." …. And just, "No, no, try, try, yes."

> Morgan: She is really encouraging?
>
> Jackson: Yes. Is um, um Filipino but is um, is, I don't know. Me love her. I love her, I love her, I love her, I love her, I love her. Yeah.

Making gains in functionality is only one component of Jackson's autonomy, but it is one he highly values. While it is unclear if the care relationship and more specifically, the affection and preference Jackson develops for this PSW is an outcome of her efforts to support his goals or its precursor, it is clear that his autonomy is strengthened through their care relationship and the relational care practices that are a central component of this relationship.

For many non-senior residents, resident autonomy is not only about making significant functional gains, but also about maintaining some control over the type and amount of care received on a regular basis. Several participants emphasize that they are more likely to receive necessary and desirable support when provided by a direct care worker with whom they have established a care relationship. Catherine alludes to this when describing her perceptions of "good care" and "good care workers". She explains,

> I'm stubborn. I want to be independent…. [The good ones], they listen. And I'm not afraid to go to them for help…. They know me. They know what I'm saying. They know me…. And they know what I'm saying. They encourage me. And they know what I'm thinking. And they encourage you.

Catherine tells me that she receives "good care" from "good workers", who, it seems, emphasize the relational components of care in their daily interactions with her (who know her, who listen to her, who know what she is saying, and who encourage her). When Catherine feels comfortable with a staff member and when the staff member is familiar with Catherine, it is easier for Catherine to guide and participate in her own care.

Relational care is also a feature of autonomy-supporting care because it fosters self-determination over the structure and content of younger residents’ everyday lives. Developing a care relationship with direct care workers results in non-seniors having more input into the timing of care tasks. Julie, for example, indicates that as she became more familiar with the staff at her facility, as they got to know her and her care routines, she had greater input into the timing of personal care. She explains:

> I like to get up at eight, you know, around eight. That’s good for me. They used to get me up really early, and why am I up at 6:30? This is so silly. And I said I didn’t like it…./ Seven is ok. It takes me a while to, you know, brush my hair and wash my teeth and you know, brush my teeth and stuff like that, and that’s pretty much what I do…./ But seven-thirty is a good time for me, or seven is ok. *But they know me now* [emphasis added], so they don’t wake me up.

Most non-senior residents involved in this project indicate that determining *when* care is received is important to them. It appears that self-determining the approximate timing of care tasks is vital to their engaging in everyday life activities that they enjoy. It means they can more easily accommodate the busy work and family-related schedules of long-time friends and family with whom they prefer to spend time.

Non-senior residents' experiences of autonomy-supporting care is also relational in the sense that caring relationships with family and long-time friends can mean getting care *where* a non-senior resident wants it. These relationships are particularly vital when younger residents choose to engage in activities outside the physical boundaries of their LTCF and are in need of some assistance. Several non-senior residents emphasize the role that family and long-time friends play in offering transportation to appointments and recreational outings, and/or accompanying them to activities they have long enjoyed or desire to experience. Marnie greatly emphasizes the role played by her friends in accompanying her on trips and on outings to various areas of the city in which she resides. Marnie describes these outings in terms of maintaining an "independent life", but she also recognizes that close friends are often key to the realization of this independence. Marnie's description of how she prefers to spend her time emphasizes a connection between care relationships and resident autonomy:

> I like to travel with friends. The reason why I want to travel with friends is if something happens to me, they can give me help. I don't travel alone…. Two years ago, I went to [Name of park] on a machine [motorized wheelchair]. Not this one, another wheelchair. Believe it or not, I went down the pathways and park areas, not on the main streets. There is a path from here all the way west to [name of park]. It was very nice actually. I had a friend come with me and we put the batteries of the wheel charger on the back of my chair because, just in case something happened, I could recharge it. And you know what, I went to a [name of coffee shop] and we recharged the chair because the batteries ran out from here to [name of coffee shop], that's near [name of park] anyways. And we stayed there a couple of hours, had a coffee and got more power for my chair. It was very nice actually. I was very happy that I could do it.

In maintaining a number of good friendships, Marnie is able to acquire some degree of informal care. She recognizes them as necessary to her autonomy particularly outside the boundaries of the LTCF in which she lives. With the support of her friends, she is confident about travelling to areas away from her facility and from formal care provision, to test out the limits of her mobility device, and deal with difficult situations if and when they arise.

Personhood and Relational Care

Resident-participants suggest that positive and/or valuable experiences of LTRC often involve care that reinforces personhood. I use the term personhood to represent the desire of younger residents to be understood and recognized as individuals beyond their care needs or position as a resident. For resident-participants, confirmation of personhood tends to mean the sharing of personal histories with others involved in their conditions of care and experiencing care practices that reinforce a positive sense of self. Often, care that affirms and/or reinforces personhood in a positive way is constructed as distinct from experiences where resident-participants feel infantilized, asexualized, stigmatized, and/or where they are identified above all else as disabled or dependent.

Similarly to the way in which relational care is key to resident autonomy, the data suggest that care relationships help ensure the recognition and acknowledgement of a younger resident's personhood beyond that of the care recipient. Catherine's definition of "good care" includes the notion that "good" care providers see her "as a regular person", and Joan tells me the "hands on" staff at her facility are "so good" because they "treat [her] the way [they] would treat other people". Julie similarly expresses that good staff members "treat [her] like a normal person, not 'you're disabled' and this and that and, you have to look after me, this and that. Just a regular person." While such comments suggest that these resident-participants may have yet to adopt a positive disability identity, they also make it clear that care relationships with direct care workers and the relational care practices these providers employ involve assertions of personhood that younger residents highly value. Non-senior residents develop close care relationships with direct care workers that affirm their sense of who they are—specifically, that they are "normal" or “regular” people. Through these practices, residents' appreciation and/or affection for such a care worker is enhanced and the care relationship is reinforced.

Relational care practices also support the personhood of younger residents because they mean opportunities for the expression of different components of one’s identity, and they provide room for sharing pieces of one’s personal history. This aspect of relational care is apparent in the stories both male and female resident-participants share about their favourite or preferred care workers, but gender differences emerge from the data. Several younger male residents describe their relationships with preferred care workers in a way that suggests these interactions offer opportunities for younger male residents to engage in flirting or reciprocal banter. Elton describes the relationship between himself and a favourite PSW in this way:

> Elton: Oh, they [the PSWs] are all nice.
>
> Morgan: That’s good. What do you think makes them good at their job?
>
> Elton: I don’t know. They’re just good. See this one here [yawns]?
>
> Morgan: Yeah?
>
> Elton: You know how guys look at girls? Sometimes you give her the old look. I sometimes give her the same look. She kept saying to me, “Don’t look at me like that.” [Laughs].
>
> Morgan: Oh, you give her a look and she tells you not to?
>
> Elton: You give her the old, you know, “come-on” look. And she says, “don’t look”. [Laughs].

While it is unclear from Elton’s narrative exactly how the worker understands this banter, Elton does not seem to perceive it as unwanted or inappropriate. He infers that these interactions are a way in which he has bonded with this worker, and they seem to provide Eton opportunities to reaffirm his identity as a (hetero)sexual being.

The stories George tells me about his care interactions with a favourite female staff member illustrates the notion that younger residents value relational care practices because they sometimes provide opportunities for the reinforcement of a positive identity. Throughout his narrative, George refers to a specific PSW that he describes as liking “the best”. He emphasizes that he seeks out this PSW when he requires assistance, and when he is looking for someone with whom he can socialize. George tells me that this woman regularly agrees to play cards with him and chat with him about both everyday events and his experiences prior to living in a LTCF. In the following quotation, George describes a common interaction between himself and this PSW:

> George: There are a couple [PSWs] here that I wish I could spend more time with. Like one, her name is [name of PSW], and she says, “If I spent all my time with you, I’d be out of a job.”… She’s got a lot of running around that she has to be with. She says, “Why do you like me so much?” I say, “I like you so much because you look a lot like my very, very first girlfriend. My very, very first fiancé.” [Laughs].
>
> Morgan: What did she say to that?
>
> George: She said, “How old were you when you had your first girlfriend?” I said, “Seventeen.”

The care that George is provided allows opportunities for him to share his personal history, and this appears to reinforce the strength of their care relationship. George’s comments may be understood as flirtatious, but comments he makes to the PSW about her appearance do not appear to be met with antagonism. Instead, they seem to act as a starting point for a conversation where George is encouraged to share stories about his experiences and relationships prior to residing in a LTCF. Through relational care, his identity as a heterosexual man seems to be positively affirmed.

It is also stories about care interactions void of relationality that make apparent the central meaning of relational care to younger residents' personhood. George's stories about his favourite PSW contrasts with what he tells me about the care interactions he has with a PSW with whom he has not developed a positive interpersonal relationship:

> George: Sometimes I think I get better service, er, better care [than other residents].
>
> Morgan: Why's that? Do you think they [the workers] treat you differently?
>
> George: Some do, yeah. Just, one of them treats me like a little kid.
>
> Morgan: One of them treats you like a little kid?
>
> George: Yeah…. I'm a man. I've got two kids, so I'm not a little kid.
>
> Morgan: I thought you were saying before that some of them [the workers] treat you better than the other residents?
>
> George: Some do. Some treat me like garbage.

George does not respond to my questions about *why* some staff members treat him like "a little kid", while others seem to provide him with preferential care. It is clear, however, that the care workers with whom George has developed a positive relationship do not interact with him in ways that undermine his masculinity or disregard his identity as an adult and a father—quite the opposite.

While the narratives of non-senior male residents suggest that care relationships with female staff are especially important to them because they have opportunities to express a (heterosexual) masculine sense of self, both male and female non-senior residents indicate a role for care relationships with female staff members in terms of their personhood. For female residents, the focus tends to be on securing assistance with highly gendered beauty practices. These practices seem important to them in terms of performing femininity and heterosexuality in ways that reinforce a positive sense of self (see below).

Individualized Care Provision and Relational Care

Non-senior residents describe positive conditions of care in ways that suggest many of these experiences involve them receiving highly individualized care. I use the terms "individualized" referring to care activities that are shifted to the individual resident's personal needs and preferences. In most instances, care of this sort seems to differ from, is more than, or goes beyond care provided to the majority of residents at a LTCF. Almost always, such practices involve, if not rely on, the presence of providers with whom younger residents have formed good relationships.

Resident-participants emphasize that they value and want care provided in ways that align with the details of who they are, what they need, and how and when they prefer to be supported. Jackson, for example, appreciates being provided with a packed lunch by the food staff several times a week to take with him to an educational program he attends a distance from his facility. Marnie emphasizes gaining access to support with personal care outside the regular evening care schedule in order for her to attend a friend's retirement party and other nighttime events. Alex and Joan both emphasize the importance of receiving assistance with beauty practices such as putting on makeup and plucking eyebrow hairs. These highly gendered individualized practices seem to both reflect and support the personhood of these younger female residents (see above).

The data indicates that resident-participants associate the likelihood of their receiving individualized care with the extent to which they develop a plethora of positive care relationships with staff at their facility. Younger residents who have developed a rapport with staff are more likely to have less conventional care practices fulfilled. They are provided with care in ways that fits their preferences even when this means care that is more than, different from, or goes beyond the boundaries of what is typically offered to residents.

As a long-time resident of his facility, George has developed care relationships with a wide variety of workers throughout his facility. His efforts in this regard mean that he regularly experiences individualized care. Shortly after we enter the dining area to begin a game of cards, George catches the attention of a female food service staff member who immediately comes over to the table at which we are sitting. The conversation that transpires, and George's explanation of its significance, is a strong example of the association between having good relationships with staff and receiving highly customized care:

> George: [Addressing the food service staff]: Hi (Name of worker), do you have any coffee yet?
>
> Food services staff: Not quite yet.
>
> George: Ok. I just figured I'd ask to find out. It's just 'cause I don't want you thinking there's something wrong with me [laughs]. [Addressing interviewer]: A couple of the staff, if I don't ask for a cup of coffee they'll go like this and stick their finger in the air, like checking your temperature.
>
> Morgan: Because if you don't ask for a cup of coffee, they think that you're sick?
>
> George: Yeah [laughs]. Well, like, they know. Like, (Name of worker), she says, " If you don't ask for coffee, we think you're sick." [Laughs]. Well, I'm a coffee-a-holic and I'm not afraid to admit it. Coffee don't bother me, never has, never will…. See, she was

> waiting for me to come over. And I said, “Can you put the coffee on?” And she said, “Yes. I’ll put it on right now.”

George has developed a good relationship with several of the food services staff at his facility. The staff seem to enjoy teasing him about his coffee “addiction”, and similarly, he enjoys the on-going banter between them. It seems these women prepare coffee for him whenever he asks. They even anticipate such requests when they see him enter the dining area. This is a care practice that clearly goes well beyond standard practice at his facility, where most residents receive beverages at mealtimes or at set times throughout the day when the beverage cart is wheeled around.

Care relationships help ensure the reception of care that tends to fall outside the boundaries of care practices regularly received by residents of a given LTCF. Joan aptly refers to these individualized practices as “the little extras”. Many of the “little extras” described by female non-senior residents involve gendered beauty practices such as putting on make-up or having one’s hair styled. The data suggest that sometimes, this type of support can be difficult to access. However, as the following conversation with Alex suggests, younger residents perceive they are much more likely to receive care of this sort when a care worker with whom they have a good relationship is around:

> Alex: Actually the nurse that comes tonight, she is my favourite nurse. She is really good.
>
> Morgan: Yeah? Why is she your favourite?
>
> Alex: Because she helps me out all the time. And I’m not scared to ask her to help me do this for me, do that. She’ll do it, and she’ll also, she tweezes my eyebrows [laughs]…. You learn who you like.

The care relationship Alex builds with this PSW helps ensure she receives care that meets her personal needs even if the specific practice goes beyond what is regularly offered to residents, and it is clear that in providing her with the little extras, this direct care worker has become someone Alex both likes and trusts enough to ask for assistance with these types of care practices.

Developing care relationships with co-residents also improves younger adults' access to individualized care. Resident-participants tell me stories about co-residents who provide them with the kinds of care not easily attained through formal services. The most poignant example comes from the narratives of Norah and Alex, two female co-residents who are both involved in the study. These women develop an interdependent care relationship through which they help fill one another's unmet care needs. Norah indicates that Alex provides her with social and emotional care. Often experiencing the conditions of care as boring and repetitive, Alex is one of the only people Norah perceives as interacting with her socially on a regular basis. Further, during the time I spend at their facility, I observe that Alex will call the PSWs for assistance when Norah requires it.

Norah also provides informal support to Alex. In the following conversation, Alex highlights the care practices that she completes without formal assistance. But she also makes it clear that Norah compensates for some of the gaps:

> Alex: Well, I do my own—brush my teeth. I do my own flossing. I wash my face at night with my cloths and […] what don't I do? I can't do my laundry (laughs).
>
> Morgan: Ok (laughs).
>
> Alex: They do that for me here, things like that I don't do. But most of the things I can do. I try and do whatever I can. And see, I can brush my hair. I'm right-handed but I use

> this hand to brush my hair and everything. And sometimes it gets that I can’t do this side. The good thing is, my roommate Norah, she helps me out. The other day I go, “Norah, you’re going to laugh at me.” Because I was at the hospital and my daughter turned around and said, “Oh my god mom, you have grey hair—greys in your hair.” I go [to Norah], “You’re gonna pull them out for me.” (Laughs). And she takes my tweezers… there’s four, so she pulled them all out. “Thank-you very much, Norah.”

The above example illustrates that the development of a positive relationship between co-residents can result in the reception of more customized care than is easily available from formal care workers. Alex and Norah each draw on their relative capacities to provide care that meets some of the other’s needs. Alex, who is able to easily communicate verbally with others, provides Norah with social support and helps her gain the attention of care workers when necessary. Norah, whose impairment has relatively little impact on certain aspects of her physical mobility, assists Alex with beauty practices that require manual precision.

Meaningful Experiences and Relational Care

Non-senior residents indicate that “meaningful experiences” are absolutely critical to living well in a LTCF. I use this term to refer to activities or practices through which younger residents feel excitement, interest, motivation, purpose and/or joy. For resident-participants’ positive conditions of care are characterized by enjoyable social and recreational opportunities and regular access to entertainment. Several mention they enjoy live musical performances that occur periodically at their facility. Social activities revolving around food and drink, participation in fitness activities and physiotherapy, playing instruments, gardening, bingo, and other games are also described as favourite activities. Non-senior residents also highly value programs organized by their facility that take them into the larger community such as trips to local malls, restaurants, or a movie theatre. Such experiences contrast greatly with the stories of those who characterize their everyday practices as boring, monotonous, inciting loneliness, and/or repetitious.

Resident-participants who indicate having regular access to spaces and programs outside their facility often construct these opportunities as vitally important to their overall health and well-being. Marnie, for example, especially enjoys engaging in activities outside her LTCF and does so on almost a daily basis. She explains:

> I go out. I go either to the gym … or I go to a mall or I go to the [museum]or [art gallery] or science center. I do like doing things…. I like to keep busy. I don't know why, but I do like to keep busy, so. Just like, for example, seeing my room is not, it's not good. And I told the girls [PSWs], if I ever want to stay in my bed, in my room, that's a sign that something is wrong. Anyways, I like to keep busy because basically, I want to do things. And that's the way I do it.

For Marnie, participating in meaningful activities is a key indicator of her health and well-being, so much so that she understands staying in her room as a sign of poor health.

The narratives of younger residents strongly indicate that meaningful experiences almost always involve others with whom they have a positive relationship. George feels joy when he spends time with several younger co-residents at his facility. Several of these co-residents have been living alongside George since the time he entered Sherwood West. On a typical day, George enjoys wheeling around to different floors to chat with these friends or to play cards or board games with them. He also emphasizes that these co-residents seek him out when they are looking for something to do. These relationships appear to be especially important to George given he only receives occasional visits from family members, and he does not leave his facility for social activity unless a day trip has been planned by the recreation department.

While George indicates that the care relationships he has developed with his non-senior co-residents help ensure meaningful experiences on a regular basis, such a situation does not appear to be common. More often, non-senior residents identify family and long-time (non-resident) friends when they describe joyful and interesting experiences. When I speak with Julie about the types of activities she enjoys on a regular basis, she tells me she spends much of her time with her husband, who visits her everyday. She also greatly values the time she spends with a group of long-time (non-resident) girlfriends. These women pick her up twice a month from her facility and they spend the day participating in activities in the larger community such as going out for lunch and shopping. In the following conversation, it becomes clear that she prefers meaningful experiences of this sort:

> Morgan: Do they [the recreation staff] ever have outings where you go into the community? The movies or the shopping centre?
>
> Julie: Yeah. I do that with my friends. I do it with them. I’ve never done it with them here. You know, they have a bus and they take you places. I’ve never done that with them.
>
> Morgan: So you have friends that come in that you go out with?
>
> Julie: Yeah. I have friends and I figure that’s better. I’m with them around and it’s better for me.
>
> Morgan: So, do you have visitors a lot?
>
> Julie: Every other week, my friends come. About five of us. So, usually we go out.
>
> Morgan: What kinds of things do you do?

> Julie: Well, we went to the outlet mall. I like it there. We go around there and look at this and that and just have lunch and stuff like that.

While Julie tells me she enjoys participating in similar outings organized by her facility, doing these activities with long-time girlfriends are more enjoyable or “better for [her]”.

The actions of resident-participants with whom I struggle to communicate also suggest an association between meaningful experiences and long-time care relationships. My interactions with Shannon suggest that maintaining long-time relationships with family members following placement in a LTCF is necessary to her experiences of joy. Shannon does not communicate verbally, and the nature of her impairment means her physical movement is minimal. In many ways, it is difficult for me to recognize the aspects of her conditions of care that she most values. However, watching her interact with a family member makes it clear that she experiences a great deal of joy from this relationship. As I describe in my field notes, she smiles and looks content in reaction to her family member tousling her hair. She clearly experiences pleasure from this interaction (and indeed, I note that her family member also seems to be experiencing joy).

Similarly, I observe Mallory experiencing a great deal of joy interacting with several family members over the telephone. Mallory is on the telephone at the nursing station when I come to meet her. A family member has called to wish her a Happy Birthday. Although she uses few words, her vocalizations and expressions suggest a particularly enjoyable moment.

While most resident-participants emphasize care relationships with family and long-time friends, several male residents describe joyful experiences that involve care relationships with staff members. Andor greatly values the relationships he has developed with some of the cleaning and maintenance staff at his facility. He describes one such relationship in the following quotation:

> Andor: Oh and there is a cleaning lady, … I love her. And then there’s another one…. Oh, I love to talk to her. She always comes in here and we talk for five, ten minutes. But she can’t stay long because she’s got to do her job. But every time she leaves, she tells me she loves to talk to me.
>
> Morgan: Yeah? She tells you that too?
>
> Andor: Yeah. And I love to talk to her. You know, there is something in common. We can talk about many things. But the rest of these people, I have nothing in common with. I just say, “Hi” and “Bye”.

This quotation represents one of the few times Andor speaks positively about his conditions of care. Andor receives very few visitors. He describes a close friend who does not make any effort to call him despite the fact that he has maintained a personal cell phone for the duration of the time he has lived in his LTCF. He also has few co-resident friends—a situation he clearly associates with being younger, male, and neuro-typical living amongst those he perceives not to not share these characteristics. However, Andor does describe spending time with a few staff members who engage him in conversation as they complete their daily cleaning and maintenance tasks. These interactions are an on-going and seemingly exceptional source of enjoyment for him.

The ways in which Steve describes the involvement of recreation staff in the activities he most enjoys is also suggestive of the relational characteristics of meaningful care experiences. Steve tells me apart from his aging parent, who is finding it more and more difficult to visit on a regular basis, he does not receive many visitors. He does, however, greatly enjoy participating in various recreational programs run at his facility. In fact, we schedule our interview times in such a way as not to prevent him from attending such activities. Steve seems to define the quality of a given recreational program in relational ways—that good programs are run by good staff members with whom he has developed a relationship, and who provide the program in a way that demonstrates they care about the residents. At one point during our conversation, he spontaneously announces,

> Steve: I love painting, oh. Paint, paint, paint. I paint with (Name of recreation staff). She's good. She calls herself [nickname], but she's so nice.
>
> Morgan: What does she do that makes her so nice?
>
> Steve: She smiles and does lots of different programs.

While Steve does not always answer my questions about why he so enjoys particular programs at his facility, his descriptions of the activities he most enjoys always include the name and a complimentary description of the staff member running that program. There is a clear connection between the joy and sense of accomplishment Steve gets from particular activities and the affection he has for the involved staff member.

Contributing to Care in Relational Ways

Resident-participants' make it clear that they are often actively involved in positive and/or valuable experiences of care. Younger residents contribute to the conditions of care in a myriad of ways. Some assist new care staff by showing and/or telling them how to provide careful, appropriate personal support. Many are responsive to care providers who practice care in ways they value. Most non-senior residents emphasize that they engage in the activities of daily living with as little support from others as possible, and some are committed to doing regular physical activity and various forms of therapy not only because they understand this as supporting their efforts to maintain or enhance their own involvement in their care, but also because it lessens the workload for direct care staff. A number of resident-participants also tell me that they provide informal care to co-residents and/or family members and long-time friends.

Many of the contributions resident-participants make to their conditions of care are relational in character. They have the intention of and/or are practiced in ways that facilitate the development and maintenance of positive care relationships. Younger residents actively participate in developing and maintaining reciprocal relationships with staff members. Here, I use the term reciprocity to describe the constructive responsiveness of non-senior residents to those involved in the provision of care they value. Reciprocity often involves displays of respect, recognition, gratitude, and/or collaboration. Andor's description of the relationships he develops with a cleaner at his facility (see above) is a strong example. He emphasizes their commonality—clearly recognizing her personhood. He also indicates that this relationship is beneficial to the worker—that she too greatly enjoys their social interactions.

Resident-participants commonly engage direct care workers in informal conversations during care practices as a means of responding to the provision of good care. Several indicate sharing jokes with staff, talking about current events, or sharing stories about their childhoods, family and life before living in a LTCF. When I ask her to explain what she means by a "good care worker", Marnie's response makes it clear that reciprocities are reserved for care workers with whom she has developed a positive relationship and those who provide support carefully, respectfully and relationally. She tells me, "Like, for me, I've told you before, when someone is not nice, I be quiet. When someone is nice, then I talk, talk, talk."

Non-senior residents also contribute to care in relational ways by creating living spaces that support the development of care relationships with staff, co-residents and other visitors. What stands out most from the range of bedrooms I observe is the extent to which rooms are customized to reflect various aspects of a resident's identity, interests, and personal history. Almost invariably, pictures, artwork, gifts, mementos, and newspaper clippings are displayed prominently. These tokens facilitate interpersonal interactions, providing residents the opportunity to share stories and to become known to workers, co-residents and visitors.

This practice is particularly valuable in situations where care workers and other visitors have difficulty verbally communicating with a resident. Through a number of tokens, Mallory, whose impairment greatly impacts her verbal articulacy, communicates and shares her stories with visitors. She spends much of our time together showing me photographs of family members who have passed away as well as newspaper obituaries of family and former co-residents she keeps around her room. Since I am not very familiar with the ways in which Mallory communicates, I consider her efforts to explain her relationships to these people to me significant. Using the contents of her side table, her purse, and the photographs and effects posted on her walls and displayed on her bedside table, this becomes a topic through which we build a rapport, and I gain a stronger understanding of the larger context of Mallory's life.

The way in which William has arranged his personal belongings within his room greatly assists him in developing relationships with care workers and co-residents. He uses this set-up to afford him opportunities to engage in personal conversations about his life history. Upon entering his room, information about William's hobbies and interests, and his former employment are on display. He points to photographs of his wife and extended family, many of whom have passed away. He asks me to read his wife's obituary posted on his wall, noting that, "practically everybody does".

Non-senior residents also contribute to their conditions of care in relational ways by managing or modifying their care needs, schedules and/or expectations for the benefit of others.

Resident-participants recognize the communal nature of their LTCF and the impact that their care has on both co-residents and staff. Matthew's description of the care relationships he tries to achieve with the direct care workers at his facility is indicative of the positive relational contribution he makes to his conditions of care. When I ask him to characterize his relationships with the direct care workers at his facility, he tells me,

> I would say I'm easy to get along with. If not, why not?... The fundamental thing is respect on both sides. What goes around comes around….Like, if there is something that I would like to have done, they'll usually do it, and if they can't, they say to me they haven't got the time and I respect that….If somebody needs help, I think if they're patient, they get the help. If they're dealing with me, I can wait. Nothing is ever that serious…. I think the easier I make it for them, the easier they make it for me.

The way in which Matthew modifies his preferences and expectations regarding the reception of care may be understood as a form of reciprocity. He stresses that his relationships with direct care workers are almost exclusively positive—an outcome he associates with his efforts to respond to the direct care workers at his facility in ways that recognize the intensity of their workloads. He does this by accepting care when it is offered, being patient, and being respectful to his care workers. These also benefit Matthew. By doing what he can to make it "easier" for the direct care workers, they in return, make the reception of care "easier" for Matthew.

Reciprocating good care by modifying or abandoning one's preferences when it comes to the reception of care is not always easy for younger residents, nor is it a natural or automatic contribution. It is clear that this practice often results in unmet needs and frustrations, and can even lead to embarrassment and/or health and safety issues. Marnie values and greatly desires greater control over the timing of her personal care. She emphasizes that being subject to the care routines set by her facility makes her feel that her “independency is gone” (see Chapter 7). At the same time, she regularly modifies her preferences in order to support the direct care workers who provide her with care. When discussing the timing of her bedtime care routine with me, she tells me,

> I know I have to accept it. They [the PSWs] have shifts. They work from six to two and then two to ten and then ten to six. So I have to accept the fact that they have shifts. And why they don’t change the shifts, I don’t know. But anyways, they have shifts, and for them to leave [work] at ten o’clock, I should try to be in my room for eight o’clock. It would be really kind of persnickety if I wanted to be in my room at nine-thirty.

Marnie is critical of the timing of PSW’s shifts. She understands, however, that the PSWs do not control this component of their work. She believes that when she accepts care according to a predetermined routine or schedule it benefits her direct care workers by helping ensure they can leave work on time. However, Marnie and other resident-participants also indicate that being willing to engage in such reciprocities is personally challenging. Several describe undergoing a process of adjustment upon entrance to LTRC whereby they “change a little bit” (Joan)—making a conscience and continual effort to modify and sometimes abandon their everyday practices, as well as their expectations and/or preferences concerning care as they come to recognize both the communal nature of their living conditions and the likely permanence of these circumstances.

While it is clear that these types of practices are understood by resident-participants as beneficial to care workers, a comment by Alex suggests that they may also be for the benefit of younger residents themselves. In the following conversation, Alex infers the value of carefully selecting when she asks for assistance from the PSWs in her home area in terms of the ensuring her care needs are responded to in a timely manner:

Morgan: How do you let the staff know if you need assistance with something?

Alex: Buzz.

Morgan: And does that work well?

Alex: Oh yeah. Because when I buzz, they come right in.

Morgan: Yeah?

Alex: And say, “Oh Alex, what do you need?” Well, what else do I need? They go, “Well, you are the one person who usually doesn’t buzz.” Like at night, I don’t buzz unless I really need something. They go, “Yeah, you don’t usually buzz.”

Morgan: Yeah? So, because you don’t do it [buzz] very often they think, “She must really need us”?

Alex: Yeah, yeah.

Morgan: And then, they are good at coming quickly?

Alex: Yeah, oh yeah.

In this conversation, Alex indicates that her patterns of behaviour in terms of asking for assistance are well-known by care staff. It appears that when she calls for care (particularly at night), direct care workers recognize this as a genuine and urgent request because this is a practice that is out of character for Alex. As such, her request is prioritized if not met immediately.

For some resident-participants, making the choice to move to a LTCF is understood as a primary way in which they are contributing to the wellbeing of and helping to maintain a positive relationship with their family member(s). Catherine and Freeman each describe the value of gaining entrance to a LTCF in terms of getting the care they need without family members having to stress, worry, or experience the physical challenges associated with providing care to someone with complex medical and personal care needs.

For Julie, gaining entrance to a LTCF is associated with ensuring both her husband's and her own health and wellbeing. She explains,

> Well, actually, when I first found out that I had—well, not when I first found out I had (Name of impairment), I knew I had [it] for years. But then, all of a sudden, I kept falling down. My husband was getting upset because he really couldn't help me because he was afraid he would hurt me. I said, "Just throw me on the sofa. I'll be fine." But you know, it's not really good to be like this. So anyway, I had my name in here …. It was hard for my husband, you know? He was getting to be an old man. He can't look after me that much.

Julie tells me that her decision to live in a LTCF was a difficult one, but the right one for her and her husband because relying on him to fill her care needs was not a good situation for either of them.

Non-senior residents also contribute to the quality of caring relationships by refusing to ask family and/or long-time friends for any or too much support once they have entered a LTCF. For example, Alex often relies on her daughter to provide support with beauty practices such as dying her hair or tweezing her eyebrows because these types of care can be difficult to attain from formal care workers as frequently as she prefers. She also relies on her brother to bring her supplies she cannot easily attain within her facility. She tells me, however, that she is careful not to be too "demanding" of the help of family members. She explains, "Like, whenever I need something I'll just tell my brother, 'Bring it over here.' But I try not to say, 'I need this. I need that.'

Matthew also indicates that he contributes positively to the relationships he has with a family member by tempering his requests for help. He tells me that he always has a “to-do list”—a list of tasks that are not easily fulfilled because the type of support he requires to complete them is not regularly provided by his facility. Matthew tells me that his wife knows his “list” and is very helpful and knowledgeable about the items on it. But he does not ask her for too much help from her because he recognizes that she “likes to play bridge” and has a “very high workload herself”. These and similar comments suggest that younger residents understand that minimizing their requests for support with care practices beyond that provided by formal providers is essential to maintaining the quality of relationships with family and friends.

The relational character of younger residents' contributions to care and the positive role these contributions play in terms of the conditions of care is revealed when resident-participants discuss the ways in which they provide informal care to co-residents and/or engage in activities that benefit the LTCF as a whole. Female resident-participants often tell stories that indicate they advocate on behalf of other residents. Julie and Joan both use their “voices” to support co-residents they perceive as experiencing barriers to good quality care. Julie tells me, “One hand I can [only] use a little bit, so I don’t help anybody, I can’t. But I can tell people. ‘Give (Name of resident) some water. She hasn’t had any water. Water for (Name of resident), please.’ And they’ll give her water.” Marnie tells me she encourages the senior women she sits with at her dining table to speak up for themselves when a PSW is too rough or unkind while providing personal care. And Joan adopts the role of a resident advocate at her facility. She participates in the Resident and Food Councils and works with a recreation staff to better ensure residents have a say in the film shown on movie night. She also understands her participation in this project as an act of advocacy. She explains:

> I'm here to be a voice to those who can't use their voices. So, I just want to be here to stand up for those that can't…. I just want for my voice to be heard for those that maybe don't. I've gone through a lot of residents since I've been here and it's been hard, but I remember them.

It is less common for men in this study to describe their contributions to care in ways that suggest an element of advocacy. Yet, younger male residents clearly contribute to their facilities in relational ways that benefit co-residents and staff members. The first thing Elton tells me about his typical day in LTRC is, "Well, I used to uh, take down the wagon—the clothing wagon, um, the beverage wagon, and […] if anybody had correspondence to go down to the, the um, the main desk downstairs, I used to take it." Steve tells me it is his role to assist a staff member with the daily fitness program carried out at each home area in his facility. He describes with great enthusiasm (and repeatedly over the course of our time together) the nature of this responsibility:

> Say, in (Name of home area), ok? What we do is uh, with (Name of instructor), ok? And I go with her over there. Balls and hoops. And then over to (Name of home area), ok? And then she comes with the weights and brings all the other people in there like that. And [we] have a program over there, hoops and balls and then weights. And after that, I clean it all up—all the balls and hoops. Then I go over there, in the corner like that.

While these and similar practices are constructed by non-senior residents as beneficial to others with whom they live, it is also apparent that these contributions enhance younger residents' own experiences of living in a LTCF. Some efforts to foster positive conditions of care for others enhance the likelihood that younger residents will develop positive caring relationships with co-residents and/or staff, and often, these practices are a source of meaning. Being an advocate for others supports female residents in having their own opinions heard. While the “jobs” that male resident-participants engage in seem to offer opportunities to demonstrate autonomy.

Securing Experiences of Positive, Relational Care

Resident-participants value, prefer and want care that supports autonomy, reinforces personhood, is individualized, and fosters meaningful experiences. Further, most younger residents prefer care in which they are active contributors. Caring relationships and relational care practices foster “good care” of this sort. But not all experiences and understandings of care are positive, and certainly, not all resident-participants have the same access to relational care of the sort they value. Non-senior participants describe a number of individual ways in which they secure it. They also draw on these means to resist or avoid “bad” care, and/or to work around any barriers to care that they come across. They do this by asking for the care they want and need, by going to get it, by drawing on family and friends who are willing and available to address the gaps and/or help them deal with the problems, and by paying for it.

Being “Vocal”

Several resident-participants indicate that being vocal—that is, asking for care when they want it and communicating their dissatisfactions—greatly assists them when it comes to securing the sort of care they want and value. As Marnie explains it, “I’m vocal. That’s one advantage I have. And when something is bothering me, I try to say it nicely to the nurse or the director of this place here.” While non-senior residents communicate their needs and preferences in a variety of ways, Marnie’s comment suggests that having the ability to communicate verbally and with relative ease is a particular “advantage”.

The relative ease with which Marnie gets the care she needs differs quite drastically to some of the challenges Catherine describes. Catherine experiences impairment in a way that often impacts her speech. At times, she uses a computerized device that she types into to make vocalizations. It also prints a text copy of her words. This process takes time, and a great deal of manual dexterity is required to operate this device. Catherine’s hands are also impacted by impairment. As such, she much prefers to use her own voice to communicate, but this requires time and effort particularly on the part of care workers who have not (yet) become adept at understanding the way in which she speaks. Given this barrier, Catherine has come to define poor care in terms of the “times you get it when you don’t want it”, and poor care workers as the PSWs who “don’t have time” to listen and to support her, particularly in terms of her participating in her own personal care.

Taken together, Marnie and Catherine’s narratives suggest that the ease with which one can communicate their needs verbally matters when it comes to getting the sort of care one wants the way they want it. Being vocal is also a privilege when it comes to developing positive interpersonal relationships with staff members within the context of the LTCF. George, for example, makes use of his verbal social interactional skills, demonstrating them to me as we travel around his facility. He continually engages staff in short, often humorous conversations—all the while filling me in on their “inside jokes” or the nature of the personal connection he has with that particular worker. Even though these interactions tend to be quite brief, George’s ability to interact in this way greatly facilitates the positive interpersonal relationships he maintains with what appears to be a plethora of care workers. It is also significant that George has lived at his facility for close to a decade. The continuity of these brief interactions appears enough to maintain their well-established bonds.

“Get[ting] Around” the Gaps and Issues

The narratives of some resident-participants indicate that they draw their capacity to travel around their facility and/or the community surrounding their facility to secure care of the sort they value and/or to resist potentially negative care experiences. George tells me that in order to get good care, one has to “go looking”. Rather than ringing the call bell and waiting in his room to get assistance from a PSW or nurse, George wheels around his unit in his motorized wheelchair until he finds a worker he knows “is nice”. He also makes sure the kitchen staff he prefers assists him at breakfast most mornings by strategically placing himself at the table for which that staff member is responsible.

It is common for resident-participants who have the capacity to leave their facility unaccompanied and often with the use of a motorized mobility device, to emphasize that they choose to do this on a regular or even daily basis in order to access meaningful experiences. Jackson leaves his facility at least three days a week to go to a community-based education and support program aimed at people with similar impairment-types to his. He highly values these opportunities and tells me that he is so exhausted after his days at “school” that he does not mind the rest of his time he spends at his LTCF. He likes this time to rest and regain his energy. Jackson’s situation contrasts greatly with Norah’s. Norah does not leave her facility, does not receive regular visitors, and she indicates that she has experienced major barriers in terms of accessing regular meaningful experiences. She characterizes her everyday experiences at her LTCF in terms of boredom and tells me she would participate in just about any program she was invited to “cause that kills time”.

Accessing the community at will impacts younger residents positively because it assists them in filling perceived gaps in the care offered at their facility, and in terms of avoiding poor care. Jackson leaves his facility to gain access to a program that better supports his specific rehabilitation goals, while Marnie takes accessible transportation to an accessible gym so she can workout on a more consistent basis. Andor uses his motorized wheelchair to travel to a grocery store in close proximity to his facility several times a week. He purchases food that he can prepare using a microwave or kettle in his room, explaining that he greatly dislikes the food offered at his facility.

Often, getting around with little assistance and at will supports care relationships because it improves younger residents' access to family and friends who live outside their facilities. Alex, for example, uses her motorized wheelchair to leave her facility once a week to visit her parents who live nearby. Neither Steve nor George leaves their facility on a regular basis, but the ease with which they get around their facility—having both the autonomy and equipment to do so—means they spend much of their days socializing with co-residents and staff members whose company they enjoy most. In fact, Steve asserts that he knows practically everyone at his facility regardless of the unit in which they live or work.

Involved Family and Friends

Despite the fact that many younger residents make concerted efforts not to rely too much on family and/or long-time friends for informal care (see above), their narratives indicate that having family and friends who visit regularly and are willing to provide some degree of support contributes positively to the conditions of care. Family and friends play a key role in filling perceived gaps in formal care provision. They take resident-participants to visit additional family members and long-time friends who live outside the facility. They organize and accompany younger residents to social activities, and while traveling away from their facility (see above). Family and long-time friends also offer assistance with the "little extras" such as changing-up the clothing in their closets to reflect the changing seasons, bringing in and assisting them with meals, shopping with or for them, and assisting with beauty practices.

The data also indicates that securing access to individualized care is sometimes facilitated by family members who are regularly involved in younger residents' care. Some resident-participants indicate that they get care when they need it and how they want it because family members are involved in and advocate for them when it comes to the development and yearly re-evaluation of their care plans. Some family members are also involved in the Family Council and/or in the Residents Council in situations where the younger resident wants a support person to accompany them. These councils not only act as advocacy groups, but they often engage in fundraising and other activities that help secure better conditions of care, for example, in the form of putting on social events. Matthew mentions the advocacy role played by his wife—from whom he receives visits many times a week. He refers to her as his “plan B…, [his] next choice”. Matthew explains that while he tends to address problems with his care on his own, he will ask his wife to provide extra support in this area whenever he deems it necessary.

Having a “few extra dollars”

Having access to financial resources also facilitates younger residents’ access to positive and/or valuable care experiences including relational care. Those who leave their facilities to engage in various activities and programs they find joyful and/or interesting are responsible for the associated costs. Marnie, for example, pays for public transportation and a gym membership—albeit she does tell me that the cost of some of these services are reduced for people with disabilities. Alex draws on her own money to ride public transportation to a nearby mall and to pay for food to eat while she is absent from her facility. Some social and recreational opportunities organized by LTCFs also have additional costs to residents. Trips to the movies, the mall, or other locations in the community often involve additional fees, as do some facility-based activities including a social club where residents order food from a restaurant once a month. Younger residents who do not have robust financial resources on which to draw may miss out on some or all of these potentially meaningful activities.

Marnie's discussion of this issue suggests that income disparities may also act as a barrier to younger residents forming interpersonal relationships with one another. When I ask her if she spends much time socializing with the other younger residents at her facility, she explains:

> Uh, we tried to get together. It didn't occur. We have different lifestyles, that's the other thing. You know, I was hoping to find someone that would enjoy things like me, but the other factor is money. I've got a few dollars and the younger people here don't seem to have money…. Maybe that's a sign that I should try to do the things I like doing with friends. Like, a month ago I went to see (Name of play) with a friend [who lives outside South River Point].

Marnie recognizes that differences in "lifestyle"—by which she seems to refer to variabilities in the social and recreational activities younger residents experience as meaningful—may contribute to the challenges she has forming friendships with her non-senior co-residents. But her comment also suggests such differences have much to do with having access to the economic resources necessary to pay for various activities.

The elements of care younger residents associate with having a private room also suggest that having a few extra dollars means greater access to care of the sort younger residents value. In Ontario, residents pay a monthly co-payment fee set by the province based on their accommodation (see Introduction). Private rooms have the highest fees and are not eligible for the rate reduction program. Non-senior residents suggest that being able to afford private accommodation enhances one's experiences in LTCFs because it affords them privacy and access to a quiet space.

Having a private room matters to many resident-participants. They suggest this means greater opportunity for autonomy and positive expressions of identity as well as personal and/or intimate interactions with others. Catherine tells me she prefers her current living environment to that of her previous facility because here, she has her own room, which she explains, allows her “more freedom”. I come to understand that having more freedom means she feels freer to do what she likes within the confines of her room. In contrast, William, who shares his room with one roommate, makes a disfavorable comparison between the extent to which he has decorated his room using various personal objects and the extent to which a non-senior co-resident has decorated her room by explaining to me that because hers is a private room, she can decorate as she wishes, and she has more room for her personal items.

Access to privacy and a quiet space facilitates interpersonal relationships between younger residents and their family and friends as well as between younger residents and care staff. Privacy for when one’s romantic partner comes for a visit is important to Joan and Julie who both have partners who live outside the facility and come to see them on a regular basis. In contrast, Elton’s bed is located in a ward-style room that he shares with three roommates. He tells me that it is extremely difficult for him to find a place in his facility where he and his girlfriend can be alone (see Chapter 8).

Structural Facilitators of Positive, Relational Care

Where possible, resident-participants draw on a variety of individual resources and capacities to secure care of the sort they value and to resist. From a health care equity standpoint, this is a concerning finding. Younger residents do not all have the same access to the types of individual resources that appear to facilitate access to relational care. Non-senior residents are in different financial situations, some experience greater barriers to having their “voices” heard and to being known by care staff than others, not all have the technology or personal assistance they need to get around their facilities and/or to engage in the larger community, and some have few family and friends available and willing to provide support when needed. However, the data also suggests that certain structural conditions facilitate younger residents' access to positive relational care.

“The best” Staff Members and Conditions of Relational Care Provision

Almost always, younger residents’ experiences of positive, relational care involve staff members who are adept at the relational aspects of their work. The data suggests that non-senior residents understand positive experiences of care within LTCFs as largely determined by the quality of staff. Resident-participants are quick to identify the workers they prefer and to indicate that good facilities and “the best” units within facilities are characterized by the presence of superior staff. When I ask Joan to to explain why she characterizes the staff at her facility as “excellent” and “so good”, her response emphasizes their capacity to provide care in relational ways:

> Morgan: Why do you think it is “so good” here? What makes it “so good’?
>
> Joan: Staff members—the ones that are hands on.
>
> Morgan: They’re really good at what they do?
>
> Joan: Yes.
>
> Morgan: What is it? Is it their skill? Is it other things?
>
> Joan: I think it’s skill, it’s passion, it’s—you need to be treated the way you would treat other people.

While linking the quality of a facility to the quality of the direct care providers, Joan's comments indicate that the way in which staff members treat residents is especially important. This is a common sentiment among resident-participants. The data clearly suggests that positive experiences of care are about more than the completion of tasks.

Overwhelmingly, resident-participants suggest that good quality staff are adept at interacting with residents on a social level. They are easy to converse with, to engage in on-going banter or debate, and often, they demonstrate a good sense of humour. Further, these staff members make and value opportunities to build interpersonal relationships with residents. They listen to residents, demonstrate empathy and understanding, and are willing to share personal stories and experiences as a means of developing and maintaining connection. Whether or not staff members are "hands on" as Joan emphasizes, whether they serve food as George describes, or where they clean your room as Andor discusses, those who practice care in relational ways are most valued by younger residents.

Many non-senior residents seem to understand the attributes of staff members who provide care in relational ways as resulting from innate, often gendered personal traits stereotypically associated with care work—although experience and training are also, albeit less frequently, mentioned. My conversation with Matthew about the staff he characterizes as "excellent" is one example:

> I think they do a pretty good job [here] and the staff is excellent. (Name of nurse), she's the captain, and she is very good at what she does. She is a qualified nurse and she is A-1…. / I really respect her opinions…because she expresses it very matter-of-factly. And she's—she also has a very good sense of humour. She has a very—her sense of humour is key.

Matthew’s description of the care workers at his facility who are excellent at their jobs suggests they possess technical skills related to their education and training. At the same time, he emphasizes the importance of social competence—that it is the way the nurse speaks to and shares humour with Matthew that he especially values.

Time to Care

Although non-senior residents attribute a variety of individual skills and traits to the relational ways in which their preferred care workers provide care, the data also suggests a number of conditions that support or in which relational care provision is likely to flourish. The ways in which care work is organized and delivered is key. Resident-participants’ stories about the positive and/or valuable aspects of care suggest that time matters when it comes to the provision of care in relational ways. Marnie seems to recognize the importance of time when she compares the characteristics of the the staff members she prefers, to those from which she do not like to receive care:

> I like the ones [care workers], to be honest, that have a good sense of humour, I do. They have a good sense of humour. Not everything is funny ha, ha, they have shit to do, but, you know? I like the ones who use humour because I can use it back to them. All that stuff…./I don’t like the ones that say, “Oh we don’t have time. We can’t stay here all day. I’m in a hurry—in a rush.” You know? I don’t like that.

When Marnie compares care workers who take the time to share humour with her to those who are rushed to leave, her comments suggest that time is central for care provided in relational ways. In this example, taking the time—even briefly—to demonstrate a sense of humour seems to be understood in terms of recognizing the resident as a person rather than an object or task to be completed as quickly as possible. The example Marnie provides indicates that some staff members will find time to provide relational care even when they have very little of it, while others will not. But it also suggests that perhaps under different conditions, where staff have more time, it is more likely that care will be provided in more relational ways.

Continuity of Care

When resident-participants describe their preferred care workers and the ways in which they provide care, their comments indicate that continuity—meaning the provision of care by a consistent provider or set of providers over time—is a common characteristic of these relationships and related practices. For example, when George describes his efforts to place himself at the dining table of a preferred staff member (see above), his comments suggest that continuity of care means getting more individualized care because the workers "get to know what you like and what you dislike." Similarly, continuity of care means the night staff at Alex's facility respond to her call bell in a timely manner (see above), and it also means that when Celine—who hates to miss her favourite recreational programs but sometimes forgets the schedule—does not show up at a program, a recreation staff who has come to know these prefers, will come by Celine's room to remind her.

Male residents tell stories that suggest continuity of care is important to them when it comes to receiving assistance with the more intimate forms of personal care. When I ask Steve, "What do you think I need to know about living [at your facility?]", he provides me with this answer:

> Steve: Um, well, for example, when I want to have a shower, therefore anyone who wants to have a shower has to make sure you get showered with the same person you do before, [so] you know, [you get them] every time….
>
> Morgan: So, you have to have the same person shower you every time?

Steve: Yeah, so they always know exactly how to handle certain situations. See, I go in and sit like that and they shower me, and it's perfect.

Morgan: Have you told her how you like to be showered?

Steve: They know. They know to water me down first, all over like that (demonstrates with his hands and arms how he is showered), right?

Pragmatically, continuity ensures that Steve is showered the way he likes to be showered, but Steve also infers that continuity makes showering a more safe and familiar practice. When he states, "they always know how to handle situations", Steve raises the notion that showering is not the same as getting assistance with other activities. Intimate care experiences require trusting relationships such that potentially uncomfortable situations are responded to in a predictable and appropriate manner.

"Location, location, location"

While particular conditions associated with the organization and delivery of care matter when it comes to younger residents' access to care relationships and relational care practices, the data also suggests that the location of one's LTCF matters when it comes to younger residents' experiences of positive, relational care. Julie characterizes a key value of her facility as "location, location, location". She explains to me that she is fortunate to live at her facility and that it was on the top of her list of preferences because of its close proximity to her home. Her partner comes to visit almost everyday, she leaves the facility at least one day a week to go home to have dinner with him and visit her cats, and she is still able to see her long-time non-resident friends on a regular basis. Alex tells a similar story. For her, finally gaining access to a facility very close to her parent's home means she can visit them on a regular basis. The situation is very different for Steve, who tells me his father, who is a senior, is finding it difficult to visit on a regular basis because he lives far away from Steve's facility and no longer drives.

LTCFs that are located in close proximity to outside services and amenities also facilitate positive, relational care experiences among younger residents. All of the facilities involved in this project were located within or in close proximity to urban centers, but some were much closer than others to public transportation, groceries stores and other resources and conveniences. Several resident-participants indicate using outside services to gain access to a variety of programs not available at or through their facility. Jackson lives close to public transportation, which he takes many times a week to get to his "school". Marnie's residence is in close proximity to an accessible pathway, and she arranges public transportation to and from her facility to engage in a variety of social activities. Having a grocery store within a few blocks of his facility allows Andor to shop for foods he enjoys on a regular basis. Some resident-participants also mention that having malls, theaters and other wheelchair accessible locations close by is important in terms of the ease with which their facility can organize outings.

Age-Informed Conditions

Resident-participants often infer that the ways in which care is structured in LTCFs is not sensitive to differences in age among residents (see Chapters 7 & 8). Their experiences also suggest some promising practices. For example, it is common for resident-participants to indicate the value of or a desire to access recreational opportunities geared specifically towards their age group. Alex explains that she particularly enjoyed participating in the types of recreational programs offered at her former LTCF—a residence with a dedicated young people's unit. She tells me the activities offered to her better fit with her interests. She assumes this is because all of the residents in her unit were under the age of 60 so tended to enjoy more of the same activities.

Here, she was offered many opportunities to engage in activities in the wider community such as going to movies and performances that she believes younger adults are especially likely to enjoy.

Alex's discussion of her positive experiences living in a dedicated young people's unit combines with the narratives of several of the resident-participants at Sherwood West to suggest that structuring LTCFs in ways that make it possible for younger residents to live in close proximity to one another facilitates their access to relational care. The resident-participants at Sherwood West differ from the resident-participants at other LTCFs in that they were much more likely to describe in positive terms, having a number of younger co-residents as good friends. Sherwood West is not a facility that separates younger residents into a specific unit nor is the relative population of younger residents at Sherwood West greater than those at the other facilities involved in the project. However, many of the non-senior residents at this facility had established long-term, continuous friendships, a situation that appears to be linked to their shared history.

Sherwood West opened at a time when a nearby hospital was closing their CCC unit. Several of the non-senior residents living at Sherwood West had also lived together in the CCC unit. Although some of the original non-senior residents at Sherwood West had since left the facility or passed away, at the time of data collection, several residents indicated they had been living together for close to a decade. It seems this situation supported the development of strong interpersonal relationships between many of the non-senior residents at this facility.

Access to Privacy

While the data suggests that having the money for private accommodation is valuable to some non-senior residents in terms of securing the types of privacy they associate with the maintenance of care relationships (see above), there is also some indication that other components of the physical care environment can help. When non-senior residents have access to private spaces throughout their facility or at least, quiet spaces, sharing a room is less likely to be understood as a barrier to relational care.

The outside grounds of LTCFs, including gardens, walking/rolling paths and terraces, are places where many non-seniors enjoy spending time either alone or with visitors. They mitigate against the negative consequences younger residents associate with sharing spaces with roommates and (senior) co-residents who are vocal, whom they find difficult to get along with (see Chapter 8), who play music too loud, or who have a lot of visitors. Matthew, whose older roommate plays his music at a volume that irritates him, regularly enjoys quiet time on the outdoor grounds of his facility. He describes this space as important for residents to go “if they are upset about something.” His comments suggest that care environments that offer sanctuary may help prevent interpersonal conflict. Similarly, Elton has always shared a room at his facility. However, this seems to have become a major problem only when the private spaces around the facility he and his girlfriend once used are no longer accessible to them.

Conclusion

While non-senior residents may understand LTCFs to be places that provide care necessary for sustaining life, their narratives also stress that this function is not enough. For LTCFs to be experienced positively by and understood as valuable to non-senior residents, the conditions of care must support their autonomy and personhood, care should be individualized, it will foster meaningful experiences, and it must actively involve younger residents themselves. As I have demonstrated throughout this chapter, such experiences are more likely to occur when care is highly relational. The presence of close caring relationships and the practice of care in relational ways are consistent features of what resident-participants indicate is good about their everyday experiences living in a LTCF.

It is also clear that a wide variety of factors shape the possibilities for relational care. Structural factors such as access to privacy, the location of the facility, age-informed conditions, and ensuring care work is organized and delivered in ways that support continuity and time for relational care provision foster the conditions of relational care. It is concerning, however, that individuals play such a vital role in securing positive, relational care experiences and in resisting or working around the issues. The extent to which resident-participants seem to draw on their own resources and capacities and rely on individual workers, family members, co-residents and friends to get care of the sort they need and value is indicative of major inequities in access to relational care.

CHAPTER SIX

The Satisfying Conditions of Relational Care Provision from the Perspectives of Direct Care Workers

Introduction

In the previous chapter, I described what younger residents perceive as positive and/or valuable about living in a LTCFs as a means of uncovering the conditions of care that go beyond those necessary to sustaining life to ones that support good, high quality everyday experiences and a more fulfilling life. Care relationships and relational care practices are a consistent feature of such experiences and understandings. Direct care workers—who provide much of the care non-senior residents experience—occupy a central position in this narrative. As resident-participants suggest, “good care” is provided by “good care workers” who are particularly adept at forming caring relationships and providing care in relational ways. However, the data also indicated that certain structural conditions play an important role in younger residents' being provided with care in highly relational ways. These conditions facilitate more consistent and equitable access to positive, relational care.

Given these findings, this chapter aims to uncover the conditions in which relational care practices flourish through an exploration of the aspects of care work direct care workers experience and understand positively. I do this by drawing on a relational feminist disability perspective (see Chapter 1) to analyze data from individual interviews with eight female PSWs, seven female nurses, and three female recreation staff with particular attention to what they tell me about what they like and what is valuable about their work, and what sort of care they want to, and feel satisfied, providing residents—non-senior residents in particular. My analysis suggests that much like residents-participants, the aspects of care work direct care workers experience and understand positively tend to involve caring relationships and are characterized by conditions in which direct care workers provide care in relational ways.

The data also indicates that when it comes to the conditions under which relational care provision flourishes, direct care workers' ideas about differences in the age of residents, often as they intersect with ideas about disability and gender, matter. While indicative of potential inequities in relational care provision, direct care workers narratives also point to a number of structural conditions that facilitate their individual efforts to provide relational care to younger residents.

The Satisfactions of Relational Care Work

The narratives of direct care workers often include multiple discussions of what they value and/or experience positively about working in a LTCF. They tell me that the “best” aspects of their jobs, what they “love” about care work, are the feelings of personal satisfaction they experience doing it. Worker-participants feel particularly satisfied when the work they do is acknowledged by others, when it is socially enjoyable, emotionally rewarding, and when they understand it as highly skilled and/or involves their own decision-making. Direct care workers also experience satisfaction when the care they provide meets the needs and preferences of residents. Further, while direct care workers provide a variety of examples of the conditions in which they experience these satisfactions, the data also makes it clear that positive care relationships and relational care practices are a regular part of these conditions.

Recognition and Appreciation

The data indicates that worker-participants feel satisfaction when the work they do is recognized, acknowledged, and/or appreciated. Melanie (a nurse) defines the value of her job in terms of being acknowledged and feeling appreciated by the residents at her facility. She tells me, “The residents are awesome. They look at you and they smile. They say, ‘thank-you’, and you know that you have made their day. That’s really rewarding for sure.” Similarly, Tamika (a PSW), seems to understand the gratitude of her residents as a particular benefit of working at a LTCF. She describes being a care worker as a “rewarding job. [The residents] tell you, ‘Thanks.’ Like, a lot of time they appreciate what you do for them. Most of the residents—they are always saying, ‘Thanks.’

Some worker-participants such as Sandy (a PSW), suggest that demonstrations of appreciation are a valuable aspect of care work in a LTCF. For her, such experiences contrast sharply with that of providing care in other contexts. Sandy, raises this point when she defines what she “loves” about her job:

> [I love] being there for the residents, making a difference in their lives and serving them. And they appreciate it. I can do laundry at home for my kids and it’s like, “Well mom, you missed this shirt.” But here, I put their laundry away and they’re so happy.

The way in which Sandy describes the personal satisfaction she experiences doing care work is tied to her understanding of care work as enhancing the lives of those for whom she provides care. At the same time, she emphasizes that the components of care that tend to be invisible or undervalued in more informal contexts such as her private home, are more likely to be appreciated in a LTCF.

Being recognized as skilled, knowledgeable, and/or dedicated to one’s job is another aspect of care work that direct care workers experience positively. Worker-participants often infer that being the preferred or favourite care worker to an individual or group of residents is especially satisfying. Verline (a recreation therapist), shows pride when she emphasizes that the residents at her facility prefer the way in which she runs the social and spiritual programs. She also tells me that the residents anticipate her arrival well before they are scheduled to meet with her for a one-to-one program, and that, when she returns to the facility after her days off, the residents let her know that she was missed by asking her, “Why weren’t you here?”

When direct care workers tell stories about being recognized and appreciated, their stories usually involve residents. However, a few worker-participants also suggest that the positive responses of residents’ family members are also meaningful. Vahlma (a nurse), describes what she “loves” about her job in this way:

> [There are] a lot of family members who respect me a whole lot. On the home area [unit] where I was just before I came here, I see the family and they ask me, “When are you coming back?” It’s a good feeling to see somebody really appreciate you for who you are and the things you do. And I love it. I love nursing.

Direct care providers appreciate it when family members acknowledge the challenges of their jobs and/or recognize and appreciate their efforts, skill and knowledge with respect to care provision. Some direct care workers, like Vahlma, draw on these experiences as evidence of the positive relationships they have with some residents’ family members. She and other worker-participants indicate that these relationships are not only personally satisfying, but pragmatic in the sense that they foster trust and open communication about the health and well-being of residents.

The connection between relational care and being recognized and appreciated is evident when direct care workers indicate they feel particularly satisfied when their work is acknowledged by residents with whom they have established a distinct care relationship. Worker-participants often tell me stories about residents who regard them as their favourite or preferred care provider. For example, Ethnea (a PSW), tells me that one thing she really enjoys about care work is providing care to a male resident who requests her support for intimate care practices. She explains:

> I have one male that just me shower him, nobody else, unless I'm on vacation. When he came, I was there working the first day. When he came as a new resident, you have to go and introduce yourself and whatever. So, you just get attached. You know? I like to take care of him and whatever I do, he is so appreciative.

Ethnea's narrative indicates that she especially enjoys care work when it involves providing care to a resident with whom she has developed a distinct attachment over time. She seems to understand this resident's efforts to secure continuity of care regarding the practice of bathing as a form of acknowledgement that both reflects and contributes to the positive relationship they have formed.

The narratives of worker-participants also suggest that care relationships are sometimes necessary to recognize when one is being valued and appreciated. Sandy (a PSW) provides one example when she tells me a story about her efforts to style the hair of a resident who had received an unflattering haircut and who rarely communicates with direct care staff by using words:

> Just because they don't talk doesn't mean that I don't talk to them or sing along to the radio to them—to stuff I know they like. It's just so funny because she sat up, I dry her hair and I turned her around in front of the mirror and for someone who doesn't say anything, she sat up straight in her chair and smiled and said "Thank-you." It was the first and only time I heard her say [it]. I cried. It was just like the first and only time I heard her say much—like, say an actual word….[They show you appreciation] with their eyes—the ones that talk with their eyes. And their smiles or rubbing your hand and

> holding on. The touching, the—not inappropriate—the touching just to say, “Thank-you.”

Similarly to other direct care workers, Sandy values being appreciated and having her efforts validated by the residents for whom she cares. But she also makes it clear that in order to discern that certain residents are appreciative of the care they are receiving, the care worker must be familiar with them. Within the context of having developed a care relationship with this resident, Sandy recognizes her verbalizations as particularly meaningful.

Social Enjoyment, Emotional Rewards, and Employing Skills in Care Provision

Not only do direct care workers derive satisfaction from being acknowledged and appreciated, they also derive satisfaction from care work that is socially enjoyable, emotionally rewarding, and when they have the opportunity to put to use their full range of skills in its practice.

Social Enjoyment

It is common for worker-participants to indicate that they very much enjoy socializing with residents at their places of work. They tell me about residents whom they perceive as very interesting to talk to, who possess great senses of humour, and with whom they enjoy exchanging personal stories. Both Sandy and Viola (PSWs) tell me that while their jobs can be demanding if not stressful, some of these challenges are eased by the “funny stories” residents tell, or the time they spend with residents who “love to tell a good joke”. The way in which Charmaine (a PSW), describes what she especially enjoys about care work also suggests that for some direct care workers, socializing with residents is very enjoyable:

> You learn so much. I like especially when they tell you about when they were growing up and their sisters and their brothers and their mom and like, it makes you get back to your roots too. Some of them will say, “We didn’t have much, but mom would do this and

> mom would do that." You realize that's the same thing that happened to you as a kid. So it's a different culture, but it's human. Oh gosh, there is common ground there.

Like many worker-participants, Charmaine tells me that socializing with some of the residents is a particularly enjoyable component of her job. Charmaine is a migrant and a woman of colour who provides care to a predominantly white, female, western-European, senior resident population. Her comments indicate that the informal conversations she has with residents allow her to relate to them despite perceived cultural and perhaps generational differences.

Emotional Rewards

The narratives of direct care workers also indicate that care work is satisfying when it is emotionally rewarding. Care work is emotionally rewarding when it involves demonstrations of affection and/or emotional support particularly from residents. For example, when I ask Mackenzie (a recreation worker) what she likes best about her job, her answer points to affection as an outcome of care work that is especially satisfying. She tells me:

> I was just talking the other day with my friend. I was saying, "What other job do you come to where every morning when I go to (Name of unit), I have a whole bunch of residents saying 'Good morning. You're back. We are glad to see you.'?" Some of them will come over and give me a hug. And everyday before I leave, they are always asking me, "Are you coming back tomorrow? Where are you going? Aren't you going to stay with us?" And again, [they] come and give me a hug before I go. In what job do you have someone waiting for you before you come in and give you a hug before you leave everyday?

Mackenzie perceives care work as distinct from other jobs because of its emotional rewards. She is rewarded by the affection of her residents who show her that they care about her and that she plays an important part of their everyday lives.

Verline (a recreation worker) also emphasizes the emotional rewards of care work. Like Mackenzie, she indicates that it makes her feel good to know that residents are happily anticipating her arrival following her days off, and that they look forward to the time she spends with them one-on-one. Verline also suggests that her residents are a source of emotional support. This value is apparent when she tells me this about the relationships she has with the residents at her facility:

> You know, with younger and older [residents], most of the residents have very good relationships with us because we are friends with them. They know—let's say, when my daughter got married, they knew about that. I share with them and they congratulate me…. It feels like family because I feel so much love from them, which I really, really, really appreciate. Sometimes if I have private problems, I come here and I feel so much love that I feel hope.

Not all direct care workers characterize their relationships with residents the way Verline does—by using terms like family or/or friends. In fact, some indicate they believe it is unprofessional or emotionally risky to become too personally attached to a resident. But for most, being cared about by residents seems to meet some of their own emotional needs.

The emotional rewards of care work also encompasses the pride direct care workers link to the moral dimensions of their jobs. Worker-participants tend to align care work with their moral and/or spiritual beliefs. Care work is discussed as a way in which some direct care workers view themselves as contributing positively to society, to humanity, or to the community in which they live. Doing care work makes them feel good about themselves because they perceive it as having a positive impact on others—particularly those they perceive as especially vulnerable.

Vahlma (a nurse) explains her commitment to care work in this way:

> I think that is what nursing is all about: It’s having all the feelings of another person. Knowing how you feel. Taking your feeling and putting it into your heart. Knowing that somebody is there who is grateful. Somebody is there who is crying and you can cry with them. You know? I think it’s a rewarding profession.

Vahlma’s comments reinforce the notion that care work is satisfying when it involves being recognized and appreciated. At the same time, she conceptualizes nursing in terms of empathy—suggesting that it is also the moral value of care work that makes it particularly satisfying.

Charmaine (a PSW) also explains her dedication to care work in relation to her moral and spiritual beliefs. When I ask her what keeps her committed to her job, she tells me:

> Um, I have a lot of empathy. In all my life’s jobs, it’s always about people in some way or another. So, I feel connected, at this time in my life, I gotta feel connected to people…. And my faith. I believe in God, so my faith too pushes me to be more compassionate. What if? The empathy stands out really high in my life.

Not all worker-participants describe their commitment to care provision in ways that link their profession to a moral or spiritual “calling”. It is clear, however, that direct care workers often understand care work—particularly when it is done well—as more than a job for which they receive monetary compensation. This finding is apparent in comments similar to one made by Edelle (a PSW), who defines her commitment to her profession as a “passion…. / It’s not only that we come here to earn money”.

Employing Skills in Care Provision

The ways in which direct care workers describe the aspects of care work they value suggests that care provision is satisfying when it involves them using their full range of skills in its practice. The data indicates that worker-participants tend to be motivated and/or rewarded by opportunities to use the skills and knowledge they have acquired through education, training and experience, to provide care in ways that contribute positively to the health and well-being of residents. Vahlma (a nurse) describes such satisfaction while discussing her desire to be more involved in the direct care of the residents at her facility. She tells me:

> Wound care is one of my priorities. When I do the wound and I see how great and how it has improved, it's like heaven come down to me. It's so satisfying. It's so good to see that something that I have been doing over the days, over the months is much better. We had a resident who went to the hospital and when she came back, oh my god. She had an ulcer of the coccyx and everyone was like, "Oh my god, what happened here?" She didn't spend three months in the hospital. And now it's like zero. I'm like, "Yes." That is satisfaction. That's how good I feel when I see the results, you know?

When Vahlma cares for her residents' wounds, she uses the skills she has acquired as a nurse to improve their health in a discernible way. Because of this, she feels immense satisfaction. Such opportunities seem particularly important to the nurses involved in this study, perhaps because their opportunities to engage in more direct forms of care are limited by their administrative duties (see Chapter 8).

Nurses are not the only direct care workers for whom employing the skills they feel particularly adept at results in feelings of satisfaction. Verline (a recreation worker) emphasizes the value of her cultural competence when describing the positive impact she has on some of the residents at the facility:

> I love to make these people happier than they are. When I see a smile on their face or they verbalize that they appreciate, this keeps me at work…. Today, I had a lady who was

> here sitting. She is a Jewish lady, she doesn't speak a lot of English. She is from Spain. She even cannot speak Hebrew. The mother language is Spanish and this is what she remembers now. But she is religious. She knew Hebrew before. She says, "This is mine. This is mine. Thank-you. I love you so much." This is why I'm doing it right? This is why she feels—she can't tell me exactly what she feels, but she feels love here. She kisses me. This is what this is about.

Verline recognizes the Jewish social and cognitive programs she provides are very important to some of the residents at her facility as they foster a sense of community or belonging. Even when differences in language exist such as when she interacts with the resident who speaks Spanish, the cultural and spiritual beliefs they share seem to positively impact the resident's emotional well-being and facilitates the development of a care relationship seemingly characterized by deep affection.

Skills in relational care provision are a common feature of stories worker-participants tell me about the satisfactions of care work. Several PSWs describe the satisfaction they experience when they have successfully navigated a challenging interaction with a resident by drawing on their capacity to easily build a positive rapport, if not gain a resident's trust. A quotation from Pilar (a PSW), illustrates this point:

> [Name of resident], I did him last month because I'm just new to [Name of home area]....With this [man], at the beginning he was very shy with me, bad attitude. He didn't want me doing anything. He didn't want me to shave him. He refused to change [for] the peri-care. But I was just back and forth, trying to talk to him. By the end of the month he was really good with me. Now every time he sees me he says, "Hi, how are you?" He let me shave him, change him, shower him, everything…. This is one thing that I really

> like—when [the residents] are mean with me or they don't really want to talk with me and I have to make them so they love me. I'm gonna change them. "You are gonna love me. You are gonna miss me by the end of the time when I am leaving."

While describing her job as "pretty hard" and "a big challenge", but also one that makes her "feel happy and satisfied when [she does her] best", Pilar indicates feeling satisfied when she employs relational skills to gain the trust and cooperation of residents.

Meeting the Preferences, Needs and Wants of Residents

Direct care workers also experience satisfaction when they meet the needs and preferences of residents. Melanie (a nurse), defines the most rewarding part of her job as "making a resident happy, fulfilling their needs." For Viola (a nurse), trying her "best to make everybody happy and give the best care that [she] can give" gives her great satisfaction.

PSW-participants tend to emphasize that when they successfully complete the provision of everyday personal care such as bathing, toileting, clothing, and ensuring a resident has eaten in a way that pleases their residents and meets their basic needs, they experience satisfaction. Ethnea (a PSW) defines "the most "satisfying" aspect of her job in this way:

> The most satisfying part of my job is when I know that I do a good job, and they like it. And they don't complain, and I go home happy. I go home after my eight hours and nobody complains. My residents are happy, they look good, they eat. So I feel satisfied about that.

In contrast, to PSW-participants, nurse-participants tend to indicate that meeting the needs of residents through the provision of skilled nursing care is a personally satisfying accomplishment. Some tell me, for example, that it makes them feel good when they ensure a resident receives the right medications at the right time, when injuries to a resident's skin are well attended to, and when feeding practices associated with those residents who use “G-feeds” (gastronomy feeding tubes) are completed in a smooth and timely manner.

The Care “I Want” to Provide

Worker- participants appear to agree that providing care that meets a resident’s desire for emotional support and social interaction is particularly satisfying. It is also clear, however, that many workers construct this condition as a goal or ideal rather than one that is consistently met on a regular basis. Kristine (a nurse) describes the type of care she *wants* to provide the residents at her facility in this way:

> I would feel better if I could provide some emotional support to some residents, talk to them. You can talk to them and they feel a lot better. Everything is not just medication. Sometimes they have pain, like, they have their emotional needs too. They need to talk to somebody. Sometimes they feel lonely and want to talk to somebody.

Similarly, Charmaine (a PSW) tells me this about the care she aims to provide the residents at her facility:

> Some of them, you would spend the whole day with them, but you work within a timeframe. You can sit with them for a little bit, you can do that if you want, but sometimes you have too many responsibilities that you have to take care of. But you would hear so many nice things about them, and you make them happy. The one-on-one time is the best thing that they love.

Kristine and Charmaine’s comments acknowledge that residents have social and emotional needs and wants that workers desire to meet. When workers provide relational care in order to meet these needs and wants, both the resident and the direct care worker feel satisfied. These comments also infer, however, that such conditions are particularly satisfying because they do not happen on a regular basis.

The Role of Relational Care

The data suggests that worker-participants often provide care in relational ways in order to meet the wants and needs of residents. They draw on their skills at developing interpersonal relationships with residents in order to foster their participation in a variety of activities and practices workers perceive as “good for” the health and well-being of the resident. For example, recreation workers talk to residents about their interests, ask them to complete surveys, call their family members, and spend time with them outside of programs in order to gain information that can be used to encourage participation in a variety of activities. Victoria (a recreation worker) tells me that once she gets to know a resident, it is easier for her to get them involved in social activities. Using the example of her efforts to encourage an older resident new to the facility to come out to programs, she tells me:

> It’s better when you know, like, more about the resident— So, what they like and everything. And once you get to know them, like, you know who would enjoy games…. (Name of resident), this lady, when she came in, I found out she was really into Scrabble and you know, [I] got her to come to Scrabble. And she can’t hear too well, so that’s really the only one—the only program she really likes. So, um, I thought it was important for her to play Scrabble as much as she can. So I put it on the calendar once a week and then, I got these girls [senior women] like all into it and they’re like, “Oh, I could play Scrabble everyday.”.... That’s why I put it on three times a week. So it depends what the residents are into.

Like other recreation workers, Victoria seems to understand residents’ participation in recreation programs as beneficial to their social, cognitive, physical and spiritual health. To foster greater participation, Victoria draws heavily on the knowledge she gains through talking to residents informally as well as during the provision of programs to develop an activity schedule that better fits their interests and is also accessible. These and similar comments point to the importance of relationship-building in terms of the provision of care that is sensitive to differences among residents, a theme that I return to later in this chapter.

Rosie (a nurse) also draws on what she knows about the residents to help ensure their participation in practices she perceives as good for resident well-being. She tells me about her efforts to encourage a younger male resident to participate in the social practices associated with mealtimes at their facility by drawing on what she knows about his food preferences:

> Like, I have one man here who only comes out of his room for breakfast and supper. And the only time he'll come out is if I'm here because I'll get his cereal out, I'll get his bananas. He knows everything is going to be on the table so he can go in and out—very depressed. And when I was gone, he didn't—he didn't come out at all. So, if I know there are little things that I can do extra, [I do them] 'cause it's going to help.

Rosie's comments infer that she perceives staying in one's room is an indicator of poor mental health among residents. In this context, Rosie draws on what she knows about this resident's food preferences to provide him with care that appears to encourage him to leave his room—if just for a brief period of time—to participate in mealtimes alongside the other residents in his unit. Rosie does this because she believes it is important to this resident's mental health, despite the fact that setting out food is not typically part of her daily job responsibilities.

When direct care workers describe their efforts to provide residents with care in ways that are interactional, that "encourages" them, "partners" with them, and/or gives them "choices", their comments suggest that relational care practices foster the involvement of residents in their everyday care, and this approach better meets their needs and preferences. Kristine (a nurse) describes it in this way:

> I'm saying, like, (Name of non-senior male resident), he has his own way. He likes to participate and he want[s] to. And the staff do according to, you know—we do our best according to whatever he's saying, because he has to be involved. And if they [the residents] are involved in their care, of course they will be more satisfied, and they will feel more independent, and, you know? So we even encourage them to participate like if they can comb their hair or they can brush their teeth and then, yeah, we do encourage it.

While Kristine's comments indicate an assumption that participating in one's care is beneficial to one's overall health and well-being—it also appears that involving residents in their care helps staff ensure residents' preferences are being met.

Some worker-participants also indicate that providing care in relational ways is beneficial to the care worker. For example, when care workers interact or "partner" with residents in order to maximize their participation in care, sometimes, the care worker benefits if this means the amount of assistance they need to provide a resident decreases. Tamika (a PSW) describes the benefit of resident involvement in personal care practices in this way: "It makes your job easier because if you have someone that can help themselves, you can just encourage them. 'Can I do this?' or 'Here's a washcloth, can you wash your face?' It makes your life a lot easier."

Sandy (a PSW) also suggests that the more she can encourage residents to participate in their care, the easier it is for her to complete her daily work responsibilities:

> There's three [residents] on the other side [of this floor] that I start with that get themselves dressed in their room. They just need assistance in and out of the tub, hair washed if that's what they're having, you know? And then they carry on [without

> assistance].... I fold towels, I do whatever. I'm there, but they say what they want to do…. And they'll carry on to their room. They go and get themselves dressed. Most people, you are doing all of that…. So you get so many of them done so quickly because they can do it.

Both Sandy and Tamika suggest that providing care to residents in a way that maximizes their participation in self-care is good for residents in terms of their autonomy and satisfaction. It also appears that at times, that providing care in this way can decrease the workloads of and/or speeds up the time it takes direct care workers to complete a given care task. This outcome is not without potential consequence. While partnering in a resident's care seems an obvious example of relational care provision, other relational components of care may suffer if, for example, getting dressed without assistance means less opportunity for socializing with workers.

Direct care workers also indicate that they practice care in relational ways in order to foster more amenable care interactions with residents. Worker-participants have informal conversations with residents, they listen to them tell stories, they walk and talk with them, and they provide them with comfort in order to establish a positive rapport if not a level of trust that facilitates positive care interactions. Daphne (a PSW) explains:

> I do know that if a resident feels more comfortable with particular staff, it's like, it takes away some of their demands—their demanding approach and what have you. Like, "Oh, you know how I like my pillow" and "You know how I like—". Like, some of them like their shoes to be put away neat and some of them like their pillows to be a certain way, some of them change their clothes everyday.

While her use of the term "demanding" points to the existence of tensions between Daphne and residents who advocate for care in ways that she perceives negatively, Daphne's initial comment about the importance of a resident being "comfortable" with a staff member suggests that care relationships may help prevent such tensions. Providing care within an established care relationship seems to improve the quality of care experienced by residents such that they respond to direct care workers in more positive ways.

PSWs in particular indicate that establishing trust through the development of positive relationships with residents is necessary to prevent tensions between workers and residents such as when residents display fear, anger, sadness, or dissatisfaction, and/or when they are aggressive, violent, disrespectful and/or resistant to care. Edelle (a PSW) learns the "individual qualities and behaviours of the residents so [she] knows how to approach them and interact with them", noting that "if you don't know them well, it is hard to provide care for them." Similarly, Charmaine (a PSW) establishes care relationships with the residents to whom she provides support by "holding their hands, talk with them, walk with them. Sometimes we walk down the hallway and just a few minutes, you walk with them and you talk with them and they trust you somewhat." She indicates that such practices are necessary to the successful provision of care when she tells me that "if they don't trust you, you are going to have a problem."

Comments made by Sandy, a PSW whose main responsibility is bathing residents, also suggest that the presence of a care relationship can conciliate residents during more intimate or uncomfortable personal care practices. She tells me this story when we hear a resident screaming down the hallway from where we are sitting:

> The lady that is screaming right now, I don't know if you hear her? If you sing to her, she stops screaming. But it has to be a hymn. She likes—she's a Christian lady, and it has to be a hymn. When I'm bathing her, I sing hymns. She just loves it—Amazing Grace. And it just quiets her down, and she is relaxed, and we get through the whole time with her.

The care relationships that Sandy has developed with the residents at her facility supports her in developing a number of strategies that makes bathing a less stressful practice. In this situation, singing the preferred song and style of music of a resident who greatly dislikes bathing practices leads to a more relaxed experience for the resident and makes it easier for Sandy to complete the care task in its entirety.

Providing Relational Care: Age Matters and Matters of Age

Thus far, I have argued that direct care workers experience satisfaction when the work they do is acknowledged, when it is socially enjoyable, emotionally rewarding, and when it means they are using their (relational) skills in care provision. They are also satisfied when the care they provide meets the needs and preferences of residents. Further, it is clear that direct care workers develop positive relationships with residents and practice care provision in relational ways in order to create the conditions where satisfying experiences flourish. However, when worker-participants talk about the positive aspects of care work, their narratives often suggest that the relationality of care provision is impacted by ideas about age particularly as it intersects with ideas about disability and/or gender.

Not all worker-participants believe that these types of differences among residents matter when it comes to providing them with care. Tamika (a PSW), for example, insists that the age of a resident has little to do with the way in which she approaches their care. She tells me that regardless of age, she “treat[s] everybody as equal”, and that, similarly, when it comes to her relationships with younger and older residents, “everybody is the same.” This statement is challenged by the experiences of younger residents who perceive the care they receive as individualized if not preferential to that of other (older) residents (see Chapter 5). It is also contradicted by the tendency of worker-participants to state or infer variability in terms of how they approach care provision with different sub-groups of residents in mind. Direct care workers appear to develop a particular rapport or relationship with certain individuals and groups of residents, which they associate with differences related to age, gender, and/or impairment-type. Some even suggest preferences in terms of which sub-groups of residents they like to provide care to.

The Needs and Preferences of Younger Residents

Most worker-participants indicate that they derive satisfaction from providing the care they believe meets a resident's needs and preferences (see above). The ways in which they do this, however, suggests that they often take a resident's age into consideration. Pilar (a PSW), for example, characterizes her approach to providing care specifically to younger residents in this way:

> Where we have to work for them [the younger residents], is like, communication—especially with them. Talk to them, "How are you? How's your family? How are you today?" We do with all the residents when I go in the morning, but especially with them [the younger residents], we have to focus more.

Pilar suggests that providing care in ways that are highly socially interactive is a practice that benefits all residents. At the same time, she believes this aspect of care provision is particularly important for younger residents. She responds to this assumption by attending to, if not enhancing the relational ways in which she provides non-seniors with care.

Reinforcing this finding, while also suggesting that the relational aspects of care are highly desired by younger residents, Victoria (a recreation worker) indicates that when she provides care to non-senior residents, she often focuses on socializing with them:

> I think I have a pretty good relationship with [the non-senior residents]. Like, even if I

> have extra time or something, like, (Name of younger resident), I'll go to her, just visit with her or whatever. Like, she's very chatty and easy to get along with… Like (Name of younger resident), I'll talk, 'cause I'm a big hockey fan, so I'll talk with him…. (Name of younger resident), I always call him "The Trouble-Maker". I don't know how that started. Every time I see him I go, "Oh, there's trouble" (laughs). And he goes like this: (Victoria makes a gesture with her hand indicating the resident is pretending to ignore her)…. I don't know, just joke around with them. It's pretty good that way.

The entirety of Victoria's narrative includes multiple examples of her social interactions with the younger residents at her facility. While inferring this aspect of care provision is particularly valuable to non-senior residents, it is also clear that Victoria experiences this component of her work as particularly enjoyable.

Many worker-participants indicate that providing care to younger residents is a particularly satisfying part of their jobs. Providing emotional support to members of this resident sub-group makes Vahlma (a nurse) feel proud, as her following comment suggests:

> Because they [non-senior residents] are young, it's hard for them [to live here]. The older ones are always saying things about them and they [the non-senior residents] think they are abused— they are insulted and so forth. But the way I interact with them [the younger residents], I take them to the side, talk to them, get it over, give them a hug, and that's it. I think I have a very good relationship with them. It's neat the way I deal with it. You know what? They call me their favourite nurse.

Vahlma's comments are indicative of intergenerational tensions among residents at her LTCF (see Chapter 8), that she seems to perceive as a particular problem in terms of younger residents' conditions of care. In response, Vahlma makes concerted efforts to provide emotional support to these non-senior residents, perceiving that this facilitates the maintenance of positive relationships with them. It also makes her feel good about the way in which she is providing them with care.

The idea that age matters in the provision of relational care is reinforced by the narratives of direct care workers who describe the efforts they make to maximize the involvement of non-senior residents in their everyday care (see above). However, the data also suggests that direct care workers believe younger residents in particular *should* be and *want* to be highly involved in care—and with as little support from care workers as possible. In our discussion, Daphne (a PSW) emphasizes her commitment to involving younger residents in everyday care practices. She tells me that she encourages younger residents who are physically capable to do their own laundry, make their beds, and do some of their own shopping. She also stresses the importance of providing younger residents with care in ways that support their self-determination:

> There are also younger people under 65. They do a lot for themselves, and these two girls that I'm talking about from the other unit, they were never married. The MS [multiple sclerosis] gripped them very early. So like, you do everything for them. But, except, they both can do a bit of eating for themselves and hold their coffee and glasses. But they are very good at telling you what they want. So as much as possible we partner in their care. We partner in serving them…. In order for us to make them feel more a person, you always strive to partner with them. It's something we do. We partner with them—partner meaning you give them them choice, you negotiate…. Yes, we are operating in an institutional setting, but we do not want to take away their ability to make choices. We don't want to take away their independence. We want to give them and allow them.

Daphne adjusts the ways in which she provides care to younger residents to align with her understanding of the relationship between (relative) youth and “independence”. For Daphne, encouraging non-senior residents to guide their care practices if not complete them with little support seems to be understood as good for the health and well-being of the residents.

It appears that Daphne also modifies her understanding of “independence” based on her perceptions of disability. For example, while Daphne encourages those younger residents who are more mobile to do their own laundry, make their beds and do some shopping for those younger residents who need assistance with most physical aspects of care, Daphne supports their independence through withholding offers of assistance with the tasks they can do on their own, and by encouraging them to vocalize their needs and preferences during care interactions.

Several worker-participants suggest that they attend to age as it intersects with gender in the provision of relational care by being cognizant of the potential sexual needs of non-senior residents. Referring to non-senior residents who are involved in romantic relationships, some direct care workers tell me they make concerted efforts to support these relationships by, for example, affording the younger resident greater privacy, or assisting them to be in closer physical proximity to their partner when requested. Rosie (a nurse) supports a younger female resident whom she indicates has a boyfriend by allowing “extra time” for staff to assist her with beauty practices. She explains:

> I think if you want to give them [non-senior residents] a better quality of life, then they probably do need more time. Like, [name of non-senior female resident] has a boyfriend. She likes to look nice. She’s young. If it was me, I wouldn’t want to look like crap everyday…. So yeah, my regular girls [PSWs] who are full time and some of my part time girls definitely spend more time with her—definitely. You go down in the morning and the radio’s going, and they’re all moving around. You know? They really try hard to

> make it as good as possible for her.

Drawing on perceived similarities in terms of age and gender, Rosie identifies with the female non-senior resident about whom she speaks and in so doing, seems cognizant of her sexuality. While potentially reinforcing negative stereotypes of aging women in terms of a loss of sexuality, this awareness translates into Rosie supporting the provision of gendered heteronormative beauty care practices. Rosie is willing to lengthen the time typically allocated to residents for morning care based on the perception that the performance of (emphasized) femininity should not end for younger female residents just because they are living in a LTCF.

When direct care workers talk about providing more intimate forms of personal care to younger male residents, their comments indicate that age as it intersects with gender matters. Assuming the potential sexuality of non-senior male residents, some direct care workers are particularly sensitive to the potential discomforts and power imbalances that can arise when providing intimate personal care to these men. Sandy (a PSW) tells me this about the differences between bathing men and women—younger male residents in particular:

> The funniest thing when I first started out, my very first patient, or client, resident, whatever we want to call it, was a man…. I have a husband you know, but it was nothing to prepare me for that. It is—it's like, "I know this is uncomfortable for you. Let me tell you a bit about myself. This is how long I've been doing this." You know? You have to build up a rapport, because you can't just jump into a room with a person of the opposite sex and say, "Take off all your clothes, I'm going to bath you now." You know? (Laughs). That's—I wouldn't like it if some guy came in and said that to me too. So you have to kind of build a relationship before you can just automatically [provide intimate care]..../The [non-senior male resident] I mentioned, we have a love-hate relationship….

> He hates having a bath, but he loves [it] when he’s done. And when he’s done he’s like, “I still love you.”… /And it’s like, “You’re naked and I'm not. And I’m not getting that way for you.” [Laughs]. It can be fun. We do laugh a lot in there [the shower room]—the younger ones. We do laugh a lot in there.

As a PSW who is largely responsible for bathing the residents at her facility, Sandy is particularly sensitive to the idea that when personal care work involves nudity, power imbalances are especially pronounced. Sandy seems to address potential discomforts associated with this situation by employing her skills in relational care provision. Taking the time to build rapport and engaging in humour seems to lessen the tensions. Easing perceived discomforts seems to benefit the resident and also makes it easier for Sandy to provide care.

Relating to Younger Residents

For some direct care workers, the rapport they establish with non-senior residents is not only different, but preferential. Some describe the particular enjoyment that they experience interacting with younger residents whom they characterize as having a good sense of humour, as easy to talk to, and easier to provide assistance to because they can tell you what they need and how they want their needs to be met. At the same time, the ways in which direct care workers discuss such preferences often contain contradictions. Consider what Kristine (a nurse) tells me about providing care to the non-senior residents in her unit compared to the older residents:

> Actually, I would say it’s a lot easier to kind of like make relationships. Like, [younger residents] are kind of like, jolly. Do you know what I mean? All my residents, except for (Name of younger resident), like, he kind of has his personality. But like, I have (Name of a different younger resident), he likes to joke and that kind of thing. It’s easy to build a really good relationship. It’s easier as compared to the older, because sometimes with the

> older residents, they are like, more confused or they don’t remember. They have dementia. You know?

Kristine is one of several worker-participants who indicates that younger residents are often easier to develop care relationships with than older residents. She seems to perceive younger residents as particularly good candidates for the development of care relationships because they are younger but also, verbally articulate and less likely to experience confusion and memory loss.

Throughout her narrative, Kristine contradicts herself by referring to a younger male resident who she perceives as especially difficult to support. It appears that this resident who “has his personality”—by which Kristine is referring to instances where he resists or refuses care, and sometimes, displays his resistance to care aggressively—does not fit into her ideas about non-senior residents as a group. While Kristine recognizes and values her experiences interacting socially with many of the younger residents at her facility, these and similar comments made by other worker-participants reflect a particular assumption about youth, cognitive ability, articulacy and compliance indicative of disability-related disparities in access to relational care.

When worker-participants describe providing care in relational ways, they often express a great deal of empathy for non-senior residents. For example, Sandy (a PSW), who describes herself as close in age to some of the younger residents at her facility, suggests that this similarity informs her belief that a LTCF should be a place that supports the continuation of life goals and experiences, not just a place where people go to die:

> Having worked out in the community and coming in here, you see [the younger ones]. You know, it’s like, this could be me. This could be my husband. This could be my sister, you know? And how would I want them to be treated? So you have to really have to be

> empathetic. So, I mean, you can say, “Oh, you poor thing, you had a car accident and now—” But it’s like, that’s not going to help them. You have to think, “Well, you are still here and you’ve got lots you can do yet. You still have a purpose. So, find it and fill it.”

Sandy’s narrative suggests that the way in which she approaches care for younger residents incorporates a consideration of their age. It appears this understanding is prompted by her capacity to imagine herself in the situation of the younger residents she interacts with because they are of a similar age.

There is also some indication that because care workers and non-senior residents are closer together in age, the ease with which they form personal connections is facilitated. Certainly, the empathy Sandy expresses for a younger male resident is tied to her realization that they are close in age (see above). It also appears that Victoria’s age relative to the age of the younger residents at her facility also impacts the ease with which she forms relationships with them. As a person in her early twenties, Victoria (a recreation worker) is still quite a bit younger than most of the non-senior residents at her facility, but she still thinks that the relative younger age of the non-senior residents impacts their relationship:

> [Our relationships are] different because somebody like (Name of non-senior resident) or even like (Name of non-senior resident), they are probably the same age as my parents even. So that’s kind of weird to think of it that way. Like, you know? I don’t know if I interact with them [the younger residents] differently, but it’s like a different rapport.

Victoria indicates that her age relative to the younger residents plays a role in her efforts to interact socially with them. In fact, Victoria seems exceptionally invested in maintaining individual relationships with a number of the younger residents at her facility. She tells me that she will seek out their companionship at the end of her shift and during her breaks. Like Sandy’s.

Victoria’s comments suggest that because direct care workers are often closer to or similar in age to non-senior residents, it may be easier to relate to them and provide care in ways that reflect this understanding.

When worker-participants describe the positive aspects of care work, they do so in ways that indicate age matters in the provision of relational care. Direct care workers provide care to younger residents according to the knowledge they have gained about them through relational care practices. They feel satisfied when they believe they have contributed positively to the wellbeing of younger residents. They also experience joy when socializing and forming relationships with younger residents. At the same time, these narratives sometimes rest on assumptions about (relative) youth, disability, gender, and care needs that suggest those non-senior residents who do not fit into such understandings may experience barriers to relational care.

The Conditions for Relational Care Provision

Time for Relational Care

When worker-participants discuss the satisfactions of care work and when they tell me about the type of care younger residents want and need, their comments reveal a number of conditions that support relational care. Above all, the data suggests that time is necessary for relational care. When Sandy (a PSW) compares the relative ease with which she provides “good quality care” to residents to that of other PSWs, her comments attest to the benefit of time:

> I have more time to provide to [residents] than the floor staff do because I don’t have thirty people to be responsible for, or fifteen, or ten, or eleven. You know, I have eight in a five and a half hour time frame and it’s nice to be able to give them that time. And some require more time due to disabilities and some require less…. I’ve got the time to

> listen to them. I've got the time for the ladies. You know, yourself as a woman, you know where that itchy spot is in the middle of your back. I've got time to scrub it and lotion, and I love to bring in lotions for them and put lotions on their legs, and make them feel human again. You know? Because in the morning, it's—[most PSWs] have got anywhere from eleven to fifteen people to get up and get dressed and down to the dining room in an hour and a half. And that doesn't give you a lot of time for all these people, right? So I've got fifteen, twenty minutes, half an hour per person, depending on their needs. So I can do those things and blow dry their hair and style it for them and stuff.

Sandy's comments suggest that having time to care facilitates the provision of relational care. While she is responsible for bathing many residents at her facility over the course of her shift and admits she often wishes for more time, her schedule is such that Sandy can offer support in a way that is more individualized to a residents' needs, goes beyond the technical components of bathing, and is dignity-affirming.

Worker-participants often indicate that building trust with residents is essential to providing them with care. Without trust, residents are much more likely to resist care and to be dissatisfied with the way in which it is being provided. However, it is clear that the types of relational practices direct care workers use to develop trust take time. When Pilar (a PSW) talks about her strategies for building trust with a resident she has yet to develop a relationship with, she emphasizes the importance of taking the time to provide personal care in a calm, unhurried, and attentive manner. She explains:

> Observing—this is one of the important things in here for the care—observing how the residents—what they like… Like, this gentleman, he's not on my team now, but it doesn't matter that he's not on my team...I know how to communicate with him, and he

> get along with me so well. The [other PSWs] say, “How do you do with him? How do [you] convince him to get a shower? He refuse a shower, he don’t want anybody to shave him, he don’t want nobody to toilet him…. “Be patient, be patient.” You need 100 percent to be patient.

For Pilar, observing residents and practicing care with patience—strategies that require time—facilitate the ease with which she gains a resident’s cooperation during personal care. She waits for the resident to indicate that he is ready for care, she asks him what practices he prefers first, and how much assistance he wants provided. Pilar has learned that providing care in this way, while time consuming, will lead to more positive outcomes. As she explains,” At the end of whatever I do with him, he always say, “Oh thank-you so much for what you do.”

For many direct care workers, the notion that time facilitates relational care provision is particularly apparent when they tell me about the importance of going beyond more essential or basic care tasks to provide the “extra” types of care they believe residents need and want. For Rosie, a nurse who defines the value of her job in terms of being an advocate for her residents regardless of the challenges she associates with care work, time is invaluable. She tells me that time with individual residents is what she wants as a care worker:

> [I want] just more time to spend with them [the residents] period. You know, doing extra things, helping them organize something in their room, being there for them, having a relationship. I mean, I do have relationships with all of them, but I just want more time with them.

While time facilitates direct care workers in providing relational care to all residents, time for relational care is a theme that consistently emerges from conversations about how worker-participants want to provide care to non-senior residents. As described above, worker-participants often encourage younger residents to maximize their involvement in the ALDs. Kristine (a nurse) discusses this focus when she explains the "restorative care" program at her facility. This is a program aimed at assisting residents to maintain if not recover physical, mental, and psychosocial functioning through participation in the ADLs. Kristine and other worker-participants who describe this or similar programs/care philosophies tend to construct it as especially valuable to younger residents. However, it is clear that providing care in this way can take direct care workers extra time—especially in the short term. Kristine explains:

> Maybe in the beginning that person might take longer but as they are gaining their skills, yeah. So we are tracking their minutes—so how many minutes they are taking in the morning…. It's kind of like, it does take time, even for the staff, because when [the residents] will do the care on their own, it would be slow and time consuming. That's why we have to track the minutes. It's like a separate program. And even though it's time consuming, you still have to improve their skills and independence.

It may be that direct care workers recognize that often, non-senior residents live in LTCFs for much longer than the average resident. This understanding may prompt direct care workers to ensure they provide care in ways that support younger residents to perform the ADLs with as little assistance as possible. Kristine's comments indicate that often, this can take extra time. She seems willing to take time for restorative care, perceiving it as a benefit to younger residents and also aligned with the type of care many of them want. Restorative care may also benefit direct care workers if, in the long-run, it means residents who live at their facility for many years maintain or improve "their skills and independence" over time. It also appears that Kristine's efforts are supported by the way in which restorative care is approached at the facility level. While the LTCHA (2007) indicates that all LTCFs must provide restorative care, Kristine tells me that restorative care is a “separate program” at her facility. Not only are workers encouraged to take the time to provide care in this way, but the facility has also added additional PSWs and implemented a system of “tracking” the time it takes to provide care in this way to ensure more time for restorative care.

Decision-Making Autonomy and Latitude

While time is a key facilitator to relational care provision, the data also indicates that time is not enough to ensure the provision of relational care. Decision-making autonomy facilitates relational care provision by allowing direct care workers to help design and make changes to the organization and delivery of care so they can better align with what they know about the needs and preferences of residents. For example, Victoria (a recreation worker) modifies the content of the recreation programs at her facility to correspond with the information she gains about the interests of the residents (see above). Mackenzie (a recreation worker) also indicates having some control over this process. She explains:

> Right now I find that a lot of the residents in (Name of unit) are very social with each other. So I do a lot of social programs. So, today in the afternoon, we are just supposed to get together and have some hot chocolate. So, it’s just getting them all together at the table, sitting down and having a snack for them. And I just find that I have a lot of residents right now that just like to talk to each other. It’s not so much having a structured topic, but so long as they are together, they will be there for hours talking. And I also have a different group of residents who are really into the physical programming right now— so games like ball toss or balloon tennis—they are really active in that. So, I find that it’s really divided into two groups at the moment. And then, there are other times, if I think back to last year, I remember having a lot more cognitive programs that I found

> worked well. I used to do spelling bees or trivia. Right now I find my residents aren’t as interested in it as opposed to residents I had a year or two ago.

Mackenzie has the autonomy to construct the monthly program schedules for the residents in her unit, making it possible for her to provide programs in accordance with what she knows about their interests and preferences. There are, however, limits to this authority. For example, in order to comply with documentation requirements aimed at demonstrating her facility’s compliance with government regulations concerning recreational programming, Mackenzie cannot make spontaneous changes to the monthly program schedule even if doing so clearly benefits the residents (see Chapter 8).

Decision-making autonomy also facilitates relational care provision by allowing direct care workers to draw on their skills and experience to make the most out of the time they have to provide care in relational ways. Vahlma (a nurse) indicates that she has the capacity to arrange the schedule for morning rounds and medication distribution. Such autonomy facilitates her efforts to meet the preferences of the maximum number of residents in the context of tight time restrictions. She explains:

> I kind of know who and who—which resident would like this and which resident would like that. Like, in the morning when I do my first rounds, I know that one lady around that end, she wants her meds in her room at this time. If I should walk around at eight or five minutes after eight, her first thing to me would be “Oh, you’re late this morning.” So the first thing I do,... I would do a few of them around this side with their puffers and everything. And then, I would go around that side and finish those [who] get patched and everything. Because I know that who my preferences are— not that they are my priorities, but they are the people who would be complaining and saying, “They don’t do

> this, they don't do that", and "That doesn't happen." But what I do, I go and I do them and let them be happy, and then I finish what I have to do. But it's kind of—you have to be organized and know who and where to go to.

Drawing on her experience and knowledge of residents' needs and preferences, Vahlma carefully designs a morning care routine in a way that best satisfies the maximum number of residents in her unit. At the same time, it is clear that providing care in this way facilitates the ease with which she completes these tasks.

Having decision making autonomy and latitude to implement policies and protocols in flexible ways also facilitates relational care provision. Worker-participants (and others) tell many stories suggesting that regulations and policies often limit worker autonomy as well as undermine younger residents' access to care relationships and relational care practices (see Chapter 8). There are instances, however, where direct care workers describe having the autonomy to be flexible in implementing the rules. Trish and Kristine (nurses) each provide an example:

> Trish: So far [the younger residents] are kind of able to, you know, to fit into the facility.
>
> Morgan: What do you think makes that possible?
>
> Trish: I think the way the staff treat them and probably the way the management as well.
>
> Morgan: What do you mean by that?
>
> Trish: Giving them the chance to do what they want to do as long as it won't effect, like—for safety issues…. Like we have here a policy for residents for a leave of absence for eight hours [where] they can't go without an escort. But if a person is capable of doing it, why can't she go by herself? As long as we give them a limitation—they have to sign out, they have to sign in when they come back and there are certain periods that,

> let's say, six hours that they are allowed to be outside and beyond that time there is a certain protocol that we follow. So we try to give them leeway.
>
> Kristine: (Name of younger, male resident), he's very active. Like, in summer, he goes out. He has a power wheelchair. Sometimes he goes out without even informing the staff. So we have a GPS to track him—because he has a power wheelchair and sometimes the power goes off. So, we had two or three incidents and the police had to bring him back. Sometimes he gets confused and he doesn't remember. So everyday—we have to make sure everyday—we have to be sure to give him a water bottle. We can't ask him to stay inside. He's young and he has to be able to go out and enjoy his life. So we have a GPS so we can track him.

In the above quotations, Trish and Kristine provide examples of instances where they have the autonomy and latitude to modify safety protocols. Drawing on their knowledge of the younger residents of whom they speak, both direct care workers make decisions about how to provide care that weighs the degree of risk associated with each practice with their perceptions about the benefits to younger residents.

Continuity of Care Provision

For most direct care workers, time for relational care is often hard to come by (see Chapter 7). However, the data suggests that continuity of care often facilitates relational care provision particularly when time for individual care practices is limited. Ethnea (a PSW) tells me that making a resident happy involves building a care relationship with them. Her comments infer that continuity is a major component of this process:

> It's how long you work with them and, you know, how you deal with them. You see them everyday. You spend I don't know how many hours with them, so, you have that

> relationship you build with them. To me, I just take them as family (laughs). You know, I’m here over eight hours, you know? Ten days for the pay period. I’m here most of my time. When I go home I just sleep. So you know, we bath them, we feed them, prepare their meals. So I would just say it’s something you just build—a relationship with them.

Ethnea’s comments indicate that working with residents for long periods of time provides her multiple opportunities to get to know them and to figure out how best to provide them with care. As a nurse, the time she has direct care provision is brief. Since she provides care to the same group of residents for many hours in a day and many days over a two-week period, however, Ethnea has the time necessary to foster good relationships. At the same time, Ethnea’s comments raise questions about the personal costs of care work. Ethnea tells me she loves her job and the residents she works with, but it is also clear that care work takes precedence over time for rest, leisure and sometimes her own family (see Chapter 7).

The value of continuity is further revealed by the comments of direct care workers who describe the ease with which they provide relational care to residents. Liz (a PSW), who switched from working a night shift to a day shift just before participating in this study, describes some of the challenges the staff member who replaced her is having with one of the younger male residents in her unit. Her discussion indicates that continuity of care helps workers interact with residents in ways that may ease potential tensions that arise during personal care practices:

> When I went to go from nights to days, I had a resident who, I think he was joking, but he was, “No. You’re not going.” And then the first day shift I had here, I guess he had a rough morning with the new night girl. And he looks at me, ‘cause he doesn’t talk. He had a stroke or something so he doesn’t say full sentences, it’s like a couple of words and you gotta kinda guess what he’s saying. But he looks at me right in front of my nurse

> [supervisor] and he says, “Come back.” [Laughs]…. Like, there are some of them that are difficult to deal with and you just have to bite your tongue and remember that this is their home. But most of them, it’s easy to get along with them. It’s easy to joke with them, especially when they know you. That’s a huge thing. You come in and you’re new, they’re different with you. Once they know you, they’re better.

Having a long-standing relationship with residents facilitates direct care workers' capacity to recognize and respond to the various ways in which residents communicate their needs and preferences. It is significant that the resident about whom Liz speaks experiences impairment effects that impacts verbal articulacy. Other worker-participants also suggest that continuity is all the more vital in terms of providing relational care to residents for whom spoken language is absent, minimal or confused. Ethnea (a PSW) provides an example during our conversation about a non-senior resident whom she has supported for several years:

> Ethnea: You know, she cannot really tell you what she wants, but we know her.
>
> Morgan: How do you know what she wants?
>
> Ethnea: The face (laughs). Like, she doesn’t like if you touch her hair back. Like, you can wash it, comb it and once you push it back, she goes (imitates the facial expression). And you know, she doesn’t like when her meal is too hot or it’s too cold. So, she gives you the face, so you know exactly that something is wrong. So if the full timer is not there and the part-timer came up, picking up a shift, and they don’t know exactly what to do with her—hair or dressing, she will give them the face, the attitude. She gets what she wants (laughs). So most of the time they [the part time worker] will come to us and ask her how to do her care, what she needs, how to dress her and like that. But she’s pretty good. Everybody, we love her so much.

Over time, Ethnea and the other full-time direct care workers on her team have learned this resident's needs and the particular ways in which she communicates her dissatisfaction with care. Recognizing and responding to these cues allows workers to provide care for this resident in ways that better meet her preferences.

Teamwork

The data indicates that having the support of co-workers and residents' family members facilitates the provision of relational care. Several of the nurses and PSWs at Northern Willow emphasize that they often rely on their co-workers to help them complete care tasks to ensure they are completed in a timely manner and also because at times, some care practices require the presence of more than one worker. As a whole, these narratives suggest that a "good care team" makes it easier for the worker to provide care and it means better care for the resident. When I ask Ethnea (a PSW) to explain why she believes she is able to provide "the kind of care [she] wants to provide", her explanation suggests some of the value of teamwork:

> Ethnea: We [the PSWs] help each other. We have a good team, and we communicate with each other.
>
> Morgan: So if you need support, you get that from your co-workers?
>
> Ethnea: Yes. I have a good team. That makes it much easier. We are really good at working together. I don't have to call for help if I need it. One of my team members will know that I'm in that room and that the resident needs help. I don't have to call, they know they should come in and help.

When Ethnea describes the value of having a good team, her comments suggest that completing care work is "much easier" when she gets the help she needs from her co-workers when she needs it. The "good team" of which Ethnea is a part seems to develop in large part because of the positive relationships she establishes with her co-workers—relationships she seems to understand as the outcome of regular communication, experience and continuity. Ethnea suggests that over time, her co-workers have come to know each other and the demands of their job so well, they are able to anticipate the needs of one another before help is called for.

Worker-participants who tell me they are part of a good care team also indicate that care provided in this way is often of better quality. Kristine (a nurse) infers this value when when she compares her current working conditions to ones she has experienced at other facilities:

> Kristine: Suppose if all my other team members are busy, if I can help them out, I would like to. We are all in it together to get [the resident'] needs met.
>
> Morgan: So, working as a team is important to providing good care?
>
> Kristine: Oh yeah. And I have a very good team.
>
> Morgan: Why is that? Why does the team work well together?
>
> Kristine: Yeah, like, I have worked in other facilities and if you ask for something, they are like, this isn't my resident. And I have seen—even the team members who don't really even talk to each other. When I used to work somewhere else, I met people like this. Here, they all work together and are supportive. Even if they have different teams, like, this [resident] has team one and this person has team two, you all have to work together for the best care, right?

Kristine associates having a good care team with the "best care" provision. Taking up a common goal, Kristine's description of her care team suggests that her co-workers are willing to help one another out regardless of the more formal division of labour. This is good for residents as it helps ensure the completion of essential care tasks. It also benefits workers by ensuring flattening workloads and increases the likelihood that support is available when needed.

To a lesser extent, direct care workers suggest that the development of good relationships with family members also contributes to relational care provision. Some worker-participants recognize family members as vital sources of information about residents, which they draw on to provide more individualized, relational care. My conversation with Charmaine (a PSW) is a representative example:

> Charmaine: A few people speak languages that others don’t understand and we sort of rely on family or friends to help us out, to help coach us through. We involve our family members because that’s how we are going to know things about our residents. And we really need to know to work with them better.
>
> Morgan: So, is it really important to have good relationships with family members?
>
> Charmaine: Oh dear, I would say it’s very, very, very, very important. It’s very important because our residents, they know our family members, they know their family members. We are new to them. It’s the first time they have seen our faces, so it is a family member who has to come in as a liaison between us and them so that they can have them understand the situation that they are in. Some people say, “Yes, they are ok, they will love you” or whatever. They will calm them down a little bit so we can work with them better.

Charmaine indicates the value of relationships with family in terms of the provision of relational care. Strong communication with family members is necessary to gain information about residents, especially in situations where staff and residents do not share a common language. It also seems that Charmaine believes personal relationships with family members are vital to the development of caring relationships between staff and residents, as family act as “liaisons” to the formation of trust and cooperation.

Some direct care workers also emphasize that developing a good relationship with family members of residents with disabilities that impact verbal communication and/or cognition is particularly important in terms of relational care provision. Verline (a recreation worker) explains the value of on-going communication with family members in this way:

> We try to talk to their families, if they have families who known them for a while if they have interests, if they used to do with their profession, their hobbies, what's their religion, the information if they are not capable to give it or if we feel what they have given us is not very truthful because they do not remember. So we go to the families and ask them the same questions—what they're interested in, what their hope is, what their preferences, how we can be more helpful, what kind of music they like, everything. How we can help them better, right? Serve them better.

For Verline, maintaining positive relationships with family members is necessary to relational care provision. She suggests that family members can provide a biography of residents that makes it possible for staff to ensure care practices meet residents' interests. At the same time, she is uncritical of the idea that defining family members as proxies for some residents she constructs as "not capable" or "not very truthful" may undermine the autonomy and/or personhood of residents.

Equipment and Technology

To a lesser extent, direct care workers indicate that the availability of properly functioning equipment and technology can facilitate relational care provision. The data suggests that such factors can make it easier for direct care workers to provide the types of care they believe best meets the individual needs of particular residents. Victoria (a recreation worker), for example, credits the availability of equipment at her facility that is commonly found in a

Snoezelen sensory room (a multi-sensory therapeutic environment commonly used to calm, reduce agitation, and stimulate people with dementia and other forms of cognitive impairment) in her efforts to provide programs appropriate to residents with certain impairment effects:

> I don’t know if you’re familiar with (Name of unit aimed at residents with advanced dementia)?... For the most part it’s lower functioning people there. So we usually do something—we’ve been trying to do as much as possible in sensory stimulation there. And I think we’ve really done a good job there. We have a Snoezelen room that we can kind of throw together. We don’t have an actual Snoezelen room, but we have stuff that we can kind of transform a room into a Snoezelen room and um, so that’s worked out pretty good.

Victoria describes the Snoezelen equipment in the context of talking about the elements of care provision that are of particularly high quality at her facility. Notwithstanding the somewhat normative characterization of people experiencing advanced dementia as “lower functioning”, it is clear that Victoria is committed to providing programs aimed at residents experiencing a wide range of impairments. This equipment clearly facilitates Victoria’s efforts.

Access to good technology and equipment can also facilitate relational care provision by decreasing the time it takes direct care workers to complete other (less relational) aspects of care work. This point is supported by what Olivia (a nurse) tells me about the value of the equipment at Spruce Hollow Central:

> It’s good with the system we have. We have good equipment here—good computers. We are on a system with medication. This is better than another place where you are doing everything on paper…./ Like I said before, there’s more equipment working here. It’s easy for you. And in the other [facility where I worked], it is working on the paper. You

> have to transcribe orders. Here, everything is going to the pharmacy. You don’t have to transcribe—the doctor's orders go right to the pharmacy. The other place, you have to transcribe the doctor’s orders in a book and send them to the pharmacy. It’s more work. Here it’s easy.

Olivia values the time she has to provide residents with “hands-on” care, but also suggests that such opportunities are limited by her extensive administrative duties. The implementation of the computer system decreases the time she spends away from the residents, giving her more time for relational care. It is notable that the PSWs and nurses at Spruce Hollow Central emphasize this positive aspect of their work environment. More often, the physical care environment at this facility is discussed as a major barrier to relational care (see Chapter 8). At other facilities, the functionality of the computer system is rarely discussed at all. It may be that when technology supports relational care provision, it is somewhat taken for granted by direct care workers.

The worker-participants involved in this study describe the satisfaction they experience forming positive relationships with and providing care to residents in relational ways. It appears their efforts to do so are supported—above all—by a work environment where they have time for relational care. But time is not enough nor is it always easy to come by. Professional autonomy, continuity, teamwork, and access to supportive technology and equipment can also foster relational care provision.

Conclusion

A key way to support younger residents’ access to close caring relationships and care practiced in relational ways within LTCFs, is to optimize direct care workers’ access to the aspects of care work that bring them satisfaction. The findings discussed in this chapter reveal that direct care workers experience satisfaction when they are recognized and appreciated, when their work is socially enjoyable, emotionally rewarding, when they use their (relational) skills in care provision, and when they meet the needs and preferences of residents. These satisfactions consistently involve and occur within care relationships and are facilitated by the provision of care in relational ways.

There are, however, clear differences in terms of direct care workers' perceptions about and experiences providing relational care. The findings suggest that age and other differences among residents and workers impact how relational care is provided and the ease with which care relationships are formed and maintained. There is some suggestion that direct care workers are more likely to form positive relationships with the younger residents at their facilities. However, these narratives also contain contradictions indicative of potential inequities in access to relational care between younger and older residents as well as among younger residents themselves.

The findings also indicate that direct care workers often draw on a number of interpersonal resources—their skills, experiences, moral convictions—and take on significant workloads and other “extras” to ensure the provision of relational care. At the same time, a variety of structural conditions including time to care, continuity, teamwork, decision-making autonomy and latitude, and access to appropriate technology and equipment support relational care provision.

There are also indications that the presence of structures in which relational care provision flourishes differs across facilities. Some direct care workers more than others experience significant obstacles in their efforts to provide care to residents in relational ways, and, relatedly, to experiences of work that brings them satisfaction. Such barriers to the conditions of relational care (provision) associated with the ways in which care is organized and delivered within care facilities is the focus of chapter seven.

CHAPTER SEVEN

Barriers to the Conditions of Relational Care: Exploring the Organization and Delivery of Care in Long-Term Care Facilities

Introduction

Thus far, I have examined the conditions of care that non-senior residents experience and perceive as positive and/or valuable. I have also considered the conditions within which relational care provision flourishes by examining what direct care workers tell me about the satisfactions of their jobs. Together, these findings point to the promise of relational conditions of care because of their benefit to *both* younger residents and direct care workers. It is also clear, however, that such conditions are often secured by the individual efforts and resources of non-senior residents and direct care workers. This is a troubling finding when viewed from a position of equity, although both non-senior residents and direct care workers also suggest a number of structural conditions that support relational care.

In order to move towards the conditions of relational care that younger residents want and need without relying so heavily on individuals, this chapter focuses on identifying the factors associated with the organization and delivery of care within LTCFs that prevent the conditions of relational care (provision). I draw on the narratives of non-senior residents, direct care workers, and family members, as well as my field notes to identify and analyze these barriers. My findings indicate that staffing level inadequacies, rigid care routines, discontinuity of care (work), and insufficient equipment are incompatible with or prevent relational care. I suggest that while these factors are likely to limit the possibilities for relational care for all residents, they are experienced and understood in particular ways by younger residents and those who provide them with care.

“We just need more staff”: Inadequate Staffing Levels

Across the facilities involved in this project, the narratives of non-senior residents, direct care providers, and family members indicate that many of the difficulties they associate with living and working in LTCFs are associated with inadequacies in staffing levels. Inadequate staffing levels are characterized by poor staff-to-resident ratios and mix. This situation reflects lean staffing arrangements and often results in short- or under-staffing situations.

Lean Staffing: Issues for Non-Senior Residents

Staffing and Rushed Care

Lean staffing is a problem for younger residents because not enough staff means care is more likely to be rushed. Resident-participants describe rushed care in ways that indicate they understand it as oppositional to good quality care. Rushed care is more likely to be incomplete, uncomfortable, and devoid of relationality. Marnie (a resident) defines “poor care” to be when “the girls are very rushed”. Julie (a resident) links rushed care directly to poor staff to resident ratios and suggests it threatens the completion of personal care practices:

> Well, I think they should have more [PSWs] on the floor, I think. They give us two people on each hallway. We have two hallways on our floor. And you get one, two for the hallway. And it’s just the two of them. And [call] bells are going at the same time. [The PSWs] go, “Who is that right now?” And they are finishing me and I say, “Nevermind that. Just finish me, ok? And then you can go. Please, just finish me.”

While Julie has some success in terms of advocating for herself that better ensures the care she is provided is complete, it is clear that she perceives the completion of care tasks to be placed at risk when there is a mismatch between the number of staff available and the needs of the residents in her unit.

Freeman’s comments also link poor staffing levels and rushed care. Freeman (a resident) indicates that when staff have too many residents to attend to, they must rush around in order to ensure everyone gets the care they require. He infers that rushed care has consequences in terms of his access to care relationships when he tells me that the PSWs at his facility are always busy, “so there is no time to joke around…. They always have something to do, somebody to attend to, somebody to look after.”

Care provided at a fast pace can also compromise the physical health and safety of younger residents. Catherine (a resident) indicates she experiences “rushed” care as “rough” and sometimes painful. Comments made by Susan (a family member) provides another illustration of the potential health consequences of rushed care:

> When we came in here, she, [Name of non-senior resident] was [Weight in lbs.]. And then she got to be [twenty-five pounds heavier]. And I said, “Enough. Stop. You guys are shoveling the food in her mouth. She’s sitting there and because you’ve taken over her feeding, you keep shoveling. And you shovel and shovel and shovel. And she can’t gain the weight. She’s had ulcers in the past…. And her chairs have all been computer digitized for her. And she can’t have huge fluctuations in weight….They wanted to give her pureed food. “No. You’re not giving her pureed food.” I had to sign all the papers for that. “She’s a choking hazard.” I ran her through—we did the hospital swallow assessment because their assessment here—“Oh yeah, she should be on puree because she doesn’t chew well.” “Well, she doesn’t chew. Um, [give her] small pieces. Don’t shove it in her mouth. She’s never really, really chewed. This is what she does.” And they finally did the whole swallow process and she corrects it. But she’s had—this has been a very tough year for health issues.

Susan's narrative indicates that the way in which her family member was being fed allows direct care workers to complete the task in a short period of time. However, this results in a number of physical health issues for the resident. The facility's decision to impose pureed food seems to be driven by a concern with time. Pureeing the food supports a faster feeding time without the risk of choking, but this "benefit" fails to consider the value that providing this resident with small pieces of food at a slow pace may have on her health, not to mention the potential enjoyment she derives from eating solid food.

Staffing and Non-Essential Care

Poor staffing levels are also an issue for younger residents because it means they are unlikely to receive support beyond the provision of the most basic or essential care tasks. Resident-participants tell me that when not enough staff is available, they are unlikely or less likely to receive any of the "extras". Joan (a resident) provides one example when she describes problems with the quality of care she experiences at her facility:

> I think the staff is doing their best, we just need more staff. I think in actuality, the staff is overworked because they are only given a few minutes per person. And in my area there are 22 residents and two workers. That's eleven residents per worker. That is too few staff…. We used to—the staff had time to do the little extras for residents. For instance, I'm a younger resident, the staff helps me with make-up in the morning. An 85-year-old is not going to need make-up put on in the morning.

While Joan admits that the staff at her facility find the time to help her with make-up in the morning, it appears that because it is not considered essential, provision of this task is often at risk. While reinforcing a stereotype about older women and the loss of sexuality, Joan's comment suggests that what is often defined as non-essential care tasks are essential for her because they support her dignity and personhood—allowing her to perform femininity in a way she views as appropriate to her age. Pointing to inadequate staff to resident ratios as the problem, Joan also recognizes the consequences for direct care staff—that under these conditions, they are overworked.

Another example comes from data collected at one facility, where direct care workers and family members of younger residents discuss a "restorative care" program aimed at maintaining if not improving resident's physical involvement in the ADLs (see Chapter 6). Susan and Thomas (family members) describe one component of this approach—a "walk-to-dine" program whereby residents are provided assistance with walking or wheeling themselves to the dining area at all mealtimes. This is a practice that Susan and Thomas believe greatly benefits the overall health of their resident-family members. Their conversation about this program, however, indicates gaps in its implementation—gaps Susan and Thomas associate with inadequacies in staffing levels:

> Thomas: She [the non-senior resident] used to walk three times or four times a week. And she was on that "Walk-to-Dine" program. So she was doing some walking.
>
> Susan: But you need PSWs to walk you in. And when it was in [Name of unit], they [the PSWs] would just come behind and wheel a person in. "Wait. He's supposed to walk." "Oh, ah." It's like [they tell the family member to] "butt out. That's not your business."

The walk-to-dine program is valued by these family members because it means residents get assistance with standing and walking on a regular and on-going basis. However, in the context of on-going staffing inadequacies, direct care workers do not have the time necessary to maintain this program. While this and similar restorative care practices may benefit younger and older residents alike, Susan and Thomas view them as particularly valuable to their family members who have been living in a LTCFs for longer than average periods of time. Susan's comments also infer a tension between direct care staff and family members that can arise when, in the context of lean staffing arrangements, family members become frustrated with direct care workers because care is not being provided to their family members on a consistent basis.

Staffing and Untimely Care

Within their narratives, non-senior residents also associate poor staffing levels with untimely care. Resident-participants tell me that not enough staff means long(er) waits for care. This is a particular issue during "down times" such as overnight and on weekends, when staffing levels are especially scant. Marnie provides a representative example:

> Sometimes it's long when I call for the call bell. It takes them a long time… I think there's a lot of [residents] on this floor. Everybody seems to want help at the same time, and that could be difficult. You know, I'm thinking of the night staff. There's only two of them from ten o'clock to two o'clock in the morning. There's only two staff members here and there's thirty-odd residents.

Marnie's comments suggest that high resident-to-staff ratios mean longer waits for care. At the same time, Manie appears to be understanding of the challenges experienced by direct care workers. Under these circumstances, she recognizes that it is very difficult for staff to attend to the needs of so many residents.

While Marnie's comments may indicate that waiting for care is a problem of inconvenience, it is clear from the data that waiting for care is about much more than this. Waiting for care can prevent residents' participation in activities they had previously arranged. It can also compromise dignity when waiting too long for care means "having an accident" (soiling oneself). Waiting for care can create or reinforce a sense of dependency or helplessness. Julie (a resident) acknowledges she has little power over how long she waits for personal care during periods of short staffing, nor can she do anything but wait. She explains, “What can you do? I mean, I can’t do it for myself, so I have to wait for somebody. So you just wait.” Julie’s comment about waiting for care seems to suggest that waiting reinforces her sense of dependency.

Staffing and Changing Care Needs

The data also demonstrates that lean staffing levels prevent access to relational care because under these conditions, staff are unable to meet both the increasing needs of the resident population as a whole, and fluctuations in the care needs of individual residents. Comments made by Susan (a family member) suggests that lean staffing levels are not enough to keep up with the increasing support needs of the residents at her family member’s facility. She explains:

> [The same] issues that have been running for [more than five] years now are still here. And what’s the solution? Staff and hiring…. / You know what, they [the management] are not one step ahead of the game. They are always two steps behind. For once, [be a] step ahead and say, “Oh, in (Name of unit), we now have 14 [residents who use] wheelchairs, versus a year ago, they only had six…. We need [this number of residents] out of bed, so that’s one more person [PSW] we need. So it’s not proactive enough…. And then, they [the PSWs] are rushing the residents to finish and get out. And when I wrote that [in the comment box], it came back to me and they said, “It’s not that they are rushing the residents, it’s that the staff are still rushing to finish their jobs.” But that feeling would rub off on the residents and they would feel that they are being rushed…. The actuality is, the staff are rushed off their feet and they cannot accomplish [all the

> care] because there's more wheelchairs and there are more people needing help…. / They [the PSWs] are so busy, they almost don't have enough time to smile.

Susan's family member, like many of the non-senior residents involved in this study, has lived at her LTCF for much longer than the average (older) resident. This situation gives Susan particular insight into both changes in the needs of the resident population and to trends in staffing levels. From Susan's perception, staffing levels have always been inadequate at this facility. At the same time, she perceives the situation as worsening over time. The consequences for residents is rushed care and care devoid of its relational aspects. But Susan also seems to recognize that this is a problem for staff who, in their attempt to complete an ever-growing number of care tasks, are providing care at a pace that is exhausting and unsustainable.

Along these lines, the narratives of some resident-participants indicate that lean staffing arrangements fail to meet their needs because they often experience fluctuating or rapidly changing impairment effects. While this is a situation that is not exclusive to younger residents, it certainly emerges in the data as a common experience among them. For example, several resident-participants describe experiences of fluctuating care needs, connecting these to the episodic, progressive, erratic or complex nature of some forms of chronic illness. Alex (a resident) describes her impairment effects using words such as "slowly climbs", "acts up on her", "attacks", and "goes into remission". She tells me that since living in a LTCF she has had problems with her kidneys, lost the ability to use her dominant hand, and at times, felt so physically exhausted that she has to have a nap in order to have the energy to brush her own teeth. Lean staffing practices mean there is no "buffer" in situations where the care needs of residents like Alex suddenly intensify or change. She tells me, for example, that at times when she loses mobility in her dominant hand, it can be difficult to get extra help with eating as staff are already busy helping other residents.

Staffing and Care Relationships

It is clear that care relationships suffer under conditions of inadequate staffing. When staff to resident ratios are poor, staff have neither the time to get to know a resident nor to maintain such a connection through relational care provision. Julie (a resident) suggests that some direct care workers who she enjoys spending time talking with cannot always do so because their workloads are too intense: “Sometimes if they got time, they will stay and talk about something—if there’s not an emergency or something. But it’s ‘Oh, there’s ringing.’ It’s constant those bells ringing. Always ringing bells.”

Care relationships between residents and direct care workers are also compromised, when, under conditions of inadequate staffing, care provision is rushed, untimely, and/or only covers the basics. Residents, frustrated by care of this sort, sometimes attribute the inadequacies of individual workers to poor quality care provision. My conversation with Catherine (a resident) about what she thinks needs to change about LTCFs emphasizes the disconnection between rushed care and care provided in a relational way. She locates this “problem” in the poor attitude of the direct care worker:

> Catherine: They [the direct care staff] need to listen. Most people like to talk. They need to concentrate on what we are saying.
>
> Morgan: Can you give me an example of what you mean?
>
> Catherine: If [the staff] are having a bad day, some often bring their home life here—bring their problems to work.
>
> Morgan: How does this impact you?

> Catherine: They rush or they are hard on you…. And they tell you not to ring [the call bell]. And when you do, sometimes they will turn your ringer off.

The negative care experiences Catherine describes in this quote involve those characteristics commonly associated with inadequate staffing levels—care provided at a fast-pace and that is rough. She also indicates that under these conditions, the needs of some residents may be rejected and/or ignored. While Catherine is not unaware of or unsympathetic to the demands placed on care workers, she links these negative care experiences to the personal inadequacies of individual workers. Here, she identifies the problem of poor-quality care as stemming from the inability of some care workers to maintain a division between their personal lives and professional responsibilities.

The data also suggests that relationships between co-residents are strained under conditions of inadequate staffing. Julie provides one example when she associates her experiences of rushed care with the older residents in her unit whom she seems to understand as overly demanding or unnecessarily impatient:

> Well a lot of people—I won't say any names—but some people are so—they want this and they want it now. They keep ringing and ringing and ringing. They [the PSWs] are helping me and the bell's going off. "Who the heck is ringing now?" "Just finish me now, ok?"

At other times in her narrative, Julie connects poor quality of care with inadequate staffing levels. Here, however, she seems to indicate that individual co-residents are responsible for the pressure direct care staff are under to finish assisting her care as quickly as they possibly can. Other resident-participants also imply that older co-residents—older women in particular—can be overly-demanding or impatient when it comes to accessing support. For some younger residents, this seems to translate into the perception that older residents get more than their fair share of care.

Lean Staffing: Issues for Direct Care Workers

Staffing and Unmanageable Workloads

Lean staffing levels are also a barrier to relational care provision. The data indicates an association between inadequate staffing and unmanageable workloads. Throughout their narratives, worker-participants provide numerous examples of the difficulties they experience completing care tasks and meeting residents' (even basic) care needs, explaining this challenge in terms of high resident-to-staff ratios. For example, Direct care workers tell me they often increase the pace and amount of care they provide in order to compensate for poor staff-to-resident ratios and/or short-staffing. Liz (a PSW) describes this tension in the following quotation:

> They [the management] keep telling us, "Oh you guys are so well staffed here." No we're not…. You come on this floor and work short and tell us. Like, I've been told that we should be grateful for how well staffed we are—especially on nights. Like, how can you say that when one PSW deals with 52 people? How do you figure that's full staffed? And that's the thing. The night I got stuck with both sides [of the floor], I went to my DOC (Director of Care) and I said, "I'm not complaining, but it was a rough night. Because I had both sides, you know, I didn't get the wheelchairs done."
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> "Well, whoever came on the next night should have done them."
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> "Well, that would be me, again."
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> And the next night, when I wasn't by myself, she's like, "Well, did you do them?" "No, I didn't."

> "Well you need to remember that being understaffed has nothing to do—or, the resident shouldn't suffer for us being understaffed."
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> So even though I did 52 people by myself, you're gonna—Give me a break. No thank-you. No, nothing, just, "you have to do your job better".... But we're not machines…. Most of them [the management] would not be able to do what we do.

Liz links the unmanageable workload she experiences to the high resident-to-staff ratios that are common during the night shift at her facility. Being responsible for too many residents means she is unable to complete the tasks for which she is responsible over the course of her shift. Notably, Liz's comments suggest that under these conditions, tensions between management and direct care workers emerge. Liz's comment about not being "a machine" indicates she experiences a lack of acknowledgement of the personhood of staff members. The satisfaction Liz may experience providing care is compromised when she feels unappreciated in terms of her skills and effort to provide good care.

According to the narratives of worker-participants, short-staffing or "working short" is a common problem across employment categories (i.e. nurses, PSWs and recreation staff). Often, it occurs as a result of unexpected staff absenteeism, such as when staff are late or call in sick. However, at Spruce Hollow Central, it appears that short-staffing has become a more permanent condition of care work. In the following quotation, Trish (a nurse), an Verline (a recreation worker) describe the situation like this:

> Trish: The job is getting more paperwork and lesser staff. It's kind of hard. You know, everyday there is paperwork that you haven't finished. And it's piled up for the next day. And the next day, something comes up. So it keeps piling up. When I started here, we used to have one RN (registered nurse) and one RPN (registered practical nurse) on the

> floor. And then it was cut off. And then we had like, partners every other day. And then it was cut off…. Two days ago, they cut off the second nurse even for the Doctor's Day. So it's like you are by yourself. I don't know. They say it's budgeting—we don't have the budget for extra nurses.
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> Verline: Right now we have three [recreation staff]. We are supposed to have four at least. One of us is sick for half a year and another one is on maternity leave, so they hired one person instead of two. And we have one girl coming who is in school…. She comes only two days weekly to help... It's not really enough for us. We don't have staff. So, this is the main problem for programs…. I work alone on Sunday [and] it's lots of trouble to run [group programs] alone.

At Spruce Hollow Central, short-staffing has become a more habitual or predictable condition of work given the tendency of management not to refill certain positions when an existing staff member quits or goes on leave. The consequence of these staffing arrangements is that workloads become unmanageable. Direct care workers are unable to complete the entirety of the tasks for which they are responsible. Given these conditions, Trish frequently arrives to work early and works through her breaks in order to come closer to completing all of her duties. When Verline becomes unable to manage her robust workload, she cancels some of the smaller and individual recreation programs in order to make room for other duties.

While inadequate staffing levels mean unmanageable workloads for most direct care workers, the data reveals differences in the problem of poor staffing among direct care workers that suggest low numbers of certain occupational groups mean unmanageable workloads. provision. Nurse-participants commonly discuss the negative impact that minimal staffing levels have had on their workloads. In the context of discussing her dissatisfaction with what she perceives as a major decrease in the amount of time she spends with residents since she started working at her facility almost a decade ago, Viola (a nurse), explains the particular problem of lean nursing levels in this way:

> [It's] just me. I'm the only nurse. We have three PSWs, but they have their role. I have mine and I can't ask them to help me. So really, I am the only person. Like, if you have some help with the paperwork, like, if you can leave some things for another person to do—even if it's a few hours a day—you would have some extra time. But it's like, every minute counts. Every minute counts.

Because Viola is the only nurse working in her unit at any one time, she continually experiences difficulty completing essential and required tasks during the course of her shift—a situation she tells me could be addressed by hiring a second nurse. She explains that many of her job responsibilities can only be completed by a nurse, so she cannot turn to the PSWs she works with for extra assistance.

Issues of inadequate staffing and staff-mix is not the only problem. When nurses (and to a lesser extent, recreation staff) describe the negative impact that documentation requirements have on their efforts to provide (relational) care, their comments indicate that these staffing problems combine with heavy, rigid documentation requirements associated with the existing government funding and regulatory process. Nurse-participants in particular suggest that increases in documentation mean they spend very little time "on the floor", providing direct care to residents. Viola (a nurse) explains it in this way:

> You know, I had [a resident] say to me recently, "We don't see you on the floor as much as we used to before." I'm always in the back on the computer doing something now.

> That’s where my time goes now. I don’t feel like a nurse anymore. It’s like you are a secretary or something. You gotta get this done and you have deadlines.

For Viola, and others, documentation requirements necessary to meeting government-imposed regulations are viewed as a problem. While some of these comments suggest that such high levels of documentation are themselves unnecessary, the bigger issue appears to be that because staffing levels and mix are inadequate, nurses have very little “face-to-face” time with residents.

While discussing the type of care she would like to provide younger residents at her facility, Kristine (a nurse), also indicates that inadequacies in staffing levels and mix in combination with high levels of documentation have a particularly negative impact on the more relational aspects of care provision:

> If there is less workload then you can spend more time with residents— meeting their emotional needs, interact[ing] with the residents, and get[ting] to know them better…. Sometimes because of the limited time and you are spending most of the time on the paperwork—you know what I mean?”

Kristine’s and similar comments suggest that documentation requirements are a problem in terms of relational care provision. They arise from conditions characterized by inadequate staffing levels and mix in combination with overly onerous levels of documentation associated with existing funding and regulatory requirements. These conditions mean unmanageable workloads and workloads that disproportionately involve practices that remove direct care workers from providing the types of care they believe younger residents want and need.

Staffing and Illness, Injury and Violence

Often connected to if not stemming directly from unmanageable workloads, the ways in which direct care workers speak about the problems of under-staffing indicate that under these conditions, providing care is riskier in terms of the potential for illness and injury. Verline (a recreation workers) and Trish (a nurse), who experience overwork associated with chronic under-staffing issues at Spruce Hollow Central (see above) experience some of these consequences:

> Verline: I was injured in this place. My back is hurting. I had a fall on the stairs. It was wet. And I'm on modified duties. Anyways, I had to push the [residents in wheel]chairs because I am alone. And the department head could not help me porter people because they were having a meeting…. I think people need to think— I mean, the management need to think about the staff. They are losing the staff. Because, if I get sick, I won't be able to come [to work]... I am injured but they expect me to get better. I was injured three months ago and I'm still here.
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> Trish: It's kind of hard [working alone]. It's taking a lot of your energy. The only thing I don't like for myself is when I'm [here], I have energy. But when I step out the front door, I just feel like I want to crawl to the subway. I finish my work at three o'clock, but I always finish like, four- four-thirty…. Sometimes I feel like, ok, get to work, do my job and go home. But I don't know, maybe it's because I've been here on this [unit] before I started working here—it feels like I am so attached to the residents and I want everything done.

Like Verline and Trish, direct care workers often tell stories indicating they regularly increase their pace of work, work alone, or do unpaid care work by working through breaks, arriving early for their shift and leaving late. While many worker-participants seem aware of the negative impact that the conditions of work are having on their physical, mental and emotional health, they tend to discuss these negative outcomes as a normal part of the job. Under conditions of lean staffing, some direct care workers seem to feel pressure to provide care alone for the benefit of the resident. Indeed, many seem to suffer through risky conditions of work for this reason. In this context, the satisfaction direct care workers derive from meeting residents needs and preferences (see Chapter 6) translates into exploitation.

Staffing level inadequacies also prevent relational care provision because they put direct care workers at greater risk of violence. When direct care workers—particularly those who do (intimate) personal care—work alone, they become more vulnerable in situations where a resident is aggressive and/or violent. Rosie, a nurse, acknowledges this risk when she tells me about some of challenges the PSWs she supervises are experiencing in providing care to a younger male resident who is sometimes physical and/or sexually violent to staff members and other residents:

> The only time that it gets a little more difficult is like, I have a man who's verbally and sexually abusive and that's tougher. He's been abusive to staff and uh, you know…. I go and speak to him and then I talk to the family. Because it's, you know, I'm wanting to talk to him about it. "You can't do that"....So I just told the girls, now they should be in there with two of them, 'cause he's a huge man and he could take any of us down in a minute. So it's scary for them, it's scary.

Examples provided by Rosie and several other worker-participants make it clear that violence against direct care workers is a common experience working in a LTCF. Often, direct care workers minimize or normalize the violence they experience, citing resident's impairment-type, age, and/or worker error in the form of lack of experience and/or taking the wrong "approach" to providing care to a resident as the cause of violent incidents (see Chapter 8). However, it is also clear that having enough staff available to work in partners or larger care teams helps protect direct care workers from such incidents. Further, having enough staff means more time for relational care provision, which may also reduce violence against them. However, such preventative measures require higher staffing ratios than the ones worker-participants tend to describe.

Staffing and Individualized Care Provision

When I ask direct care workers about the challenges they experience providing quality care to non-senior residents, their responses emphasize the notion that under conditions of poor staffing, workers are unable to provide care in ways that meet the individual needs and preferences of residents, including non-senior residents. While resident-participants emphasize that poor staffing means it is difficult to get assistance with “the extras” (see above), this is also an issue for direct care workers because doing only the basics and providing care in more standardized ways is in opposition with the type of care they feel satisfied providing. For example, Daphne (a PSW) continuously discusses the importance of a “resident-centred” approach to care (see Chapter 4), particularly when it comes to providing care to younger residents. Daphne associates a resident-centered approach with supporting residents to maintain their autonomy. However, her efforts to provide care according to this model is severely limited by staffing level inadequacies. Daphne describes this tension in the following comment:

> We don’t want to take away their independence. We want to give them and allow them. It will be slow for them. Like, if I go to a resident and say she rings the bell and she needs to go to the toilet and I go there and well, each resident is assessed whether they are one-person or two-person or lift or whatever, right? So I will go to the resident and I will say, “What would you like?” And she says, “Oh, I need to go to the bathroom.” Now I know she will take half an hour to walk with her walker from where she is sitting in front of her

> TV to go to the washroom. Now, I don’t have half an hour, but that’s what she wants, so I need to strive to do that…. It’s hard. Somebody else may have to wait—another resident may be waiting to go to the washroom first, but I always have to give her choice. I would say, “Ok Daphne”, or I would say, “You know what, I don’t really have half an hour. Can I put you—”. I will negotiate now and I say, “Can I use your wheelchair and take you there faster because you know, your neighbour needs to go to the washroom as well?” That sort of a thing, so you renegotiate care. You give them the choice as much as possible and then you negotiate with them, because we are in an institutional setting and our staff ratio is like—each floor has over 30 residents and each of our floors have 3 PSWs.

Daphne’s comments are indicative of a tension between the type of care direct care workers believe younger residents prefer and need, and the practice of everyday care work within conditions of lean staffing. With a care ratio of one PSWs to ten residents, Daphne—who wants to provide residents with more individualized and resident-involved care—does not have the time she requires to do so. Her emphasis on negotiating further points to the necessity of adequate staffing ratios in terms of giving staff enough time to communicate with residents in ways that encourage them to self-direct their care and otherwise participate in the ADLs.

Staffing and Care Relationships

The narratives of direct care workers indicate that poor staffing levels are incompatible with relational care when they infer that such conditions prevent the formation of care relationships with residents. As discussed in Chapter Six, time is a key facilitator of relational care provision. Yet under conditions of short and understaffing, direct care workers only have time to provide care in rushed, task-oriented ways.

The problem of inadequate staffing in terms of the maintenance of good care relationships with residents is also noticeable in the contradictions apparent in the narratives of direct care workers. While worker-participants often emphasize the satisfaction they experience meeting the needs and preferences of residents and providing care in relational ways (see Chapter 6), when they experience overwork due to conditions of inadequate staffing, those individual residents who advocate for timely care or who want to socialize with care staff come to be constructed as a problem. Consider how Trish (a nurse), characterizes some of the residents in her unit while talking about the problems she and her co-workers are experiencing with short-staffing:

> Everyday there is something that will come up—short staff. Like today, we are short-staffed…. And then, we have residents who you know, once they see you the complaints start: "I have this, I have pain." Or, other residents will say, "I've been here waiting for a long time, you haven't given me my medication." And everything is just—you know? You just finished giving the shift report and you have to make rounds. So, it's like, once you come, they want to have their medication. It's more like attention-seeking residents, I have a lot of that.

Poor staffing means that direct care workers are both overworked and unable to meet the needs and preferences of residents. Under these conditions, positive care relationships may be undermined, as residents who fail to demonstrate patience or express their understanding of if not appreciation for the volume of care being provided are viewed as "demanding", "impatient", or "attention-seeking" by direct care workers.

Comments made by Mackenzie (a recreation worker) also indicate some groups of workers are less likely than others to provide care in relational ways because of the interaction of staffing levels and the nature of the jobs for which they are responsible. Throughout her narrative, Mackenzie emphasizes the importance of building relationships with residents. Building good relationships fosters appreciation and affection from residents and helps her ensure she is meeting their preferences (see Chapter 6). When I ask Mackenzie how she thinks these relationships could be improved, her answer focuses on the role played by staffing ratios:

> If there is one staff who has 10 residents to get ready, there is often—they are always in a rush, and it's hard to be able to build those relationships with each resident. I think that is where communication can go wrong. You are so wrapped up in your day and what you need to do that it's hard to be able to do that. I think that's where improvements need to be made. What's the answer for that? I think maybe having more staff and having that time to build those relationships. It would help communication between staff and residents.

Throughout her narrative, Mackenzie emphasizes the relative ease with which she forms good relationships with the residents at her facility. In this quotation, however, she indicates that recreation workers can more easily provide care in relational ways because care of this sort is built into the nature of their jobs. Her comments suggest that it is all the more vital to ensure appropriate staffing levels among those who provide the "hands on care", in order to ensure they have time for the provision of care in relational ways.

Issues of staffing level inadequacies emerge from the data as *the* primary barrier to relational care (provision). For younger residents, it means care that is rushed, limited to essential care tasks and untimely. While there are some differences among direct care workers, not enough staff means unmanageable workloads, increased risk of illness, injury, and violence, and it prevents the provision of more individualized care. For both younger residents and direct care workers, poor staffing levels have a particularly negative impact on the development and maintenance of care relationships.

“Now I have to keep up with everybody’s schedule”: Rigid Care Routines

Staffing level issues are not the only factor preventing relational care (provision). When care is provided and received according to inflexible schedules and routines, it often acts as a barrier to relational care. The data suggests that many of the ways in which care provision is organized across facilities is remarkably similar in the sense that it often follows rigid, pre-established, time limited schedules and routines. Younger residents, their family members, and direct care workers describe daily morning (a.m.) and nightly (p.m.) care routines whereby the timing and order of care practices such as washing, dressing, having one’s incontinence product changed, eating, and taking medications are consistent. Residents tend to receive support with bathing or showering twice a week, on the same days of the week, at the same time. Residents who leave their rooms to eat are assigned to a place at their dining table according to a prearranged (sometimes) rotating seating chart. Residents who attend recreational, social, spiritual and therapeutic programs do so at regular time slots according to a predetermined calendar, and residents receive personal care and are “put to bed” at the same time every night. Many of these routines are time-sensitive in the sense that staff are given a certain number of minutes per resident within which they must complete these tasks.

The imposition of care routines is not always constructed as a problem. Some younger residents seem to appreciate routines and schedules because they mean the reception of particular forms of care at predictable times. This supports residents in the planning of other aspects of their daily lives. Direct care workers also recognize the value of routines and schedules. Providing care in this way can help ensure the timely completion of care tasks. Routines are also valued by direct care workers when they are understood as “good for” residents. Gathering in a common area for meals, for example, encourages socialization and/or is beneficial for mental health, and having a schedule for medications is important to ensuring they are taken as prescribed. However, when routines are inflexible, they create problems for both younger residents and care workers.

Care Routines: Issues for Non-Senior Residents

Routines and Self-Determination

Despite the benefits, the prearranged, relatively fixed nature of care schedules and routines are a problem for the resident-participants involved in the study because they frustrate efforts to determine the particularities of one’s everyday life. Marnie (a resident) indicates that having to adhere to a personal care schedule is perhaps the most difficult aspect of living in a LTCF. As a single professional, she describes herself as previously experiencing “a lifestyle that is what [she] wanted to do.” She explains, “I basically did what I wanted to do and I didn’t ask too many people their opinions. I just did what I wanted to do.” Entrance into LTCF, however, required her to become highly “structured”—to pre-plan daily activities according to when personal care is made available to her. With hesitancy, she describes the impact of this change on her sense of autonomy: “Was there a big adjustment? Yeah. Now I have tears in my eyes. [She is crying]. I had an independent life. The independency is gone. I have to keep up with everybody’s schedule.”

Challenging notions of person- or resident-centred care (see Chapter 4), resident-participants discuss the routinization of care in ways that suggest it prevents choice and/or is experienced as the imposition of unnecessary “rules”. Being awoken early in the morning for a.m. care is a commonly described example of how care routines are in tension with their preferences. Several resident-participants tell me they dislike being woken-up early most days of the week. Some tell me they are prompted to wake up earlier at the facility than when they were getting up to attend work and/or woken by their young children at home. Others are particularly aggrieved with the fact that being woken up early is accompanied by being quickly washed, dressed, assisted with toileting, and transferred into a wheelchair (when required), only to be left with nothing to do for a period of time before breakfast is served.

At some facilities, direct care workers construct the inflexibility of personal care routines as a problem for most residents, regardless of age. Liz (a PSW) describes a lack of resident-choice over the timing of a.m. care at her facility in this way:

> [The residents have] no say in the morning…They have to be in the dining room by eight thirty. That's what time breakfast is. The thing is, we, the PSWs, have to be in the dining room right at 8:30 to serve and feed. So, we have to be in there. So if we're in there, they have to be in there… I've been at other nursing homes where it's a staggered breakfast, but there's also a lot more PSWs working there. You'd have a certain amount of PSWs in the dining room by a certain time. The rest of the PSWs are finishing everybody else's care… Like, you didn't have to go in their room and say, "Ok, you have to get up." Like, if they didn't want to get up at that point you'd say, "Ok, I'll come back in half an hour." You go back in half an hour and if they still don't want to get up, "Ok. I'll come back in half an hour."

By comparing the a.m. care routine at her current facility to the one where she previously worked, Liz points to the inflexibility of care routines at her current facility and provides an alternative that offers residents more choice. She seems to understand offering more choices to be in the best interest of residents because it allows them greater self-determination over the particularities of their day. But this practice is also likely to benefit direct care staff. If residents are more satisfied with the timing of their care—particularly in the morning—they are less likely to resist care and more likely to interact with staff in a positive way. As Ethena (a PSW) explains about the challenges of a. m. care, “if they are lousy and don’t want to get up, it’s hard for you.” Liz’s comments, however, also make it clear that higher staffing levels are required to support this practice of giving residents more choice. However, as Liz infers, this requires having enough PSWs and nursing staff to assist residents in the dining room *and* with a.m. personal care at the same time.

Routines and Personhood

It is also clear that inflexible care routines can prevent relational care that supports resident-personhood. Susan’s description of her family member’s morning care routine is a striking illustration of how the routinization of care can mean care that is undignified and disrespectful:

> Well, (Name of non-senior resident) gets dressed by the night staff. So no, she [does not pick out her own clothes]. She’s in bed. They can dress her anywhere from four a.m. to five-thirty. They would half dress her. They would change her and half dress her. And when days [the day shift staff] come on, they would put her pants on and her socks and her shoes, and her boots. And so, she has already been half stripped and half dressed.

What Susan describes is the efforts of a facility to implement a routine that makes workloads more manageable particularly under conditions of lean staffing. However, when a resident’s morning care involves being disturbed at four-thirty in the morning and left half-dressed in her bed, it is clear that while this routine may make care provision more efficient, there is little consideration of what this practice means in terms of the resident’s personhood.

Routines and Care Relationships

For some resident-participants, the rigid timing of particular care practices act as barriers to the types of care relationships in which they prefer to be involved. Fixed mealtimes, for example, get in the way of visits from family and friends, or can limit opportunities to engage in activities outside one's facility. At one facility, early and inflexible mealtimes made it unlikely that one non-senior resident's husband would join her for dinner. The meal was provided too early in the day to fit into his work schedule.

Several resident-participants also express particular dissatisfaction with routines that prevent them from interacting with other younger residents at their facility. For example, it is common for resident-participants to indicate they are told where and with whom they can sit at mealtimes. Marnie tells me that being placed at a table with co-residents not of her choosing does not provide adequate opportunity for socializing. She explains, "The ladies that I sit with [at meals] are elderly…. They are nice ladies, but I can't say I get along with them. Like, they talk about the weather [laughs]. What are you going to say about the weather?" Rules around mealtimes also prevent social engagement for resident-participants like George, who prefers the company of two younger residents at his facility but is not allowed to sit with them at mealtimes because they reside in a different unit. At one facility, resistance among some younger residents to such routines created tensions between co-residents. Staff reported older residents being offended by younger residents who refused to sit at their assigned seats, or who would eat quickly and leave the dining table without socializing or without waiting for their tablemates to finish eating (see Chapter 8).

Given the perception among resident- and direct care staff-participants that informal social interactions with staff are often very important to younger residents (see Chapters 5, 6 and

8), it is a problem that time for the more relational aspects of care provision is not built into care routines and schedules. When resident-participants tell me that the workers at their facilities do not have time to “talk”, “chat”, “joke around” or “listen”, their experiences point to the relationship between care routines, staffing levels, and time for relational care. Maximizing the efficiency of care tasks allows facilities to maintain lower staffing levels. However, the time that staff members have to complete these tasks is clearly insufficient. Many worker-participants tell me that there is not enough time in the schedule to complete basic care tasks, let alone time for the provision of care in relational ways. Comments made by Andor (a resident) indicate that under these conditions, it is difficult for residents and staff to maintain care relationships. While discussing what he tells me is one of the only positive relationships he has built at the facility—a relationship with one of the women who cleans his room (see Chapter 5)—he tells me that since she only has a short amount of time to clean each room, she cannot spend more than a few minutes talking to him.

There is also some indication that the division of care tasks associated with highly efficient care routines can act as a barrier to relational care. Some non-senior residents tell stories suggesting when the work done by PSWs is divided in such a way that each worker is made responsible for assisting a set number of residents, they are unlikely to form good relationships with workers who focus on the residents to whom they have been assigned. George (a resident) describes a “couple [PSWs] who [tell him] ‘You’re not my resident, so I’m not going to help you.’” Alex describes a similar situation, emphasizing that she will “ask nothing” of such workers. In both situations, it is clear that these younger residents have little respect for and are unlikely to develop positive relationships with those direct care workers who adhere to the strict division of care associated with care routines. In fact, there is some indication that those direct care workers who are unable or unwilling to provide more than task-oriented care to the number of residents to whom they have been assigned are understood by non-senior residents as having individual character flaws. These are often the workers that residents “don’t like”. They are the ones who “don’t like their jobs”, and who only work “to get the pay cheque”.

Care Routines: Issues for Direct Care Workers

Many of the issues direct care workers associate with inflexible care routines are linked to the problems of inadequate staffing arrangements (see above). For PSWs and nurses in particular, the time they are allocated to complete care tasks is not enough. As mentioned, under these conditions they experience overwork and dissatisfaction knowing they have not met the needs and preferences of residents. Some worker-participants indicate that not having any extra time built into care routines and schedules to allow them to deal with various issues that unexpectedly arise, for example, when a resident becomes ill or has a fall, or when a piece of equipment malfunctions, it becomes very difficult to provide care according to the schedule. Under these conditions, some residents will express dissatisfaction with the worker.

Reproducing gendered and ageist stereotypes while speaking specifically about older female residents at her~~,~~ facility Liz (a PSW) suggests that when the care schedule is disrupted, these residents become “bitchy”: “You know, it’s almost like—well, I think it’s because they’re used to such a rigid schedule in what they do and how it gets done. So if it’s not done that way, it’s wrong. Yeah, I find them very by the book.”

Trish (a nurse) also emphasizes that as a consequence of not being able to maintain the imposed care routine, residents become “irritated” or “demanding”. This is an issue for Trish because it increases the likelihood that some of the residents will demonstrate their dissatisfaction in ways that she experiences as personally offensive. Accusations of laziness such as “she’s not doing her job, [she’s] just sitting there”, frustrate Trish because they suggest a lack of understanding among residents of the arduousness of the “kind of work [she is responsible for] in the time that [she] has... [for] bedside care”.

It is also clear from these and similar discussions that rigid care routines and schedules are a problem for direct care workers because they do not include time for the more relational components of care provision. Viola (a nurse), infers that the time she is allotted to complete provision does not include time for social and emotional support. She explains:

> You can’t pay attention the way you would like to. Like, sometimes really, you have residents who want to talk but you don’t have the time to converse with them. You know, all you are thinking about is time. You have to manage your time no matter what, you have to manage your time.

While Viola’s comments speak to the dissatisfaction she and other worker-participants experience when time for relational care is not figured into the care schedule and routine, Pilar (a PSW) tells me that this is a particular problem when it comes to meeting the needs of non-senior residents. She explains:

> [The younger residents should have] one-on-one [with staff]—take them for a walk or like for a movie for them, or just talk to them, stay with them for half an hour. We want to do that. Like, I want to do that, but we have so many things we have to do…. I want to spend a certain time more [with younger residents] than the other one. But, it’s really—the time is not enough.

Like other worker-participants, Pilar believes when it comes to younger residents in particular, direct care workers *should* provide them with more individualized, highly relational care because this is the sort of care they need and value. However, this form of care is not built into care routines meaning that staff are limited in terms of the time they have to meet these needs and preferences.

“Everything is nice, and then they move me”: Discontinuous Care

While conditions of lean staffing and rigid care routines result in a variety of problems for younger residents and direct care workers, the data also indicates a number of issues with conditions characterized by discontinuity of care. Discontinuity is associated with the tendency of facilities to over-rely on part-time and casual workers, and to maintain a large number of non-permanent positions. The use of part-time and casual —particularly when this position is involuntary in the sense that the worker desires full-time, permanent employment—results in high turnover as workers are dissatisfied with the precarious nature of their employment. Further, many of these workers—so-called “floaters”—are placed in various units of a given facility rather than being assigned a permanent position on a single unit. This situation leads to inconsistencies in and dissatisfactions with the relational aspects of care work.

Discontinuity: Issues for Younger Residents

Continuity of care emerges as a facilitator to experiences of the type of relational care younger residents value (see Chapter 5). However, lack of continuity means gaps in care provision. While discussing some of the issues with the recreational programming experienced by the residents at Northern Willow, Susan and Thomas (family members) suggest that the facility’s reliance on part-time and casual recreation staff has created conditions of high turnover among these workers. When turnover is high, residents experience gaps in care provision:

> Susan: One of the huge, huge problems is staff. And it’s hiring. You get somebody hired and of course, you don’t give them enough hours…. And every time we lose one, it’s months of zero [recreational programming]. Months. It’s not a turnaround, it’s months.

> Thomas: And then, when they do hire, they hire a casual. A casual you are going to lose within three months because as soon as [they] get a little experience under their belt—
>
> Susan: [They go] where they can get hours…. Look at our part-timers, they get 25 hours. Who wants 25 hours every two weeks unless it's an add-on to what you already do?
>
> Thomas: But then, the problem there is, you are on-call. If you are in fact working elsewhere—casual or part-time—it limits your ability to, in fact, fulfill the needs of this particular home…. The problem we have at the present moment is that casual is basically on-call. When [the recreation workers] initially start, they are basically on-call—I was going to say 24-7, but more like 12-7 (laughs). And very, very soon after they start, they are on the lookout for [a job] that will give them more hours. So they are gone. Many still remain casual, interesting enough, but it's on their terms. They are called in for special events. The problem I have with that is, they are not part of the on-going day-to-day recreation…. So this is where we are having a major problem.

For Susan and Thomas, hiring part-time and casual recreation staff undermines the continuity of care as staff are difficult to retain under these precarious employment conditions. It takes time for new staff to be hired and trained, leading to gaps in the provision of programs.

Thomas' comment about the importance of having staff involved in the "on-going day-to-day" recreation program infer that the problem of discontinuity is about more than program cancellation. When I consider the ways in which resident-participants talk about their relationships with long-time staff members, it becomes clear that discontinuity is a problem for younger residents because new workers have yet to learn residents' care needs and preferences, they do not know residents as people beyond their care needs, and in some situations, they are unable to communicate with particular residents because they are unfamiliar with the non-verbal ways in which they express themselves. Being unknown to a staff member can lead to inappropriate or unwanted care, as misunderstandings between staff and residents are more likely. Andor (a resident) describes one such situation when he tells me about the negative interactions he recently had with a PSW who is new to his facility:

> I have no restrictions. I can leave anytime I want to. I'm a free man. I mean, I would like to see someone stop me…I mean, I'm not crazy. I can't walk, but this thing [motorized wheelchair] takes me anywhere I want to. There was one Filipino [sic] lady [PSW]—I was coming out [the front entrance] and she was coming in. She stands in my way and says, "No, you can't go out." I says, "What?" And I told her—the lady at the reception desk—"Who's this thing?" (Laughs). I said [to the PSW], "Get out of my way or I'll run you."… She thinks she's got some kind of a power. But she made me so angry that I would have even slapped her…. Then the lady at the reception told her, "You better get out of his way" (laughs), because she knows me. I'm a really nice guy, but they don't want me to lose my temper.

Seemingly assuming that Andor is not permitted to leave the facility unaccompanied and/or is "exit-seeking", this new staff member tries to prevent Andor, who is unknown to her, from exiting the building. Andor experiences this interaction negatively—likely because the worker's assumption challenges his identity as an autonomous man. The worker's assumption, while clearly ableist, is also about a lack of familiarity or the absence of a care relationship. She does not know that unlike some of his co-residents, Andor comes and goes from his facility often and as he pleases.

The risk of discontinuity may also compromise younger residents' access to care relationships. Some resident- and worker-participants suggest that staff and younger residents should not form close relationships given high staff turnover rates. Trish (a nurse) raises this issue when I ask her to describe the relationships she has with the younger residents at her facility:

> You know, as the days go by, you don’t really want to attach yourself. It’s hard. You shouldn’t do that—you know? It’s hard because sometimes if the residents get attached to you, what if you are not here?

Believing that the formation of friendships or “attachments” may have negative consequences for residents in the future, Trish’s indicates that high turnover may stifle workers' desire to foster and maintain close caring relationships with residents. Since non-senior residents often view workers as better companions than their co-residents (see Chapter 8), they may be especially likely to experience emotional distress as a result of high staff turnover, and workers may be especially reluctant to form close bonds with them.

Indeed, there is some indication from the narratives of resident-participants that there is some emotional risk to forming close relationships with staff members. Throughout their narratives, younger residents describe care workers with whom they have built strong relationships. This does not seem to be understood as a problem for most, but as Jackson and others emphasize throughout our conversations, it is difficult when a staff member with whom one has a strong bond leaves the facility. Jackson tells me that he misses a PSW who recently left the facility, and that he has yet to find another staff member who is willing to spend time talking with him like she did. This situation is complicated by the tendency of non-senior residents to live at a given facility for a longer than average LOS. When staff retention is a problem, their conditions of care become characterized by on-going experiences of loss.

Discontinuity: Issues for Direct Care Workers

While discontinuity compromises younger residents access to relational care, the data also suggests that this condition of work is a problem for direct care workers. In Chapter Six, I demonstrate that direct care workers build good relationships with residents to provide care that better meets their needs and preferences and to foster their participation and cooperation. I also argue that time is the most commonly described facilitator to such relationships. In contrast, discontinuity disrupts the formation of care relationships between residents and staff. When part-time and casual worker-participants describe working in multiple facilities, moving from facility to facility in order to secure more permanent employment, and when they are used as "floaters" to fill gaps in staffing within a given facility, their comments indicate that it is often difficult for them to form the types of relationships with residents that facilitates care provision.

Pilar's work as a full time, temporary PSW is characterized by discontinuity. Although she has worked at the same facility for over three years and gets full time hours, she is non-permanent and as such, has not been assigned a specific unit. Our discussion of the difficulties she experiences providing care under these conditions alludes to some of the consequences of discontinuity in terms of her the ease with which she provides care:

> Morgan: What do you think is most challenging about your job?
>
> Pilar: It's when I don't get along with somebody…. One of the challenges is to get used to the floor, get used to your co-workers, get used to my residents.
>
> Morgan: So when you get to know everyone, it gets easier?
>
> Pilar: That's the problem. Everything is nice and then they move me because I'm not permanent on any floor yet…./ The main thing is I've been on all the floors.
>
> Morgan: Do you like that?

> Pilar: It's well, certain things…. It is nice because you know a lot of the people. You know a lot of residents' families…. Everybody I see, they know me. [After I move units] it's always, "Oh, when are you coming back? I miss you. I want you to come." I say, "Well, one of those days I'll be back." (Laughs).

While Pilar considers the benefits of having a non-permanent position in terms of getting to meet a wider range of residents and their family members, it is also clear that regular transitions are a challenge for her. Under these conditions, it is hard to provide care to residents and work with staff members with whom she does not get along because she has not had time to establish relationships of trust and understanding. She also admits that it is difficult for her to leave the residents and co-workers with whom she has previously established good relationships.

The data also suggests that in the absence of a permanent, full-time position, it is difficult for workers to form the kind of care teams that facilitate relational care provision (see Chapter 6). The data suggests the existence of tensions between some full-time, permanent direct care workers and those with less than full-time and/or non-permanent positions. Sandy, a part-time PSW, and Pilar, a full-time, non-permanent PSW, talk about some of their full-time, permanent co-workers in ways that are suggestive of such tensions:

> Sandy: Some people get very complacent in their jobs. And I mean for me, everyday is going to be different. I'm not doing the same person everyday—they are. But the circumstances change everyday….It's just, I'll go do this, this, and this, and they don't do any extras. They'll kind of neglect [that] part of their job
>
> Pilar: I really would like to work together, but some people, they take advantage of me. Some people, they know, "Oh, she do this one [provide care for this resident] for me, she take that one for me, so took my garbage, she did my room." Because I know if one team

> is heavy [is responsible for residents with more intense care needs] and my team is light, I will go and grab two residents for them. But then, when my time is coming, nobody comes and do it. It’s pretty bad, that, sometimes. But what can we do?

The narratives of part-time and non-permanent PSWs involved in this study seem to indicate that they are sometimes perceived as “add-ons” to the “regulars”. This perception reflects the tendency of part-time and non-permanent workers to be used as substitutes for regular workers, or to bolster staffing levels at times where extra workloads are anticipated. Under these conditions, Sandy and Pilar appear to feel compelled to do more than they are assigned. They complete extra tasks, help their co-workers who have unmanageable workloads, and do some of the “extras” that full-time staff seem not to have time for. However, this sometimes results in feelings of animosity or resentment towards their colleagues who they perceive as only doing the minimum.

Full-time, permanent worker-participants speak less overtly about such tensions. They do tell me, however, that new, casual, part-time, and/or non-permanent workers are significantly disadvantaged in terms of their familiarity with the care routines and needs of the residents. This can translate into additional work for the “regular” staff who may have to assist or train more temporary workers. In addition, some full-time, permanent staff suggest that they sometimes compensate for deficits in the effectiveness and efficiency of more precarious workers, particularly when residents complain about them or refuse to let them provide care because the resident does not know them and/or the worker lacks familiarity with the resident’s preferences.

While in many ways, discontinuity in care provision is not in the best interest of workers or residents, the narratives of part-time, casual and non-permanent worker-participants provide multiple explanations for why these conditions of care (work) exist. This group of workers experience a variety of challenges related to the more precarious nature of their employment. For some, this situation means that they struggle financially. Some of these women hold jobs at multiple facilities to make enough money to live on. Some worker-participants describe picking up additional shifts and/or running their own side-businesses from home. This group of workers are also less likely to receive the full bundle of employment benefits associated with full-time, permanent employment. Pilar is a full-time, temporary PSW meaning she has yet to secure a permanent position at her facility. She explains this situation means she is excluded from some of the employment benefits received by her more permanent counterparts such as banking lieu days when she works a holiday shift even though she works full time hours. These and similar comments help explain discontinuity of care as the employment arrangements used by facilities lead to high staff turnover.

“Nothing works here except the girls”: Inaccessible Equipment

Lack of access to a range of equipment involved in care practices also negatively impacts relational care. Several of the direct care staff at Spruce Hollow Central describe difficulties they experience accessing proper equipment for lifting, transferring and portering residents to the dining room and recreation programs. A nurse tells me this facility does not have enough nor the necessary lifts to help with turning, lifting and transferring residents. In order to get access to such equipment, PSWs have to walk across the floor or to other floors to find one that is not in use. This negatively impacts the quality of care direct care workers are able to provide residents given that waiting for the use of equipment results in less timely care provision. This situation also means direct care staff may forgo use of this assistive equipment because it takes too long. Doing so puts residents and staff safety at risk.

Access to such equipment appears all the more vital given what participants at multiple facilities tell me about the younger resident and staff population. Some worker-participants indicate that increasingly, they are providing care to a number of larger male residents as well as a growing number of younger residents who need significant if not “complete” physical support during care practices. A nurse also emphasizes that several of the direct care workers at her facility are older women. Having access to the types of equipment that assist them with the physically difficult aspects of their jobs is vital.

Lack of access to a variety of functional mobility and other assistive and medical devices is also an issue for younger residents in terms of their autonomy and access to enjoyable or meaningful experiences. During the time of our interview, William (a resident) tells me that over three weeks ago, the Director of Care had his wheelchair, which had a cracked frame, taken away. He was told he would receive a new chair, but had not. This situation made it difficult for him to wheel around his facility to visit the other non-senior residents with whom he is friends.

Alex (a resident) uses a specialized motorized wheelchair to get around her facility. She also uses it to come and go from the facility as she pleases. However, her comments indicate that the type of transportation that is used by her facility to get residents to recreational programs in the larger community prevents her from taking part in these activities. She explains:

> I don’t like the outings [run by the recreation department] because they won’t take my chair on the bus. I have to go in my other chair—my transfer chair. And you know what’s funny? I’ll tell you. They want you to have—to learn to be your mobility. But right there, it’s taking your mobility away from you because someone has to push you. It’s like, I have to rely on somebody else to push me. And [the chair is] uncomfortable…. Change it to get a bus that accepts these chairs. That would be good.

While her facility organizes an "accessible" bus to transport residents from the facility to activities outside the facility, there are clear limitations in terms of the extent to which this mode of transportation is accessible to residents who use a variety of mobility devices. While Alex emphasizes that she gets around well on her own, this experience means she is unable to participate in activities outside the facility alongside her co-residents.

Conclusion

The findings reported in this chapter demonstrate that the ways in which care is organized and delivered within LTCFs facilities play a key role in relational care. When the conditions of care (work) are characterized by lean and inadequate staffing arrangements, rigid care routines, discontinuous care/employment, and insufficient equipment, quality of care provision is severely compromised. Residents do not get the care they need nor the care they desire. It is also a problem for staff by compromising their health, safety and (financial) wellbeing. Direct care workers experience dissatisfaction and frustration knowing that they cannot provide the types and amounts of care they know residents deserve. The issues described in this chapter undermine or are in opposition to conditions in which positive care relationships and the provision of care in relational ways flourish. Instead, they are linked to tensions between staff and residents, between co-residents, and between co-workers.

Many of the issues described above are supported by research that has examined issues in LTCFs in Ontario during the period of time on which this project focused. This literature demonstrates, for example, that in the decade leading up to the COVID-19 pandemic, staffing levels and mix did not keep pace with the needs of the changing resident population (LTCSSAG, 2020; Marrocco et al., 2021), and care workers did not have access to the working and employment conditions necessary to support their efforts to provide care residents need and want, let alone sustain and retain them.

Discussions of the particular impact of these conditions on the younger population and those who provide them with care were virtually absent in these reports, despite acknowledgments that the resident population was diversifying (see Marrocco et al., 2021). The results presented in this chapter suggest that when it comes to the organization and delivery of care, differences in the age of residents, particularly as it intersects with disability and gender, matters. The barriers described above have consequences for residents regardless of age, but some of them are experienced in particular ways by younger residents and those who provide them with care. This is not only because of differences between older and younger residents related to impairment-effects and LOS, but also because these barriers are often understood in relation to particular ideas about gender, disability and youth. Moreover, it is clear that some of these barriers are tied to larger tensions regarding the appropriateness of LTCFs for non-senior residents. These tensions are the focus of Chapter Eight.

CHAPTER EIGHT

“That’s not appropriate for me”: Tensions in the Situation of Younger Residents Living in Long-Term Care Facilities

Introduction

In the previous chapter, I examined factors associated with the organization and delivery of care (work) that prevent the conditions of relational care that younger residents' value. Many of these barriers—inadequate staffing levels, rigid care routines, discontinuity of care (work), and insufficient equipment—are likely to have consequences for all residents, but the data also suggests that they are experienced in particular ways by non-senior residents. Higher staffing levels, more flexible care routines and similar changes to the ways in which care is organized and delivered may facilitate relational care of the sort younger residents value. There are, however, several indications that changing these structures is not enough to ensure the LTC system is one in which younger residents can “survive” *and* thrive. Indeed, non-senior residents tell me they need LTCFs in order to“survive”, but they also wonder how they will “survive” living in a LTCF for an indeterminate number of years or even decades. It is clear that when it comes to living well in a LTCF, younger residents experience many challenges. It is these challenges that are associated with the inappropriateness of LTCFs for younger residents and the perception that they “don’t really belong” in them and are being “left behind”.

Aiming to better understand this issue, I draw on the entirety of the data collected for this project to uncover what aspects of living in a LTCF participants perceive as inappropriate or a problem for younger residents. Drawing on a relational feminist disability perspective (see Chapter 1), six key issues are explored: age-insensitive programs and services; problems with the social environment; a culture of discrimination and violence; rigid safety protocols; deficiencies in the physical care environment; and inaccessible public LTC services. Situating these issues within the context of neoliberalism (see Chapter 1), I argue that while these problems impact those who live, work, visit and want access to care, they have particular impacts on and have produced particular tensions for non-senior residents.

“They are catering to the culture of aging”: Age-Insensitive Programs and Services

Gaps in Recreation and Therapy

The data reveal that the programs and services provided to residents living in LTCFs largely ignore the needs, preferences and interests of the younger resident population. The area of recreation and “therapy” (physio-, occupational and speech language therapy) stands out in this way. Resident-participants tell me that these programs only cater to the interests of the older resident population—older women in particular. George (a resident), tells me that the younger people at his facility “ask to play different games, but the old people don’t like the games.” Joan (a resident) indicates that the care offered to her could be improved if recreation programs were developed with younger people, but also men, in mind:

> [I want] more for my age group—more activities, different types of food, more outings. Even if we had—I know the majority of the population here are women, but there are some men. What about woodworking? What about gardening?... I wish there’d be more music for my age group.

It is not uncommon for younger residents to resist participation in recreational programs because they do not match their interests. Some draw on their own resources, leaving their facilities on a regular basis to engage in more appropriate activities in the larger community (see Chapter 5). The family of one younger resident hired a private support worker to take her out of the facility two or three times a week to participate in community-based programs. But for those who do not have these extra supports, the provision of age-insensitive recreation prevents their access to experiences they find joyful or engaging. Mackenzie (a recreation staff) describes this consequence while telling me a younger resident who rarely receives visitors and does not leave the facility on a regular basis:

> [One] thing that comes to mind is a [non-senior] resident who is also now downstairs. He loves coming up here and doing programs with everyone…. So when it comes to something like trivia for example, he'll always come into the program because he loves group programs in general and he likes to keep busy. But many times, the trivia topics we tend to gear towards seniors who are 65 and older because that's what they remember and that's what they are interested in. And you can tell that he is just bored. And about ten minutes into the program, he's up and he's gone. He doesn't know any of the answers and he gets frustrated…. Another young adult who used to be upstairs here, it was kind of the same issue. He didn't attend much programming and when he did—rarely—he would often leave with a comment saying it doesn't apply to him or he doesn't know the answers or it's not something that he's interested in.

Mackenzie recognizes a disconnect between typical recreation programs offered at her facility and the interests of the younger residents. Her comments suggest that this mismatch results in poor program attendance among younger residents and/or boredom, frustration, and early departure.

Direct care workers express concern over the impact of non- or limited participation in programs among younger residents. They cite depression, sedentariness, and social marginalization as potential consequences. There are also relational consequences: attending social and recreational opportunities separate from those offered by their facilities, leaving early from facility-based programs, or simply not attending programs at all, the development of relationships between co-residents including among younger residents is prevented. Catherine, who does not leave her facility on a regular basis, makes comments to suggest that standard recreational activities offered at her facility are not enjoyed by many younger residents. This creates a situation where opportunities for younger residents to build relationships with each other are prevented. In the context of describing what she thinks people need to know about the non-senior adults living in LTCFs, Catherine tells me:

> Sometimes [the younger residents] are left behind. They may forget about them because there may not be very many here…. [They need to] create more programs...one's that I like…. Sometimes I'm the only one. They need to encourage the younger ones to get involved. And they won't be so lonely. And won't be afraid to try something new.

The data also indicates that programs and services in the area of "therapy services" do not match the needs and preferences of non-senior residents. Several resident-participants express dissatisfaction over the amount of time and/or number of sessions per week that they are provided with fitness, physiotherapy and similar programs—all of which aim at helping them maintain or improve their mobility, speech, and other physical capacities. Throughout his narrative, Jackson (a resident) points to both the struggles he experiences gaining support in the areas of occupational and to speech-language therapy. He also indicates that the amount of time he gets to spend on the treadmill and the intensity of the program he is expected to follow is not enough to meet his goals. Julie (a resident) suggests that she too experiences gaps in terms of the services she needs to be as physically active as she deems appropriate:

> Well, I go to fitness. I was going to say something about that. I don't think they have enough fitness. I don't stand up on my own. I have to have somebody to watch me all the

> time and I don’t get enough of that...I mean, ok, I like to stand, and when I have to sit, I sit…. I don’t use my legs and they are weak and they used to be fine, but I can’t really stand up very much…. But there’s nobody there. People have to be around to watch you.

Julie indicates major gaps in therapy services in terms of the frequency with which they are provided. She perceives that this has had a negative impact on her body weight and physical strength over time. This issue appears to be compounded by gaps in the consistent provision of restorative care. Julie tells me that she would like to stand and walk more, but she requires help with these practices, and staff do not have enough time to provide assistance of this sort.

Standard allotments for therapy prevent these younger residents from engaging in the types and amounts of therapy they deem necessary to maintain their physical health and/or improve their physical capacities in particular areas. Jackson leaves his facility to get this assistance elsewhere, but not all residents have such opportunities, and even for Jackson, it seems like this is not enough. This gap may also be an issue for some older residents, but it is a particular problem for those residents who are more likely to live in a LTCF for longer than average periods of time. Consistent and on-going access to such programs and supports are necessary to maintaining and improving certain skills over time, but this requires adequate programming and staff support.

Gaps in Nursing and Personal Care

It is not only in the area of recreation and therapy that younger residents experience gaps in care. Andor (a resident) expresses disgust over the standard whereby residents are permitted two showers or baths a week. He tells me:

> It’s only twice a week. I think this is ridiculous, especially in the summer. In the winter it’s ok, but in the summer, you’re hot and you sweat…. You know, you can’t help it, but

> you kind of smell. So you know what I do? I go in there and get a large towel and a small face towel, and I just wash myself…. I wash here, and I wash my legs, and it's ok. But twice a week? That's crazy…

Andor's comments indicate that residents are not always provided with enough care to help ensure they feel clean, indicating that this standard is incompatible with care that is respectful of residents' personhood and helps ensure basic health and hygiene. While Andor addresses some of this gap by cleaning himself with a cloth, he regards this as insufficient. Further, not all residents are able to participate in this practice without significant assistance.

Only being permitted to shower twice a week is a problem for Andor and other younger residents who tell me it not only represents a significant change from their self care practices prior to living in a LTCF. This is likely a change for most residents, but many of the non-seniors involved in this study perceive themselves as spending a lot more time outside their facility than most of their co-residents. Regular engagement in the larger community is important to them for reasons of enjoyment and in order for them to access programs and services not available at their facility, but doing so while feeling unclean and/or smelly, is uncomfortable and degrading.

Food preparation is another area of care that appears not to match the needs and preferences of younger residents. In our conversation about the food at her facility, Marnie (a resident), who seems quite satisfied with its overall quality, tells me that the way in which it is prepared is not ideal in terms of her physical health. Explaining to me the benefits of consuming raw, whole fruit in terms of her digestive health, Marnie indicates that this is not what is typically available to residents. Instead, fruit tends to be offered in liquid, cooked and pureed forms presumably because this better meets the needs of the older resident population.

Julie (a resident) tells a similar story. She indicates that the food at her facility does not match her health needs because it caters to older residents:

> Julie: We have our own cafeteria. I wish they had more lettuce or stuff like that.
>
> Morgan: You want like, more healthy foods?
>
> Julie: Well, lettuce or stuff like that. That's not healthy, just less calories. But um, they don't eat lettuce. They don't have their own teeth, you know?
>
> Morgan: Right. So the food needs to work for people who can't chew a lot?
>
> Julie: Yeah. But every time they [serve] something like lettuce, I'm like, "Lettuce please. Salad please." And that's it.

Julie seems to explain the problem with food is that it is prepared based on the needs of a much older population. While drawing on an ageist stereotype about the needs of older residents, her comments suggest that her food preferences—which she perceives as different from the needs of older residents—are not regularly attended to by the facility. When salad is served, Julie tries to "stock up", recognizing this as an infrequent provision.

When family-member-participants describe problems with the quality of personal and nursing care at the facility where their family member resides, their comments suggest the presence of gaps in nursing care when it is provided to younger residents. Susan (a family member) provides one example when she tells me about the difficulties direct care workers have diagnosing the symptoms of discomfort displayed by her female family member:

> Well, with (Name of resident), because her liquid intake isn't huge and because she's not moving, her bowels have always been an issue. Half the time when she has a stomach ache, I say to them [the direct care workers], "Where is she in her period?"… And, "When was her last bowel movement?" It's like, what are you guys doing? But what

> they’ve done is, they’ve given her [a laxative], plus Metamucil, and they were giving her prune juice. It’s like, if she has an explosion—what’s wrong with you people? Her stomach is sore…. So she cries. Well, they get used to her crying and they don’t look to see—they don’t ask questions. She’s um, [her] period is due next week so she’s been cranky and weepy and stomach is aching kind of thing…. And most of them [the direct care workers], she’s their age group, so they should be aware. And one [former] nurse used to say, “Oh yeah,” their timing [of their periods] was about the same. So you know what, if you have a stomach ache and you are cranky, guess what, I am too.

As a resident who experiences disability in a way that impacts her verbal articulations, the direct care staff who provide Susan’s family member with care must rely on the ability to identify the causes of concerning behaviours (e.g., crying, crankiness, or indications of having a sore stomach) in order to provide appropriate care. Despite the fact that some of the staff are also female and of a similar age to her family member, they do not consider her symptoms as reflecting changes in her menstrual cycle. In the context of providing care to a population that is primarily composed of much older female residents, it may be that some direct care workers are unaccustomed to thinking about the difference that being a younger female of childbearing age might make when it comes to experiences of the body. Susan’s comment about the value of a former nurse who knew her family member well and recognized changes in her cycle also indicates the importance of continuity of care in terms of quality of care provision.

Adrianna (an administrator) also suggests that there are gaps in services in terms of supporting the sexual and reproductive health needs of younger residents. She provides this example to illustrate her point:

> I don’t know how well that area [sexual and reproductive health] gets addressed when you are living in an institution. I don’t know how [non-senior residents’] sexual needs would vary from someone who is eighty, or if they would vary at all…. But at the other facility [where Adrianna worked], one of the residents, she came in quite young and she was still menstruating. And she was going off-site and approaching strangers and offering them sexual intercourse and things like that. So it was like, what do we do here? There is the potential that she could get pregnant and have a baby, right? So, but, obviously her sexual needs were not being met.

Adrianna’s comments suggest gaps in care concerning younger residents' sexual and reproductive health. While she seems to recognize that assuming older residents are asexual or do not have sexual needs is problematic, she also seems to perceive this gap as having particular consequences for younger female residents who are still menstruating. This raises additional questions about the rights and potential desires of residents to become pregnant while living in a LTCF, but Adrianna’s point here is that the reproductive health needs of non-senior residents may not be well addressed in LTCFs given assumptions of an older, non-menstruating resident population.

Comments made by Fred (a family member) also suggest that nursing care in LTCFs may not be appropriate for non-senior residents when differences between younger and older residents in what Aubrecht and colleagues (2021) call “symptom profiles” are not recognized nor accounted for. In the following quotation, Fred describes how care workers reacted when his family member—a younger man with acquired brain injury (ABI)—was experiencing seizures:

> I was up here [at the facility] three or four times because he [Name of resident] is lying on the floor, passed out. And then he starts to wake-up. They [the direct care workers] are

> shouting at him saying, "(Name of resident), why do you have to be so stupid? Get up on your feet." It [the seizure] just stiffens him up more and more. So, I have to come up here and ask them to leave, and then quietly talk to him to get himself to move. But the way the girls [direct care workers] were doing it—and they still do it at times, because they are so damned busy looking after everybody—. You know, they get impatient, and he's, you know, lying on the floor. He's not moving. He's not talking. But he's like this (tenses his hand, arm and facial muscles)—tense—because he can hear them and he's tensing because it's hurting.

Fred associates a lack of knowledge about and inexperience working with people with ABI on the part of direct care workers with his family member's experiences of poor, neglectful care. While older residents are also at risk of care of this sort, Fred and other participants indicate that because younger residents represent the numerical minority in LTCFs, direct care workers are less likely to have experience providing care to residents with the particular types of impairment-effects younger residents are more likely to experience. Further, the data indicates an overall absence of training specific to the types of impairments younger residents may experience (e.g., ABI, MS, IDD). In contrast, direct care workers frequently tell me they are provided with Alzheimer's and dementia-specific training.

Gaps in Social (Work) Services

Social work is another component of the programs and services provided in LTCFs that do not meet the needs and preferences of the non-senior resident population. Several resident-participants indicate a need for additional support when it comes to their finances. Marnie (a resident) tells me she is experiencing difficulties completing her taxes as well as understanding the guidelines around the application process for accessing reduced accommodation rates. While she indicates that she has a “relationship” with the social worker at her facility, whereby he has offered some assistance with completing paperwork regarding her financial stresses, the time they have together is not enough. At the time of our interview, she had not received enough assistance to resolve her concerns, resulting in considerable stress and worries about potential financial hardship.

Non-senior residents who are close to turning 65 describe barriers to assistance from social workers. These younger residents describe upcoming changes in their finances as they anticipate losing some forms of economic support such as the Ontario Disability Support Program (ODSP), their parents’ pensions, and/or government drug benefits, and needing to apply for and ensure they receive different or additional supports such as Old Age Security. During the period of time I spent with a non-senior male resident who turned 65 over the course of data collection, he received two pieces of news that required his immediate attention. First, he received a letter from his facility indicating that his monthly co-payment had not been paid. He explained that this money is paid via his father’s pension, which, it appeared, was no longer available to him. He told me he had given his social worker several documents to ensure arrangements, but clearly this issue had not yet been resolved and he was unsure of how to get in touch with the social worker to deal with this urgent matter.

That same afternoon, this resident was informed by a nurse that the pharmacy had called indicating that one of his prescriptions is no longer being paid for by the government. She asks him if he is willing to pay for the medication out of his own pocket. He tries to explain his situation to her, but she does not have the time necessary for him to fully explain the financial issues he is having. The nurse tells this resident to get in touch with the social worker and leaves the room, indicating she will come back tomorrow to get his answer about paying out of pocket for medication—an expense he tells me he cannot afford.

There are also several indications that services aimed at supporting the emotional and psychological health and wellbeing of residents may not be enough to meet the needs of non-seniors. Marnie (a resident) tells me she needs someone to talk to about the difficulties she has and continues to experience adjusting to both life with a chronic illness and coming to live in a LTCF. She explains,

> I'll be here another 30, 40 years. I think to myself, how am I going to change in that time? I know I'm going to get older—60, 70, 80. How am I going to change? How am I going to survive a place like this?.. I'm also realizing that my goals have changed. Initially, I was going to go back to my house and live my life there. But now I'm thinking I can't really do that. I have stairs in my house…and I'm by myself, so I don't think it's a smart thing…. In a way, it makes me feel like a loser. I need someone that I can talk with.

This comment is revealing not only because it makes visible this gap in care, but also because age plays such a key role in the difficulties Marnie describes. She is concerned with how she might change and if and how she can adjust to living in a LTCF for what might potentially be a very long period of time.

Other resident-participants suggest similar challenges. They tell stories about the difficulties of transitioning away from paid employment, they indicate that the onset and intensification of chronic illness or changes in impairment effects can be difficult, and they suggest that they have to learn to "adapt" or "change a little bit" in order to fit into the conditions of their care. Some younger residents also talk about the grief they have experienced when a co-resident has died or a preferred worker has left her position. Most express that they experience ongoing difficulties living alongside a much older co-resident population (see below). These issues indicate that many non-senior residents are likely to benefit from having someone to talk to. They may also benefit from having their own room (see Chapter 5). But while LTCFs are required to provide social work and social services, it appears that what is typically offered is not enough to meet their needs.

Age-Informed Programs and Services in the Context of Neoliberalism

When it comes to the areas of recreation and therapy, personal and nursing care and social (work) services, the findings indicate that LTCFs are not meeting the needs, interests and preferences of younger residents. This gap raises questions about why LTCFs in Ontario structure their programs and services in ways that appear to overlook differences in the resident population particularly in terms of age and what potential there is for change. Understanding the context within which services and programs in Ontario's LTCFs are designed and delivered provides some answers. This context is one in which the logic of neoliberalism plays a central role. Inadequacies in funding for LTCFs associated with austerity and a lack of minimum care standards mean inadequate staffing levels and budgets for services and programs. Under these conditions, providers struggle to meet the needs and preferences of diverse groups and individual residents. Victoria (a recreation worker) provides one example:

> We used to have um, I don't know what happened to the program. We used to have a program for a seventy and under group. And it was run by a volunteer here and they would have some classic rock music and get some pizza. And once in a while they would watch a movie or just do something together. 'Cause it's kind of hard, 'cause there's not a lot of them, so you can't really plan a program like that. That was [the] trouble with that

> program, like, not everybody would want to come and if there's only seven or eight of them in the building … that's not really—you can't really reason having it all the time.

While Victoria infers that this was a program that younger residents very much enjoyed, it appears that the costs associated with it (in terms of staff labour and food) could not be justified because the program only involved a small group of residents.

Direct care workers also tell me that overall inadequacies in government funding for LTCFs makes it difficult for them to provide care in ways that meet the diverse needs of an increasingly diverse resident population. While speaking at length about her efforts to provide care that aligns with a RCC model (see Chapter 4) Daphne, a PSW, suggests that the meager raw food budget makes it impossible to individualize meals. She explains:

> We had a dining room protocol in-service last week in this room and one of the things they told us—I mean, what we actually found out is the budget to feed one person per day…[for] breakfast, lunch, dinner, two snacks in between. Some of them [the residents] are on special diets. Like, you have renal—people on dialysis and [with] different health [issues], whatever. Then you have people for religious reasons, don't eat this and that and the other. And some, well, "I just don't eat pasta" or "I just don't eat this." You know, you have to cater to all this kind of stuff.

As these examples suggest, care workers experience a number of structural barriers to the provision of age-informed and other more individualized programs and services that may better fulfill the needs of residents. This is a particular issue for younger residents who view themselves and are viewed by direct care workers are having their needs, preferences and interests that differ from the "average" resident.

“They don’t want to be with those old people”: Issues with the Social Environment

The notion that non-senior residents do not “fit in” or “belong” in a LTCF despite their “right” to be there is a key tension that participants in this study raise while describing the social environment within which younger residents are situated. It is clear that many non-senior residents experience the social conditions of care as unacceptable and not accepting of them.

Social Disintegration

Across facilities, participants detail how the social environment is designed to meet the preferences of older residents. Viola (a nurse) provides this example:

> We don’t cater to the younger ones as much. Like, even if we put on the music, they always think about the music that the older people would enjoy…. Like (Name of younger resident), he really enjoys different types of music, but it’s never really his type— for his age group, which is around my age group too, you know? So, it can become a little boring sometimes too, because you have to listen to everything a 70, 80 year old person is listening to. Come on, you know?... (Laughs). It’s no fun. I mean, I too sometimes don’t want to hear it (laughs).

Viola describes one aspect of the social environment at her facility that is not age-appropriate for younger residents. She is not the only participant to raise this issue. Interestingly, however, her comment suggests that changing the music once in a while to match the preferences of the younger resident population may result in a social environment that she (and perhaps other staff members) would find more enjoyable.

The inappropriateness of the social care environment in LTCFs is most often associated with the difficulties non-senior residents experience in terms of social integration. Participants indicate that with some exception, the formation of friendships between younger and older residents is uncommon. Marnie (a resident) tells me she experiences difficulties accepting life in a LTCF and needs someone in which she can confide (see above). When I ask her about her co-residents, she tells me that the older women with whom she sits at mealtimes are nice, but they have different interests than she does, and that they are unlikely to understand and/or empathize with her situation and concerns.

Direct care workers make similar comments suggesting that younger and older residents do not form easy friendships. Edelle (a PSW) repeatedly refers to the difficulties experienced by a former younger male resident to whom she provided care, emphasizing that he had difficulties "interacting", "connecting" and "relating" to the residents around him.

Some narratives suggest that when positive relationships develop between younger and older residents they are complicated by differences in lifespan and/or LOS. For those non-senior residents who live for multiple years or even decades at a given facility, surviving the deaths of older co-residents—including those with whom they form close bonds—is a common occurrence. William (a resident) spends much of our time together talking about and showing me pictures of a co-resident who was "like a second mother" to him, but who had passed away. Andor (a resident) indicates that he is hesitant to form new relationships with older residents, noting that the two older male residents he was once close to both passed away. Joan (a resident) tells me that while, she appreciates the opportunities that living among an older population offers here—that she "get[s] to learn from those residents who are those age maybe what I have to look forward to in the future or what [she] didn't know from the past"—she also tells me that a lot of her co-residents have died "and it's been hard, but [she] remembers them."

Intergenerational Conflict

In addition to the challenges younger residents experience forming and maintaining relationships with older co-residents, the data suggests that on-going friction between younger and older residents is not uncommon. Alex (a resident) provides an example:

> [The older female residents,] they get on my nerves...I think they must just be jealous of me because I'm young. They're at least 20 years older than me and they say—all the time—certain things about me. Like, leave me alone. It's like, I'm sitting there talking to someone…. I sit in front of the tuck shop, because I talk to the person who runs it. And they say, "Oh, with you sitting there, there's no room here for other people to come. You're blocking the way." I don't block the way at all. I don't know what they're talking about. So they put a sign up: "No Parking" (laughs). And it's because of me. "No parking here" (laughs).

If this was the only negative interaction with an older resident of which Alex spoke, I would suggest that inadequacies in the layout of the physical environment have constructed a situation where competition for access to a particular space or service culminates in tensions between two co-residents. But this is not the case. Throughout her narrative, Alex makes multiple mentions of a small number of older female residents whom she perceives as constantly criticizing and complaining about her.

Alex is not the only participant who describes on-going intergenerational tensions of this sort. Carrol, an administrator, expresses concern over on-going problems between some of the younger and older residents that she suggests has resulted in a negative social environment:

> Two, three weeks ago, we had lots of tensions because of you know, this young couple—these young kids really—and they met here, so they became a couple. But sometimes

> their behaviour was not really appropriate for somebody in their eighties and nineties. Um, so the tension was growing between the seniors and these young folks, and it's because sometimes the language, the TV's so loud—two TVs in the same room are very loud for somebody living across or beside them…. And the tension grew when somebody in their late eighties said, "Well, I was brought up a certain way and do things a certain way." And when the young couple hear that, well, "Oh, I don't care." You know? "Why should I be here?" And that's what they blurb out. "Why should I be here? I'm so young, why should I be here with the seniors?"… Sometimes [the younger male resident] comes out of the dining room not in a housecoat, but in his pajamas. And [the older] residents will throw things, like, remarks. And they say to him, "Why don't you get cleaned up nicely?" [I say] "It's okay to wear a housecoat because in our own homes, you go to breakfast in your housecoat, that's okay. But be mindful that there are people around you too. And yes, they are seniors, so respect like you would respect your parents."… That was not going down too well. It's really sad.

Vahlma, a nurse at the same facility, also perceives the conflict between young and older residents as a problem. Her discussion of this issue indicates that she perceives the problem as linked to intergenerational differences that make it difficult for younger and older residents to live in the same space. She explains:

> It's just because it is two completely different generations, and that [older] generation does not understand the younger generation and vice versa…. For example, we had a younger [couple] that were together—they were boyfriend and girlfriend, but they weren't married. They were in two separate rooms and then they got to be in the one

> room. The older generation didn’t believe in that. You know, you get married, you don’t have any relations [outside of marriage].

In both quotations, explanations of on-going tensions between younger and older residents suggest that tensions between residents are situated in ideas and assumptions about the importance of age in the formation of positive relationships. The existence of different standards of acceptable or customary behaviour across generations seem to make it difficult for younger and older residents to live together without ongoing conflict. Such perceptions are linked to stereotypes of aging that seem to disregard individual, economic, cultural, gender and other potential differences among residents, and they also seem to imply that the tensions are not easy to resolve.

Other comments, however, indicate that the conflict between younger and older residents is not (only) about “generational differences” but about the dissatisfaction younger residents experience living in close proximity to (older) residents who make noises and behave in ways that resident-participants find disturbing, scary, or irritating. Marnie (a resident) describes her dissatisfaction with this aspect of the social environment in this way:

> I’m thinking, the thing that drives me crazy is people next door who are vocal and complain a lot, or scream. That’s not appropriate for me. And I don’t understand why they do it that way anyways. It’s so different. It’s not even like an apartment living here. You are talking to a lady who is by herself all these years and then all of a sudden, I’m not by myself. I’m with others. So I have to accept it and learn to live with it actually. It sounds cruel, but I’m learning to live with it by sort of ignoring it.

Other non-senior residents indicate that living in close proximity to residents who moan, scream, yell, talk incessantly, cough, or play their music or television at a loud volume makes living in a LTCF difficult and/or inappropriate for them. The stories they tell invariably involve co-residents whom they indicate are old or older. But while Marnie suggests this is an aspect of the social environment she is learning to ignore, two non-senior male resident-participants tell me that they have become so frustrated with the noises and behaviours of noisy older co-residents, that they have become physically violent with them.

Issues with the Social Environment in the Context of Neoliberalism

It is clear from these findings that younger residents experience difficulties “fitting in” to a social environment where they tend to be the numeric minority. It is also clear that participants' perceive the integration of younger and older residents in LTCFs as resulting in a number of tensions. It is also clear, however, that the conditions of care and work in LTCFs play a role in these tensions. For example, younger residents tell me that living in a LTCF is inappropriate for them when the social environment is characterized by excessive and sometimes disturbing noises and behaviours. While resident-participants tend to associate this problem with living alongside “old” people (and as one resident overtly indicates, old people who experience cognitive impairment), the way in which care is provided in Ontario’s LTCFs in the context of neoliberalism also plays a key role. For example, many of the noises and behaviours non-senior residents are concerned with could be reduced when the conditions of care are changed. Research has indicated that when care is provided at the “right time” and at the “right tempo” for each resident, agitation (including verbal agitation) and aggressive behaviours are reduced (Helleberg & Hauge, 2014). However, structures that make possible care provision of this sort are incompatible with inadequate staffing levels and relatedly, conditions in which care workers are overburdened and where regulatory mechanisms and organizational practices mean care provided in standardized time-constrained ways.

Insufficient public funding to keep up with demand for LTCFs and other residential health and social services make it unlikely that this sector will adopt practices that might address some of the tensions younger residents describe with respect to the appropriateness of the social environment in LTCFs for non-senior residents. Some participants indicated that the development of special units aimed at non-senior residents within LTCFs could mean greater access to others similar in age, who are more likely to have similar interests and concerns. This certainly fits with Alex's experience of living in a dedicated young person's unit at her former facility (see Chapter 5). However, the development of such units is unlikely in the context of neoliberalism. When I ask administrators why separate units for younger residents are not being established in LTCFs, their comments suggest that the barrier is largely financial. Reserving a unit for younger residents is in conflict with pressures to keep facilities at full capacity and this was a problem given waiting lists for access to a LTCF. Indeed, one facility involved in this study had planned to have a unit for younger adults when the building originally opened, but this plan did not come to fruition because there were not enough non-seniors to fill it.

At a second facility, where this possibility was raised, Kavita (an administrator) explains that creating special or segregated units is contrary to the care philosophy laid out by the owners. Her explanation of this philosophy suggests that it is driven by a need to maximize efficiency:

> Some homes tend to have special care areas or special units that they sort of put all of their certain [groups] of residents in…. This building, at the time it was opened, the philosophy has been to have an inter-mixed group of residents in [each] home area [unit]. What that does, Morgan, is it allows you to staff each area in the same capacity. It's sharing resources and the knowledge base and the experiences staff have in providing

> care to residents across the board…. But the decision was made based on sort of making the staff more efficient and effective and sort of equalizing the workload throughout.

Regulatory policies for provincial funding for LTCFs also make it unlikely that facilities will develop units aimed at non-senior residents. At the time of data collection, LTCFs could apply to their LIHN to have a designated younger resident unit, but doing so did not appear to have much economic value. Extra funding for specialized units was not available for a unit of this sort, although it did allow facilities to maintain a separate waiting list for access. Given that younger residents comprised less than ten percent of the overall resident population at the time of data collection, maintaining a unit for younger residents was likely to mean unoccupied beds—this is a situation that was discouraged by the provincial funding model and by the pressure on some for-profit providers to make a return.

"I'm not a little kid": A Culture of Discrimination and Violence

Age and Disability-Related Tensions Among Residents

Throughout their narratives, participants often describe negative interactions and tense relationships between younger and older residents (see above). These narratives suggest conditions of care where experiences of discrimination and violence are not uncommon. Discriminatory ideas about age as it intersects with disability (and sometimes gender) are often drawn on to explain tensions between younger and older residents. Andor's (a resident) explanation of why he rarely interacts with the older co-residents at his facility is a particularly severe example. He tells me: "A lot of them [older residents] are kind of, you know, sick in the head. They can't even talk. When they do, they talk nonsense".

While the toxicity of age-related disablism is much more noticeable in Andor's narrative than other participants involved in the project, assumptions of the incompatibility of younger and older residents that rest on oppressive ideas about age/disability are not. For example, Trish (a nurse) tells me that the younger residents at her facility tend to “look at the other people like they [the older residents] are sicker than them.” Comments made by Arlene (an administrator) make a similar point. She tells me she “will get complaints if you put a younger resident who is functioning well but just has physical limitations on a floor with residents who are not functioning at all and who are not cognitively able to converse with them. You will get complaints.” While both examples suggest younger residents experience challenges fitting into the social environment (see above), in explaining the misfit between younger and older residents, these comments suggest that tensions are situated within discriminatory attitudes about age as it intersects with disability.

Lack of understanding and acceptance of differences related to age and disability are also apparent when some participants indicate the tendency of older residents to ostracize or be “hard on” their younger counterparts. Resident and worker-participants tell stories that suggest some older residents question the acceptability of younger residents living in a LTCF. Alex (a resident) tells me that some of the older female residents she has conflicts with (see above) also question the legitimacy of her disability because of the fact that her capacity to use her right arm fluctuates.

Valhma (a nurse) also suggests a lack of acceptance and understanding of the younger resident population among older residents is a problem at her facility:

> They [the older residents] even say to me, “They [they younger residents] should not be here. They are too young to be here. They should be somewhere else”.... They don’t understand that the younger have a right to be here. And because of their condition—that

> is why they are here. Because [the older residents] don't know about [the non-senior residents'] condition, they think the younger are fine and that they should not be here.

It is not only misunderstandings and stereotypes of disability and youth that drive interactions among younger and older residents that are characterized by violence and/or aggression. Edelle (a PSW) tells me about a younger resident who often displayed aggressive "behaviours" while interacting with his co-residents. Her comments suggest that younger residents experiences of boredom and social isolation in LTCFs may play a role:

> [The younger residents] have different interests. That's why that client moved to a different place…. He's very intelligent…. It's like, picture that you are intelligent and then the people around you can hardly speak or they hardly connect. He could not relate…. He wants to talk, he reads books, you know? And he could not relate to the [older] people…. And it will trigger his behaviour…. His case is behavioural, and he has no one to talk and express what he wants to express…. Just to be in your room, facing the four walls, it will cause aggression like that.

In this quote, Edelle makes a connection between social disintegration and aggressive behaviours among younger residents when she talks about a non-senior male resident who experienced a number of barriers to enjoyment and meaningful social interactions while living in the LTCF in which she works. At the same time, she seems to medicalize the issue when she suggests that this resident has an impairment that predisposed him to aggressive behaviours.

Age and Disability-Related Tensions Among Younger Residents and Staff

The data suggest that at times, staff members interact with and/or understand non-senior residents in ways that reproduce dominant stereotypes of disability as they intersect with ideas about youth. Within the data, there is a direct care worker who refers to a female resident in her late twenties as a “baby girl”, and a second who characterizes a female resident in her thirties as having the “mental ability of an eight-year-old or ten-year-old child”. Others describe the challenging behaviours of some younger residents (particularly those with cognitive disabilities) in terms of acting “like a child”. At one facility, a staff member discusses her efforts to foster a romantic relationship between two younger residents in a way that reminds me of how some adults tease children about their romantic interests. These and similar actions perpetuate the construction of younger adults with disabilities as “eternal children”—a stereotype that furthers the association of disability with dependency, asexuality, and pity.

There is also some indication from the data that younger residents with cognitive disability may experience disablism in the form of their sexuality being regulated, discouraged, or denied. Consider what one male resident-participant tells me about his relationship with an older female resident whom he tells me he thinks of “like a sister”:

> You saw that girl out there? Yeah, well now, I always was with her for a long time ago. We like music and we sit side by side. We weren’t allowed to hold hands…. And I say, “Why aren’t we allowed to hold hands?” There were two ladies over there, they were sisters and they were allowed to hold hands.

This resident does not provide me with an explanation for the restrictions placed on him in terms of having what appears to be consensual physical contact with an older female resident. A PSW at the same facility, however, offers some insight into this situation when she discusses how the family members of an older female resident have complained to the administration about what they perceive as an inappropriate and potentially exploitative relationship between their mother and a younger male resident. While neither the residents involved nor this direct care worker seem concerned about the nature of this relationship, it is clear that the PSW and her co-workers have been instructed to monitor and discourage it.

These and similar incidents can sometimes result in conflict between younger residents and staff. When resident-participants tell me they prefer direct care workers who treat them as “normal” or “regular” people, and not as “disabled” (see Chapter 6), their comments suggest that they are unlikely to form positive relationships with those workers who construct them in ways that foregrounds disability or their “needs” above all other aspects of their lives and identities.

In this study, several male residents speak explicitly about their dissatisfaction with direct care workers who infantilize them or treat them in ways that undermine their autonomy. When I ask George (a resident) to explain why he dislikes receiving care from a particular female PSW, he tells me that she “treats [him] like a little kid” and ignores that he is “a man [who’s] got two kids, so [he’s] not a little kid.” When Andor responds with anger and aggression to a PSW who tries to prevent him from leaving the facility based on her assumption that he requires supervision to leave (see Chapter 7), he is reacting to the paternalism apparent in this interaction. However, this interaction is complicated by the fact that Andor’s threat of violence is directed at a female PSW who he refers to as “Filipino”. The power dynamics involved in this interaction are complex because the care worker is a visible or racial minority working in a context where racialized (often immigrant) women are attributed low status associated with gendered and racialized ideas about the value of care.

Age, Disability, Gender, and Violence

Along these lines, worker-participants describe tensions in the provision of care to younger male residents in ways that indicate gender-based violence is a feature of direct care workers interactions with younger male residents. Verline (a recreation worker) provides an example when she describes some of the challenges she has getting along with a younger male resident at her facility:

> This gentleman is cognitively very good. He fights sometimes, even with me. You know why? Because he wants to watch TV and I'm running the activity…. He can be very violent with the nurses [and] with me, if I am not doing what he wants. But, he respects me at the same time. He says, "sorry". In a while, he remembers, right? … He says, "I'm sorry about last time." Sometimes he doesn't, but a few times he did…. Sometimes, he was trying [asking for sex]. But you have to put on blinders. He was not implying to me, but to another [worker] who is sick now…. She told me he was asking her for favours—sexual favours. And he wouldn't ask me…. He can fight for TV, but he would never ask me for favours. But he did ask [the PSW] because I know that it was reported…. He even says, "I pay you." And the doctor was laughing about it—the doctor I know for a long time…. He [the doctor] said, "He's young. What do you want? He had his accident and after that he was disabled."

Verline provides an example of gendered violence that contrasts with the tendency of direct care workers to explain if not excuse resident aggression and violence by pointing to impairment. What is striking about Verline's story is the doctor's reaction to the issue of the younger male resident pressuring a female care worker for sex. While seemingly challenging stereotypes of asexuality (or loss of sexuality) among men with a disability, the doctor does this in a way that excuses if not normalizes incidents of sexual harassment against female care workers.

Verline is not the only direct care worker whose narrative includes instances of violence and aggression against female care workers by younger male residents. Consider what Roise (a nurse) tells me about this issue while discussing what she perceives as differences in providing care to younger and older residents:

> The only time that it gets a little more difficult [to provide care to younger residents] is like, I have a man who's verbally and sexually abusive and that's tougher. He's been abusive to staff…. I go and speak to him and then I talk to the family. Because it's, you know—I'm wanting to talk to him about it. "You can't do that." And the family was surprised and very supportive of what I needed to do…. I'm firmer with him than I was when he got here. I used to do lots of extra things for him. Every morning I used to go out of my way [for a younger male resident] to get him a glass of orange juice to bring down his pills because he'd rather take them with orange juice than water. And I stopped doing that. Because I thought, you know, he's being very aggressive in the dining room…. I'm not going to give you rewards for bad behaviour. It's like a child. I don't mean to say that, but, you know what I mean? [It's] because of dementia, whatever. So behaviour, the sexual stuff has since—I haven't had another episode. I have to look after everybody.

It is clear that while Rosie has made efforts to build a positive relationship with this younger male resident, the quality of this relationship is complicated if not undermined by incidents of unwanted and violent behaviour —particularly that of a sexual nature—against female care workers. Rosie seems unwilling to tolerate physical and sexual aggression in her workplace and takes steps to address the issue. However, when she likens taking away the younger male resident's "rewards" to the way in which one might punish a child for bad behaviour, she infantalizes this man.

Discrimination and Violence in the Context of Neoliberalism

Research exploring the issues LTCFs in Canada in the years leading up to the COVID-19 pandemic suggest that discrimination and violence are pervasive and often, normalized conditions in Ontario's LTCFs (Banerjee et al., 2012; Daly et al., 2011). This issue has been connected to the neoliberal agenda and associated adoption of NPM that have driven LTC reform. For example, the absence of basic care standards, inadequate staffing levels and mix, and the presence of structures that deprioritize social care over medical care practices make it extraordinarily difficult for staff to provide care in relational ways (Silas & Armstrong, 2021). Such conditions have consequences including their tendency to agitate residents (Banerjee et al., 2012). Further, poor employment conditions including low pay experienced by many women (particularly unregulated) workers in LTCFs (LTCSSAG, 2020) reproduces patterns of gendered (and racialized) exploitation that may serve to reinforce the discrimination and violence experienced by direct care workers.

"They want their independence, but we have legal obligations too": Rigid Safety Protocols

Tensions associated with the imposition of rules around safety arise in the difficulties participants associate with the situation of younger residents living in LTCFs. The strict imposition of safety protocols and guidelines are an aspect of living in a LTCF that non-senior residents deem inappropriate. Some resident-participants tell me that they are unnecessarily supervised by staff during showers or baths, while using the exercise equipment, and while cooking. Others tell me they are irritated by having to sign in and out of their facilities in order to access the larger community. Sometimes, there are limits on how long residents can leave the facility or rules around what time they must return by. Some non-senior residents express dissatisfaction with having to ask staff for permission to leave their unit when they want to visit co-residents on different floors or participate in programs in other areas of the facility.

Resident-participants take issue with safety regulations when they limit access to the things, activities, and people they most enjoy. Joan (a resident) describes a policy at her facility that, at times, limits her (and other residents') opportunities to experience a diversity of foods and/or to eat the foods they prefer. She explains that direct care staff are not permitted to assist residents when the food they are eating has been prepared outside the facility, unless it has been ordered from a list of "approved" commercial vendors. This means for example, that staff are not permitted to assist residents with food cooked for them by family members and friends. Joan emphasizes that this is not usually a problem for her because on most days, she can feed herself. It is, however, an issue on days when she cannot and for residents who require assistance with feeding on a regular basis.

The inflexible implementation of safety regulations can also prevent younger residents from engaging in activities they enjoyed prior to entrance into a LTCF. At one facility, Kavita (an administrator) tells me about a younger resident who, prior to her entrance into the facility, barbequed every Sunday with her family members. Safety regulations, however, prevent anyone but staff from using the facility's barbeque. Kavita explains that when it comes to LTCFs, there are some rules that "cannot be bent"—particularly rules that protect facilities from liability. While Kavita tells me this tension is rectified when a social program whereby staff barbeque for residents is implemented, there is little recognition that this "solution" may not be enough to support the younger resident's desire to maintain this important family tradition.

Tensions between non-senior residents and direct care staff often center on disagreements over the implementation of safety regulations. Worker-participants describe the difficulties they experience providing care to non-senior residents who “want you to do it [their] way—not our policy of doing care”. At the same time, some direct care workers are understanding if not supportive of the efforts of some non-senior residents to challenge some of the rules. In the context of characterizing LTCFs as inappropriate for younger residents because they are “institutional” settings that “cater to the culture of aging”, Daphne, a PSW, suggests that the strict implementation of safety regulations is a large part of the problem:

> I think younger people should be in a different environment because honestly, we have had some problems with some of the younger adults who are more independent, who want more freedom, who want more choices. And like, we have a policy here where we supervise their showers…. We have a schedule for the week for showers. Legally, according to Ministry standards, everybody should have two showers or baths per week. And they can have more if staff is available. But for people who are independent, they will tell you, “I want to go and shower everyday.” But then we have to supervise them. We have to know when they are in and out of the shower. Because you never know, somebody can slip in the shower and things can happen. They don’t like to be supervised…. They want their independence, but we have legal obligations too.

Daphne describes a situation where risk mitigation seems to take precedence over creating the conditions that foster resident autonomy. While Daphne seems sympathetic to the preferences of younger residents and wants to support their independence, she also suggests that when it comes to this safety policy, she has little decision-making autonomy and latitude.

There is some indication, however, that direct care staff at some facilities have more autonomy and altitude to implement safety protocols in a more flexible way. Vahlma (a nurse) tells me that part of the way in which she and her co-workers encourage the younger residents in their unit to participate in their care is by affording them greater privacy during showering. She explains:

> We encourage them [the younger residents] to do it as much as possible. As I said, in their personal care, because if they are going to have their bath or anything, they have to make sure to tell us because they aren't supposed to be in the shower or the bath by themselves because they can slip and slide. They are capable of doing it, but we are supposed to monitor them. So they [the resident] will say, "Ok, nurse, I'm going to have my bath now." They ask us for their towels and whatever…. One of the staff would go peek in, and they [the resident] don't close the door. [the staff] go peek in and make sure they are ok.

Some facilities also come up with methods that better balance the tensions between risk management and resident autonomy. In Chapter Six, I discuss one such promising practice involving the use of a GPS tracker on a wheelchair to ensure both the autonomy and safety of a younger resident who likes to leave his facility alone for long periods of time, but who sometimes gets lost or the battery on his chair loses its charge.

Rigid Safety Protocols in the Context of Neoliberalism

The issue of rigid safety protocols emerges in the context of the increasing regulation of particular aspects of LTRC that allowed the government to govern "from a distance" (Armstrong et al., 2016, p. 350). The implementation of "hard and fast rules (or guidelines and protocols)" based on a particular evidence-base (Armstrong et al., 2016, p. 351) is a reflection of neoliberalism and the adoption of techniques associated with NPM. Within this context, LTCFs find themselves establishing and implementing protocols in rigid ways in order to adhere to complex regulations. This evidence-base on which these protocols are based, however, privileges evidence from clinical trials. This narrow form of knowledge does not translate well to LTCFs (Armstrong et al., 2016). It tends to over-privilege activities of medical care even though much of what residents need is social care, and the voices and perspectives of residents and of the workers and family members who provide care in LTCFs are rarely included in LTC policy. It has also been argued that these types of protocols limit the decision-making autonomy and latitude direct care workers to draw on what they know about residents to implement guidelines and protocols in more flexible and individualized ways (Armstrong et al., 2016).

There are also indications from the issues raised above, that some safety protocols are an issue for younger residents not because the protocol itself is a problem, but because of the conditions of care within which it is being implemented. Daphne's discussion of younger residents' dissatisfaction with not being permitted to shower everyday indicates that this issue is about more than the tension between the legal obligations of the facility and resident autonomy. This protocol is at work within a context where inadequate funding and staffing level inadequacies associated with the implementation of for-profit management strategies prevent residents from being able to shower/bath more than the minimum two-times a week set out in the LTCHA. So, while the requirement that all residents be supervised during showers/baths may be a problem of forced dependency, it may be less of a problem when there are enough staff available to ensure those who want to can bath/shower more frequently.

"In the beginning, there were lots of places for us to go": Deficiencies in the Physical Care Environment

The data also reveal a number of issues related to the physical care environment that limit the appropriateness of LTCFs for younger residents. Much of the dissatisfaction resident-participants at Spruce Hollow Central have with living in a LTCF are linked to issues of physical inaccessibility. This facility is by far the oldest research site in this project. It contains more than five floors, each of which are made up of a long narrow hallway. Residents' bedrooms, which are positioned on both sides of the hallway are small, and this is the only facility that had ward-style rooms characterized by four beds separated by curtains and a shared washroom. While each floor contains a small common area with a television and where the nurses’ station is positioned, the area where most recreational and therapy programs occur as well as the dining room and the staff lunchroom are positioned in centralized locations, floors below where most residents’ bedrooms are located. This is a particular issue because the facility only has two main elevators and a service elevator all of which are much smaller than those in newer facilities that can accommodate larger wheelchairs. According to participants, the elevators at this facility frequently go out of service.

The problems this creates for most residents and staff members in terms of their dignity, health, safety, and mobility are numerous. Small room sizes—particularly ward size rooms shared by three to four residents—offer little privacy for residents including during personal care. It also means that when residents want to go to a program or to the dining room at mealtimes, they line up along the hallways and wait for long periods of time for an unoccupied elevator. Both resident- and worker-participants tell stories that indicate the physical environment compromises their health and safety. For example, direct care workers—particularly for those who work on the upper floors of Spruce Hollow Central—getting residents to meals and to activities means walking down numerous flights of stairs or waiting long periods of time for an elevator. As such, worker-participants report that they tend to walk long distances, often up and down numerous flights of stairs, over the course of their shift. One nurse describes the consequences in terms of her own physical health:

> You have to go walking—lots of walking back and forth, downstairs, up. My legs are so tired. My legs are so tired, every time I get home, all I want to do is sit on the floor and put a pillow under my legs.

The safety risks associated with the physical environment at Spruce Hollow Central become clear to me during an incident that occurs while I am interviewing a non-senior resident at this facility in his semi-private room:

> Morgan: [Alarm sounds] What's that?
>
> Resident: Fire alarm. So now they are gonna come and close the door. Most of the time it's a false alarm, you know?
>
> Morgan: Does this happen very often?
>
> Resident: Not too often. But it happens at least once a month. They are gonna bring my roommate in and then they are gonna have to close the door. That's the rules you know, the procedure. My roommate's not even here.
>
> P.A. Announcement: Code Red, Room #. Code Red, Room #
>
> Resident: That's next door!
>
> [A PSW enters the room. She leaves a laundry rack full of clothes just inside the door, blocking our access to the hallway. She tells us she has to put the laundry cart here during the fire alarm in order to clear space in the hallway. She then leaves, closing the door behind her.]
>
> Resident: That's ok. They block us in.
>
> Morgan: What does a "Code Red" mean?
>
> Resident: "Code Red" means it's a fire or something like that. Either a fire or something bad.

> [Several minutes pass. The alarm stops.]
>
> Resident: Look, she left all this shit here and do you think she's gonna come back and take it out? No way…. That's what they do. This is the laundry thing [cart]. I am gonna have to do it [push it out of the room] myself…. This is crazy.

This resident explains that fire codes necessitate the adequate clearance of hallways during fire alarms. However, since the hallways at Spruce Hollow are so narrow and there is little storage space, large objects such as the laundry cart are placed in residents' rooms to clear the way. This incident—which according to the resident I am interviewing is not uncommon—raises questions about the impact of inadequate physical space on the safety (not to mention dignity) of those who live in and are visitors to LTCFs.

In the following conversation, a long-time male non-senior resident at Spruce Hollow Central describes, with frustration, the impact that decreases in the availability of private spaces for residents has on his relationship with his partner:

> Resident: The residence—this place—has gradually declined because the staff needs more room. The rooms that have computers in them now used to be family rooms. And uh, that was their little space. But now the computers are in there…./ The square footage...has changed. Because [my girlfriend] and I would be able to uh—where the office is—
>
> Morgan: You could have privacy?
>
> Resident: [Yes,] where the office is now. In the beginning, there were lots of places for us to go. And the home has expanded….Well, we could go places in the basement and we wouldn't be disturbed. But now there's more people and more staff.

Access to private spaces is also a problem identified by residents and staff at Spruce

Hollow Central, although resident-participants across facilities indicate the importance of having privacy particularly when they share a bedroom. It seems that over time, changes in the amount of private space have decreased over time—a condition this long-time resident attributes to increased occupancy rates and the need for more storage and staff spaces to accommodate the growing amount of equipment and technology in LTCFs. Notably, this participant does not indicate that living in a multiple-occupancy room is a problem for him. However, not having any access to privacy throughout the facility clearly is. In this way, having access to private spaces outside one's bedroom may mediate the issues some of the issues residents in shared accommodation may experience (see Chapter 5).

There is also some indication that the physical environment at Spruce Hollow Central poses particular issues for younger residents. For those who leave the facility on a regular basis in order to fill the gaps associated with age-inappropriate services and programs, traveling between floors to leave the building means navigating long line ups for the elevator, even when they time their activities to avoid periods of high demand (such as mealtimes). A nurse provides one example when she tells me about a non-senior, male resident at Spruce Hollow Central who experiences a great deal of frustration with the elevator situation:

> [Name of non-senior male resident], he hardly goes down to the dining room. He has some kind of behaviour that—he gets irritated. Like, if he wants to come out of the elevator and it's breakfast time, and people have to line up by the elevator, then he can't get out… He's gonna say, "why are these old people lining up here?" He's gonna say, "It's so early." It's eleven-thirty and they have to go down [for lunch at noon]. It's only one elevator that's working most of the time…. So you need a lot of patience for this resident—a lot, a lot, a lot, a lot of patience. And sometimes you're gonna lose it.

> Sometimes you are gonna lose it. You just have to back off…. Go away in a quiet room. Lock yourself in a bedroom or a washroom. Just take a big, big, breath.

These comments suggest that competition for the elevator and narrow hallways that block access to and from the elevators lead to disagreements if not hostility among co-residents. The nurse seems to suggest that the younger resident's impairment plays a role in the way in which he reacts to the elevator situation, but it is clear that the inaccessibility of his physical care environment is what is triggering these frustrations.

While the above examples describe problems with the physical environment at Spruce Hollow Central in terms of its failure to ensure the safety, wellbeing, mobility and privacy of residents and staff and other visitors, there is also some indication that aspects of the physical environment in newer facilities can also pose issues for younger residents. Some of the frustrations that younger residents express about the physical environment also indicate that even newer facilities are not designed with the needs of longer-stay residents in mind. When non-senior residents express dissatisfaction with the plain, small, under-personalized, and seemingly unchanging characteristics of their rooms and facility more generally, their comments imply that facilities that feel like hospitals or institutions are inappropriate for them particularly when they are living at their facility for many years.

Elton's observations about the absence of major physical changes to his facility for well-over a decade is a notable example. He points to and describes the drab, unchanging pale green paint of his bedroom walls, which he also tells me, has recently been peeling off. Susan (a family member) also indicates that even at the newer facility in which her family member resides, there is not enough storage space for those who live there for extended periods of time. She tells me that as a result, she has to "haul" clothing back and forth to the family home as the seasons change, and that she has had to store decorations for seasonal programs and special events she volunteers to run at her own house.

Along these lines, it appears that room size may be inadequate for longer-stay residents because there is enough space for residents’ furniture and a variety of other personal items. Steven (a resident) greatly enjoys accumulating and arranging small items of importance to him in his bedroom. But a small, shared living space means he has little room for such endeavors. Steven uses his bedside table and a chair as display areas. But this means there is nowhere for visitors to his room to sit—including workers—apart from on his bed.

The issues younger residents experience with respect to the physical environment are often ones that have consequences for many residents (and workers and visitors). Reliance on a small number of small elevators, one of which is often out of service, is a problem for everyone I speak to at Spruce Hollow Central. However, the findings also suggest that some of these issues associated with the physical environment in LTCFs are experienced in particular ways by younger residents. While differences in the physical environment across the facilities involved in this project exist, it appears that most do not well accommodate residents who are likely to live there for extended periods of time.

The physical inaccessibility of some LTCFs, which is a major issue at Spruce Hollow Central, is also a concern of some younger residents living in newer facilities who use motorized mobility devices that do not fit well in hallways. Such barriers to access are a particular problem for non-seniors who, throughout their narratives, emphasize the importance of living in a physically accessible space in terms of fostering self-determination, facilitating access to programs and services outside their facility that fill gaps in facility-based care, and maintaining relationships with family and friends. Younger residents also need an accessible facility in order to go and get the care they want, when they want it, from the person they want it from (see Chapter 5).

The Physical Environment in the Context of Neoliberalism

When it comes to younger residents' problems with the physical care environment, the consequences of neoliberal health care reform are apparent. This is particularly the case for Spruce Hollow Central as the only facility involved in this project built prior to 1998, when the government introduced a new set of design standards that among other things, eliminated ward-style rooms and increased minimum room sizes in newly built facilities as part of the enhanced capital funding policy (see Chapter 4). The issues younger residents and care workers at this facility describe are associated with a lack of government investment in infrastructure and more specifically, the introduction of LTC reform policies that disfavoured smaller ownership groups who were unable to secure the capital funding necessary for them to upgrade their facilities to more contemporary standards. Curbs to public funding in combination with the deregulation of rules around profit-making provide little incentive for facilities to make changes to the physical care environment that would better meet the needs of younger residents— particularly those who use larger motorized mobility devices or who desire more privacy, storage and personal space associated with their extended lengths-of-stay.

“The only thing that was available”: Barriers to Accessing Public Long-Term Care

When participants discuss the circumstances surrounding younger residents' entrance into a LTCF, their stories reveal that the appropriateness of living in a LTCF is complicated by a number of tensions in the process of gaining access to LTC. Most of the non-senior residents involved in this study tended to gain access to a LTCF when limitations, eliminations, restrictions, and/or gaps in other forms of publicly-provided LTC services failed to meet their diverse and often medically-complicated care needs. For Thomas (a family member) gaining access to a bed in a LTCF for his family member is associated with major inadequacies in the amount and timing of public home care services available—particularly when one's care needs intensify. He explains:

> Well, originally, with (Name of younger resident), as she was deteriorating, I looked at home care. And once again, I was totally disillusioned because my understanding was that they give a certain number of hours per week, right? And I might have been able to manage. I'm glad I didn't go that route. But I found out they would give one half day, once a week. In other words, it means I would have to be there 24-7 except for that half day.

Despite Thomas' willingness and capacity to provide multiple forms and significant amounts of informal care to his family member, inadequacies in the amount and timing of public home care services prevent this from being an appropriate option. Limitations in home care mean it is not possible for Thomas to continue to work outside the home or to participate in social and leisure time activities if his family member continues to reside in the family home. Given this situation, Thomas turns to a LTCF.

Susan (a family member) raises similar issues when reflecting on the period of time when her family member came of age and became ineligible for many of the services and supports that made care at home possible. Like Thomas, Susan characterizes her family member's entrance into a LTCF as the only option available to them at the time:

> (Name of younger resident) did fall through the cracks everywhere. Because she couldn't totally direct her care, she did not qualify for the small group homes. She needed to be able to say, "I'm wet, please change me. I'm tired, please put me to bed. I'm hungry, feed

> me please.” And she wouldn’t. And because she didn’t and couldn’t [direct her care], she wasn’t accepted in…. I am the at home caregiver. And I turned [over 60] this year. You know what, if anything had happened to me, where would she be?... So she needed to be somewhere where her care was good, close to me…. There was no place else for her to go. [After she finished high school], the first two years, three years, I did all the day programs with her. We took her out twice a week, three times a week. I just got too tired, just too tired…. After high school…they turn into a pumpkin…That is where there is a gap—because the kids are so used to being and doing and suddenly, they are home. And parents aren’t getting any younger. And there’s nothing.

Susan’s experience gaining access to a LTCF for her family member occurs in the context of wanting to secure LTRC in close proximity to the family home. Doing so is important to Susan because she recognizes that as she ages, she is becoming less capable of supplying the various forms and intensities of care her family member requires. Care in a LTCF was not Susan’s first or even second choice, but given her family member’s eligibility restrictions, it was the only option.

When non-senior residents describe their experiences of gaining access to a LTCF, their narratives indicate that this process often involves choosing between timely access to care, and care that better meets their preferences. Andor (a resident) describes the circumstances surrounding his access to a LTCF in this way:

> Somebody died on this bed and I was in (Name of hospital). After they [did surgery], they wouldn’t let me go home. So I just had to pay for my stay. I was there for almost six months in (Name of hospital). And when this bed opened up, then they brought me here.

What Andor is describing is a process whereby he is deemed an Alternate Level of Care (ALC) patient. Following surgery, Andor required on-going medical and personal care in the hospital. However, once he was considered medically stable and no longer in need of acute hospital services, he was deemed ALC. Since Andor was living alone at the time, since he is no longer married, and because most of his family lives elsewhere, the hospital would not discharge him to his previous residence because the intensity of support he would require was beyond that available to him through home care. He was placed on a waitlist for entrance into one of three LTCFs in his geographic area. Andor waited six months in hospital, paying a chronic care co-payment fee, until a spot became available. Under these conditions, Andor took the first available bed rather than waiting for placement at his preferred facility. He is not happy living at this facility but believes there is no better option. “I got used to it” he explains, “so I’m going to stick around. I think I’m going to die here.”

Male resident-participants often described their entrance into a LTCF in ways that suggest they understand this process as a tension between necessity and choice. William (a resident), for example, tells me he had “no choice” when he came to live at his facility. The hospital where he was previously receiving LTC was “making a lot of changes and stuff.” “Somebody (makes a slashing motion across his throat indicating death), and this was the only one—the only thing that was available”. What William is referring to is the lack of options presented to him in terms of accessing LTC services at a time when hospital restructuring in the form of mass closure of continuing care beds meant he no longer had a place at the facility in which he had been living for several years. In this context, William experiences entrance into a LTCF as his only option.

The way in which Elton describes his entrance into a LTCF is also characterized by tensions. His story is notable because it involves the institutionalizing potential of LTCFs. This non-senior resident, who has lived at the same facility for several decades, describes his entrance into a LTCF as involuntary—“I was put in here by my father” he insists. Elton’s larger narrative is saturated with stories of discrimination and abuse, of a father who, at the time of his birth, did not want him, and who, prompted by the ideas of medical professionals, believed Elton’s concerns over his health were signs of hypochondria. For Elton, understanding LTCFs as appropriate for younger residents is prevented by his subjection to multiple forms of disability-related oppression—of institutionalization, medicalization and paternalism. In this context, it is difficult for him to identify what he “likes about “, and what the “good things” are about living in a LTCF.

Some resident-participants describe gaining access to a LTCF in ways that suggest a degree of choice *is* available to them. Most often, this choice is characterized by their being provided an opportunity to apply to multiple LTCFs, and, once a bed opens, having the option to accept a placement, remain on a waiting list, or accept a placement while also remaining on a waiting list for their preferred facility. These choices, however, are also characterized by conflicting pressures. Younger residents and family members indicate that they regularly make concessions in order to secure care that meets their most pressing needs at the time they become eligible for entrance. For Andor, the need for timely access to care associated with the pressure he was under to be discharged from hospital meant he “chose” the facility that had the first available bed.

Alex’s entry into a LTCF is also characterized by tensions in choice. She tells me that Eastern Sunrise—the facility she is residing in at the time of this project—was her first choice because of its proximity to her parents' home. However, this is not the facility into which she first gained access. In fact, Alex waited three years at a different facility before she got a bed at Eastern Sunrise. When Alex compares her current living situation to that of her previous facility, her comments suggest that choosing a LTCF involves conflicting pressures between different needs and preferences. Consider Alex's comments:

> This was my first choice—to come here—but there was no empties, so they put me at a place down at (Name of intersection). But yeah, I was there for three years until a person here died and made some room. So I came here…. I was in a young adult unit [before]. Everybody there was younger. There, if you became 65 years old, you got shipped upstairs…. There was nobody older than 65. And here, it's like, oh my god they're like 90-something.

Alex's experience of gaining access to a LTCF included some degree of choice. She had the opportunity to put her name on the waiting lists of three facilities and she was permitted to remain on the waitlist for her preferred facility even though she had gained entry to a LTCF elsewhere. However, even though Alex indicates that she (eventually) gains access to her "first choice", doing so means giving up what she clearly perceives to be a more socially appropriate care environment.

Access to Long-Term Residential Care in the Context of Neoliberalism

The value of LTCFs for non-senior residents is limited by the conditions under which they enter these facilities. The findings suggest that most younger residents are living in LTCFs in the absence of other options. They and their family members experience a variety of barriers in terms of accessing the amounts, types, and intensities of services they need in locations that are affordable, desirable and safe. The logic of neoliberalism and associated adoption of NPM that drove contemporary changes in public LTC services and impacted the development of community-based social services and programs for people with IDD associated with the closure of public residential institutions plays a key role. During health care reform, hospital restructuring in combination with the mass closure of large-scale public institutions for people with disabilities moved long-term health and social care into communities and households. But this change was not accompanied by enough public investment in and the development and expansion of public services necessary to accommodate these changes. HCC services were reformed in ways that made them less accessible. Certain services were delisted, amounts of care clawed back, eligibility requirements tightened, and the capacity of providers to meet the needs of clients and provide high quality care was undermined (see Chapter 4). Trends associated with neoliberalism and NPM played a role in deinstitutionalization such as “concerns with the costs of institutions… [and] the ability to privatize group homes, and the lower costs associated with decentralized care” (Linton, 2021, p. 129). But this logic has also been associated with gaps in the health and social services used by adults with IDD (Lin et al., 2019). Key issues include inadequate funding resulting in long waitlists for access to services, lack of alternative housing arrangements, unenforced regulations, issues of understaffing and lack of training among and health and safety protections for personal support workers (Lin et al., 2019; Linton, 2021, p. 129). Given this context, it is not surprising that resident-participants came to live in a LTCF despite perceiving this situation as undesirable if not disabling.

Lack of choice also characterizes the experiences of some younger residents once they gain access to a LTCF—an issue that is also tied to the logic of neoliberalism. Since the number of available beds in LTCFs has not kept up with demand leading, among other things, to long wait times for admission, individuals are more likely to accept placement in a less than desirable or ideal facility. It seems this is a pressure most often experienced by resident-participants who enter LTCFs from hospital, either because they are deemed an ALC patient or because their unit is closed. It also means younger residents often make concessions by “choosing”, for example, between a facility in a desirable location or a facility with a more age-appropriate social environment.

Conclusion

In this chapter I identify issues in LTRC that prevent LTCFs from being experienced and perceived as appropriate for non-senior residents. While the life sustaining role that LTCFs play in the lives of younger residents should not be underestimated, survival is not good enough. The findings discussed in this chapter indicate that in order for LTCFs to foster good, high quality everyday life experiences, and a fulfilling future for non-senior residents, several key components of the system must change. First, age-appropriate and aware programs and services are required to ensure younger residents get care that meets their needs, preferences and interests. Further, younger residents require a social environment within LTCFs where they belong, where they have opportunities for genuine friendships and meaningful interactions with others to whom they can relate. Tensions between younger and older residents and exposure to noise and distressing behaviours must also be balanced if not minimized. Addressing the culture of discrimination and violence between and among residents and workers should also be prioritized. Rigid safety protocols that prevent younger residents' access to meaningful experiences, limit their autonomy, fail to support relationships with family and friends, and result in unnecessary conflict between residents and direct care staff must also be addressed. Significant efforts must be made to resolve physical accessibility issues within Ontario's LTCFs. Doing so is necessary to ensure younger residents have full access to their facilities and to the areas around their facilities.

This is also important in terms of ensuring the health and safety of all residents and those who provide them with care.

Finally, LTCFs cannot be experienced and understood as places for living when non-senior adults with disabilities and their family members have no other choices when it comes to accessing public LTC services. This finding highlights the importance of a strategy that not only focuses on the conditions of care within LTCFs, but also aims to expand and improve the state of public LTC *and* social services to ensure they are accessible, affordable, flexible, high quality, and relational. Given that issues raised in this chapter appear to have been shaped by neoliberal logic and the adoption of NPM discourses and strategies in the funding, regulation, organization and delivery of public LTC services, it also appears that this logic is incompatible with a system in which younger residents both “live” *and* “survive”.

CONCLUSION

A Future for Relational Care? Learning from the Experiences of Younger Residents

> I’m thinking to myself, to be honest, I’ll be here another thirty, forty years. I think to myself, how am I going to change in that time? I know I’m going to get older—sixty, seventy, eighty. How am I going to change? How am I going to *survive* [emphasis added] a place like this?—Marnie (Female Resident)

> [She’s] in here for the *long haul* [emphasis added]. She’s not piecework.—Susan (Family Member)

In this dissertation project, I sought to explore the situation of non-senior adults living in LTCFs in Ontario in the two decades leading up to the emergence of the COVID-19 pandemic. I did this by uncovering younger residents' conditions of care—the broad collection of circumstances that combine to comprise their everyday experiences and perceptions of being a resident in a LTCF. Responding to an overall gap in scholarly research on this topic, as well as analytic limitations of existing work, my research sought to develop a deep, nuanced understanding of these conditions amidst the multiple contexts within which they are situated.

Employing a qualitative case study design, I examined the conditions of care for 18 younger residents living in five private, for-profit LTCFs in the Greater Toronto and surrounding areas. I drew heavily on what they told me and showed me about living in a LTCF to uncover their conditions of care. By assuming that care is a relationship and recognizing the relationship between the conditions of care and the conditions of work, I also explored these circumstances by capturing the experiences and perspectives of direct care workers, family members, and administrators. My analysis was further informed by field notes, facility-specific informational documents, and a body of sociological literature examining issues in LTCFs in Ontario during the period in question. This latter body of information aided my understanding of the organizational and broader contexts and processes shaping the more specific conditions of care for these residents.

Collectively, the conditions of care that I uncovered reveal both the “promise” of LTCFs for non-senior residents and the ways in which it is inappropriate. My findings demonstrate that for younger residents, the promise of LTCFs is associated with conditions that support relational care. Relational care fosters what non-senior residents value most about living in a LTCF, and it supports direct care workers in providing care accordingly. Conditions of this sort are largely secured via the efforts and resources of individual residents and direct care workers. But relational care is often prevented by the ways in which care tends to be organized and delivered in LTCFs and the ways in which it is funded. Relatedly, relational care is also incompatible with neoliberal processes that have marketized and medicalized the LTC system in Ontario. In uncovering younger residents' conditions of care, this project thus demonstrates the problem of non-senior residents living in LTCFs as linked to the privatization of the public system.

Thriving Means Surviving

My examination of the conditions of care for 18 younger residents living in five for-profit facilities in the Greater Toronto and surrounding area brought forth a key tension in this situation. The findings indicated that LTCFs play a valuable and valued role in sustaining the life of non-senior residents. My analysis also suggested, however, that for younger residents, the conditions of care need to mean more if they are to be experienced positively and understood as appropriate. Aubrecht and colleagues (2021) frame the issue as going from “surviving to thriving”, but I would suggest, based on the results of this project and referring to the quotation from Marnie that opens this Conclusion, that for younger residents, thriving *means* surviving.

By centering on the experiences and perspectives of younger adults living in LTCFs, this project addresses the overall lack of empirical research in this area, particularly research in Canada. While other researchers have documented the gaps and problems younger residents experience from their perspectives (see Barber et al., 2021; Hay & Chaudhury, 2015), this project also uncovered the conditions in which they are more likely to flourish. The findings suggest that these conditions are relational—they are characterized by care relationships and the provision of care in relational ways.

Relational care appears to challenge some of the characteristics of LTRC associated with its more institutional and institutionalizing forms. Relational care fosters autonomy and personhood among younger residents, it means care provision is more likely to be individualized to their needs, interests, and preferences, and they are more likely to have meaningful and/or joyful experiences. When care is relational, it is also more likely to involve younger residents in all aspects of its provision, including when they determine it is not wanted. As such, relational care challenges conventional notions of autonomy, self-determination and personhood, viewing them as closely linked to if not emerging from care relationships. Further, it resists notions of younger residents as the passive recipients of care.

Certainly, the existing research, albeit scant, indicates that care relationships matter to non-senior residents. Hay and Chaudhury (2015) and Watt and Konnert (2007) identified connections between younger residents' quality of life and the presence of positive relationships with particular care aides who knew their routines. Maintaining connections with close family members and friends, receiving frequent visitors, and having a "confidant" relationship within one's facility were also indicators of quality of life among non-senior residents. Results from this project, however, suggest that the importance of relational care for younger residents may, as-yet, be under-recognized.

One indication of this oversight is the tendency of research on this topic to include the perspectives of younger residents *or* the perspectives of care providers and other stakeholders. Focusing solely on the perspectives of non-senior residents is an understandable approach given that knowledge about LTCF has largely been developed without the “voices” of residents, non-senior residents in particular (Aubrecht et al., 2021). However, by including the perspectives of younger residents *and* those who provide them with care, this project was also able to uncover the conditions of work that make the provision of relational care more or less of a possibility. The findings of this project suggest that when conditions of work in LTCFs are relational, younger residents are more likely to receive care in a positive way because under these conditions, direct care workers are more likely to experience satisfaction. Not only do direct care workers experience satisfaction when they provide care in ways that meet the needs, preferences and interests of younger residents, but also, they experience satisfaction when care is relational because in these conditions, direct care workers are recognized, appreciated, they experience a number of social and emotional rewards, and care interactions are smoother if not easier.

The findings of this project also make a contribution to the literature on this topic by uncovering the ways in which individual non-senior residents and direct care workers act to secure relational care (provision) and resist (potentially) negative, institutionalizing, and repressive experiences and structures. Younger residents may actively direct their care. Many involved in this study ask for it, go and get it, advocate for themselves, and seek out care of the sort they value from workers they identify as good if not exceptional at their jobs. Some non-senior residents also draw on their personal finances, organize and participate in services and programs beyond their facility, and rely on informal care providers to fill the gaps in care.

Younger residents also secure relational care by engaging in practices that support the care relationships in which they are involved. Many actively develop a wide variety of positive care relationships inside and outside their facilities and engage in a variety of measures to maintain them. As much as possible, they do their own care and try not to ask for too much assistance, they provide care to their co-residents and family members, they assist new care staff, and they acknowledge those responsible for their more positive care experiences.

Individual direct care workers also make the difference when it comes to relational care. The extent that younger residents value and seek out those workers who treat them as people, who are willing to find the time for and provide “the little extras”, who listen to them and who like to socialize or “joke around” is indicative of how important “good” workers are to relational care. The findings also indicate that relational care is fostered by workers who employ significant skills in and are morally and/or professionally committed to providing care in relational ways even when this means doing more than their job requirements or doing work for which they are not paid. This situation arises because inadequate staffing levels and mix, intense workloads and pace, and complex regulations and onerous reporting requirements that favour medical over social care, make it extraordinarily difficult for direct care workers—most of whom are poorly paid and many of whom are racialized and/or migrant women—to provide relational care within the boundaries of work for which they are paid.

The extent to which younger residents draw on their own finances, their informal support networks, and their capacities to be mobile and verbal in order to fill the gaps in care and ensure its relationality is a problem. It is a problem for younger residents if these gaps are linked to age-insensitive services. It is also an issue because not all younger residents have the (same) resources, capacities, or willingness to secure relational care and/or resist bad care. Over-reliance on the individual efforts and capacities of direct care workers is also a problem. When the conditions of work do not support relational care provision, workers’ health, wellbeing, and safety are put at risk. In this context, the highly gendered, moral dimensions of relational care provision are exploited and become exploitative.

The Experiences of Younger Residents in Context

By examining the structures that shape younger residents' conditions of care, this project contributes to the research literature by moving beyond describing these conditions. Such knowledge is particularly timely, given, as Hewitt argues, “younger disabled people in LTC cannot wait until a sizeable body of work documenting their lived experience has been achieved for this research to move…from “what” to “how” and “why” so that there can be deep, systemic, lasting change, from a place of knowledge and understanding” (2022, p. 3). By linking the conditions of care experienced by younger residents within the working conditions and organizational context that shape them, this project identified a number of structural facilitators and barriers to relational care. Time for care, continuity of care, access to care in a desirable location, age-informed services, and access to privacy, are structures that foster relational care. Relatedly, time for care provision, continuity of care provision, a good care team, and access to appropriate equipment and technology are structures that facilitate the efforts of direct care workers to provide care in relational ways.

Uncovering younger residents’ conditions of care as shaped by the organizational context in which it is situated also revealed that relational care is more often constrained by the structure and organization of care in LTCFs. Lean staffing levels, rigid care routines, discontinuous care provision, and inaccessible equipment prevent younger residents from experiencing and workers from providing timely, consistent, high quality, careful, flexible, safe, dignified, individualized, resident-centred, health *and* social care. The consequences in terms of the health, well-being and dignity of younger residents *and* direct care workers are severe. They also directly impact relational care because they compromise care relationships within LTCFs.

In doing so, this project provides support to prior work that has used a feminist political economy lens to demonstrate the consequences of the direction of contemporary LTC reform in Ontario on those who live in, work in, and visit LTCFs (H. Armstrong et al., 2016; P. Armstrong et al., 2019; Badon, 2021; Barken & Armstrong, 2020; Daly, 2015; Day, 2014). This direction is one that is characterized by the marketization and medicalization of care, and it is one that prevents the conditions for relational care (provision). However, this project adds to this broader literature by demonstrating that these structures are experienced and understood in particular ways by younger residents. It appears that relational care takes on particular meaning for younger residents who live in a LTCF for the "long-haul", who perceive themselves (and are perceived by others) as having different needs, interests and preferences than the numerical majority of residents because of their relative youth and the forms of impairments they experience, and because the ways in which direct care workers provide relational care are shaped by their ideas about youth particularly as they intersect with ideas about disability and gender.

My examination of younger residents' conditions of care within the context of neoliberal processes also uncovered a number of tensions and dissatisfactions that together, suggest that public LTRC services in Ontario are particularly inappropriate for non-senior residents. Programs and services are age- (and disability and gender) insensitive, meaning they do not match younger residents' particular experiences of impairment, their different interests and preferences. The social environment in LTCFs is inappropriate leading to feelings that younger residents do not belong. Safety protocols are overly rigid, limiting resident self-determination and their access to meaningful experiences. Instances of discrimination and violence are common, and younger residents sometimes experience issues with the physical care environment. The findings also emphasize that the appropriateness of LTCFs for non-senior residents is compromised by a system in which non-senior residents experience significant barriers in access to public LTC services, rendering LTCFs the only option rather than a “choice”.

The stories that participants tell about younger residents conditions of care lend support to previous studies that suggest LTCFs often fail to meet the physical, sexual, social, nutritional, psychological and emotional support needs of non-seniors (Oliver et al., 2022), and are often characterized by institutionalizing practices that fail to support their “independence” (Beattie et al., 2004). This project, however, goes beyond documenting the problems by understanding them as shaped by neoliberal processes of LTC reform and dehospitalization. Exploring the problems experienced by younger residents and those involved in their conditions of care from this lens begins to address questions of how and why the public LTC system and LTCFs themselves exist in ways that make them inappropriate for non-senior adults. In doing so, the project also lends support to the possibility of change—that public LTC services can be changed in ways that make them more appropriate for and better meet the needs, preferences and interests of younger residents and those who provide them with support.

A Relational Feminist Disability Perspective

A secondary outcome of this project was the development and implementation of a relational feminist disability perspective to explore younger residents’ conditions of care. This framework was key to generating a deeper understanding of the situation of and conditions of care experienced by younger residents living in LTCFs in Ontario that goes beyond a description of the issues. As a critical, politicized approach to LTRC, this perspective was about (re)conceptualizing it as “relational” at multiple levels of abstraction and making it more “accessible” not only by situating it within a legacy of oppression, revealing its on-going institutionalizing conditions, and its role as an exploitative gendered and racialized form of labour, but also in terms of uncovering its “promise” or best potential.

This understanding of LTRC prompted the use of a multi-level analytic strategy whereby younger residents’ conditions of care were examined at the interpersonal level (where everyday practices, interactions, people and relationships are located), as shaped by the meso-level (including the organizational and delivery context within LTCFs), and situated within macro-level forces, contexts and processes. It also meant looking for difference, diversity and inequity—asking questions about who does and does not experience relational care (provision), and what accounts for the particular experiences of different younger residents. In doing so, this project’s findings help fill analytic gaps in existing research that hardly accounts for how and why these conditions exist as they do.

The development of a relational feminist disability perspective was in itself a significant outcome of this project. By integrating concepts, analytic frameworks and methodological principles and practices from FDS and FPE, this project contributes to scholarship that aims to move beyond paradigmatic divisions among feminist and DS approaches to “care” (see Lloyd, 2001; Kelly, 2011; 2013; Thomas, 1999), without glossing over the tensions (Kelly, 2013). It adds to the efforts of FDS scholars to make care more “accessible” (Kelly, 2011; 2013) by situating the younger residents' conditions of care within historical and ongoing violences against people with disabilities associated with institutional forms of public care (Leblanc Haley & Temple Jones, 2020). By locating this issue within the processes of health care reform and dehospitalization in the context of neoliberalism, this project also reveals the issues for women as the majority of formal and informal care providers, and as the majority of older residents. This project thus fills theoretical gaps in existing FPE approaches to LTRC that have not, as yet, paid much attention to the history and on-goingness of institutionalization, while also challenging CDS scholars to examine LTRC from a feminist, relational lens.

The application of a methodological approach that integrates FPE approaches to research in LTCFs with FDS methodologies was also an important contribution of this project. Until very recently (see Aubrecht et al., 2021; Barber et al., 2020), social research in LTCFs in Ontario rarely drew on the methodological insights of FDS to engage in research with residents. In fact, as Aubrecht and colleagues (2021) argue, knowledge about people living in LTCFs has largely been developed without the perspectives of residents, particularly non-senior residents. Researchers in Canada have begun to examine the lived experiences of younger residents, using a variety of methods to generate accounts from the perspectives of non-seniors themselves (see Barber et al., 2021; Hay & Chaudhury, 2015). At the same time, FDS researchers have developed useful methodological approaches and research methods to assist researchers "doing" research in LTCFs (see Armstrong & Lowndes, 2018; Baumbusch, 2011). I offer my own project as a demonstration of the benefits of bringing these insights and approaches together.

Finally, I would suggest that the integration of FPE and FDS approaches to LTRC is a particularly important endeavour in these political times. Since the time of data collection for this project, it has become even more clear that the direction of public LTC is one that has negative consequences for residents, paid care workers *and* informal care providers. The time is now to "build bridges" (Kelly, 2013) across the cracks in disciplinary knowledge. A relational feminist disability approach provides a useful framework for future is a useful way forward in this regard.

Reflecting on the Challenges and Opportunities

Notwithstanding the contributions of this project to both knowledge about the situation of younger residents living in LTCFs in Ontario, and more broadly, to theoretical and methodological scholarship in FPE and FDS, I experienced a number of research challenges throughout this process. As discussed at length in Chapter Three, each stage of the process from gaining access to sites, recruiting participants enough to generate robust data sets for cross-case comparison, to interacting with participants in ways that made them feel comfortable, and using tools that supported the ways in which they communicated their narratives, came with its own challenges. Even though many of the issues that arose were not completely resolvable, they often led to the development of a new approach, method, or tool that improved my methodological perspective and methods. At the same time, I have often reflected on the need to develop a "toolbox" of communication aids—one that might remove some of the difficulties associated with acting as one's own methodologist (Owens, 2007). This does not, however, replace the need for flexibility and reflection.

The challenges I experienced did not only lead to methodological opportunities, but some also led to a deeper understanding of the data. Recognizing the structures that were negatively impacting the research process attuned me their role in shaping the conditions of care. I came to understand the challenges I experienced recruiting and maintaining the participation of direct care workers, for example, as a reflection of larger structural issues with the conditions of work in LTCFs. A lack of personal space available for interviewing some direct care workers, the presence of work hierarchies that may account for some of the challenges associated with building trust, and issues with direct care workers being too overworked and not having time to participate made me more aware of the particular conditions of work that prevent relational care.

Many of the challenges I experienced arose as I recognized tensions between my methodological principles and the contexts framing my completion of the project, particularly as a non-disabled PhD student who was a novice to research in LTCFs. For example, despite my efforts to involve a diverse non-senior resident population and modify my research methods accordingly, my reliance on others to recruit potential participants likely led to an under-representation of those with more complex cognitive impairments, those who display reactive or resistant behaviours, and/or those who experience impairments that significantly impact verbal articulacy.

I also struggled to challenge more normative researcher-researched power dynamics and develop a product that was more reciprocal in nature. I had some successes, culminating in an original contribution to academia that I am hopeful can be used to inspire change that will improve the system for younger residents. However, I have also become aware that the personal and academic contexts within which student researchers carry out their PhD projects do not always sit well with the methodological principles they espouse. Students and researchers who are new to LTRC can certainly learn a lot from these struggles, as I certainly did. In fact, I am hopeful that my efforts to carefully describe my methodology and methods, and to document my reflections on this process will benefit others who are similarly positioned and/or interested in "doing" feminist disability research in LTCFs.

Finally, while a key finding of this project is that "age matters" when it comes to issues in LTRC, this finding should not be misunderstood as suggesting that LTCFs are not inappropriate or an issue for older adults. Herron and colleagues (2021) raise this concern, arguing that while the construction of LTCFs as inappropriate for younger residents is common, the institutionalization of older people may be viewed as an acceptable way to provide public care. Guided as it was by a relational feminist disability approach, I am confident that this project avoids such a problem. Examining the situation of younger residents living in LTCFs in Ontario raised a plethora of issues with the structure, organization and delivery of care within the LTC system that are a potential problem for all those who use it, provide it, and need access to it. In this way, the "case" of younger residents living in Ontario's LTCFs in the decade leading up to the COVID-19 pandemic is a "snapshot" of the consequences of privatization.

Future Directions

Over the past decade, researchers have identified longstanding, on-going issues in and promising ways forward for LTCFs in Ontario (see Armstrong & Armstrong, 2020; Baines & Armstrong, 2015; Estabrooks et al., 2020; Marrocco, 2021; Ontario Health Coalition, 2019 see also, Chapter 4). But despite arguments that Ontario's LTCFs must respond to an increasingly diverse and complex resident population (Estabrook et al., 2020; Marrocco et al., 2021), as a group, younger residents are still infrequently mentioned in policy and research. It is my hope that in light of the findings of this project, younger residents will no longer continue to be overlooked.

However, it should be noted that while this project involved participants from five LTCFs in Ontario, it was an exploratory project, not meant to produce a generalizable account of the conditions of care for non-senior adults living in LTCFs. In fact, generalization was not the primary goal of this project. Instead, my focus was on generating a thick description of the conditions of care experienced by a particular group of non-senior residents. The richness, depth, and details of the results define the quality, credibility, and the significance of the study. This research offered some rich insights into the topic through the development of thorough descriptions and explanations made possible through the use of appropriate theoretical and methodological concepts and processes of data collection and analysis that went beyond what exists in the literature to date.

These initial insights raise a number of considerations for future research. First, future researchers should consider differences among younger residents in terms of their length-of-stay. There is very little information available about what length-of-stay might mean in terms of residents' conditions of care. Through this project, I have come to recognize the substantial institutional knowledge held by some non-senior residents. But there is very little discussion of those residents with exaggerated lengths-of-stay and/or who are likely to live in a LTCF over decades. Such knowledge is especially needed now, as LTCFs in Ontario increasingly become places for end-of-life care (Marrocco et al,. 2021).

Second, many of the impairment effects or symptom profiles of younger residents differ from that of older residents. The findings of this study indicate that direct care workers lack the specialized skills to provide appropriate care to people experiencing the types of disability younger residents are more likely to experience, and administrators are unaware of training geared towards working with the non-senior resident population. Future research should examine this gap and consider how the entire care team can be supported to best meet the needs of younger residents.

Third, we also know very little about dedicated units for younger people in Ontario. Although a number of participants in this project suggest this model may have value, only one participant had actually lived in and none of the direct care workers involved had provided care in this type of unit . The situation of the younger residents at Sherwood West does provide some support for this idea. At this facility, younger residents had developed long-time relationships with others similar in age. These relationships were especially meaningful to those younger residents who rarely left their facilities to engage in social activities as they meant regular access to meaningful experiences.

Concluding Remarks

What then, is the possibility of relational care and of a public LTC system in which younger residents can survive and live well? Despite numerous calls to action and mounting evidence of both the problems with and potential solutions to issues with the system, very little has changed over the past decades (see Estabrooks et al., 2020). Years of LTC privatization, the consequences of which are most apparent with the COVID-19 crisis, will not be easy to correct. In fact, it appears we are not moving away from the oppressive legacies of public care in Ontario, but towards them and beyond. One cannot help but draw comparisons between the conditions of care in LTCFs in recent years and that of the provincial institutions for people with disabilities.

This study argues for the importance of relational, equitable conditions for younger residents and by extension, all those who live in, provide paid and informal care in, and need and want access to LTCFs. This means removing the structures that prevent care relationships and the practice of care in relational ways. It also means investing in LTCFs to improve the conditions for residents, staff, and family members, and doing so in ways that take seriously the difference that age, disability, and gender can make. Finally, LTCFs will never be appropriate for younger residents until a range of high quality, affordable, home, community, and residential public health, disability and other social services and programs exist. For this, we need significant change in political will.

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Appendix A:

Resident Informed Consent Form

Study Name: Falling through the cracks? Conditions of care and adults with disabilities in long-term care homes

Researcher: Morgan Seeley

Sponsor: York University

Purpose of the Research:

The purpose of this project is to learn about non-senior adults with disabilities living in long-term care homes in the Greater Toronto and surrounding areas. Information on this topic will be gathered through individual, open-ended interviews between the researcher and a small number of residents in five long-term care homes. Residents will also have the opportunity to answer interview questions in written-form via the use of a personal journal. The researcher will also interview at least four care workers, an administrator and two or more family members. This project tries to answer three main questions: (a) What does care look like for non-senior adult residents with disabilities living in long-term care homes? (b) What factors effect how care is given and received? (c) Do gender, disability and other differences impact how care is given and received?

Understanding how care is provided and received and how different factors effect this is important because long-term care should be high quality, equitable, recognize diversity and promote dignity and respect.

The participants in this study include a minimum of four adults with disabilities between the ages of 18 and 64, who are currently living in one of five private long-term care homes in the Greater Toronto and surrounding areas. Participants also include four female care workers who work in each long-term care home as well as an administrator and 2 or more family members.

As a resident, the researcher will ask you to describe what you do everyday. Based on your description, you will be asked to describe what care you get and how you get care. You will be asked who provides care for you and also, how you care for others. You will also be asked about your relationship with direct care workers. You will be asked to describe the factors you believe makes caring a good and/or bad experience. You will also be asked if you believe your gender, ability, age, ethnicity or other differences effect caregiving. Finally, you will be asked if you think your experiences with care at this long-term care home can be improved and how they can be improved.

What the Participant Will Be Asked to Do in the Research: You will be asked to participate in an individual open-ended interview that will be audio-tape recorded. The researcher will show you a set of interview questions and you will decide the number of interviews you would like to participate in and the length of time you would like each interview to last. The goal is to complete the interview questions. You can choose to have a guardian or advocate sit in on the interview with you. You can also choose to keep a personal journal where you may write answers to the interview questions. You can also choose to read and make comments to the researcher about an early version of the research findings that she will give to you.

Risks and Discomforts: We do not foresee any risks related to your participation in this research project. However, a bit of discomfort could occur if you find it difficult to speak in front of the researcher and/or talk about issues related to how you get and give care.

Benefits of the Research and Benefits to the Participant: Potential benefits include the opportunity for you to talk about your concerns related to the care you receive. This research may produce a better understanding of the experiences of younger adults with disabilities living in long-term care homes. This is particularly important because most often, only the experiences and concerns of senior residents are heard. A better understanding of the conditions of care among non-seniors with disabilities may help health professionals, administrators and policy-makers create changes that will improve the quality of long-term care services especially for younger residents.

Voluntary Participation and Withdrawal from the Study: Participation in the study is completely voluntary. You may choose to stop participating at any time. You may also choose not to answer particular questions. Your decision not to take part in this study or not answer some questions will not effect your relationship with the researcher, York University, or any other people associated with this project. If you choose to stop participating, all of the data the researcher has collected from you will be immediately destroyed.

Confidentiality: The tape-recorded interviews and personal journals will not contain your name or any other information that could identify you. All of the information you provide during the research is confidential (private). Your name will not appear in any report or publication of the research. The researcher will collect information from you using an audio-tape, asking you to write in a personal journal and taking handwritten notes. All of this information will be safely stored in a locked cabinet and only the researcher and her supervisor will have access to it. At the end of the study, all of this data will be stored for 5 years. After 5 years, the data will be destroyed. Transcripts, journals and field notes will be shredded, audio-tapes and computer files will be erased.

Confidentiality will be provided to the fullest extent possible by law.

The research collected for this project will be reported in the form of a dissertation required for the completion of a PhD in the Department of Women's Studies at York University, Toronto, Ontario. It may also be reported in publications and presented at conferences.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Morgan Seeley, Graduate Student, Women's Studies, 206 Founders College, York University by telephone at (416) 736-2100, extension 33754 or by e-mail (mseeley@yorku.ca). You may also contact Morgan's supervisor Pat Armstrong by telephone at (416) 736-2100, extension 22550 or by e-mail (patarmst@yorku.ca).

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact Ms. Alison Collins-Mrakas, Senior Manager, Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail acollins@yorku.ca).

Legal Rights and Signatures:

I__________________________, consent to participate in *Falling through the cracks? Conditions of care and adults with disabilities in long-term care homes* conducted by Morgan Seeley. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature______________________ **Date**___________________
Participant

Signature______________________ **Date**___________________
Principal Investigator

Appendix B:

Guardian Informed Consent Form

Study Name: Falling through the cracks? Conditions of care and adults with disabilities in long-term care homes

Researcher: Morgan Seeley **Sponsor**: York University

Purpose of the Research:

The purpose of this project is to learn about how care is given to and experienced by non-senior adults with disabilities living in five long-term care homes in the Greater Toronto and surrounding areas. Information on this topic will be gathered through individual, open-ended interviews that will take place between the researcher and a small number of residents, workers and an administrator. Residents will also have the opportunity to answer interview questions in written-form via the use of a personal journal. An open-ended focus group interview will also be conducted with family members. The interviews will focus on answering three main questions: (a) What does care look like for non-senior adult residents with disabilities living in long-term care homes? (b) What factors effect how care is provided and received? (c) Do gender, disability and other differences impact how care is provided and received?

For each of the five homes, the participants in this study include a minimum of four adults with disabilities between the ages of 18 and 64, who are currently living in a private long-term care home in the Greater Toronto and surrounding area. Participants also include at least four female care workers, a facility administrator and two or more family members.

The researcher will ask participants to describe their daily activities and talk about how and when caring occurs as part of these activities. They will be asked to describe what care they receive, how care is received, who provides care, and how they provide care for others. Participants will also be asked to describe what their relationships are like with their direct care workers. Participants will be asked to pick out factors they believe make caring a positive and/or negative experience. They will also be asked if they believe their gender, ability, age, ethnicity or other differences effect how care is provided and received. Finally, participants will be asked if and how their experiences with caring can be improved.

What the Participant Will Be Asked to Do in the Research: Participants will be shown an interview guide and asked to participate in an audio tape-recorded individual, open-ended interview. Based on the interview guide, the participant will decide the number of interviews they would like to participate in and the length of time they would like each interview to run in order to complete the questions in the guide. Participants may choose to keep a personal journal where they may write answers to the interview questions. Participants will also be given an opportunity to review and make comments on an early version of the data analysis.

Risks and Discomforts: We do not foresee any risks related to participation in this research project. However, minimal discomfort could occur if the participant finds it difficult to speak in front of an interviewer and/or talk about issues related to how care is experienced. In order to reduce discomfort, the participant may choose to have a guardian or advocate present at the time of the interview.

Benefits of the Research and Benefits to the Participant: Potential benefits include the opportunity for participants to talk about their experiences and concerns related to their conditions of care. Further benefits include producing a better understanding of the experiences of younger adults with disabilities living in long-term care homes. This is particularly important because research and policy in this area tends to focus predominantly on the experiences and concerns of senior residents. A better understanding of the conditions of care among non-seniors with disabilities may help health professionals, administrators and policy-makers develop interventions that will improve the quality of long-term care services.

Voluntary Participation and Withdrawal from the Study: Participation in the study is completely voluntary. Participants may choose to stop participating at any time. The participant may choose not to answer particular questions. The participant’s decision not to take part in this study and/or not answer individual questions will not effect their relationship with the researcher, York University, or any other group associated with this project. If the participant chooses to stop participating, all of the data collected from the participant will be immediately destroyed.

Confidentiality: The tape-recorded interviews and personal journals will not contain the participant’s name or any other information that could identify the participant. All information provided by the participant during the research is confidential. The participant’s name will not appear in any report or publication of the research. Data will be collected by audio-taping interviews, asking residents to write in personal journals and taking handwritten notes. All data will be safely stored in a locked cabinet and only the researcher and her supervisor will have access to this information. At the end of the study, all data will be stored for 5 years. After 5 years, the data will be destroyed. Transcripts, journals and field notes will be shredded, audio-tapes and computer files will be erased.

Confidentiality will be provided to the fullest extent possible by law.

The research collected for this project will be reported in the form of a dissertation required for the completion of a PhD in the Department of Women’s Studies at York University, Toronto, Ontario. It may also be reported in publications and presented at conferences.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Morgan Seeley, Graduate Student, Women's Studies, 206 Founders College, York University by telephone at (416) 736-2100, extension 33754 or by e-mail (mseeley@yorku.ca). You may also contact Morgan's supervisor Pat Armstrong by telephone at (416) 736-2100, extension 22550 or by e-mail (patarmst@yorku.ca).

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact Ms. Alison Collins-Mrakas, Senior Manager, Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail acollins@yorku.ca).

Legal Rights and Signatures:

I__________________________agree to allow __________________________ to participate in *Falling through the Cracks? Conditions of care and adults with disabilities in long-term care homes* conducted by Morgan Seeley. I understand the nature of this project and freely and voluntarily consent my ward to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature__________________________ **Date**____________________
Guardian

Relationship to Participant______________________________

Signature__________________________ **Date**____________________
Principal Investigator

Appendix C:

Direct Care Worker/Administrator Informed Consent Form

Study Name: Falling through the cracks? Conditions of care and adults with disabilities in long-term care homes

Researcher: Morgan Seeley

Sponsor: York University

Purpose of the Research:

The purpose of this project is to learn about how care is given to and experienced by non-senior adults with disabilities living in five long-term care homes in the Greater Toronto and surrounding areas. Information on this topic will be gathered through individual, open-ended interviews that will take place between the researcher and a small number of residents, workers and administrators. An open-ended focus group interview will also be conducted with 2 or more family members of non-senior residents. The interviews will focus on answering three main questions: (a) What does care look like for non-senior adult residents with disabilities living in long-term care homes? (b) What factors effect how care is provided and received? (c) Do gender, disability and other differences impact how care is provided and received?

Understanding how care is provided and received and how different factors effect the conditions of care is important to ensuring long-term care services are high quality, equitable, recognize diversity and promote dignity and respect.

For each of the five homes, the participants in this study include a minimum of four adults with disabilities between the ages of 18 and 64, who are currently living in a private long-term care home in the Greater Toronto and surrounding areas. Participants also include a minimum of four female care workers, a facility administrator and two or more family members. The researcher will ask you to describe what care looks like for non-senior residents and how and when caring occurs over the course of a day. You will also be asked to describe who provides care, what your role in care provision is, and how the residents themselves participate in caring activities. You will also be asked to talk about what your relationship is like with non-senior residents and what factors you believe make caring a positive and/or negative experience. Finally, you will be asked if and how the conditions of care can be improved for you as a care worker or administrator and how they can be improved for the non-senior residents.

What the Participant Will Be Asked to Do in the Research: You will be shown an interview guide by the researcher and asked to participate in an audio tape-recorded individual, open-ended interview. Based on the interview guide, you will decide the number of interviews you would like to participate in and the length of time you would like each interview to run in order to complete the questions in the guide. You will also be given an opportunity to review and make comments on an early version of the data analysis.

Risks and Discomforts: We do not foresee any risks related to your participation in this research project. However, minimal discomfort could occur if you find it difficult to speak in front of an interviewer and/or talk about issues related to your work experiences and the conditions of care at this long-term care home.

Benefits of the Research and Benefits to the Participant: Potential benefits include the opportunity for you to talk about your experiences and concerns related to your work conditions and/or the care being provided to non-senior residents. Further benefits include producing a better understanding of the challenges and rewards experienced by workers who provide care to the younger resident population and the administrators who are responsible for the home. A better understanding of the conditions of care that exist for non-seniors with disabilities may help health professionals, administrators and policy-makers develop interventions that will improve the quality of long-term care services.

Voluntary Participation and Withdrawal from the Study: Participation in the study is completely voluntary. You may choose to stop participating at any time. You may choose not to answer particular questions. Your decision not to take part in this study and/or not answer individual questions will not effect your relationship with the researcher, York University, or any other group associated with this project. If you choose to stop participating, all of the data collected from you will be immediately destroyed.

Confidentiality: The tape-recorded interviews will not contain your name or any other information that could identify you. All information you provide during the research process is confidential. Your name will not appear in any report or publication of the research. Data will be collected by audio-taping interviews and taking handwritten notes. All data will be safely stored in a locked cabinet and only the researcher and her supervisor will have access to this information. At the end of the study, all data will be stored for 5 years. After 5 years, the data will be destroyed. Transcripts and field notes will be shredded, audio-tapes and computer files will be erased.

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The research collected for this project will be reported in the form of a dissertation required for the completion of a PhD in the Department of Women’s Studies at York University, Toronto, Ontario. It may also be reported in publications and presented at conferences.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Morgan Seeley, Graduate Student, Women's Studies, 206 Founders College, York University by telephone at (416) 736-2100, extension 33754 or by e-mail (mseeley@yorku.ca). You may also contact Morgan's supervisor Pat Armstrong by telephone at (416) 736-2100, extension 22550 or by e-mail (patarmst@yorku.ca).

This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact Ms. Alison Collins-Mrakas, Senior Manager, Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail acollins@yorku.ca).

Legal Rights and Signatures:

I__________________________, consent to participate in *Falling through the cracks? Conditions of care and adults with disabilities in long-term care homes* conducted by Morgan Seeley. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature______________________ **Date**___________________
Participant

Signature______________________ **Date**___________________
Principal Investigator

Appendix D:

Family Member Informed Consent Form

Study Name: Falling through the cracks? Conditions of care and adults with disabilities in long-term care homes

Researcher: Morgan Seeley

Sponsor: York University

Purpose of the Research:

The purpose of this project is to learn about how care is given to and experienced by non-senior adults with disabilities living in five long-term care homes in the Greater Toronto Area. Information on this topic will be gathered through individual, open-ended interviews that will take place between the researcher and a small number of residents, workers and an administrator. Residents will also have the opportunity to answer interview questions in written-form via the use of a personal journal. An open-ended focus group interview will also be conducted with family members. The interviews will focus on answering three main questions: (a) What does care look like for non-senior adult residents with disabilities living in long-term care homes? (b) What factors effect how care is provided and received? (c) Do gender, disability and other differences impact how care is provided and received?

For each of the five homes, the participants in this study include a minimum of four adults with disabilities between the ages of 18 and 64, who are currently living in a private long-term care home in the Greater Toronto Area. Participants also include at least four female care workers, a facility administrator and two or more family members who are involved with non-senior residents.

Family members will be asked to describe what care looks like for non-senior residents and how and when caring occurs over the course of a day. You will also be asked to describe who provides care, what your role in care provision is, and how the residents themselves participate in caring activities. You will be asked to describe the role of the family council and how its presence impacts the conditions of care for non-senior residents. You will also be asked to talk about what factors you believe make caring a positive and/or negative experience. And, finally, you will be asked if and how the conditions of care can be improved for non-senior residents.

What the Participant Will Be Asked to Do in the Research: You will be asked to participate in an audio tape-recorded, open-ended, focus group interview with the researcher and one or more family members. The focus group interview will last approximately 60-90 minutes. You will also be given an opportunity to review and make comments on an early version of the data analysis.

Risks and Discomforts: We do not foresee any risks related to participation in this research project. However, minimal discomfort could occur if the participant finds it difficult to speak in front of an interviewer and/or in front of other family members on this subject.

Benefits of the Research and Benefits to the Participant: Potential benefits include the opportunity for participants to talk about their experiences and concerns related to their conditions of care for non-senior resident family members and to discuss the role that family members and the family council play in the conditions of care. As a whole, this project may produce a better understanding of the experiences of younger adults with disabilities living in long-term care homes. This is particularly important because research and policy in this area tends to focus predominantly on the experiences and concerns of senior residents. A better understanding of the conditions of care among non-seniors with disabilities may help health professionals, administrators, family members and policy-makers develop recommendations and interventions that will improve the quality of long-term care services.

Voluntary Participation and Withdrawal from the Study: Participation in the study is completely voluntary. You may choose to stop participating at any time. You may choose not to answer particular questions. Your decision not to take part in this study and/or not answer individual questions will not effect their relationship with the researcher, York University, or any other group associated with this project. If you choose to stop participating, all of the data collected from the participant will be immediately destroyed.

Confidentiality: Transcripts of the tape-recorded focus group interview will not contain the participant's name or any other information that could identify the participant. All information provided by the participant during the research is confidential. The participant's name will not appear in any report or publication of the research. Data will be collected by audio-taping the interview and taking handwritten notes. All data will be safely stored in a locked cabinet and only the researcher and her supervisor will have access to this information. At the end of the study, all data will be stored for 5 years. After 5 years, the data will be destroyed. Transcripts and field notes will be shredded, audio-tapes and computer files will be erased.

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Legal Rights and Signatures:

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Signature______________________ **Date**____________________
Participant

Signature______________________ **Date**____________________
Principal Investigator

Appendix E:

Resident Interview Guide

Care Activities

1. What is the first thing you do when you wake up? What do you do after that? What is the last thing you do before you go to bed?
2. At what points over the course of the day do you receive care from staff? From others? (Refer back to the participants description of his/her activities over the course of a day)
3. What types of care do they provide for you? Can you decide when and what?
4. Are there any activities that you would like to participate in but don't have the opportunity?

Care Needs

5. How do you let staff members know when you need care or assistance?
6. What kinds of care do you need on a daily basis?
7. Is there always someone available to help you when you need it? Are staff members available when you need them? If not, why?
8. Do you ever receive care when you don't need it or want it? Can you give me an example of when this situation has occurred?
9. Do you need different kinds of care or help than older residents? If so, how are your needs different from older residents? From other young residents?

Care Relationships

10. Do you get along well with the staff members that provide care for you? Do you enjoy talking to them and spending time with them?
11. How would you describe your relationship with your nurses and personal support workers? Can you think of 4 or 5 words that sum up your feelings about them?
12. Are there any staff members that you are particularly fond of or feel close to (you don't need to give me any names)? Why do you think you get along so well with these people?
13. Are there any staff members that you do not get along well with (you don't need to give me any names)? Why don't you get along with these staff members?
14. How do you know staff care about you and your health? What kinds of things do they say or do to show that they care about you?

Residents' Contributions to Care

15. Do you help others? Who do you provide care for on a regular basis? How do you provide care for these people?
16. How do you care for yourself? How do you assist staff members in providing care for you?
17. Do you get to make decisions about how you get care, when you get it, and who provides it? How are these decisions made? Would you like to have more input into the way care is provided to you?

Quality of Care

18. How would you define good care?
19. Can you describe a situation where you received good care? Can you describe a situation where you did not get good care?

20. What factors do you think impact the quality of care you receive (e.g. staffing levels, the staff member's skill level, number of residents, type of task, etc.)?
21. Is there an increase in the number of younger residents living in this residence? If so, has this impacted the care you receive?
22. Is there an increase in the number of residents that have complex health issues or care needs residing in this long-term care home? If so, has this impacted the care that you receive?
23. Has there been a change in the amount of time staff members are able to spend with you since you have lived here? If so, how has this impacted you?
24. Can you think of any other issues or factors that impact the quality of the care you receive here?

Relations of Difference and Care

25. Do you think your age, disability, gender, etc. impacts the care you get from staff members? Explain.
26. Do you think it is more difficult or easier for staff to provide care to younger residents? Explain.
27. Have you ever experienced discrimination based on your gender, race, age, sexuality, etc. from staff members? If so, how has this experience (or experiences) impacted you?
28. Are there staff members you prefer to receive care from? Why?
29. Are there any staff members that you prefer not to get care from? Why?

The Potential for Change

30. What are the top 3 things you would change about how care is provided to you at this residence? What are the top 3 things you would keep the same about how care is provided to you at this residence?
31. What are the top 3 things you would change about how care is provided to non-senior residents at this home? What are the top 3 things you would keep the same about how care is provided to non-senior residents?
32. How could the quality of care you receive from staff members be improved?
33. How could you improve the quality of care you provide for others?
34. Do you think you could participate more in your own care? If so, how?
35. Is there anything else you would like me to know about your experiences living in this residence?

Appendix F:

Resident Personal Journal Guide

1. What did you do today?

2. Who provided care or assistance to you today?

3. What kind of care or assistance did they provide to you?

4. Describe the quality of care or assistance provided to you?

5. Did you get good care today? How do you know?

6. How would you describe your relationship with the staff member that provided care to you today? Can you think of 4 or 5 words that sum up your feelings about them?

7. Did you provide care or assistance to others today? How?

8. How did you care for yourself today?

9. What would you change about the care or assistance you received today? What would you keep the same about the care you received today?

10. What activities did you participate in today? Are there any activities you would like to participate in today but didn’t have the opportunity?

Appendix G:

Direct Care Worker Interview Guide

Care Activities

1. What is the first thing you do when you get to work? What do you do after that? What is the last thing you do before you leave work for the day?
2. Who do you provide care for during your work day? Age/ health issues/ capacities?
3. Referring back to your description of your work day, at what points during this day do you provide care for non-senior residents? Do you work on a schedule for tasks or respond to calls? What different types of care do you provide for residents?

Care Needs

4. What kinds of care do you think non-senior residents need?
5. Do non-senior residents require different kinds of care than older residents? How do their needs differ from older residents?
6. Are you available to provide care to non-senior residents when they need you? What factors get in the way of you providing care to non-senior residents when they need it?

Care Relationships

7. How would you describe your relationship with the younger residents? Can you think of 4 or 5 words that sum up your feelings about them?
8. Are there any differences between your relationships with younger residents and older residents? If so, explain.
9. Are there any non-senior residents you are particularly fond of or feel close to? Are there any that you do not get along well with? If so, explain.
10. How do non-senior residents respond to you?

Residents’ Contributions to Care

11. Do non-senior residents care for others working or living in this long-term care home? If so, how?
12. Are non-senior residents active in managing their own care? If so, how?
13. Do non-senior residents participate in decision-making about the nature and quality of the care they receive? If so, how?

Quality of Care

14. How do you define good care? What factors make it possible to provide good care?
15. Please describe a situation where you were able to give the best care you have ever provided while working in a long-term care home.
16. Are there any factors that make it difficult for you to provide good care? Are there any factors that make it easier for you to provide good care?
17. Are there any factors that influence the quality of care you provide to non-senior residents (e.g. staffing levels, training, workload, scheduling, care needs, etc.)?
18. Is there an increase in the number of younger residents you provide care for? If so, has this impacted the quality of care you provide? If so, how?
19. Is there an increase in the number of residents that have complex health issues or care needs residing in this long-term care home? If so, has this impacted how you provide care?
20. Is there an increase or decrease in your workload since you began working here? If so, has this impacted how you provide care?

21. Does scheduling impact how you provide care? If so, how?
22. Are there any other factors that you believe impact the nature and quality of the care you provide? Are there any factors that specifically impact the quality of care you provide to non-senior residents?
23. Are there any factors that specifically influence your relationship with the non-senior residents?

Relations of Difference and Care

24. Have you ever experienced discrimination based on gender, race, age, sexuality, etc. from residents or other people while working in this home? If so, has this experience (or experiences) impacted how you provide care?
25. Do you think it is more difficult or easier to provide care to residents because you are a woman? Explain.
26. Is it more difficult to provide care for residents who are male? Older than you? Younger than you? Speak a different language or have a different cultural background than you?
27. Do these differences effect your relationship with the younger residents? If so, how?
28. Are there any other kinds of differences that impact your relationship with the non-senior residents?

The Potential for Change

29. What are the top 3 things you would change about how care is provided at your place of work? What are the top 3 things that you would keep the same about how care is provided at your place of work?
30. What are the top 3 things you would change about how care is provided to non-senior residents? What are the top 3 things that you would keep the same about how care is provided to non-senior residents?
31. Do you think the care practices for younger residents in this long-term care home could be improved? How?
32. Do you think your relationship with younger residents could be improved? How?
33. Is there anything else you would like me to know about your work or about the kind of care non-senior residents get at your place of work?

Appendix H:

Family Member Interview Guide

Care Activities

1. What types of care do you provide for your resident family member over the course of a typical week? When and where do you provide this care?
2. Are there any care-related activities that you would like to be involved in but don't have the opportunity?
3. What types of care do residents receive from staff at the long-term care home?
4. How are decisions made about when and what types of care residents will receive?

Care Needs

5. How do residents let staff members know they need care or assistance?
6. What kinds of care do you think your family member needs on a daily basis?
7. Is there always someone available to help residents when they need it? Are staff members available when residents need them? If not, why?
8. Do residents ever receive care when they don't need it or want it?
9. Do younger residents need different kinds of care or help than older residents? If so, how are their needs different from older residents? From other young residents?

Care Relationships

10. How would you describe your relationship with the resident you assist?
11. How would you describe your relationship with the nurses and personal support workers at this home? How would you describe your relationship with the administrative and managerial staff?
12. Are there any staff members they are particularly fond of or feel close to or who are particularly helpful (you don't need to give me any names)? What contributes to this relationship? Are there any staff members they have problems with or that you have problems with (you don't need to give me any names)? What are the issues with these staff members?

Residents' Contributions to Care

13. Do residents themselves contribute to care giving? If so, who do they provide care for on a regular basis? How do they provide care for these people?
14. Do residents care for themselves? How? Do they assist you and/or staff members in providing care?
15. Do residents get to make decisions about how they get care, when they get it, and who provides it? How are these decisions made? Would they like to have more input into the way care is provided to them? Would you like to have more input into the way care is provided for your resident family member?

Quality of Care

16. How would you define good care?
17. What factors do you think impact on the quality of care residents receive (e.g. staffing levels, the staff member's skill level, number of residents, type of task, etc.)?
18. Has there been a change in the quality of care your family member receives since they have lived here? If so, what factors are responsible for this change? How has this change impacted your family member? How has it impacted you?

Relations of Difference and Care

19. Do you think a resident's age, disability, gender, etc. impacts on the care they get from staff members? Explain.
20. Do you think it is more difficult or easier for staff to provide care to younger residents? Explain.
21. Has your resident family member ever experienced discrimination based on gender, race, age, sexuality, etc. from staff members? If so, how has this experience (or experiences) impacted on them? How has it impacted you?

The Family/Friends Council

22. What is the purpose of the family/friends council? What are its main goals?
23. What activities are council members involved in at this home?
24. What impacts does the council have on the residents at this home?
25. Why did you become a member of the council?
26. Is there anything you would change about the council, its responsibilities or activities?

The Potential for Change

27. What are the top 3 things you would change about how care is provided to non-senior residents at this home? What are the top 3 things you would keep the same about how care is provided to non-senior residents?
28. How could the quality of care received by residents be improved?
29. Is there anything else you would like me to know about your family member's experiences living in this residence? About your experiences providing care for your family member? About your experiences as a member of the family council?

Appendix I:

Administrator Interview Guide

Care Activities

1. What is the purpose of your job position at this home? What are your main roles/responsibilities?
2. What is your role in caring for residents? What different types of care do you provide for them?
3. How would you describe the residents who currently live here in terms of age/sex/health issues/capacities, etc.?
4. Have you received any specialized training for working with younger residents? If so, please describe.
5. Do direct care staff at this home receive any specialized training for working with younger residents? If so, how is this training provided?

Care Needs

6. What kinds of care do you think non-senior residents need?
7. Do non-senior residents require different kinds of care than older residents? How do their needs differ from older residents?
8. How are decisions made about the types of care residents need? Who is involved in developing their care plans?
9. Are staff members available to provide care to non-senior residents when needed? What factors get in the way of providing care to non-senior residents when they need it?

Care Relationships

10. How would you describe your relationship with the younger residents? Can you think of 4 or 5 words that sum up your feelings about them?
11. Are there any differences between your relationships with younger residents and older residents? If so, explain.
12. How would you describe your relationship with the family members of non-senior residents? Other paid staff members?
13. Are there any factors that impact the quality of these relationships? If so, what are they?

Residents’ Contributions to Care

14. Do non-senior residents care for others working or living in this long-term care home? If so, how?
15. Are non-senior residents active in managing their own care? If so, how?
16. Do non-senior residents participate in decision-making about the nature and quality of the care they receive? If so, how?

Quality of Care

17. How do you define good care? What factors make it possible to provide good care?
18. Are there any factors that make it difficult to provide good care? Are there any factors that make it easier to provide good care?
19. Are there any factors that influence the quality of care provided to non-senior residents (e.g. staffing levels, training, workload, scheduling, care needs, etc.)?
20. Is there an increase in the number of younger residents living in this home since you have worked here? If so, has this impacted you, other staff members or the quality of care provided? If so, how?

21. Is there an increase in the number of residents that have complex health issues or care needs residing in this long-term care home? If so, has it impacted care provision?
22. Is there an increase or decrease in your workload since you began working here? If so, has this impacted care provision?
23. Are there any other factors that you believe impact the nature and quality of care provided to non-senior residents?

Relations of Difference and Care

24. Have you ever experienced discrimination based on gender, race, age, sexuality, etc. from residents or other people while working in this home? If so, how has this experience impacted you and your job?
25. Is it more difficult or easier to provide care for residents who are male/female? Older /younger? Speak a different language or have a different cultural background than you?
26. Do these differences effect your relationship with the younger residents? If so, how?
27. Are there any other kinds of differences that impact your relationship with the non-senior residents?

The Potential for Change

28. What are the top 3 things you would change about how care is provided at your place of work? What are the top 3 things that you would keep the same about how care is provided at your place of work?
29. What are the top 3 things you would change about how care is provided to non-senior residents? What are the top 3 things that you would keep the same about how care is provided to non-senior residents?
30. Do you think the care practices for younger residents in this long-term care home could be improved? How?
31. Do you think your relationship with younger residents could be improved? How?
32. Is there anything else you would like me to know about your work or about the kind of care non-senior residents receive at your place of work?