

Mount Saint Vincent University
Department of Family Studies and Gerontology

The Role of Family Councils in Long Term Care Facilities in Nova Scotia

by

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ABSTRACT

The Role of Family Councils in Long Term Care Facilities in Nova Scotia

'Family councils' (FCs) composed of family members of people living in long-term care (LTC) facilities are meant to exist throughout Nova Scotia according to current provincial guidelines. Ideally, FCs function as voluntary, democratic and self-organized groups to bring forward the family standpoint regarding how to enhance or improve LTC systems and procedures. They also provide advocacy on behalf of those living in LTC facilities.

Based on a small-scale qualitative study conducted using a critical theory framework and an institutional ethnography (IE) methodology, the primary research aim is to understand how the institutional ruling relations of the LTC system provide the context for the formation, roles and functions of FCs at the facility level. The thesis critically reviews selected disciplinary perspectives on family engagement with LTC systems and describes lived experiences of FC participation in Nova Scotia LTC. It explores intersections and tensions between LTC institutional practices and policies, and the family activities and interests underlying FCs.

The research describes four main phases of family carework in relation to the LTC system. It then describes some characteristics of FCs as well as positive benefits for LTC practices resulting from the work of FCs within LTC facilities in Nova Scotia. Benefits include: sharing information regarding licensing inspections, structure and roles in facilities, LTC policies and regulations, and dementia care; helping facilities achieve LTC accreditation; suggesting improvements to facility handbooks and orientation packages; and improving practical issues such as timing of meals, resident nourishment, laundry, furniture, recreation, communication, and staff identification.

However, the research reveals several underlying tensions in FC-facility dynamics, based on institutional relations in the LTC system. The complexities of the institutional setting at both the province-wide and facility levels provide the context within which FC members seek to have their viewpoints known as well as share their knowledge and insights as family careworkers. Five key disjunctures or tensions in FC-facility institutional relations are noted: attracting and maintaining consistent family participation and motivation; negotiating the balance between ‘personal’ and ‘impersonal’ perspectives on FCs; the role of facility staff on family councils; challenges of ensuring appropriate means for information sharing by and about FCs, as well as negotiating privacy-confidentiality concerns; and how best FC members can provide critical input on both system-wide and facility-based procedures and policies. Description is provided of the interplay and ambiguities of these tensions in the experiences of FC members.

Analysis involves explication of how institutional ruling relations are created and maintained in on-going interactions between FCs and LTC facilities. The conclusion focuses on how to critically assess the extent of ‘embeddedness’ or ‘independence’ of existing and new FCs in relation to the LTC institutional system, combined with gauging whether they have a ‘facility-centric’ and/or ‘family-centric’ ideological orientation. Recommendations are provided to potentially strengthen FC capacities and skills as well as increase respect for the unique standpoint of FC members regarding how to improve both the Nova Scotia LTC system and individual facilities.

DEDICATION

To my parents C. David Gillies (1918-2014) & Mavis Merle Martin Gillies (1925-2006)

To my aunts Norma Martin (1921-2016) & Prudence Martin Bathurst (1923-)

To my husband Nathan Chandler Brett

To my wonderful nieces Anne-Marie Martine Gillies & Julia Daphne Gillies

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Chapter One: Introduction

This thesis, which uses a critical theory framework and an institutional ethnography (IE) methodology, explores the work, role and functions of voluntary, democratic and organized groupings called family councils (FCs). According to recent regulatory directives, FCs are ideally meant to exist in all long term care (LTC) facilities in Nova Scotia. The main purpose of my research is to find out more about how the institutional patterns and structures of the LTC system intersect with the role and functions of FCs, starting from the first-hand experiences of family members involved in them. A secondary and activist purpose of the research is to support and strengthen the role of FCs by highlighting how they can potentially help empower family members to make a constructive contribution to the LTC system in Nova Scotia.

This research situates FCs in Nova Scotia within the context of the voluntary but often unrecognized work performed by the family members (both women and men) of those living in LTC in Nova Scotia. I refer to this labour as ‘family carework’ in this thesis (see Chapter Two for definition of key terms). The IE approach and methodology described in the last part of Chapter One and in Chapter Three were used by me to investigate the institutional ruling relations surrounding families’ roles and work on FCs. In this thesis, I describe some of the power dynamics between FCs and the selected policies, practices and discourses in the institutional setting (Smith, 2002, 2005, 2006).

LTC facilities in Nova Scotia provide health care and personal daily care for the people who live there (usually referred to by service providers and the general public as ‘LTC residents’). LTC facilities are multi-room, publicly subsidized collective housing sites where people with complex health and social needs including various forms of

memory loss live in centrally managed institutional settings.¹ These facilities fall under the jurisdiction of the Nova Scotia Department of Health and Wellness (DHW). Their size varies from around 50 beds to over 200 beds. Some facilities were built in the 1970s while others were constructed as recently as the late 2000s. As of March 2015, there were 136 LTC facilities in the province which housed approximately 7800 residents (Nova Scotia Office of the Auditor General, 2016). The current provincial budget for continuing care (including LTC facility services) is approximately \$868 million (Government of Nova Scotia, 2019b), or roughly 20% of the overall DHW expenditures.

Government funded LTC facilities are operated by a number of different service providers under multi-year contracts with DHW and the Nova Scotia Health Authority (NSHA). Operators include private for-profit companies and community-based non-profit corporations (Nova Scotia Legislature, 2016). LTC facilities function according to various ‘models of care’ related to specialized support for older people. Because they fall under the jurisdiction of the provincial DHW they are organized, managed and assessed according to norms and regulations of the mainstream health system.

My motivation to study gerontology and to research the role of families and FCs in LTC is deeply personal. For a period of five and a half years from early 2009 to late 2014, I was the main family support person for my father David when he lived in three different LTC facilities in Nova Scotia. After going to live in LTC at the age of 91, he required increasing help with bathing, dressing, toileting, moving about and eating. He also became blind and gradually lost his ability to speak very clearly due to neuromuscular degeneration, possibly as the result of a mild form of Parkinson’s disease.

¹ These facilities are also called ‘nursing homes’, and I will use the two terms ‘LTC facilities’ (or simply ‘facilities’) and ‘nursing homes’ to refer to them interchangeably throughout this document.

David was not cognitively impaired although he sometimes got confused, stressed and upset because of his blindness, isolation and lack of mobility. One of the most moving aspects of his stay in LTC, even towards the end of his life, was the effort he made to offer friendship, kindness and understanding to other residents and staff in his facilities.

During this time period, I spent an average of ten to 15 hours a week inside the LTC facility with my father. Besides offering him practical and emotional support when I came to visit him, I sought to advocate for greater sensitivity towards his needs on the part of facility personnel. Many of them were fine people who cared deeply about their work. I attended annual care team meetings and had extensive weekly and sometimes daily discussions with staff at all levels. This involved 'learning the ropes' of the LTC institutional system, which took time, patience and effort. In the last facility David lived in, however, I encountered what I felt was a highly dysfunctional institutional environment. It was an older facility close to my home, with one floor reserved for those with memory loss or extreme frailty. But there was no manager on this floor to discuss issues with, and the organization of the space and staff morale were both poor.

After about two months of observing the situation, I requested a face-to-face interview with the Administrator of the facility to discuss my concerns. I wanted to talk about my father's situation, of course, but I believed that there were systemic issues underlying them that merited closer attention in order to improve the situation for everyone living in or visiting my father's floor. Unfortunately, the upshot of the meeting was that the Administrator told me never to speak to her again about any of my concerns. I was basically ordered out of her office and told by her to direct any complaints I had to the staff on the floor. Unfortunately, those underpaid frontline workers were powerless to

change most procedures and practices followed in the facility. The situation made my father and I feel helpless, exhausted, frustrated, marginalized and disempowered. We had to develop numerous ‘work-arounds’ in the remaining months of his life to maintain his dignity without attracting the attention of facility managers.

These first-hand experiences of being a family member of someone in LTC made me acutely aware of the gap or disjuncture (Smith, 1987, 2005) that seemed to exist between the actual lived experience of, on the one hand, people like my father along with the family members like myself, and, on the other hand, the professional discourses, normative practices, policies, regulations, and frameworks by which LTC facilities operate. Perhaps not surprisingly, by virtue of their institutional standardization, LTC facilities may be viewed by some residents and family members as overly rationalistic, instrumentalist and insensitive given the complex situations surrounding elder care (Rockwell, 2012; Gubrium, 1991). In my own experience, while the LTC system in Nova Scotia purports to encourage family involvement and input, it is a highly regulated and risk-averse environment where individual and collective family voices or perspectives are not treated with the respect or compassion that they deserve.

During the time I was involved in my father’s LTC facilities, I was unable to participate in a FC as none existed in any of the places where he lived. Neither did I come across any information at that time about FCs. When I started my gerontology studies, I was curious to know if, where they did exist, FCs might make a positive difference for family members. I thought that by investigating FCs, I would be able to find a more easily viewed intersection point between the institutional regime of LTC and families. The FC provides another window on how families interact with the institutional system

of LTC, but with its own specialized characteristics and more open for outsiders to view. In my view, FC participation is a unique type of family involvement that has a policy dimension and concrete implications which lend themselves well to critical institutional analysis. It is therefore useful to compare and contrast the family lived experiences of FCs (both positive and negative) with the official frameworks and expert knowledge discourses comprising the institutional structure of the formal LTC system.

Theoretical Framework

Critical theory and critical/feminist gerontology. In order to analyze the complex role of FCs in LTC in Nova Scotia, I chose to use a critical theory framework. Broadly, this paradigm recognizes the importance of social justice values as an underpinning for politically and socially engaged research. This research paradigm promotes progressive social change (Kirby, Greaves & Reid, 2006), so as to develop deeper knowledge about the economic, political and institutional power relationships that exist in society and how they work to create oppressive or inequitable conditions for people enmeshed within those systems (Barton & Bishop, 2014; Kincheloe & McLaren, 2011). A critical theory framework is based on concepts such as: 1) ideological critique and critical questioning of how social categories, professional discourses, and institutional systems are organized; 2) identifying inequitable social, age-related, gender and institutional power relations; 3) analysis of differential access to resources, power, knowledge, policy tools, assets and entitlements, sometimes using a political economy approach; and 4) potential for social activism to advocate for rights-based, human-centric approaches and institutional reform (Brookfield, 2005; Kincheloe & McLaren, 2011).

Within social gerontology, the field of critical gerontology and critical aging studies has been described by its proponents as “blending humanities and social science ideas to challenge the instrumentalism of mainstream gerontology and broader aging studies beyond biomedical models” (Katz, 2003, p. 15). This perspective focuses on ‘unpacking’ the largely unquestioned ideologies and policies linked to neo-liberalism, globalization, gendered and racialized power relations, regulatory frameworks, institutional arrangements, and the health and social services systems that play a role in the lives of aging individuals (Baars et al., 2006; Baars et al., 2013; Katz & Calasanti, 2015).

Feminist perspectives are also closely linked to critical theory and have contributed to critical gerontology, both by providing the analytical tools to uncover unequal gender relations in the aging process and by “holding in tension what is normative and viewing it through the multiple lens of lived experience” (Allen & Walker, 2008, p. 521). Feminist gerontology goes beyond theorizing around gender *per se*, to challenging social exclusion based on age and/or authority hierarchies as well as dominant ideologies around both the family and aging (Allen & Walker, 2008). Estes (2001), for example, proposes a complex multi-level model for linking political economy and feminist critiques of aging to understand the relationships between aging individuals (both men and women) and the social and structural forces at work in society. Feminist gerontology research incorporates principles of empowerment and criticality, allowing alternative or marginalized voices to be heard (Ray & Fine, 2008; Calasanti, 2008). From a critical feminist gerontology research perspective, Neysmith (1995) highlights the need for “meaningful social action” (p. 103). Critical feminist gerontology thus provides

another basis for examining the structural inequities that can be referred to as ‘age relations’ (Calasanti, 2003), and then seeking ways to effect positive social change.

Institutional ethnography. IE’s main concepts and epistemological assumptions are described here. More details about its specific application within the research process are found in Chapter Three.

Dr. Dorothy Smith, a Canadian feminist sociologist who is usually credited as the originator of IE, recommends starting from identifying a ‘problematic’, gap or ‘disjuncture’, in the ‘everyday world’ of lived experience to uncover hidden yet oppressive social and institutional relations in which people are enmeshed (Smith, 1987, 2002, 2005). Smith bases her approach on the selection of a particular ‘social location’ or embodied experience from which to conduct research (that is, ‘starting from where people are’), such as that of women in societies where unequal gender power relations are the norm. The ‘standpoint’ of any marginalized group of people (such as women or the elderly) who are outside mainstream social or institutional discourse “... is a specific location in physical and social reality that provides an opening for developing knowledge about how the social world works” (Sprague, 2005, p. 68). Smith’s ethnographic focus in IE is on revealing how some concrete, material features of institutional mechanisms and settings (which pervade modern life) have remained invisible, unproblematized or unexamined. Mykhalovskiy & McCoy (2002) call this process a “critique of ruling processes that objectify people’s lives” (p. 20). Investigating the power relations that underpin interactions between individuals and complex institutional regimes is therefore central to institutional ethnography, based on the localized experiences of socially marginalized participants within these systems.

In putting forward the concept of standpoint as the starting point for critical social enquiry, Smith does not assume that any grouping of people (such as women or families of those living in LTC) have exactly the same experiences, nor that their understanding or analysis of institutional structures will be identical. Crucial differences of race, class, education, gender identity, ability, and so on imply that marginalized groups will have different experiences that are mediated by these additional intersections. Using a standpoint from which to conduct research is a political move. By starting with the concrete world of peoples' lived experiences as the basis for research (especially those occupying a subordinate or 'bottom' location in any official institutional setting), the IE approach "... provides the opportunity to see the 'line of fault' between official accounts of social life and the everyday experience of most social actors" (Sprague, 2005, p. 74). This fault line (or disjuncture) is analyzed and investigated as the source or location of the research 'problematic' (DeVault & McCoy, 2006; Smith, 2002, 2005). Investigating the problematic thus becomes "a line of enquiry that holds the promise of opening up the ruling regime" (Burstow, 2016, p. 7).

Understanding the concreteness of institutions and institutional relations is a major preoccupation for IE. Smith (2005) refers to institutions as 'complexes' that perform specific societal functions like education or health. Other IE practitioners define them as "processes that stretch across time and place to coordinate people's activities" (Bisaillon, 2012, p. 614). Mykhalovskiy & McCoy (2002), again quoting Smith, characterize an institutional setting as "the multiple activities of individuals, organizations, professional associations, agencies and the discourses they produce and circulate" (p. 19), in order to produce and maintain power relationships. Institutions

function routinely and usually invisibly (to most actors) to deliver services within the welfare state. IE describes and maps “processes of social organization” to reveal the “various social and institutional forces that shape, limit and otherwise organize people’s actual, everyday/night worlds” (Mykhalovskiy & McCoy, 2002, p. 20).

IE focuses on the structural and systemic analysis of unequal power dynamics that are embedded in frequently obscured or obfuscated institutional processes, as uncovered through stories of direct, lived experience and work as well as key policies, discourses, coordinating documents, forms and texts (Campbell, 2006; McCoy, 2006; Smith, 2005). Smith refers to this process as mapping and critically analyzing the ‘institutional relations of ruling’ that are reflected in taken-for-granted practices and discourses (Smith, 2005, 2006). This concept derives from Smith’s assertion that, “in Western industrialized societies, administration, management, and government are accomplished through work processes that rely on distinctively organized ways of knowing those aspects of the world that are to be ruled” (Campbell & Manicom, 1995, p. 9). These accepted ways of knowing are also called ‘discourses’, and they are a common feature of any professional or expert group operating within an institutional complex, such as researchers, administrators, teachers or bureaucrats. Discourses function to ensure that the dominant ideological assumptions of the institution are embedded in how it functions.

IE started with theorizing about women’s oppression and experiences of systemic exclusion. Nonetheless, it can be used in researching any marginal group of people so as to make visible the broader institutional complexes that link together individual sites of work/activity – what Smith refers to as ‘extra-local’ relations of ruling (Smith, 2005). Using IE can help “... make sense of what seems to be irrational in everyday life by

showing how it is the product of power relations that are not immediately visible to social actors” (Sprague, 2005, p. 155). IE provides “... a political ground from which individuals can name their experience of oppression” (Campbell & Manicom, 1995, p. 3) and “analyze a variety of relations of power” (Campbell & Manicom, 1995, p. 5). IE is used by critical and feminist social researchers to reveal the nuances of social and regulatory organization in the fields of health care (Rankin, 2014; Mykhalovskiy, 2008), education (Khayatt, 1995; Smith, 2006), mental health systems and psychiatry (Burstow, 2016), and social/legal services (Pence, 2001; Townsend, 1996; Smith, Mykhalovskiy & Weatherbee, 2006), starting from the standpoint of grassroots actors, clients, participants or beneficiaries in each of these systems.

Based broadly on Smith’s IE approach, the conceptual framework for my research design is depicted in Figure 1 below.

Figure 1. Investigating the Family Standpoint and the Role of Family Councils in Long Term Care

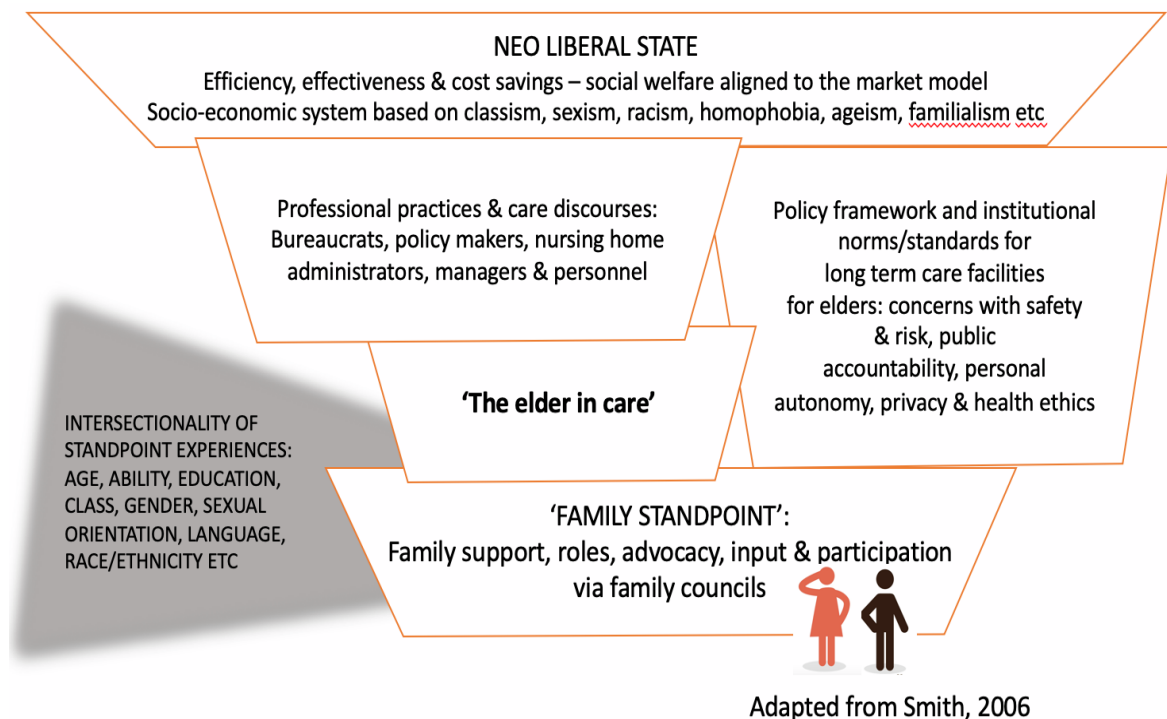


Figure 1 makes reference to the broader structural framework of the neo-liberal state that manages the flow of resources and provides the policy and ideological context for the health and LTC systems. The functions, regulations, practices and discourses found within the LTC system (as depicted in the middle layers of the diagram) are a concrete reflection of these broader neo-liberal forces at work, even if the actors are not consciously aware of this. At the very bottom of this institutional complex, which is arrayed around the LTC resident or 'person in care', the family standpoint is a non-official location that provides the starting point for investigating the institutional ruling relations surrounding FC work.

I chose to use IE as my methodological framework and research approach for two main reasons. First, IE is an activist-infused approach that seeks to reveal frequently unexamined ideological and/or institutional forces that intertwine with peoples' lives -- in this case the situation of family involved in FCs in LTC. Second, like myself, IE researchers are often people who have themselves already experienced the situation that gives rise to a research problematic or gap to investigate. Based on my own experiences as recounted in the first part of this chapter, IE therefore aligned with my desire to undertake values-based and socially engaged research (Kirby, Greaves & Reid, 2006), in order to help advocate for greater awareness of the family standpoint in LTC.

Chapter Two: Background

Definitions of Key Terms and Concepts

I define here several terms and concepts central to my research that I use throughout this document. Other terms and concepts are presented in the theoretical framework in Chapter One as well as the methodology in Chapter Three.

Family. There is no unitary definition of what constitutes a ‘family’ in our current world. I wanted to use as open and inclusive a definition as possible. Accordingly, I like the definition offered by Barken, Daly & Armstrong (2016): “Family includes women and men who are spouses, adult children, relatives who frequently visit [LTC] facilities, those who care from a distance, and unpaid carers who fall outside the traditional definitions of family (e.g., LGBTQ partners, close friends)” (p. 341). Another useful and similar definition, taken from the Accreditation Canada standards guidebook for LTC services (Accreditation Canada, 2017), states that family is any “... person or persons who are related in any way (biologically, legally, or emotionally), including immediate relatives and other individuals in the resident’s support network. Family includes a resident’s extended family, partners, friends, advocates, guardians, and other individuals. The resident defines the makeup of their family and has the right to include or not include family members in their care, and [they can] redefine the makeup of their family over time” (p. 3). A simpler but equally useful definition is that family can be considered as “anyone who is supporting, caring or advocating for a resident” in a care facility where people live (Alberta Covenant Health Network, 2017). All of these definitions go beyond biological affiliations and encompass the fact that family may take many forms that are equally valid to consider.

Family carework. The term ‘family caregiving’ is common in the gerontological literature (Chappell & Funk, 2011). It is usually defined as a form of unpaid socio-emotional support provided by family members for older people, but there are debates about its precise definition and parameters given the many variations of skilled/unskilled, paid/voluntary and emotional/practical labour involved. Rather than use this term in my own research, I chose to adopt a more explicit labeling of family’s unpaid and voluntary contributions (including FC involvement) as a form of work. Mykhalovskiy (2008), for example, refers to tasks undertaken by HIV positive individuals in dealing with the biomedical system as ‘healthwork’. This term highlights the time-consuming unpaid personal labour involved in learning about and interacting with these institutional arrangements in the course of accessing health care services. Smith and others using IE contend that work encompasses a wide range of both productive (paid/formal) and reproductive (unpaid/informal) activities undertaken by participants in the research (DeVault & McCoy, 2006). Family labour is voluntary, complex, many faceted, based on diverse socio-emotional obligations, and largely taken-for-granted in most analyses of the LTC system (Barken, Daly & Armstrong, 2016). As already noted in Chapter One, I have accordingly adopted the term ‘family carework’ to denote any formal or informal task, activity, skill, involvement, contribution and/or interaction with LTC service providers and the LTC system that family members perform as part of their commitment to their elderly relatives both outside and within LTC facilities. Family carework thus includes the labour of understanding how the LTC system works, and then learning how to adapt and negotiate. In this research, I consider FC participation as a type of family carework in LTC (as will be described more fully in Chapter Four).

Family council. A FC can be defined as “an independent, self-determining group of [nursing home] residents’ families and friends” (Curry, Walker, Hogstel & Walker, 2007, p. 245). Another simple, common definition is as follows: “A family council is an organized, self-led, self-determining, democratic group composed of family and friends of the residents of long-term care homes” (Family Councils Ontario, 2016, p. 11). One LTC advocacy group provides a more general definition as follows: “A family council is a group of individuals who are the contact person, representative or relatives of care facility residents, and who meet regularly for a common purpose related to the care facility” (British Columbia Office of the Seniors Advocate, 2017). The definitions and underlying descriptions offered by many advocacy groups emphasize the *independence* of FCs, that is, their ability to function without undue interference from formal structures in order to provide a space for non-institutional perspectives, concerns and voices. As will be discussed later in Chapter Two, the educational, support, advisory and advocacy roles of FCs are quite diverse and often open to interpretation. FCs are intended to be completely different entities than either family support groups offering specialized emotional counselling, or family, patient and/or community advisory committees formed by health institutions to provide consumer or patient input on service quality and delivery mechanisms (West & Brown, n.d.). In some institutional settings, however, the literature shows that these entities are occasionally confused or conflated with FCs. It is also important to note that FCs are quite distinct from resident councils, although in many jurisdictions including Nova Scotia the two types of councils are encouraged to function as joint or linked entities where it may be appropriate.²

² For a variety of practical, strategic and policy reasons, resident councils and family councils are frequently closely intertwined in practice. For example, recent research by the Change Foundation (2017)

Use of institutional terms. Due to its theoretical and practical orientation to uncover what is largely invisible and uninterrogated within institutional settings, IE critically examines the taken-for-granted use of standardized and objectifying institutional terminology. Such terminology arises from (and reinforces) various discourses which, as noted in Chapter One, are embedded in formal systems of expert or professional knowledge. Objectifying discourses and standardizing terminology are a common feature of any institutional complex, and they usually permeate the daily language and interactions of those who manage, administer, work within or otherwise support this system (Bisaillon, 2012; McCoy, 2006). Discourses underpin and shape the ways in which people communicate with each other and/or organize information and they are ideologically based and often reinforce institutional power relations. People within institutions master the discourses and use them to construct and maintain institutional ruling relations (Smith, 1987, 2005).

As an institutional system, LTC is permeated with a large number of discourses and related jargon. Because this terminology is so convenient, it is common in LTC to find many people using or seeking to acquire it over time. Some examples of normally unquestioned institutional terms encountered in LTC discourses include (in no particular order): elder/elderly; frail/frailty; practitioner/service provider; special needs; responsive behaviours; dementia/Alzheimer's; memory/identity; social support/stimulation; care/service delivery; physical needs; care needs; personal care; physical therapy; memory care; social/recreational activities; care model; philosophy of care; care team; care assessment; plan of care; care quality; quality of life; person-centred, resident-

in Ontario emphasizes the need to foster close linkages and synergy between resident and family councils. However, resident councils are not the focus of my research.

centred, and/or client-centred care; and so on. Many common terms that I use throughout this document such as resident, elder, family, family council and family involvement could be critiqued or unpacked as part of and/or arising from institutional discourses. This partial list (which could likely be expanded indefinitely) provides some indication of the challenge of unpacking the institutional discourses that structure the social interactions of the participants in LTC settings. IE researchers such as Bisailon (2012), Burstow (2016) and McCoy (2006) also note the risks or challenges of ‘institutional capture’, which is when researchers themselves (and those whose standpoint is the basis for the research problematic) use institutional language uncritically themselves in describing what they encounter or experience. These terms can co-opt the researcher and/or participants into thinking from within the institutional standpoint. As we shall see in Chapter Four, however, the acquisition of discourses and key terminology can provide strategic ways for some FC members to build alliances and find a sense of place within institutional settings that they are trying to master or learn.

In IE research, each institutional term would ideally need to be carefully unpacked, critically defined and then deconstructed as part of the process of institutional analysis. To highlight the constructed nature of terms or discourses that form part of the institutional regime, these words or phrases can also be placed within quotation marks. In my own research, I take a somewhat pragmatic approach. I find that many institutional terms are unavoidable due to ease of use and difficulty of finding an alternative, so they are integrated within the research write-up – for example, use of common terms such as ‘culture change’ or ‘LTC facility’. Throughout, I consciously try to avoid using some institutional terms (or to use them selectively or in quotes) because they reinforce the

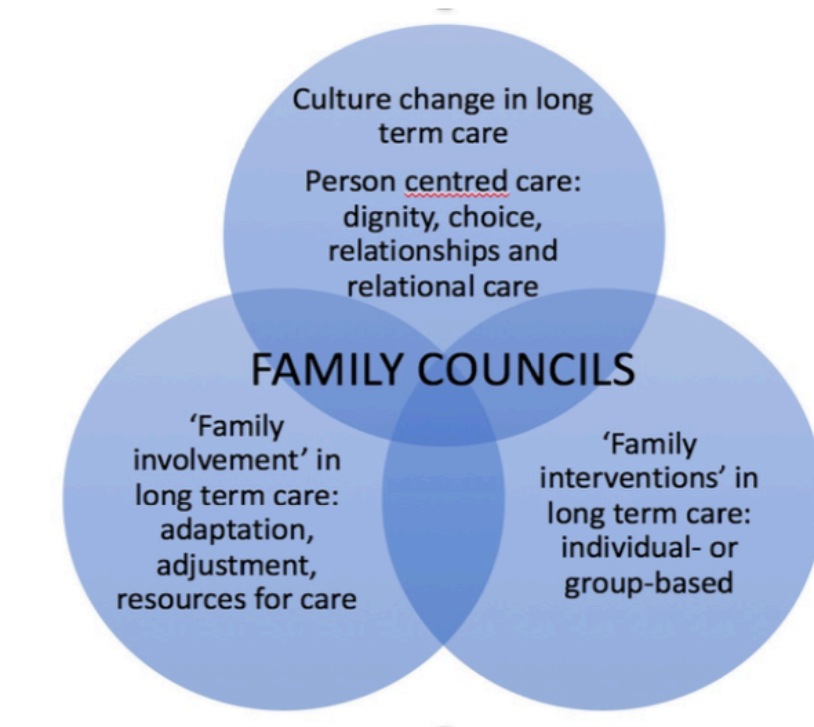
dominant institutional discourse of LTC. Readers are invited and encouraged to flag for themselves any institutional terms that have crept into this document and which may unwittingly sustain institutional ruling relations in how they are presented.

Literature Review

Similar to many forms of feminist and emergent research, the literature review is a dynamic on-going process that evolves in parallel with the research itself (Hesse-Biber, 2014; Kirby, Greaves & Reid, 2006). The aim of the IE background literature review is not necessarily to identify the gaps in existing formal academic knowledge to be filled via research (Campbell & Gregor, 2008). It is used to identify institutional discourses and patterns or themes in institutional and professional or disciplinary thought underlying the specific problematic under investigation by the researcher (McCoy, 2006).

To contextualize my FC research, I focus on three interlinked areas of knowledge about the role of families and their involvement with FCs in LTC. The three areas are depicted in Figure 2, as follows: 1) the culture change movement in LTC which has the aim of transforming or reforming LTC systems and approaches through (among other things) strengthening the relational and non-medical dimensions of care; 2) the practice-oriented research surrounding family involvement and interventions which focuses on finding appropriate ways to foster cooperative relationships between facilities or care providers and family members; and 3) the policies and regulatory frameworks and tools related to the creation, role and functions of FCs in selected jurisdictions. Both formal published research and grey literature are included in this review.

Figure 2. Interlinked Areas of Background Knowledge About Family Councils



Culture change. The culture change movement arose during the 1990s in the United States to reform and improve the quality of life and care in LTC facilities. The antecedents of this movement as well as the philosophy and practices that flow from it are well documented (Baker, 2007; Koren, 2010; Brune, 2011; Fagan, 2003; Pioneer Network, 2017).

Culture change covers a wide variety of approaches and practices which have in common the desire to create new structures and systems in LTC facilities and thereby transform care processes and values (Weiner & Ronch, 2003, 2014). These approaches propose changes in the institutional systems that deliver care, away from hospital-like procedures and norms driven by health professionals and paid caregivers, towards more humane, social, and relationship-oriented processes that engage elders and paid, professional caregivers in mutually nurturing care partnerships (Grabowski et al., 2014;

Rahman & Schnelle, 2008; Zimmerman, Shier & Saliba, 2014). Various alternative care models such as Eden, Greenhouse, Live Oak and others are allied with the culture change movement (Thomas, 1996). Priority in these facilities is placed on elder choice, autonomy and decision making rather than bureaucratic convenience and high task orientation found in traditional care institutions (Jurkowski, 2013; White-Chu et al., 2009).

The literature on and discourse around culture change in LTC is linked to the concept of person-centred care, as well as the parallel emerging concept of relational care (Rockwell, 2012). These concepts incorporate a strong community oriented and humanistic approach that appears to take the focus away from the institution as the centre of the elder care process. A person-centred approach to elder care involves a multi-faceted perspective that prioritizes autonomy, dignity and self-worth for elders in care, as well as broader professional, organizational and leadership dimensions of change (Corazzini et al., 2015; Jones, 2011). It proposes that the individual identities and psychosocial needs of people with memory loss or other life or health challenges must be recognized along with the importance of linkages to community and family structures both within and outside care facilities. At the heart of culture change and related approaches to person-centred care are several core principles: the formation of strong multi-dimensional care partnerships including recognizing the role played by family and friend caregivers; the importance of emotional connectedness between elders and caregivers; and the restructuring of top-down institutional control (as is the norm in the health sector and the LTC system) towards more flexibility and choice (Kitwood, 1997; Kitwood & Bredin, 1992).

In spite of over two decades of culture change research and on-going implementation, the reflexive, educational and policy-based aspects of this approach continue to present challenges to professionals, administrators, policy makers and the nursing home sector overall (Misiorski & Kahn, 2005; Shield et al., 2014; Rockwell, 2012). The process of nursing home culture change and implementation of person-centred (sometimes also referred to as person-directed care) is complex, non-linear and ongoing. It requires extensive continuing education and training at all levels to create incentives, break down negative attitudes and overcome policy barriers. Terminology is also confusing, as various concepts such as personhood must be unpacked. Various interchangeable labels are used including client-centred, consumer-centred, resident-centred and/or family-centred care, but with slightly different implications for those involved. Hierarchical professional and institutional decision-making and management structures must at times be dismantled, which involves intensive reprogramming of entrenched systems (Weiner & Ronch, 2014). There are also cost, accountability and time implications to instituting culture change.

In addition, some critical gerontologists argue that culture change and person-centred care can be co-opted without true structural transformation of the underlying market-oriented and depersonalizing forces found in bureaucratic, neo-liberal health systems (Dannefer & Lin, 2013). Although the consensus is that extensive progress has been made in introducing culture change, researchers continue to suggest that more investigation of organizational barriers is required in order to make culture change a reality (Rahman & Schnelle, 2008; Shier et al., 2014; Williams et al., 2015).

There is less written directly about Canadian experiences with nursing home culture change and the promotion and implementation of person-centred care in Canada. What exists appears to corroborate that many Canadian jurisdictions and facilities are seeking ways to reform and improve elder care facilities along person-centred lines, as this is now the accepted international discourse for progressive LTC (Banerjee & Armstrong, 2015; Baines & Armstrong, 2015; Armstrong & Braedley, 2016; Keefe, Kelloway, McInnis, Earl, Stadnyk & Rak, 2015). The Canadian emphasis on improving quality in long term care appears to derive from the culture change movement, although the linkages are not always stated explicitly (Canadian Healthcare Association, 2009; Canadian Association for Long Term Care, 2017). Similar to U.S. experiences, there have been some challenges in Canada with implementing alternative approaches in LTC due to the gaps between rhetoric and reality at the facility level (Donnelly & MacEntee, 2016). These gaps arise from structural impediments and power/knowledge imbalances within the LTC sector. These include tensions between institutional policies and norms and the perspectives of professional caregivers on the one hand, and the insights of those who are care recipients and their allies on the other (Armstrong, 2018; Rockwell, 2012).

Various references to family engagement and inclusion are found throughout the culture change literature. The Pioneer Network (2017), for example, places emphasis on ‘family care partnerships’ in its research and advocacy work. The culture change movement posits that family relationships (for the most part) can provide elders in LTC facilities with strong social value in terms of their quality of life, via emotional continuity and stability, additional socio-emotional support, and a sense of connectedness that will enhance dignity, memory, identity and a sense of belonging. This is especially true in the

case of dementia care (Woods, Keady & Seddon, 2008; Morhardt & Spira, 2013), but the same principles can be extended more broadly to all LTC facility settings.

Family engagement and interventions. In parallel with the culture change movement, there is a cluster of closely related research dealing with family involvement (or engagement) and family interventions in LTC. Two key disciplines with a strong interest in improving the scope and quality of family involvement in LTC are nursing and social work, with the latter most concerned about family intervention strategies. For example, Naleppa (1997) highlights key themes from the social work perspective, such as family stress due to the placement of elders in long term care, difficulties for families in the transition process to an institutional setting, and the extent and importance of continued family involvement after placement. Naleppa's work also notes the lack of clarity regarding whether families should be viewed as clients or resources in the LTC system, leading to role ambiguity for family members at the level of facility interactions.

Gaugler's work on family involvement in the mid-2000s focuses to a large extent on understanding and improving interpersonal communication issues between families and professional/paid care providers in facilities from the perspective of social work (2005a, 2005b). Gaugler confirms through empirical research the high level of family involvement in nursing homes, and he provides a useful conceptual model for understanding family involvement from the social worker perspective. His work also notes that the diversity of family relationships, structures and experiences must be taken into account when discussing and analyzing family involvement.

To help fill perceived empirical research gaps and hopefully encourage family involvement in LTC, Gaugler, Anderson & Leach (2005) combine social gerontology,

social work and behavioural studies to conduct an in-depth study of predictors of family involvement in LTC facilities. In the field of social work, Ruess, Dupuis & Whitfield (2005) describe the personal and interpersonal experiences of family members who move a close relative to LTC. They note the possibility for various communication and knowledge sharing strategies to overcome family transition stresses at an individualized level. Other studies by social workers confirm the existence of staff-family tensions and the need for improvement in communications, as well as suggesting that both institutions and social workers need to better prepare families for appropriate roles, such as regular participation in care team meetings, within LTC facilities (Zimmerman et al., 2013). Gladstone, Dupuis & Wexler (2006) study changes in family involvement after the move to a nursing home and conclude that facilities need to be aware of factors that influence family involvement including family-oriented institutional policies.

Social workers with an interest in gerontology have proposed a methodology to assist families throughout the LTC placement process via family education and interpersonal support groups (Peak, 2000). Similarly, Pillemar et al. (1998) proposes a program to reduce staff-family conflict and improve interpersonal as well as formal communication methods. This program uses a series of self-reflexive educational workshops facilitated by social workers to encourage joint exploration among families and staff regarding how to restructure interactions. In some cases, these initiatives led to the formation of FCs and enhanced consultation processes. Similar approaches to family and staff co-engagement facilitated by social workers in LTC are described in Wells, Singer & Polgar (1992) and in LaBrake (1995).

These techniques for enhancing family involvement in LTC settings have been evaluated and replicated since the 1990s (Pillemar et al., 2003; Robison et al., 2007). Strong support from facility administration at the planning stages is deemed crucial for these initiatives, as well as funding for staff positions for social workers who could be involved with family liaison. Both Pillemar et al. (1998) and Peak (2000) note that while educational workshops for both staff and families to talk about their respective roles, model positive interpersonal behaviours, and improve communications skills can be very successful, such techniques and interventions are also time consuming and costly. This might be a problem when facilities either do not have any social workers on staff due to lack of funding for these positions, or when social workers are engaged elsewhere so that they cannot be spared to do family-based work.

Key issues for nursing personnel working in LTC include challenges with low visibility and weak professional acceptance of families, mainly due to lack of organizational enabling policies and conflicting attitudes about the family role (Bambusch & Phinney, 2014). Janzen (2001) highlights the organizational context and the enabling environment for family involvement, including the need for nursing homes to promote a broad pro-family philosophy. She notes that families have a potential role to play in critically monitoring the quality of care, and that communication can be improved by facilities having a designated contact person for family members. Other nursing studies note specific challenges with communication between nursing staff and families during family adjustment to the nursing home context, as well as the need for better understanding of the family perspective on the part of facility staff and care professionals (Davies & Nolan, 2006; Ryan & Scullion, 2000; Friedemann et al., 1997). An

ethnographic nursing study by Marquis, Freegard & Hoogland (2004) identified factors in the LTC context that enabled families to stay involved in facilities, most notably improved communication techniques on the part of professional staff and administrators.

Research on family involvement also incorporates perspectives from management studies, organizational development, political economy, and social gerontology. These reveal similar themes as the social work and nursing articles but with somewhat more emphasis on the institutional enabling factors and context. Barken & Lowndes (2017) stress the importance of family involvement in terms of emerging concepts of relational care, but also the need to focus on communication skills, teamwork, and organizational policies to create meaningful rather than token family involvement. In an earlier study, Keefe & Fancey (2000) identify both indirect advocacy or oversight roles and direct emotional or physical care roles for families in long term care, but they also highlight the complexity and changing dynamics of involvement. Majerovitz, Mollott & Rudder (2009) describe barriers to nursing home-family communication and how to enhance communication among staff and family to ensure flow of information. From a management studies perspective, Hamann (2014) explores the direct linkages between family empowerment strategies and higher service quality rankings at LTC institutions. Hamann notes the reluctance of some administrators and paid caregivers to actively integrate family input regarding organizational policies and care models, as well as noting how the exclusion of family involvement undermines LTC quality.

Family councils. In the United States, FCs are supported and promoted as a key form of family intervention in LTC by both national advocacy bodies and by independent research and professional groups influenced by culture change. Two key national US

advocacy programs (the National Consumer Voice for Quality Long Term Care and the National Long Term Care Ombudsman Program) both lobby for the quality and accountability of services in LTC by promoting FCs and offering networks, linkages and support to them. On-going culture change initiatives in LTC, combined with a focus on consumer rights within the sector, have led to policy and/or regulatory frameworks both federally and in many states regarding FCs. For example, the federal Resident Bill of Rights mandates that local facilities funded under Medicare or Medicaid must allow space for families to meet and advertise that families have the right to form a council to make their views known (Persson, 2008; Mandrich, 2000; Anderson, 2004). This can lead to the formation of independent FCs that may sometimes be combined with resident councils. Under the legislation, service providers are required to respond in a timely and satisfactory fashion to the issues raised by FCs. State surveyors carrying out audits of facilities must respect the role of FCs and are encouraged to solicit their input during the inspection process of individual facilities.

There has been little formal study of FCs *per se*, aside from three oft-cited review and summary articles by Anderson (2004), Curry, Hogstel, & Walker (2007) and Persson (2008). In general, researchers and culture change advocates outline four main goals for FCs: 1) ensuring quality of life for residents by giving input about how to improve services; 2) helping input on policy decisions related to resident care; 3) resolving problems encountered between family members and the facility; and 4) providing emotional and strategic support to members, families, and new residents. Other roles mentioned for FCs include policy advocacy, education among family members, and

collective empowerment of families to have a voice in facility or care improvement, as well as orientation of new families to facilities.

Persson (2008) notes that as of the early 2000s fewer than 50% of US nursing homes had FCs, possibly due to low 'family orientation' of many facilities not yet touched deeply by culture change. Several different models for FCs are noted in the existing studies and grey literature, such as councils initiated and overseen by the facility via a liaison person, advisor or social worker, as well as those that function completely independently and only call on facility resource people as needed. However, the pros and cons or implications of different models are not discussed in depth. In general, key barriers for FCs are identified as lack of facility support, attempts to control FCs by facilities, lack of family participation and leadership, poor meeting dynamics, and weak governance structures, leading to family discouragement and high turnover (or limited participation) in FC meetings.

Curry, Walker, Hogstel & Walker (2007) report on a small-scale qualitative study to determine the characteristics and effects of FCs in LTC facilities in the US, which shows some positive culture change outcomes related to improved quality of resident care as a result of FC work. The research emphasizes the need for families to have a voice in facilities in order to combat powerlessness and frustration, as well as undertake different levels of advocacy. Suggested advocacy topics range from dealing with common issues around day-to-day care practices for elders such as timing of bathing and meals, to lobbying for potential legislative change that influence the sector as a whole. Similarly, Anderson (2004) reports from a review of the current research and the practice-oriented knowledge base in social work and gerontology that the effectiveness of FCs depends on

several factors, such as active family participation, strong governance structures, consistent leadership, constructive approaches, and high levels of support and cooperation from the facility. Aasve (2007) outlines the perspective of the private nursing home industry by emphasizing how the existence of FCs have the potential to improve competitiveness and market share in the highly commercialized LTC sector in the US. Reflecting a neo-liberal and market-oriented perspective, Aasve argues that facilities with FCs will be more likely to attract ‘consumers’ (i.e. residents) due to their perceived openness to social aspects of care, including encouraging families to play an active role.

Canadian context for family councils. In Canada, the Canada Health Act provides federal funding for health which includes provision of facility based LTC, but policies and service delivery models are organized at the provincial level. In line with LTC culture change values and principles, a 2009 Canadian Healthcare Association national report notes the need for respect for volunteers and families as well as positive engagement of families in LTC facilities as key aspects of quality care (Canadian Healthcare Association, 2009). As well, many LTC facilities across Canada are now encouraged or required by provincial ministries to become affiliated with Accreditation Canada quality standards on LTC (Accreditation Canada, 2017), which derive from efforts to reform or improve care standards according to culture change tenets. While they do not mention FCs specifically, these accreditation standards emphasize strongly the family role at the facility level, both in individual care planning as well as broader policy input and quality monitoring of care – although it is partly up to the discretion of facility operators as to how best to ensure family input.

Currently, many activities related specifically to espousing and strengthening FCs have taken place in three of Canada's wealthier and larger provinces: British Columbia, Alberta and Ontario. In these provinces, non-profit research and advocacy groups and government agencies are actively involved (often in close partnership) in promoting and assisting FCs to play a role in the LTC sector, whether via legislative directives or practical guidance (Government of Alberta, 2018). This is mainly due to the recognition that many older, infirm residents in LTC can no longer speak up for themselves, and/or that they may lack the individualized support of family members and therefore require collective advocacy from an organized body such as a FC (Change Foundation, 2017). The key activities and resources concerning FCs in each of these provinces is summarized briefly in Appendix A (as of mid 2018), outlining some of the differences and similarities in approaches.

Family councils in Nova Scotia. In Nova Scotia, the provision of LTC services is governed by the Homes for Special Care Act (Government of Nova Scotia, 1989). This act is generally acknowledged to be outdated -- for example, an in-depth study of LTC by the Nova Scotia Nurses Union (Curry, 2015) and the Minister's Expert Advisory Panel on Long Term Care (2019) both recommend the need to reform the act.

During the mid 2000s, under the previous Conservative and NDP governments, the Nova Scotia DHW started to modernize its approach to LTC at the same time that it was funding the building of improved facilities. In accordance with LTC culture change trends, this modernization focus included encouraging more homelike and community-oriented environments in newly built nursing homes, a greater focus on resident choice, and introduction of practices to monitor care quality. The Nova Scotia Continuing Care

Strategy (Government of Nova Scotia, 2006) which is under the jurisdiction of DHW highlights the need to have a “high-quality, client-centred” care system (p. 4), based on “client-tailored care plans” (p. 9). Principles and policies related to continuing care in Nova Scotia are still undergoing a review process at the present time (Government of Nova Scotia, 2015a, 2015b), as the 2010 Continuing Care Strategy is now out of date. The assumption is that renewed frameworks and strategies will continue to reinforce progressive trends in LTC. Recent government audit reports (Nova Scotia Office of the Auditor General, 2016) as well as the recommendations of the Minister’s Special Advisory Panel on Long Term Care (2019) highlight the need for urgent administrative, quality oversight, staffing and technical improvements in the LTC sector in Nova Scotia, given the widespread public perception that the services and resources available are lagging behind the growth in elder care needs (The Chronicle Herald, 2013, 2016).

To provide guidance and oversight for new nursing homes being built in the late 2000s, in 2007 the Nova Scotia DHW produced a Long-Term Care Facility Program Requirements handbook that provides a detailed list of minimum standards for care to be adhered to in these facilities (Government of Nova Scotia, 2007). For the first time in the province, the requirements stated explicitly that nursing homes be resident- and family-focused, meaning that residents and families should be treated as partners in the care process, and stated clearly that consultation was needed to ensure their views are considered. FCs were specifically mentioned and defined in the 2007 document as “... a forum for families to have a voice in decisions that affect them and their loved ones and to improve the quality of residents’ lives” (Government of Nova Scotia, 2007, p. 8). Section 7.2.2 mainly emphasized the role of resident councils, but facility operators were

also required to have a FC in new facilities. Annual family engagement or satisfaction surveys as well as circulation of notes or minutes from the FC were other requirements.

The LTC Program Requirements were updated in 2016 and again in early 2019. As of 2016, application of these standards was extended to all existing nursing homes in the province (Government of Nova Scotia, 2016, 2019), not only to nursing homes built in the late 2000s. In recent versions of the LTC program requirements, no changes are made to the 2007 definition of FCs, but the topic is split off from resident councils and provided with its own new Section 7.3. This section expands on the roles and responsibilities of family councils to some extent and specifies a few more details about the requirements of nursing homes in relation to them. The overall requirement is that family councils "... are provided with regular opportunities to meet with management to discuss issues related to the care and well-being of residents and the safety and security of the home" (Government of Nova Scotia, 2019, p. 25).

Due to their inclusion in the LTC Program Requirements, the existence of a functioning FC currently is one of the minimum acceptable standards to be applied by DHW during regular licensing inspections of Nova Scotia nursing homes. However, licensing inspection reports by DHW for nursing homes are not available to the public at the present time without a special request under the province's Freedom of Information Act (The Chronicle Herald, 2016). The government currently posts some data obtained from the LTC inspection process on publicly accessible DHW websites, but it does not yet systematically cover all LTC facilities nor all components of the licensing process. Some facilities (at their own initiative) apparently post some or all of the results of their licensing inspection reports on their websites, but this is not an official requirement.

Unfortunately, these information gaps mean that there is currently no easy way of finding out how many FCs exist in the province or how well they function. Unlike other jurisdictions in Canada, such as British Columbia, the DHW has no guidance on its website about FCs and their functions and governance structure. Neither is there any public or non-profit group in Nova Scotia dedicated to supporting and networking with FCs as there is in some other provinces. The implications of these apparent gaps or inconsistencies for the institutional relations surrounding FC work in LTC will be discussed in Chapter Four.

Summary of Background Ideas

The preceding scan of the family role in LTC plus the ideas surrounding FCs is certainly not intended to be exhaustive, but it provides a snapshot of how FCs as both a concept and a concrete intervention are situated within various disciplinary and policy backgrounds. The culture change literature as well as research on family engagement in LTC seems to indicate that, in theory at least, the role of the family in LTC is viewed quite positively by service providers and healthcare professionals. Research confirms that there has been a strong impetus to involve families over the past two decades, both as underutilized or underappreciated care resources in LTC facilities and as a psycho-emotional support for LTC residents.

However, the literature also reveals that miscommunications, misperceptions and misunderstandings between facilities and families are common, and that there are some gaps between theories of family involvement and concrete implementation. There are clearly some tensions and ambiguities between the desire to adapt families to the requirements of institutional systems and professional care protocols, and the ability or

desire of families to form independent groups dedicated to advocacy, empowerment and critical consciousness about the situation of elders in care who sometimes cannot speak for themselves. Families are sometimes still viewed from various professional and disciplinary perspective as additions (or even impediments) to individualized elder care and there is some ambivalence about family roles even as research and practice shows their central importance in care. Families are framed as valuable or useful in many studies when they participate efficiently and effectively in helping adjust their relatives to an institutional care regime and/or offer assistance and reinforcement to the formal system. Also, many reports about what promotes or encourages family involvement in LTC are mainly from the institutional or health professional perspective, rather than from the standpoint of families themselves. Arrangements that promote the visibility and critical input of families still must be negotiated with those within the formal LTC system. Therefore, while in theory some degree of independent family activism and advocacy is considered desirable, the background information shows that there remains a tendency for LTC institutions to maintain well intentioned control over families. What might be some sources of this disjuncture?

First, in most jurisdictions, LTC (even when influenced by culture change principles and values) is situated as a part of the health care system and/or a health care delivery approach. Complex health institutions like LTC facilities are hierarchically structured, in spite of best intentions for client-centred care. They are part of a larger institutional construct which is administered within a hierarchy of accountability and a professional knowledge base arising from instrumentalist and rationalist health management principles. These tendencies may be in direct contradiction to the more

diffuse role and aims of family in these settings (Gubrium, 1991; Barken, Daly & Armstrong, 2016). Within this institutional construct, for many health professionals and facility administrators, person-centred care implies an ethical, professional, regulatory and legal obligation to put the needs of the resident or patient first (Blustein, 2004). This obligation can mitigate against health professionals listening seriously to family perspectives or taking the time to engage with family members. As we have seen, health-related professional discourses sometimes position families as ancillary or oppositional to the needs of LTC institutions and their direct ‘clients’.

Second, the degree to which differing ideological systems within LTC influence the family role need to be taken into account. For example, Levine (2003) and Levine & Murray (2004) note that ‘family culture’ exists in complex and nuanced ways that are hard to reconcile with the large-scale institutional management systems under which much of LTC care still operates. In spite of efforts around culture change, the highly structured, task-driven environment of LTC, combined with paid care worker stress and burden, means that families are sometimes perceived as trouble or interlopers to staff within LTC facilities (Foner, 1995; Diamond, 1996; Barken, Daly & Armstrong, 2016).

Third, the strong emphasis on *individual* choice and values in the culture change movement means that, according to some advocates, elders do not necessarily need family involvement to be well looked after, once these institutional norms and values are put into effect by professional and paid caregivers. The priority is still on the institutional perspective and on continued (albeit well-intentioned and enlightened) institutional control of care, in spite of culture change philosophies and practices.

All these competing factors obviously present challenges for families seeking space for involvement in LTC, especially if they wish to undertake independent, critical advocacy around making improvements in how care of residents is planned, managed and delivered. Professionals within LTC facilities may prefer to have families play a largely passive role. This professional perspective mitigates against families taking critical or activist roles in some cases. As well, formal care facilities continue to render invisible the complex caring labour of family members, especially women, as they interact with the LTC system (Barken, Daly & Armstrong, 2016). According to Hamann (2012) and Barken & Lowndes (2017), negative administrative attitudes means that the policies and structures for full respect of family contributions to LTC are frequently still lacking.

Not surprisingly, this brief overview of the U.S. and Canadian contexts indicates that there is considerable diversity in how the role, identity, structure, priorities, activities and scope of FCs are conceptualized. FCs are frequently presented as potential sites of education, community development, networking, peer counselling, social support, family cohesion, fundraising, advocacy, and monitoring or oversight functions. In theory at least, it is recognized that FCs can potentially help provide a collective voice for families that adds considerable value to the LTC system. In practice, however, as will be described in Chapter Four, this intent may be challenging to realize in practice in the current context of Nova Scotia LTC due to the institutional relations surrounding the role of FCs in LTC.

Chapter Three: Methodology

Adaptation and Challenges of the IE Approach

The condensed or modified type of IE used in this research is similar to the approach described in studies by Khayatt (1995) and by Hande, Taylor & Zorn (2016). I relied heavily on Campbell & Gregor's (2008) simplified approach for use of IE by M.A. students, as well as work by Bisailon (2012) and Bisailon & Rankin (2012) which defines key terms and procedures used in IE plus lays out the steps and challenges found in some recent IE research. In addition, I referred to Smith's (2002) description of the IE research project she carried out in Toronto schools during the 1980s which used a small number of intensive qualitative interviews with selected standpoint participants. Methods used in IE are similar to those used in feminist ethnography, activist ethnography, critical ethnography and rapid site-switching ethnography (Baumbusch, 2011; Bisailon, 2012; Armstrong & Lowndes, 2018; Hesse-Biber, 2012).

The trajectory for planning the use of IE is, in practice, adaptive, iterative and exploratory, and this was indeed the case in my own research. IE is closely related to many other forms of feminist alternative research as well as socially grounded, politically oriented, experiential, and critical qualitative social research, in that it necessitates organizing the research process in a somewhat exploratory and emergent way, from conception to writing (Janesick, 1994; Lincoln & Guba, 1985; Kirby, Greaves & Reid, 2006). Some descriptions of how to implement IE are usually somewhat sketchy, so that it is necessary for the neophyte researcher to learn-by-doing and to adapt to the research context, which involves a combination of reading, thinking and trial-by-error. My IE

research process therefore reflects the provisional nature of how this research unfolded via adaptations over the period of several months.

In its basic form, IE involves use of research techniques such as listening deeply and looking carefully via interviews and participant observation. In early versions of IE, for example, Smith (2002) did not rely heavily on textual analysis but on primary data collection from standpoint participants. Interviews can help reveal the regulatory or discursive features of institutional relations surrounding the experiences recounted by participants. Common approaches to IE (similar to what I applied in my own research) include in-depth immersion in an institutional location, site or topic, personalized connection to the problematic, and slow research techniques such as long unstructured interviews and dialogical co-discovery with participants (DeVault & Gross, 2012; DeVault & McCoy, 2006; Smith, 2002).

Overall, the research and analysis process involved a steep learning curve for me due to the adaptive nature of IE as well as the normal constraints of time and energy facing an M.A. thesis. In my own research, I ultimately decided not to use participant observation both because of the time that it involves as well as the potential difficulties of getting ethical approval for this type of in-depth data collection. In larger IE research initiatives, the process sometimes involves a long timeframe, teams of researchers, and multiple periods of participant observations and textual investigation within institutional settings as well as iterative layers of interviews with up to 30 or 40 standpoint participants. The application of all these approaches was obviously outside the scope of what I could do.

Research Design

Research problematic. As described in Chapter One, IE research does not start with a formal research question that provides a hypothesis to prove or disprove. It begins by defining a problematic as a starting point to help uncover concrete lived experience. These then allow the researcher to describe and analyze the institutional structures/relationships from the standpoint of those involved in these experiences (DeVault & McCoy, 2006). A problematic can arise from the personal experience of the researcher, or from initial investigation with standpoint participants to identify their disjunctures, or a combination of both. In IE, the initial problematic is not fixed, as the investigation and the analysis may change the focus of the research towards different aspects of institutional relations as the process unfolds.

In my own case, as described briefly in Chapter One, I initially experienced a disjuncture based on my personal experiences as a family member of someone in LTC. I then defined a broad problematic as a starting point, namely: *Based on the standpoint of family members who are already involved in or are seeking to create family councils, what features in the institutional environment for LTC in Nova Scotia (both within facilities and in the broader policy context) come into play surrounding the formation, role and functions of family councils?* During the research, other disjunctures arising from the family members' own FC experiences emerged as I went along, and they form the basis for the detailed findings and analysis found in Chapters Four and Five.

Research participants. IE researchers do not attempt to construct samples (DeVault & McCoy, 2006) as in standard social science research, because they are not seeking to obtain a representative cross-section of individual views or experiences that

are generalizable in the conventional sense. The focus is on using selected individual interviews as entry points for analyzing their encounters with a complex institutional system that has standardizing features due to extra-local policies or practices. The issue of achieving a sufficiently wide sample to reach saturation of data is not a factor in IE. In fact, some IE research may rely only one or a very small number of key standpoint informants (Khayatt, 1995; Hande, Taylor & Zorn, 2016). In practice, however, IE researchers do seek out participants from “varied circumstances and settings” (DeVault & McCoy, 2006, p. 32) based on “experience, diversity, and social location” (Bisaillon & Rankin, 2013, p. 5). Other selection techniques described by DeVault & McCoy (2006) are selecting for diversity of experience, following chains of action, identifying good thinkers, mapping social relations, and snowball sampling.

Bisaillon & Rankin (2013) make the distinction between standpoint informants and extra-local informants in IE research.³ DeVault & McCoy (2006) refer to some types of extra-local informants as intermediary informants. I adopted the terms *standpoint participants* and *intermediary participants* in my own research in order to decide who and how to interview, as follows.

Standpoint participants can be defined as people within a subordinate social location in an institutional setting, who are invited to provide rich descriptions of what they actually do in day-to-day life, so that the patterns of institutional ruling relations at both the local and extra-local levels can be perceived and then traced as the underpinnings of these experiences (Smith, 2002; Campbell & Gregor, 2008).

³ I prefer the term ‘participants’ over ‘informants’ and will use this terminology throughout.

Standpoint participants in my study are family members currently involved in a FC in a LTC facility in Nova Scotia whose voices and experiences embody the family standpoint. Their knowledge and experience of daily/nightly family carework and FC participation is the starting point for the research. Via the process described below, I selected *three* people for my research (two women, Carol and Linda, and one man, Bryson)⁴. More details about them will be provided in Chapter Four when their experiences are described. Throughout this document, standpoint participants are referred to interchangeably as FC participants, FC members or simply family members.

Similar to what is outlined in Khayatt (1995) for selection of participants, I used direct contact with people I knew who either worked in or conducted research in the Nova Scotia LTC system combined with outreach to selected organizations. I designed an information poster to be circulated electronically by email and Facebook that described the purpose of my research. It invited interested FC members to contact me directly via phone or email if they wished to take part in the research. I also reached out via personal contacts to a small number of LTC facility administrators and staff to ask them to put me in touch directly with their FC members. One of the challenges of the research is the fact that there is currently no central repository of information about FCs in Nova Scotia. In order to recruit standpoint participants, I sometimes relied on people within the formal LTC system to help broker my contacts with FC members.

Over the course of several weeks, I received approximately a dozen email enquiries from family members across the province who had seen my request for participants. I created a short list and screened potential participants according to several

⁴ Names have been changed as well as other identifying characteristics.

criteria: 1) accessibility from Halifax (within a two hour drive), so that I could travel to interview them without a huge expenditure of time or money; 2) location and type of the LTC facility, so that I could obtain a mix of perspectives from new, old, urban, small town, suburban and/or rural facilities; 3) type of ownership or operator of the facility, that is, not-for-profit (with community boards) and for-profit (privately-owned) organizations; 4) size and age of the facility; 5) receptiveness and level of interest in FC work; and 6) length and type of involvement in the FC.

Intermediary participants can be defined as people in formal, paid roles and responsibilities within an institutional hierarchy, or they may be in supervisory or policy oversight positions in relation to the standpoint participants (DeVault & McCoy, 2006). These participants provide insights about the social organization of processes from an institutional perspective (in contrast to the standpoint participants), usually relying on institutional discourses, concepts or modes of expression.

Intermediary participants in my research are staff liaison people who interacted with FCs in LTC facilities, and who help implement the policy and regulatory frameworks surrounding families and FCs. I was eventually able to select and interview *two* intermediary participants for the research (one senior manager and one staff member). These people were identified by the two standpoint participants. At the beginning, my intention was to interview one staff counterpart at each of the three facilities where I interviewed FC members. However, in one facility, I was ultimately unable to contact the staff person who initially expressed an interest in being interviewed.

Interview methods. Following the IE approaches that are outlined in DeVault & McCoy (2006), Khayatt (1995), Campbell & Gregor (2008), Townsend, (1996), Bisailon

& Rankin (2013), and Smith, Mykhalovskiy & Weatherbee (2006), the research relied mainly on in-depth interviewing conducted sensitively and reflexively. Interview questions in IE are exploratory, open-ended, descriptive and focused primarily on sharing functions, processes, steps or activities (Smith, Mykhalovskiy & Weatherbee, 2006; DeVault & McCoy, 2006; Bisailon & Rankin, 2013; Deveau, 2008). Personal feelings and reactions are of course acknowledged and paid attention to in IE, but they are not the main focus of the research. IE interviewing requires specialized attention and skills on the part of the researcher so as to keep institutional not interpersonal issues firmly in view (McCoy, 2006; Bisailon & Rankin, 2013), and in fact I did find this to be a challenge as I describe at the end of this chapter.

Standpoint interviews were lightly structured to get FC participants to talk freely and descriptively about their routine activities with a particular focus on: 1) what tasks or work they performed as family careworkers to support their elders entering into and living in LTC; 2) what specific activities or tasks they were involved in as members and participants of FCs; and 3) ideas about institutional frameworks, attitudes, practices, texts, regulations and/or situations they encountered as FC members. Similar lines of questioning for intermediary participants were used but the focus was on the second and third areas. An *aide memoire* (see Appendix D) was used with the standpoint participants and a list of open-ended questions (Appendix E) were shared with intermediary participants in advance.

All three interviews with FC members lasted approximately three to four hours (with one or two short breaks). They were carried out in person by me during December 2018 and audio recorded on a password protected iPad. In advance of each interview, I

provided a detailed information letter and a consent letter to each participant by email (see Ethical Considerations below). I spoke on the telephone to one participant to answer additional questions. Two interviews were conducted at the person's home. One interview took place in a private meeting room in a LTC facility. The digital file for each interview was uploaded to the MAXQDA software platform and later transcribed by me within this program. Transcripts were shared back with each person interviewed to verify and any information shared. One standpoint participant made minor factual changes to their transcript.

The two intermediary participant interviews lasted approximately 60 minutes each and were conducted in February and April 2019. One was conducted over the phone and the other inside a LTC facility in a private office. The same process for information, consent, recording and transcribing as in the standpoint interviews was used, but due to time constraints the interview transcripts were not shared back with intermediary participants.

Texts and documents. In IE, 'texts' are broadly defined as "material artefacts that carry standardizing messages" (Bisaillon, 2012), and they may include legislation, regulations, policies, on-line interactive forms, and guidance tools or instructions. Texts can be written or unwritten, and they are treated as evidence of coordinating functions in institutional actions and locations (Smith, 2006). IE researchers consider them to be sources of evidence for tracing what is called 'textually mediated social organization' (Campbell, 2006; Smith, Mykhalovskiy & Weatherbee, 2006). Bisaillon & Rankin (2013) advocate making the textual collection and analysis part of the interview process, by

jointly identifying and then discussing relevant texts or documents with the interview participants, which is the approach that I followed.

I identified key institutional policy texts for FCs during the literature review, as well as sought clues from the interviews as to which texts standpoint participants commonly encountered or were somewhat aware of in the background of their FC work. The idea was to find texts that had some bearing on institutional relations. In bringing key texts into the research, my intent was to trace how various institutional “hooks and traces” can be discerned in and intersect with the actual lived experiences of FC members (McCoy, 2006). In IE, some central documents or policy instruments are also referred to as ‘boss texts’ because they define the broad parameters or framework for how institutional relations are constructed and maintained (Burstow, 2016). Smith also refers to these texts as ‘extra-local coordinators’ of standpoint participants’ daily activity (Smith, 2006). The texts I learned about included: policies or frameworks at the facility level pertaining to resident and family involvement or other aspects of LTC that touched on the role of families; guidance documents or tools directly related to the work of FCs (where they existed); forms, minutes, memos, regulations or other standardized bureaucratic documents in the larger system; and various other institutional documents or policies that seemed relevant to understanding the institutional context. Some of the key documents do not specifically mention families or FCs at all, but they still provide hints about the institutional dynamics underlying the role of FCS (see the partial inventory of these documents found in Appendix B). In Chapter Four, I provide more details about two key LTC texts that I chose to focus on regarding their role in institutional relations surrounding FCs in the LTC system and discuss their implications for FC work.

Analysis. In IE, the analytical process is multifaceted and begins right at the data collection stage -- “the analytical goal is to make visible the ways the institutional order creates the conditions of individual experience” (McCoy, 2006, p. 109). Campbell & Gregor (2008), Campbell (2006) and Khayatt (1996) use data from both standpoint interviews and texts to analyze the social relations of the institutional setting. Key institutional patterns surrounding the role and participation of standpoint participants are referred to as “chains of action and procedures” (DeVault & McCoy, 2006), which are combined with analysis of prominent institutional discourses.

Most IE researchers do not recommend using standard interpretivist or constructivist approaches for the sorting and coding of thematic categories based on individualized perceptions, as captured in the raw data. This narrow focus on patterns of individual responses contradicts the underlying intent of IE, which is to focus on a broader *structural* analysis of the sometimes hidden or obscure institutional systems that underlie specific sets of activities, building from but not limited to individual perceptions and accounts (Rankin, 2015; DeVault & McCoy, 2006). Selected texts are looked at in conjunction with interview data to build a two-step analysis of description-explication. Analysis involves connecting individual experiences to local and extra-local institutional ruling relations in a systemic way.

My analytical process involved linking pieces of first-person accounts by both family members and LTC personnel to the way in which texts, regulations and institutional discourses surround and interact with the role of FCs in LTC (Turner, 2006; Bisailon & Rankin, 2013). To do this, I listened and relistened to recorded standpoint participant interviews, developed transcriptions and detailed notes from these interviews,

and, for each standpoint participant interview, identified gaps, tensions or disjunctures within the accounts of work/activity processes related to FC participation. Based on this information, I sketched out a narrative concerning what actually happens when family members participated in FC. I then integrated selected information from the facility perspective, in contrast or comparison to the family standpoint. I also inventoried and analyzed the content of various documents or texts that were referred to in both the standpoint and intermediary participant interviews.

The intertwined process of mapping-describing-analyzing in IE is complex and could be done in many different ways. In my case, I identified common activities and strategies around FCs (both positive and negative) arising from the three family standpoint interviews. I then created a descriptive account of FC involvement which allowed me to trace how individual activities of FC participants were closely connected with evidence of institutional coordination and institutional ruling relations.

Research ethics. Ethical risks relate primarily to protection of human participants in research and in preventing unfair and insensitive treatment of people who participate in data gathering activities that might lead to disclosure, exploitation, discomfort or distress (Bryman, 2014). My research was designed to be minimal risk to the participants and my proposal was approved by the University Ethics Review Board according to their guidelines (see Appendix C). I performed the following tasks and activities to safeguard the integrity and well-being of research participants and data collected: 1) Prepared a detailed information letter and informed consent form that all research participants read and signed prior to each interview; 2) Conducted all the interviews in a sensitive and careful manner to show respect to the participants, paused the interviews as needed to

deal with personal feelings if necessary, and offered empathy and emotional support; 3) Anonymized the names and locations of the research participants and the facilities by changing names and disguising any locating or identifying data; and 4) Enacted standard ethical procedures for storing, managing and disposing of all research data (both written and digital) in secure and confidential ways.

My role as a researcher. IE, like other feminist-influenced methodologies, requires self-reflexivity, awareness of positionality and intersectionality, and identification of the researcher's own stake in the research, meaning her own personal connection to the problem being investigated (Hesse-Biber, 2012; Hesse-Biber & Yaiser, 2004; Sprague, 2005; DeVault & Gross, 2012). As outlined in Chapter One, I started with a relatively strong awareness of my own position in this research, in terms of how my approach was shaped by my personal experiences of being a family careworker in LTC. A key personal aim from the research is to support advocacy and further research about the important role of families and FCs in LTC, from an activist perspective.

My stance as an engaged researcher helped me immensely in identifying and maintaining my passion and commitment for the research topic over an extended time period. One other key advantage of being an engaged researcher with first-hand family carework experience in LTC was my ability to build strong rapport or empathy with the FC participants I interviewed. As a white, middle class woman with family roots in rural Nova Scotia, I could identify strongly with their life backgrounds and experiences. In fact, I have tried to stay in touch informally with the three FC members I interviewed since conducting the research, by sending them follow up information about FCs, and they also have reached out to me to maintain contact and continue dialogue.

During both data collection and analysis, I was very aware how my own engagement influenced the dynamics of the research carried out (Bisaillon & Rankin, 2013). I kept a reflexive journal throughout the research process, as it was difficult for me not to be emotionally affected by some of the stories that I heard. The journal was a record of what moved me as well as flashbacks of my own experiences. It helped me re-acknowledge the importance of the research and kept me going throughout the process.

I did not feel conflicted about being an activist researcher at any point in the process. I shared my own personal experiences freely with standpoint participants and readily empathized with them about what they had encountered (both positive and challenging) in the LTC system. This allowed us to co-create many aspects of the shared experience of the family standpoint in LTC, thereby (in my view) greatly enriching the analysis. This is fully consistent with engaged feminist research approaches in IE shared by DeVault & Gross (2012).

At the same time, I felt constantly challenged in terms of avoiding institutional capture (Burstow, 2016). For example, I was inevitably drawn at certain points (especially when conducting the intermediary participant interviews) into thinking within and through institutional terminology and frames of reference. The uniqueness of the family standpoint as a social location tends to recede into the background at these times and become obscured by institutional norms. I therefore repeatedly reread the interview transcripts (up to 20 times each) in order to immerse myself in the family perspective, with the sole intent of refocusing my attention to the concrete family experiences of the institutional setting, terminology and dynamics being described.

Chapter Four: Findings

Daily/Nightly World of Family Carework

What concrete lived experiences constitute the family standpoint in LTC? What is it like to be connected to someone living in LTC in Nova Scotia, as seen and felt from the inside of the process of becoming directly involved with the LTC system? How do daily/nightly experiences of family carework lead to FC involvement? According to IE researchers, the everyday/everynight world of those engaged in actual work (whether paid or unpaid) forms the basis for understanding and critically unpacking the institutional systems with which they interact and connect (Smith, 2002). Understanding the nature of family carework in LTC in Nova Scotia was therefore my research starting point, in order to lay the foundation for analyzing the role of FCs in the LTC system.

With all three family participants I interviewed, I made it quite clear at the start that I was there primarily to discuss their FC work. But, to me and to them, a logical place to start was with their broader stories of family carework. Family carework in LTC obviously varies widely among different people depending on their circumstances, but it has many commonalities as well. I begin this chapter with a brief overview of the complex 'lifeworld' of my research participants and their family carework as the background for discussing the role of FCs in LTC. This is not intended to be a comprehensive account of family carework, but I hope that any person who has participated in family carework in LTC facilities would recognize part of what they have experienced in these personal accounts.

To set the background, the standpoint participants Carol, Bryson and Linda are all very different people but shared many similarities. They are all in the same age range

(early to mid 60s), white, middle class, retired or semi-retired from their careers (which included both paid work and homemaking). They all live relatively secure and peaceful (some might say ‘privileged’) lives in rural or small-town Nova Scotia communities. Based on what they told me (and by what I observed), they all apparently have stable lengthy marriages, own their own homes, are currently in good health, were educated at the college or university level, and are well settled in their respective community settings. One of them (Linda) takes regular trips to a seasonal home outside Canada. Two of them, Bryson and Carol, live in the same community (and in one case, next door to the same house) in which they were born and grew up.

Each of them has a parent in their 90s, with whose situation they are closely involved, who is diagnosed with some form of memory loss combined with physical frailty and has lived in a nursing home for three to five years. Bryson’s father’s facility is in a close-knit small Nova Scotia town where the family has lived for decades. Linda’s mother’s facility is in a suburban area within an urban municipality. Carol’s mother’s facility is a newer one located in a semi-rural area about an hour’s drive outside a major urban centre. At the time of the interviews, Carol, Bryson and Linda all visited the facilities where their parents lived at least twice a week (sometimes more frequently). Carol’s mother’s facility is owned and run by a private for-profit company, while the facilities where Bryson’s and Linda’s parents live are both run by registered not-for-profit corporations with boards of directors drawn from the surrounding communities.

For each of Carol, Bryson and Linda, their apparent rootedness in Nova Scotia community life as well as profound loyalty to their remaining parent is very marked. My own personal experience of growing up in the Annapolis Valley of Nova Scotia resonated

with what I heard from them about dedication to their parents, families, local values, community and work. Their carework stories are particularly compelling to me because they reveal the complex texture of the family standpoint that is so often rendered invisible in the formal LTC system. It should be noted, however, that their (and my own) carework stories also reflect the experiences of white, educated, middle class people who live in or close to the same places they were born, and who have secure incomes and homes, mainstream gender identities, and a degree of quiet self-confidence due to all these privileges. Their experiences of the LTC system would not necessarily be shared by family members with different racial, ethnic, gender, socio-economic or educational backgrounds – in fact, for non-mainstream families, interacting with the LTC system might be even more difficult. Nonetheless, the IE standpoint approach posits that all family members, regardless of their varying social identities and circumstances, likely share a particular marginalized relationship to the LTC system, which is that of unpaid and unacknowledged family caregivers outside official institutional structures.

In general, the stories Bryson, Linda and Carol told me of the evolution of family carework for each of their parents in LTC fell into four main phases.

In the first phase of family carework, they all had an aging parent or parents living in their own homes who gradually encountered difficulties related to physical decline and/or memory loss, which pointed the way towards eventually having to enter the formal LTC system to receive additional support. This transitional phase lasted several years for each of them, and in two cases involved offering support for both aging parents at home. Early confusion or memory decline, compounded by hospitalization or growing risks of being at home on their own with live-in support, compelled all three to encourage their

parents to enter the LTC system. Carol, for example, looked after her mother in her home and said that “physically I could handle it”, but on a psychological level it “was very draining”. Her mother would not accept outside caregivers to help out and, according to Carol, “the only way she would have been happy would have been if I could have shrunk her up and put her in a backpack”. This was a stressful time for Carol and her mother, although they attempted to maintain some degree of normalcy in family life by going out for drives and walks and doing volunteering and housework together, but eventually Carol’s mother could not live at home with her.

Bryson’s father, who had been a respected tradesman in a tightly knit Nova Scotia community, was diagnosed with Alzheimer’s at the age of 80 and lived at home for five years with support from Bryson’s mother and the extended family. After his mother died, Bryson and his siblings decided it was impractical to keep their father at home which eventually led to entering the LTC system.

Linda’s story of at-home family carework was equally detailed, complex and emotional as Carol’s, which perhaps indicates the gendered dimension of much family caregiving. Linda’s mother and father lived on their own at their suburban home for several years after her mother was diagnosed with dementia. Eventually, things came to a head when Linda’s father experienced a serious health crisis that necessitated hospitalization for him. The decision to place her mother in the LTC facility was not an easy one but a downward spiral of circumstances contributed to the family as a whole eventually being somewhat reconciled to this choice.

The second phase of family carework consisted of initial encounters and negotiations with the formal system required to access LTC, such as being assessed for

and then waiting for the offer of an LTC bed under the Nova Scotia continuing care system. All three mentioned that the initial screening continuing care services and policies for assessment and placement of their loved one was a turning point. Bryson noted how “fortunate” his father was to be placed in a local facility near his home, due to the “option for a radius where they can decide to put your relative [according to] room availability”. Both Carol and Linda, however, noted a more difficult liaison with the formal continuing care system but for varying reasons, apparently related to the intrusion of institutional requirements into the complex, emotional world of family carework.

Linda’s mother received a formal assessment because her husband (Linda’s father), the primary caregiver, was hospitalized and therefore an option had to be found quickly. Accordingly, he did “sign the papers” (Linda’s words) and the first placement available was an older facility fortunately not too far from their home and somewhat known to the family. Subsequently, when it became clear that her father could not live at home on his own, he also had to apply and was ultimately placed in the same facility. The family had already applied to move Linda’s mother to a more modern nursing home, but her father decided (once he had moved into the same facility himself) that it was easier on everyone if they both stayed together there.

Carol’s contention was that the LTC intake process had been intrusive and inappropriate for her mother. She was concerned that the assigned government social worker doing the assessment had probed too deeply into her mother’s personal history of marriage and divorce. But, because her mother’s situation was considered somewhat acute, she was accepted very quickly into a very new, up-to-date facility within an hour’s drive of Carol’s home.

The third phase of family carework entailed having to sort out how to make the physical move and settle people in a facility, which brought the family careworker into even closer proximity to the institution and its frameworks. Anyone who has accompanied a beloved elder moving into a nursing home, myself included, will likely attest to the anguish that they experience at that time, and all the personal and logistical stresses involved.

Bryson did not elaborate on the actual day of arrival for his father in the nursing home, aside from noting (in general) how the admissions process involved “lots of paperwork” – presumably, with a large extended family nearby, many family members had performed different tasks. However, the actual physical move stood out for both Linda and Carol as being significant, in the sense that they knew their respective parents were undergoing an irreversible change. Concretely, for both of them the day-of admissions process entailed reviewing a sheaf of documents, guidelines, and signing a number of formal agreements, legal directives for care, admission/financial forms and other papers that would subsequently help define and manage their mothers’ lives in their respective institutions. The mandatory completion of an institutionally sanctioned admissions package is standard practice when entering any LTC facility in Nova Scotia.

In Carol’s case (as a former nurse), she anticipated the requirement to fill out the papers and made special arrangements to go a day early to the facility to do so. Linda’s experience, unfortunately, was more difficult as the facility provided her with a small window on the morning of that day for her to arrive with her mother, which she felt was unrealistic due to the complexity of her mother’s cognitive state: “It was a horrible experience, it was not good”. When Linda arrived at the facility with her mother, she was

expected to fill out the forms in the admissions package immediately upon arrival, even though they were late, both she and her mother were stressed, and “we weren’t told very much”. As an aspect of family carework in this key transition time, these processes provide a glimpse of the ways in which the formal institutional mechanisms are often focused primarily on fulfilling legalistic or managerial requirements, in direct contrast to the nuanced and emotionally laden interpersonal preoccupations of family members.

The fourth phase of family carework, which all the FC participants were still actively involved in at the time of conducting the interviews, consisted of the initial process of gaining knowledge about the facility’s own systems. It is this last phase that led directly to FC participation, which will be described below. Family carework at this stage evolved into the day-to-day (and in some cases, nightly) interactions with the LTC facility around on-going arrangements to keep the elder stable or otherwise adjusted in a formal care setting.

The stories that Carol, Linda and Bryson shared about their evolving carework in the weeks, months and years following admission of their parents to LTC were to me particularly moving and insightful. All three were very committed to visiting their respective parents regularly in the nursing homes. Bryson’s description of his visiting carework showed that it both informally filled the gaps found in some understaffed facilities, as well as ensuring maintenance of social contact for his father (whose health and memory declined after entering the nursing home). Bryson also mentioned the role he played in trying to review and regulate the medications administered to his father to aid with the side effects of his memory loss. He saw his evolving carework role mainly as an interlocutor between his father and the facility, trying to understand the facility’s needs

and point of view on care and safety, as well as helping to keep his father calm and comfortable under the circumstances. His approach to carework within the facility, therefore, relied on ensuring clear understanding of facility guidelines and constraints, and on-going support for smooth functioning of the organization so that it would provide the best care possible to his father.

Linda's approach to carework was somewhat similar, but she was slightly more concerned (possibly related to her role as daughter) about establishing a solid emotional environment for her mother. When her mother entered the nursing home, Linda was mainly concerned with finding practical and constructive solutions to immediate concerns. Her immediate carework tasks were to figure out 'who was who' in the facility, and then try to identify appropriate allies or sympathetic staff with whom she could discuss her concerns and establishing caring relationships for her mother. Negotiations about how to improve her mother's situation in the nursing home took some time, due to the lack of (in her words) "clear answers" from staff about how to effect changes.

Carol's carework trajectory had some similarities to Linda's, in that the initial adjustment to the facility was quite difficult for both her and her mother. Her main concern, as her mother's substitute decision maker, was that her mother not be administered any drugs that might contribute to her physical or mental decline. According to her, her mother's agitation, confusion or what staff referred to as 'responsive behaviours' (an institutional term used in LTC for some actions or communication patterns displayed by those with dementia) were often treated as further evidence of her mother's mental decline, rather than as manifestations of poor care interactions and inadequate understanding of her mother's needs. As a result of these early challenges in

the nursing home, a large portion of Carol's carework for the past three years involved tactfully but persistently educating staff about her mother's needs as well as carefully monitoring her mother's behaviours to provide feedback to staff about how to further improve care. Besides advocating that her mother be included in as many recreational activities as possible, Carol prepared some tactile materials for her mother (which staff could use) to help calm her down when she was agitated. Other ongoing aspects of Carol's carework included responding to medical emergencies for her mother (such as falls or abrasions), regularly reviewing her list of medications, and attending annual care meetings with a team of facility staff to discuss her mother's evolving needs. Also, due to the length of time between official care team meetings (which usually take place once or twice a year in most facilities and are the only official times at which time families get to discuss in-depth issues with a staff team), Carol sometimes prepared lengthy letters and emails outlining her concerns with her mother's situation and requesting adjustments to her mother's care.

As shown in these brief sketches, the daily/nightly world of family carework for Carol, Bryson and Linda involved an ever-deepening set of encounters with a complex, multi-faceted and sometimes confusing or frustrating institutional regime in LTC. At first family members had only light interactions or partial glimpses of the institutional framework, mainly via such activities as becoming gradually aware of regulations governing the LTC system, being put on a waiting list for entry into a LTC facility, filling out required admission forms, and then learning which tools, rules or procedures might apply under certain circumstances. These experiences or institutional encounters gradually became more normalized over time as family members gained more knowledge

about the facility and how it worked, but in some cases tensions remained. It is important to note, however, that the family members in my research were not passive in these institutional encounters. They continued to learn, adapt, negotiate and cope as needed to make their parents' lives more comfortable.

Activities and Work of Family Councils

Linda's, Carol's and Bryson's experiences of family carework provide valuable context for their FC participation. At the same time, their carework experiences within the LTC facility indicate the complex ways in which the institutional structures, norms and relations of the LTC institutional regime start to become more apparent to family careworkers, as well as the evolution of their own personal strategies for integration, accommodation and adaptation which eventually seemed to lead them to FC involvement. For each of the three family standpoint participants, their growing commitment to making their parents' lives comfortable and dignified in their respective facilities was an entry point to more formal engagement with the nursing homes via FCs. For them, FC engagement was a logical next step in their family carework journey, in which their encounters with the social relations of the institutional complex of LTC gradually became more visible.

In terms of their FC engagement, at the time of their interviews, Bryson was a five-year FC participant at his father's facility, Carol had been involved over a two to three year period, and Linda was a founding member of the FC in her mother's facility and had been regularly attending meetings for approximately four years. Carol estimated she had been a family participant in approximately three to four FC meetings in total,

while both Bryson and Linda had each attended a minimum of four FC meetings annually over the preceding three years.

What follows is a brief outline of Linda's, Bryson's and Carol's learning and engagement experiences with FC structures and activities under three categories: 1) the background knowledge they had developed concerning the general mandate and practices of the FCs they participated in; 2) insights into their personal motivation for supporting and/or participating in a FC; and 3) the main positive benefits or accomplishments they noted that came from FC work, either individually or for the facility as a whole.

Structures and practices. Although there were similarities in the experiences of all three family members when they initially joined, formed and/or continued to attend their respective FCs, the actual functioning of each FC involvement was quite different. This was partly because it became clear from the information that they shared, that each FC had a slightly different history, leadership structure, membership recruitment approach, staff liaison role/function, and number of meeting times. This was not surprising, as we shall see, given that the broad regulatory guidelines that give rise to FCs in Nova Scotia can be interpreted or applied in different ways.

Each of the three FCs in which Bryson, Linda and Carol participated had a Terms of Reference and/or a Mission Statement, outlining the vision, goals and general intent of the group, which they shared with me after asking the permission of facility staff. These documents were, in Bryson's and Linda's case, posted both on internal bulletin boards and on the facility's website, while Carol's facility only had hard copies available. Each Terms of Reference varied slightly but followed a similar model, mentioning such items as the need to provide various forms of support to family members, improve the quality

of care and/or quality of life of residents, improve education and/or communication of issues that the family members might be concerned with, and play some type of advocacy role for residents. Two FCs (Carol's and Linda's) specified that meetings were to be only one hour in length. Carol's FC met only twice a year, chaired by the Director of Care and with the Recreation Therapist attending along with other staff as appropriate or requested. The Terms of Reference specified that staff had to be present throughout the meeting. Bryson's FC met five times a year with a family volunteer as chair and a staff person to take minutes and it included a section for family-only discussions, while Linda's FC met six times a year and was chaired by a family member. Both Bryson's and Linda's meetings could include any staff deemed appropriate, but only at the specific request or invitation of family members.

Carol, Linda and Bryson all seemed to be aware at the time we spoke that the existence of FCs and basic elements of their structure and functions were officially mandated under the regulations governing LTC in the province. Linda, in fact, referred to FCs as being "required by law", although technically FCs in Nova Scotia derive from departmental regulatory guidelines -- that is, the DHW LTC Program Requirements noted in Chapter Two (to be discussed in more detail later in this chapter), rather than from specific legislation found in Alberta or the United States. They knew something about the existence of the official LTC Program Requirements and had possibly looked up the document on-line or had slowly become more informed about its existence and contents through participating in FC meetings. Bryson and Carol both mentioned that they knew something about the LTC Program Requirements partly because their respective facilities had offered some information in FC meetings about recent provincial licensing

inspections, while Linda had come across the document when doing her own background research about FCs.

Motivation for involvement. Carol, Bryson and Linda all expressed common ideas about the way in which family carework (in the many diverse forms outlined in the first section of this chapter) was closely intertwined with their decision to become involved with the FC in their respective nursing homes. As might be expected, the details differed depending on their evolving relationship with the facility and the ways in which their carework trajectories unfolded.

Carol thought that the FC had existed at her mother's nursing home for at least a couple of years before her mother entered the facility, but she did not know personally how it had formed or where the impetus came from. She could not remember precisely at what point she heard about the FC in the facility, and from whom, but through her family carework she became quite closely involved with the Recreation Therapist, whom she saw as her "best ally" (her words) in helping ensure her mother received sufficient stimulation to keep her memory and identity functioning. It was after her mother had already lived in the facility for several months that Carol saw the FC advertised as an upcoming event/activity and she decided to attend because it seemed to be a logical extension of her one-on-one carework.

I think I saw it on the [recreation] calendar. The way I look at it, if I'm going to say something I just don't want to complain and then walk away and say nothing. You know, like, not put myself in the game ... It was so hard because I've never been involved [in anything similar], so I really have nothing to compare it to. All I hoped was that when ideas were presented, that they [the facility] would be open to those ideas, and they seemed to be, so that was good.

She felt that at first the staff involved with the FC were grateful for her participation as the group was not normally well attended. In spite of her deep personal concerns about her mother's care, Carol did not want to personalize the issues she raised via the FC but tried to keep her input and ideas at a general level: "It's going to help Mum but it's also for the other residents". As we will see below, over time Carol's FC engagement (and the facility's response) was not exactly what she hoped it would be. In her interview, she therefore expressed some ambivalence about whether the FC really made a difference to the facility or not. Overall, however, she felt committed to following through on anything that would make the facility a better place, not just for herself but for others in the same situation. She admitted that her motivation began with her personal dissatisfaction with some of the challenges surrounding her own mother's care in the facility, but she had developed a broader view of why FC involvement was important.

I'm selfish in some ways because I think I'm going down the road, all of us baby boomers are, so [do] we want it like it is? I say to them [other family council members and staff], I'd think it would be better, wouldn't you?

Similarly, Bryson heard about the existing FC at some point after his father entered the facility to live five years previously, but he could not say exactly when and how. He was motivated to become involved not necessarily because of any immediate personal grievances or concerns, as he was largely satisfied with the quality of care his father received. However, he expressed a strongly held belief that it was an 'obligation' that came with being a family careworker, as a way to 'give back' to the facility and community.

I can't really tell you how long it's been in existence, although I can find out ... But I've been involved since my father came here, and frankly when you have a family council, then families should show up. So, it was

like, why wouldn't I be involved? If it's something that has to do with me speaking to a group of family members, in a private setting to improve this facility, I just assumed it was part of the program.

In concrete terms, FC work was a way for him to better understand more about how the facility operated, what were the factors underlying the type of care his father received, and how to support the facility in as constructive a way as possible.

From my perspective, I mean, I can sit over there and read the Terms of Reference [for the FC], but ... the council should be a bridge between both [the family and the facility]. I have my family member being looked after in the facility and I have concerns that they're well taken care of. If I understand what the facility is trying to accomplish in the context of how much money you've got and all the other crap that goes on, what I'm trying to do is educate myself relative to what their mandate is and what restrictions they [have], and to try to translate that to make sure [that] my family member is going to get the best care they can, and if they're not, who have I got to talk to? ...

The other thing is that if you look at the way it's going for boomers, if nothing else I'm here [with the family council] for vested self-interest. I mean, if you don't visit your family members, and I visit other people in the facility too besides my father, there is no one advocate for them And I just personally see a family council as, I guess, in the system itself, to be able to advocate not just for your own family members, but the health of the facility that your loved one is in. So you can connect with people who come to the meetings and sort of make sure that they are all paying attention too, and at the same time ensure that (and I don't mean to sound this in a negative way), the administration know that you are paying attention.

Bryson's constructive perspective on the role of the FC in the facility was reflected in his ongoing efforts to reach out to staff and ensure his daily visits to the facility involved something more than simply personal support for his father. Over time, he became quite friendly with the facility administrator, who apparently was quite open to having regular discussions with individual family members via an open-door management policy. Bryson took time to forge a personal rapport with that person by regularly dropping in to chat. In some cases, he went out of his way to identify any

instances of very positive or negative staff behaviours which he observed, and then quietly pass these background observations along to the administrator. Although this was outside his direct FC involvement, he saw FC work as mainly providing an interpretive or mediation function between individual family complaints and the broader facility environment. In line with this, Bryson believed that recognition of the staff's contributions was essential to the FC's work, and he was personally highly motivated to provide this feedback via the FC.

Family council needs to keep an eye out, but they also need to acknowledge the staff and the good works that they do and somehow communicate that through one-on-one, hey, I appreciate what you do for my father every day, I leave, you're here.

Like both Bryson and Carol, Linda's original motivation towards FC involvement was mainly to improve her parent's care as well as facility life, but she actually took on the lead role of formulating the idea of a FC in her facility and then getting it started. When her mother first entered the nursing home and was getting settled, as we saw in the previous section on family carework, Linda was concerned that as a family member she received little personal support and had virtually no idea about how to raise questions about what she saw happening within the facility.

So, through all of this, and my experience, I started to see things at [the nursing home] that, you know, they could do this and it might benefit the residents, and they could do that and maybe this would be a good idea. I felt that one thing they had to improve on was the [timing and process of] admissions ... And I felt that we weren't given enough information about the [nursing home] itself, what they provide. They gave us a handbook, that's all well and good. It would have been nice to ... and I'm still trying to advocate this, it would have been really nice to have been met by another family member. If somebody had come in and said, oh, I'm so glad your Mum is moving here, we've had such a great experience, these are a few hints, this is what I would do if I were you ...

Linda learned there was no FC at the facility and she then started to do internet research to see what was happening in Nova Scotia and in other provinces, at which point she encountered the LTC program requirements and its provision mandating the formation of FCs. She eventually attended a public forum at the facility at which the administrator laid out some strategic directions as well as expressed an interest in forming a FC.

So, I asked [the CEO] during a Q and A [at the public meeting], what about family council, do you have a family council here. And he said ... I would love to have a family council. So, after the meeting I approached him personally, and said I'd actually been doing a little research and I said I have files at home and I've been compiling my notes, and I would really appreciate an opportunity to meet you. And he said that would be wonderful So, I met with him and with [another staff], and they agreed with everything I had in my presentation, they said this is perfect, let's do this, so I think our first meeting was in November of that year.

Linda was very pleased to meet this quick positive reception from the administrator and immediately developed a strong collaborative relationship with the assigned staff liaison person to get the FC off the ground. Linda was able to consolidate the ideas from her research and present them. She then worked jointly with the administrator and the staff liaison person to develop an appropriate Terms of Reference, structure and process. At the time of Linda's interview, she had been involved for over four years as one of the rotating chairs of the group. Linda's motivation towards FC work apparently had not waned over this time period, and she expressed considerable pleasure and pride in being able to contribute to the nursing home in this way -- similar to Bryson's confidence in the FC's ability to play a positive role in facility life.

It was quite clear that Linda and Bryson believed that their respective facilities provided an enabling environment for FC formation and participation, in the sense that the positive attitudes of senior staff made them believe that their work was valued and

might have an effect. For reasons that will be explored later in this chapter, motivating and retaining family participation and ownership over FC work seemed much more precarious at Carol's mother's facility. However, it was clear that all three FC participants were personally motivated by the need to transform personal challenges or issues with their loved one, into a deeper understanding of what was going on in their respective facilities and in the LTC system as a whole.

Benefits and accomplishments. Bryson, Linda and Carol each referred to some personal and collective benefits of their involvement in the FC, including opportunities to meet other family members and to share ideas and discuss topics with them, learn more about the facility structure and staff roles, and become more conversant with the broader issues that the facility faced in terms of public funding shortfalls and staffing shortages. Several key FC accomplishments that they mentioned included the following (with brackets indicating whose FC):

1) Encouraging the facility administrator to share more information about the results of provincial licensing inspection reports and discuss with family participants the effects/implications of key 'critical incidents' such as residents with bedsores and complaints investigated officially under the Protection of Persons in Care Act (Bryson);

2) Assisting family members to obtain more information about how the facility is run, who to talk to about specific individual care problems, and/or become better acquainted with the structure and/or roles in the facility (Bryson, Carol and Linda);

3) Giving input to help the facility rewrite or improve handbooks and other admission information shared with family members (Bryson and Linda);

4) Writing letters to the provincial government on behalf of the FC (with the support/approval of the facility) to express concerns about provincial funding cuts and their effects on staffing and service delivery in nursing homes (Bryson and Linda);

5) Assisting the facility to reach or obtain Accreditation Canada standards for long term care facilities (by demonstrating family engagement and involvement) (Bryson and Linda);

6) Informing family members about results and implications of provincial licensing inspections (Bryson, Carol and Linda);

7) Assisting the facility to deal strategically with 'risk management issues' through encouraging FC members to serve on internal advisory bodies such as facility Ethics Committees (Bryson);

8) Arranging educational information or seminars/talks to families about specific topics or items such as provincial health care funding policies in LTC, dementia care, family legal matters such as power of attorney, and responsibilities/roles of key facility personnel (Linda, Bryson and Carol); and

9) Suggesting constructive improvements that the facility could make to the general environment, common areas in the nursing home, furniture, laundry services, parking, food services and meal delivery, interpersonal communication methods between staff and residents, staff identification, recognition of staff contributions to resident wellbeing, and general feel or welcoming attitude of the facility (Linda, Bryson and Carol).

Each FC member provided some information about how what they considered as the positive interface between FC and the facility led to constructive dialogue and

concrete change, even if in a limited way. They each described how FCs were able to get at least some new or improved approaches implemented by the facility, mainly because (in their view) the FC members were able to offer new perspectives around nursing home processes and life that had not previously been considered by the staff. This may have been because staff were overloaded, but perhaps also because the staff were so used to working within and around what already existed in the facility that an outsider perspective was useful to effect change. Although several tensions or challenges arising from FC work within facilities will be described and discussed in the next part of this chapter, a few examples of the positive accomplishments of FCs are also worth highlighting briefly here in research participants' own words.

Linda noted in her facility how a FC member was able to bring forward concerns about handling of resident meals, due to lack of staffing. That person then suggested ways to provide more volunteer help at mealtimes so that each person was able to get personal support with eating their food.

[The dietician] was one of the guest speakers [and it was brought up] by one of the members of the FC, [that] they noticed during mealtime, a lot of residents weren't getting individualized attention, simply because staff can only spread themselves [so far] And then the meals were taken away and that person hasn't eaten and that's serious. So, what they've done is, the dietary staff have trained volunteer family members on how to correctly feed a resident ... And she's doing a second training coming up in January for more family members ... If I had this training, Mum doesn't need help, but I could sit with another resident and help them eat.

Linda saw this as being a win-win situation for individual residents and the facility overall, by ensuring stronger family involvement (another way to help meet their Accreditation Canada requirements), helping the residents get proper nutrition, and filling in for staff shortages which meant it was impossible for all residents to be adequately fed

during mealtime (a situation I also witnessed firsthand in my father's nursing home).

Linda also noted the importance of learning, via the FC, the background structure and procedures of the facility (and the LTC system overall), as a means of strengthening family understanding about who does what and why things get done the way they do.

But it does get easier when you know more about the facility, it does get easier when you understand what happens behind the scenes, and that's where FC, you know, helps family members. If you're bringing in department heads and they're explaining what's going on and you have a better idea of how things work, it's easier for you to understand.

Bryson touted many benefits of the FC's work, ranging from family members receiving more information about facility procedures and policies, to having useful background briefings from the administrator to enable what Bryson termed a more 'balanced' perspective on LTC conditions and constraints. For example, as a FC member, he was invited to become a member of the facility Ethics Committee (family participation being another requirement of accreditation). In that capacity, he was able to participate and offer the "family perspective" on discussions around "risk management" in the facility. Bryson was then able to then take back some of these insights to enrich the discussions at the FC via deeper understanding of some LTC policy constraints.

What it opened up for me was ... they're paying close attention to issues associated with 'the push' or 'somebody fell down', or whatever. So that to me is what's happening in the background all along, but I was unaware of that. So, the environment here is heavily assessed for issues, but I'm not sure most family members are aware of the due diligence that the facility is actually doing. And it's not because there was an ugly thing in the paper about it, that's [routine] practice here. So, to me that will be a perfect thing ... for FC, what do we do on a day-in, day-out basis ... They're up there in the Board Room about what happened last week If you're going to get an issue associated with an inspection or there's a serious lapse for whatever reason, to me that should become automatic on the agenda of the FC.

All three FC participants were somewhat aware of some of the larger structural issues around funding, staff and regulations in the LTC context in the province. Bryson was strongly sympathetic to the many ways in which his father's facility had to deal with larger crises or concerns that sometimes emerged in the media about the LTC system, such as presence of bedsores leading to complaints, investigations under the Protection for Persons in Care Act, and the safety risks related around allowing some residents not to be medicated or restrained.

The localized situation they encountered in each of their facilities gradually brought the three FC participants into more awareness of the broader LTC policy landscape and context. Both Bryson's and Linda's FCs had taken it on themselves to prepare letters to send to provincial officials about the situation of LTC funding in the province, lobbying them regarding potential budget cuts to the system. Bryson found that by participating on the FC, the larger picture fell into place for him and for others, so that they could contextualize local issues within the broader framework of the LTC system and its challenges. While he believed that what the FC could accomplish within the facility itself (in terms of changes to routine practices) was what really mattered, he noted his growing understanding of the larger advocacy role of FCs – something that his FC had, in fact, taken on through writing letters to local politicians.

From my perspective, we just need to engage family members here through FC in a way that will, I guess, make sure they're familiar with what it is happens here and to proactively try to avoid some of the issues that other facilities have [and how can we] help the bigger system. So if we're aware of what it is happens here and why, we have the ability to make little improvements with management, then [when] we come up against something like "we can't do that, I'm sorry, because the funding formula is like this", [then] if you have an engaged group of family members, they can call people and write people, and say, why is this? To me that's the biggest benefit of FC, [it's] to advocate for the system when

the FC is capable of doing that. You want to get your feet wet on the local stuff, and then okay, let's see if we can take this on and we need to take this on because obviously, it's not something that [the administrator] can deal with. [The Administrator] needs our support ... We're just going up the food chain. He can't do any more for us, because this is the way the funding formula is.

Carol's perspective, however, was that it was much more difficult to work through the FC at either the facility level or at the broader system advocacy level to bring about constructive change. Due to the somewhat fragmented nature of the FC at her mother's nursing home, as well as the tensions that arose when she brought forward critical issues with the staff at FC meetings (as will be described more below), her commitment to the FC and her sense of accomplishment was less marked than either Linda's or Bryson's.

Interestingly, and perhaps not coincidentally, Carol's mother's facility was a private for-profit institution, in contrast to Linda's and Bryson's, which both were not-for-profits and had community boards – a factor that may have made them somewhat more receptive to family input. This is not to say that Carol felt nothing had been done by her FC. For example, she cited some instances of useful information being shared at the FC meetings about the facility staff roles and areas of responsibility, as well as educational events about specific topics like dementia care. She also noted how useful family feedback was provided to improve the look and feeling of the common spaces in the facility, and to obtain some helpful materials such as a 'dementia-friendly' digital clock. Overall, however, the challenges she faced as a FC participant in effecting changes were seen by her as indicative of the need for family members to lobby more to achieve a situation of mutual accommodation and dialogue. These were things that Linda and Bryson felt, to a large extent, had already been achieved or were at least partially realized through the work of their respective FCs.

Tensions and Challenges in Family Council Work

Bryson, Carol and Linda also noted some challenging or difficult issues in their descriptions of how their FC work intersected with some of the norms and procedures in their parents' facilities and, by extension, with the larger LTC system. In IE, as noted in previous chapters, these issues can be treated as disjunctures (Smith, 2005) which provide a window into how institutional ruling relations are constructed and maintained around FC work in LTC. These critical or problematic issues varied in seriousness, intensity and scope for each FC participant, although they were all quite closely interconnected. What follows is an overview of five selected issues or tensions in facility-FC institutional relations that emerged from the standpoint interviews:

- 1) the on-going challenges of attracting and maintaining adequate or regular family participation on FCs;
- 2) negotiating how to balance personal issues and concerns of FC members with broader impersonal issues in the work of FCs;
- 3) understanding the roles of facility staff on and around FCs;
- 4) the challenges around finding appropriate ways to share FC information while still respecting the privacy/confidentiality of both FC participants and (by extension) the residents connected to them; and
- 5) finding acceptable ways for FC participants to provide critical and constructive input on facility procedures, as well as to increase facility accountability to FCs.

In the following section, each issue is described first from the standpoint of FC members in terms of their daily/nightly family carework at the facility level, drawing on

direct quotes and underlying information as appropriate. Information obtained from the two LTC staff interviewed is used to compare/contrast their institutional perspectives with what emerged from the FC interviews. The implications for FC work arising from this analysis will form the basis for the final summary in Chapter Five.

Family participation. Bryson, Carol and Linda all spoke about ongoing challenges with ensuring what they considered to be an adequate level of regular or consistent family participation in FCs. According to them, the relatively low rates of FC participation that they all experienced had potential implications for the sustainability, credibility and effectiveness of FC work. This was a complex issue and they all registered in different ways their lack of personal understanding about how family members could possibly refuse to become actively engaged in family carework in the facility, much less FC work. For example, Bryson had a very hard time understanding how family members might not want to come to the nursing home at all. Although he noted that this could be perceived as an emotional response of some individuals to family stress, in his view it obviously had some bearing on whether or not family members could be attracted to FC work or could even overcome their anxieties and stigma about such hard-to-deal-with issues as aging, decline and memory loss.

I think it's disappointing ... the number of people that are here that aren't visited by family members period, and they have just been left here. In a facility that has a high percentage of Alzheimers and dementia, at what point I guess for some family members, your loved one is in the final stages of the disease and it could take a very long time ... And I'm not going to deny that it can be painful for people to come and see their loved ones, there are different reasons. But I think a bigger issue is how as a society we treat older people.

Bryson believed that the FCs meetings were well advertised at his father's facility. He was pleased there had been a small and loyal core group involved over the course of

several years at his father's facility (about six to eight people on average at most FC meetings), but he was frustrated that more people did not attend the meetings regularly. He believed that the "biggest issue with family council is lack of interest from family members". Bryson wanted to see more family members involved in the FC. In order to address this problem, he consistently encouraged the facility to publicize the FC meetings via increased email outreach to all family members, provide better information on the facility website (as will be discussed below), and improve opportunities for families to provide remote input to the FC.

To me, that's the step that I'd like to take ... about, we need to know first off, if everybody is getting an invite, why aren't they coming? We've tried different things, like guest speakers or we'll do other things. If you can't make it, fine, you can look at the minutes on the website, you can read the minutes or you can submit questions ... So, I think we need to know why they're not showing up. Maybe they all think it's perfect here, but I still think they [family members] should occasionally show up just to make sure we're paying attention.

Carol perceived her mother's nursing home as being quite 'out of the way' in a semi-rural setting near a growing suburban area. She thought the facility staff found it hard to identify, attract or involve family in the FC because it was physically isolated from surrounding communities. The FC was poorly attended in her facility with usually only three or four family members (sometimes not the same ones) present at any given meeting. She herself had a very hard time meeting and talking to other family members at any time outside the meetings due to her personal preoccupation with her mother's care, and she knew it was the same for other family members. She tried to mention the FC to them when she got a chance at some facility social events. Carol believed that low family participation was partly because high resident turnover (through re-placement or death) meant that family members often cycled through the facility relatively quickly,

sometimes in a matter of months. However, for her, it was a catch-22: the FC could not attract family participants because it was not run in such a way as to permit full family control and input, but because family participants were hard to involve, the FC ended up being managed more by the facility staff anyway. She believed that the FC therefore was not attractive to family members who wanted to meet in an independent manner without so much staff oversight (see below for discussion of staff roles in FCs).

Advertising or promoting FC as an activity for family members of those living in LTC was described as being done in a number of ways by family participants. Word of mouth and peer-to-peer recruitment was used widely at Linda's mother's nursing home by both family council members and by the staff liaison person who briefed family members when they arrived at the facility for their orientations. This type of lateral networking with families by FC members appeared to be somewhat less evident at Bryson's and Carol's nursing homes, but it was not clear why. Linda herself described how she made extra efforts to talk to any family member she personally encountered in the facility and encouraged them to get involved in the FC.

As I said to these people yesterday, Mum's new roommate's family, I said to her daughter: You know, our mums can't communicate and speak for themselves, so we have to be their advocates. I said, A community of voices has more say than one voice, so I said if you want to come to the family council, we've done all sorts of neat things ... It will be interesting to see if she comes to the January one.

Linda also alluded to the fact that, from her own observations of family-staff interactions, different levels of education or socio-economic status sometimes served as impediments to greater family involvement in carework and/or FCs. Linda implied that she was not judging less advantaged family members for their reluctance to participate. However, she implied that it would be very beneficial for family members who were economically or

educationally disadvantaged to be more aware of what was going on inside the facility so that they could have more input into their elders' care.

Linda's mother's nursing home was the only one that appeared to have relatively consistent attendance of around 10% of the residents' families or around 15 to 20 people (even though not at every meeting). She expressed satisfaction about this level of involvement, a perspective shared by staff as will be described below. It was difficult to tell why or how this relatively high participation level was achieved, but according to Linda's account, it might have been because so much emphasis was placed on recruiting for the FC via face-to-face encounters among family members, as well as highlighting it in the resident/family handbook, a welcome letter, and a brochure about the FC that family members received when their elder moved into the facility. Even though staff involvement in Linda's FC was somewhat challenging in other ways (as will be described below), the staff liaison in her mother's facility was highly committed to the FC and promoted the role of the FC in many of her routine activities.

Carol located one source of low family involvement at her facility in the initial sense of confusion or exclusion she had experienced when first entering the facility. However, Bryson and Linda, who both played leadership and coordination roles in their respective FCs and believed that they were now treated (to some extent as least) as peers and allies by their respective facilities, appeared less willing to make this linkage. Once they had achieved a certain comfort level or insider knowledge in the facility, over a period of several months or even years, they no longer felt like complete outsiders. It therefore seemed slightly harder for them to identify with those neophyte family members who still struggled to find their footing in the system -- an unconscious

exclusionary attitude which might itself have presented barriers against wider family involvement. Carol, on the other hand, in spite of several years' involvement, expressed a lower comfort level with her FC and the facility as a whole than Linda and Bryson, so she found it easier to understand and express why other family members might not want to join the FC and participate in something they did not trust or understand completely.

Not surprisingly, as a counterpart and complement to family views, well-functioning FCs were seen by the facility staff interviewed as being of strategic benefit to the facility, so to enhance their reputation around the quality of care via successful accreditation and/or licensing reports. Their perception was that keeping FC as well-organized as possible with clear guidelines and parameters made it easier for family members to be attracted and to participate. This included, in their view, keeping meetings brief and to-the-point, as well as focusing each meeting around an interesting educational topic that would appeal to family. In contrast, some educational events were seen as capable of scaring people off if they were seen as too demanding or intense. Facility staff stated several factors that in their view could be impediments to higher levels of FC participation: 1) the relatively short stay in LTC by many residents (due to entering at a frailer stage and dying within a shorter timeframe than in the past), which could make it difficult for FC members to be motivated to be engaged; 2) families not having any complaints about the facility, and therefore not being motivated to attend to express any concerns; and, 3) lack of time among busy family members as well as distance from their home to the facility.

Attracting participants to FC meetings therefore presents an on-going challenge and a conundrum for the three FC participants and for facility staff. They all openly

acknowledged that there were potentially many more ways to get the word out, but also expressed some confusion and many unanswered questions regarding what was perceived to be primarily family reluctance or recalcitrance. Bryson, Linda and Carol, in their accounts, alternated between criticizing family attitudes as the source of this reluctance and voicing concerns that the facilities could be doing a better job of reaching out to families, given that the facility staff (and not family members) had in some ways assumed the main responsibility for FC outreach. Facility staff also located many of the impediments to family involvement in the situations and attitudes of family members themselves. There appears to be limited critique on the part of FC participants or facility staff regarding the effects of institutional approaches and attitudes as a key source of this disjuncture.

Balancing personal and impersonal perspectives. Bryson, Linda and Carol all noted ongoing challenges faced by FCs with balancing what might be called personal and impersonal issues in relation to FC meetings and work. On the one hand, the apparent intrusion of personal concerns by FC participants into FC discussions and processes into what were considered as more formal meetings and procedures with an institutional or impersonal focus was judged to be sometimes irritating, unsettling or even inappropriate times. Personal concerns appeared to be any personal issues which arose directly from families' daily/nightly experiences of family carework and contained some strong emotional content. The mixing of personal complaints or questions with broader, non-specific impersonal or 'institutional' topics introduced an emotional element into the FC proceedings. To some FC participants, this intrusion undermined a balanced or thoughtful

process that was meant to be more neutral in nature, especially because it was aligned with official facility requirements.

As a long-term FC member with a largely positive view of his father's not-for-profit facility, Bryson appeared to be particularly unsympathetic about the desire for some family participants to give voice to their personal problems and challenges at FC meetings, even as the basis for broader discussions that concerned systemic issues. He expressed genuine compassion on many topics having to do with family carework and the struggles of families and residents in LTC, but he appeared to have little patience for the 'soft' side of family interactions that sometimes arose during FC meetings. In that sense at least, Bryson appeared to be more aligned with the facility's perspective, as he thought that strengthening the impersonal side of FC interactions was most beneficial for both families and the facility. He believed it was especially difficult if family personal comments in FC meetings were based on incorrect factual information about how the facility operated, and/or if the people voicing these concerns really needed to be redirected to the appropriate staff person for a discussion about their loved one's care.

So, there is a lot of discussion around the room about perceptions and first off, why do you let this fester? And you perceive that the home is not doing a good job, versus why don't you just go and talk to [the administrator]? If you really were concerned, you really didn't have to wait three months and come here I can't think of anything directly, but certainly for the first little while, it can be after the administrators have left, it became a bit of a bitch session. But from my perspective sitting there, most it had to do with that they didn't understand the policies and procedures in a place like this, if you actually follow them I wouldn't say I would defend the facility, but I would at least say to the person who was having a meltdown about care of their individual family member, that I think you need to talk to [the administrator], I think maybe you need to understand how the processes work for your loved one

Linda was likewise very cautious about the intrusion of personal items within the FC, but she ultimately took a slightly more nuanced view than Bryson. She believed that these intrusions were one of the reasons that people were sometimes reluctant to get involved in FC, as they created the perception that FC meetings were a form of support group that focused on emotional issues and could get easily sidetracked.

I think a lot of people when you say family council, it needs a new title, when you say family council, they're thinking meetings, nobody wants to go to a meeting because they think, number one they may have to have responsibilities. They want to sit for a long time, and I think some people think that family councils may be, excuse the expression, bitch sessions. Nobody wants to sit and listen to people complain all the time, you have enough stress in your head you don't need to listen to everybody else's.

On the other hand, as a mature person with her own challenging family carework experiences, she recognized that there were valid emotional reasons why people might be distressed enough to share their personal problems at FC meetings, especially given the lack of other outlets for them. Linda acknowledged that families often had no choice but to share personal experiences about the demands placed on them as family members, as well as express their confusion about how the facility operated and how the LTC system worked. Nonetheless, she believed that detailed discussion of these issues unfortunately did not fit easily within the frame of the FC as it functioned at her mother's facility, which had led to some conflict on the FC over time.

A couple of years ago, there was a lady whose husband was [living at the facility] and she would come, and every meeting, she would go on and on, so you'd answer the question but she would still say the same thing over and over and over again. And I felt sympathetic towards her, because you don't know what else she's dealing with in her life. She's living by herself, and then she comes in and she sees her husband not the way she used to see [him] and she probably needed more help than what a family council could give her. I felt she was rudely cut off and then she got up and left one of our meetings And then she was banned from our meetings [by the facility staff liaison], which I felt was not appropriate I mean, it

was annoying and everybody was, like, rolling their eyes [But] until you've walked those shoes, it's hard to judge I just felt the whole situation could have been handled differently and I don't think anyone should be banned from the family council.

Carol had a slightly different take on this issue. Her personal feelings and experiences as an outsider in relation to the facility made the presentation of collective concerns at FC meetings a delicate balancing act between what she perceived as her mother's for-profit facility's desire to depersonalize and thereby control FC meetings, and her own personal need to speak truth to power. She too was quite aware of the need to negotiate personal and nonpersonal items in the FC process: "I'm aware of that so I try always to keep it [general]. It's going to help Mum but it's also for the other residents". However, she was critical of the way in which staff members who chaired the FC appeared to shut down or minimize issues that she sincerely believed were broader concerns, but which were sometimes attributed as Carol's own personal concerns. She thought she was sometimes marginalized in the FC for being persistent and thorough about her concerns.

And that was the thing I brought up ... when I was at the [family] council I mentioned about the handwashing [for visitors]. I mentioned that too, the mask [placement of sterile masks for visitors at the front door of the facility], but they sort of blew that off, they said you really shouldn't come in, but you know what, if your loved one is going to pass away or is really sick, maybe you don't care for your mum or dad because they're already going, but for other residents you come in contact with. And I also said when they go to mealtime, for residents that have dementia and go to the bathroom on their own, they might forget to wash their hands. And I said, is there a way to go around when they're sitting at the table and give them a wipe or something. So, they said sort of, next time we're going to have it And I'm the only voice saying, there's not a lot of people sitting around the table listening, other family members, so who's the other eyes that are going to be on some of this stuff that I'm suggesting? And [the facility staff] maybe leading me to believe they will implement. But who's watching besides me, you know what I'm saying?

As a former nurse, Carol occasionally raised somewhat more technical issues at FCs than other family members, such as the absence of nursing staff from the building on certain shifts, and she was particularly concerned with accountability issues – for example, once an issue was raised at a FC meeting, how the follow up would be tracked and changes or adjustments reported back on by the facility to the FC members. Carol had observed first-hand situations where nurses who had done a double shift at the facility would sleep off-site and then come in when called during the night instead of being on duty in the building as required under LTC regulations, so she thought this needed to be raised. She also noted the need to keep consistent communication logs for staff on the various units. In addition, Carol had raised questions at the FC meetings about whether her mother’s facility was really adhering to its avowed vision and mission, which was purportedly based on a ‘progressive’ care model. In her view, the facility’s discourse and ways of managing family involvement and resident centred care contradicted these stated values. She was concerned that staff were not open to constructive critique around how some values were compromised in order to get things done as efficiently as possible.

Carol believed that raising these issues (which she said she always did in what she considered a “respectful” manner) made her unpopular, because it looked like her personal issues with her mother’s care were taking precedence over more general ideas for improvement. She was perceived as a “lone ranger”, in her words, even though she expressed firm principles about seeking ways to improve the facility as a whole via the FC and other forms of input. To support any points she raised, she documented and researched the background carefully so that it would not be seen as a personal outburst.

Carol kept a detailed log consisting of numerous notebooks and binders around all her interactions with her mother's facility, so she shared with me copies of letters and emails she wrote to the facility staff about key issues she observed both about her mother's care and the quality of care in the nursing home as a whole. In each letter, in addition to her personal items, she was careful to document everything precisely and she emphasized repeatedly how the items she raised were brought forward to benefit the quality of life for the entire nursing home, not only for her own mother.

The balancing of personal and impersonal concerns in FC meetings was also a particular concern for the facility staff, who expressed concerns about sometimes seeing meetings dominated by concerned, agitated or (in their view at least) 'negative' family members. In addition, facility staff thought that if any personal information about a facility resident was shared at the meetings, even as general background/context for discussing broader concerns, it might inadvertently violate provincial regulations related to privacy of health information. The issue of maintaining privacy and confidentiality in relation to FC meetings and activities is a separate but closely related topic which will be discussed below. From the facility staff standpoint, which reflected institutional values, there was also the need to follow procedures and ensure that decorum was maintained in order that meetings comply with an official tone. In their view they needed to be vigilant and discourage any untoward incidents from happening.

Overall, facility staff expressed strong wariness about any personal complaints being raised by families at meetings. In their view, airing information about personal issues or providing individual complaints was not considered the purpose of FCs. They emphasized that there were adequate mechanisms within most facilities for families to

raise more personal issues about individual care issues with unit managers, at annual care team meetings, or via an official complaints process. They said that some of their work at FC meetings was to redirect these concerns and provide information about the facility's official policy framework as well as alternative complaint channels.

While it is true that it is good practice in any bureaucratic or professional setting to standardize meeting procedures and maintain at least a façade of impersonality or neutrality, the application of these ideas to FC work is somewhat complicated in practice. In reality, due to the heavy and sometimes troubling emotional content of family carework (as described in such detail by Bryson, Carol and Linda), it could be very difficult for many personal experiences and feelings as a family member *not* to intrude into more formal processes for family involvement. Stepping back from these feelings (to some extent at least) via FC work could be a useful exercise for family members to put perspective on their daily concerns -- both Linda and Bryson attested to the positive effects of this approach. However, in the absence of dedicated family emotional support groups in LTC settings or other forms of family counselling services in Nova Scotia LTC facilities, FCs could by default become the focal point for airing emotional pains or personal grievances and misunderstandings.

At the same time, it is important to question whether the facilities' concerns to downplay the role of family emotions within FC dynamics could be a way of consciously or unconsciously maintaining distance between the professional discourses and attitudes that are the norm in LTC and the complicated lives of families and family carework. The taken-for-granted bureaucratic service delivery model in LTC, could also be perceived by some FC members (like Carol) as quashing critical or emotional responses that are still

based on valid concerns. The lack of officially sanctioned alternative spaces for families to voice personal concerns might also lead to contentious issues being raised in FC meetings. In addition, continuous raising of family personal issues might indicate gaps in the institutional approaches for incorporating family perspectives or input. For example, emotional family feedback within FC meetings might be based on valid feelings of family marginalization within LTC facilities that Bryson, Linda and Carol all voiced to one extent or another when recounting their experiences of family carework. As well, many important underlying issues, such as poor care practices or rigid institutional rules, are the ones most likely to give rise to emotional responses on the part of family. It is therefore in the best interests of facilities not to arbitrarily limit emotional content and to listen carefully to families when these reactions occur. Emotional issues can in fact be an important source of insights and further learning for all concerned if treated correctly.

Facility staff involvement. The complex dynamics surrounding the role and participation of facility staff in FC activities and meetings had some parallels in each of the three facilities where Carol, Linda and Bryson were active. However, there were also key differences in the situation and perceptions around staff involvement for the three FC participants. For example, Bryson's FC was the only one of the three with a habit of having a family-only session that was automatically built into the FC meeting. The FC meetings in his father's facility were normally chaired by a family member, but the facility Administrator attended the first part of the meeting to present official items and respond to any concerns – in effect, often co-chairing the meeting, it appeared. After this session, however, the Administrator left the room so that the family participants could have the time to discuss issues on their own for the last hour of the meeting. According to

Bryson, this session meant that there was an independent space for the families to share their issues privately. Bryson fully supported this approach, even though sometimes, to his personal frustration, this section of the meeting ended up focusing more on family complaints or on clearing up misunderstandings and incorrect assumptions among newer family participants about the operation of the facility.

Bryson believed that his FC was very fortunate to have an Administrator with a strong background and interest in community engagement, so his overall perception of the dynamics between facility staff and the FC was quite positive. He thought the FC in his father's facility had evolved over the past years to become deeper and more meaningful, and that this was partly due to the Administrator's open attitude.

... When I first joined the group, attendance was pretty thin, discussions tended to be 'he-said', 'she-said' at the end of it when were [discussing], what I call 'shit stuff' administratively, which could have been dealt with by the unit nurse And not a lot of meat, maybe some don't want meat like I do, but I think if you want to engage people in a meaningful activity, then you have to have a reasonably good agenda and the agenda has to have some [substance] ... I think that [the Administrator] says, if you have any good ideas ... but the bottom line is [the Administrator] is open to suggestions.

For this reason, he did not mind at all having the Administrator and usually other staff members attend the first part of every FC meeting. To him, steady staff involvement was a clear sign that the FC was being taken seriously and listened to by the senior managers of the facility.

Neither Carol's nor Linda's FC had an independent family-only session at the meetings without the staff present, even though families were of course free to interact in any way they chose outside the meetings themselves. However, it appeared to be usually quite difficult for family members to find other times to interact due to the stressful and

somewhat fragmented nature of family carework. At Carol's mother's facility, the facility Administrator or Director of Care normally set the date, developed the agenda, and then chaired each FC meeting. At least one of the senior staff members always attended and sometimes presented an educational component. Carol was very concerned that the structure and process of staff-led meetings ran contrary to the interests of many family members, and that this dynamic contributed to the difficulty of recruiting or involving family in meaningful ways.

The only thing that I think is that some family councils, because they're called family councils, they're more run by the family, but this one's run more by the [the facility], because they don't have family to run it. It's [run by] the Care Coordinator and the Administrator [is] always there. And [the Recreation Coordinator] ... takes the notes.

Carol expressed strong concerns about how staff dictated the structure of meetings as well as type and content of the educational events offered to families. As alluded to previously, Carol's experiences of raising tough questions in the meetings or even suggesting how the meetings could be run a different way were largely negative. The staff present at the FC meetings had a habit of deflecting or minimizing these concerns. She believed this was because having multiple staff present at the meetings (sometimes consisting of as many or more people than family members) enabled staff to present a united front as well as narrow the opportunities for meaningful participation by family members. Although she said some topics offered at the only two FC meetings organized by staff per year were important to her and other family members, they were not structured in such a way to really benefit FC participants.

The idea came down that they wanted to have more education type [in the meetings], so then I felt that if you take the slot and put an hour of education into that, well, where is the chance for someone like me or some other family member to present our [ideas] ... And it takes me awhile to

think over all that's been said and everything, so when I got home and thought about that, I thought that's not going to be very good because they're not going to give any time to families to say much of anything. And I found at the last meeting that we had just about a month ago, I found at that meeting it was pretty much driven by them.

Linda's FC meetings were chaired by a family participant, but the designated staff liaison person helped develop the agenda, attended each meeting, sometimes co-chaired the meetings (with a family member), intervened in meetings if they went off-topic, took minutes, and was the person ultimately in charge of all official communications that took place around the FC. In Linda's view, while some aspects of this multi-tasking by the staff liaison person were extremely positive, other roles were more problematic. For example, as noted above, Linda described how the staff person overseeing the FC had intervened inappropriately in one meeting to block some emotional comments made by a family member. The family member was asked to leave the meeting by the staff person, and then subsequently banned from future FC meetings without any explanation provided. Linda expressed deep concerns about the way this situation was dealt with, and she believed strongly that it should not have occurred in this way. However, she was also very diplomatic and polite, and so she sought to give the facility the benefit of the doubt.

So, we don't have complete autonomy, I feel. We are kind of limited in some things ... I know some people are reluctant to say things because they may feel some repercussions from it ... And I don't think [the staff liaison] has been detrimental to the functioning of the FC, although I feel that there are ... things that we've wanted to do that she's not given us the opportunity to explore more ...

Linda also described a situation where a facility staff member had unexpectedly taken over the process of a crucial FC meeting from family facilitators, with (in Linda's view) somewhat negative consequences for the dynamics and participation of family members. But she said that she "just sort of went with it, we still accomplished at the end

of the day when we wanted to accomplish”. Her own pragmatic view was that “life was too short” and it was more important to build bridges with the facility rather than risk alienation through any form of conflict with staff. She was not interested in confronting staff, as she believed it was much more fruitful to find points of collaboration and leave contentious issues behind. Interestingly, however, an email I received from Linda after I completed her interview noted that another situation that had arisen with the same staff liaison person involved in the meeting she described. In this email, she shared her growing concern that something would eventually need to be done to address some of the ambiguities around the level and type of staff involvement in the FC.

The facility staff interviewed were certainly well intentioned and expressed their keen interest in ensuring a smooth functioning FC. There is no doubt from their descriptions and that of FC participants that facility staff played a key role in getting FCs started, partly because they saw it as part of their regulatory mandate under DHW. This was in addition to achieving Accreditation Canada certification, which was another institutional motivating factor. They played their roles as FC facilitators and supporters to ensure family input and get FCs organized as well as keep them active to the extent possible. They saw their main tasks as providing appropriate background information and education about the facility structures, practices and policies, as well as stepping in as needed with specific skills, resources or expertise that might help the FCs along. Both staff people interviewed expressed strong interest in encouraging family ownership of FCs. Ironically, however, this had potential implications that might lead to tensions. For example, they said that they wanted family members to play a more active role in directing FC work. One facility staff person admitted that the training and background of

some LTC staff might prevent them from being able to listen to complaints or criticism from FC members, as they were not accustomed to family questioning and dialogue – this certainly appeared to have happened more than once in Carol’s FC meetings. The other facility worker readily described situations where she became active in chairing or directing FCs meetings so as to (in her view) assist family members. At the same time, she appeared to be unaware of the potential implications for FC openness and initiative of being so prominent in this role.

The role of facility staff on FCs therefore illustrates several contradictory or confusing elements in FC work, some of which are also linked to the information sharing and privacy or confidentiality issues discussed below. In Carol’s FC, staff played regular leadership and chairing roles mainly because of low participation of family members – although paradoxically, according to Carol, too much staff control might lessen the interest of family members in becoming involved. In Linda’s and Bryson’s FCs, the meetings were supposed to be chaired by family, but in Linda’s case, sometimes the key staff liaison person became more involved in this process than might be desirable because of the need to keep meetings on track and effective according to facility norms. Inevitably, the facility staff interviewed emphasized the regulatory context for FCs and the need to have FCs help the facility achieve its goals. The facilities and their liaison staff undoubtedly have a vested institutional interest in making sure that the FC meetings took place regularly and in an orderly fashion, which perhaps was more likely to happen when they are able to control (to a large extent) the outreach, recruitment, agenda, minutes and information sharing from the FC meetings (see below).

The three FCs researched therefore sometimes had the appearance of being closely organized by, for and around the facility's needs or requirements, rather than vice versa – this situation had pros and cons in the view of FC participants. All of them acknowledged that it was hard sometimes for family participants to take proactive leadership roles in FCs due to such issues as distance from the facility and the competing demands of home, employment and family carework. The staff liaison people therefore provided some continuity, although in Carol's facility there also appeared to be turnover in some of the key staff roles. But because selected staff attended all or most FC meetings (except for the second part of the meetings at Bryson's facility), it meant that it was difficult for FC members to discuss openly among themselves the pros and cons of various types of staff involvement. As a result of the overarching institutional imperatives (i.e. licensing requirements and accreditation standards), FC participants appeared to accept, for the most part, that staff had an unavoidable role to play – although it did not prevent them from highlighting the contradictions and tensions in this situation.

Information sharing, privacy and confidentiality. Bryson, Linda and Carol each alluded to challenges they observed or encountered with the strategies and procedures for sharing FC materials and/or for communicating information about the FC with the families connected to their respective nursing homes. Many of these concerns were interlinked with items raised about the staff role on FCs, as the staff liaison person for each FC appeared to be the main scribe for each group in terms of devising agendas, keeping minutes and doing other forms of routine administrative support. Another related concern was the effect of privacy and confidentiality regulations or norms over various types of information shared at FCs, as well as how FCs could function. These issues are

grouped together here for convenience and to tease out some of the linkages between them.

Bryson, Carol and Linda all described how various LTC facility protocols or norms for information sharing either directly or indirectly played a role in the ability of FC participants to access information as well as undertake routine FC recruitment and communication. On the positive side, all three family participants described how notices about upcoming FC meetings were routinely found in facility newsletters, monthly recreation activity calendars, and facility welcome packages for residents and families, as well as on specified bulletin boards where information was posted inside the building and (less frequently) on facility websites. I uncovered many examples of FC information sharing, which corroborated or added to their descriptions. The broad picture they presented was that it was mainly the facility staff who were in charge of promotion and information sharing about FC activities, because the facility covered the costs out of their operating budget to get the word out about FC meetings and do follow up. However, sometimes the methods and processes for information sharing around FCs were not clearly understood by family members. For example, for reasons that were not known to her, the circulation of FC minutes via electronic means was not practiced at all at Carol's mother's nursing home. Only physical copies of the minutes that FC members were provided to direct meeting participants and then placed on a public bulletin board inside the facility which Carol believed was poorly located. FC participants were explicitly told by staff not to share or reproduce these minutes electronically.

Carol thought that the confusing or somewhat truncated ways in which FC information was shared might be linked in some way to the hierarchical managerial

relations among staff in her facility. Because her mother's home was a privately-owned, for-profit nursing home, the management model seemed to her particularly complicated, with some of the senior managers located off-site and (in her view) rotated too rapidly through their positions. For example, the facility Administrator was not located in the facility -- this person was also responsible for managing two other facilities that were not close by and only visited Carol's mother's facility on a rotating basis. The designated liaison person for the FC often did not appear to be well informed about the facility, and the schedule and background for FC meetings were not shared consistently.

I bet you if I was to go and ask every family member of a resident in there, did they see that [the announcement of the FC meeting] on [the recreation calendar], they would probably say no. I was shocked when I saw the last time that they had announced in that way, because they said they were going to put the information on the back of calendar, but I think the [facility recreation staff] is in a hard spot, because it's driven by management, the upper ones. And if [the recreation staff] doesn't get the information or the say-so, then what can she do? Her hands are tied.

Carol requested the involved staff to improve the circulation of FC information out to other families, as she thought that this might help attract new participants to the FC meetings. She contended that part of the problem of attracting family members to the FC meetings could be due to the inadequate way that information was shared about the FC and its work. She told me that she raised this at the last FC meeting she attended, but that she received what she felt was a patronizing response that did not address the underlying reasons for her request.

I said to them at this last meeting, most of my generation are a little computer savvy. They laughed at that, they thought that was a funny statement, I guess. And I said, so why can't it [the information about the upcoming FC meeting] be sent [via email]? I don't know if they don't have the time, I said, What is the problem, when you have someone enter [the facility], could they [the front office] not ask the family member, Do you have an email address, do you mind if [we] send it out? But all they

were interested in [during the admission] process was getting the statement of payment for Mum's care, they wanted to be able to email that out.

Linda's mother's facility also had a public bulletin board for hard copies of FC information which anyone could see who came inside the facility for visits. It was curated by the staff liaison person for the FC in consultation with FC members. There was some general information about the FC on the facility website and in the revised resident/family handbook that Linda and other members of the FC were asked to provide some input on. Linda also mentioned how she personally promoted the FC via writing updates for the facility newsletter and other means of family outreach.

So, [the nursing home] gets one page every month [about the FC], I also put up posters in the elevators and on all the neighbourhoods, by the sign in book. Sometimes if I'm here, what I'll do is I'll make up little pieces of paper with the date and everything [about the next FC meeting] and put it by the sign in book, so people can pick it up.

Linda was convinced that having the facility's publicity materials highlight FC work was indicative of the facility's receptive attitude towards family involvement. On the other hand, as I will describe below, there were some ongoing challenges with broader circulation of the FC agenda and minutes via electronic means, which Linda admitted were somewhat contradictory.

In contrast, Bryson had pushed successfully in his father's facility for the FC minutes to be circulated electronically to FC participants, and for these materials also to be routinely posted and regularly updated on the website for his father's nursing home (he said that this latter item was in the works but he was confident it would be accomplished soon). He noted that the facility administrator already ensured that the FC agenda was regularly sent to all family members on the general facility email list (not only to family members who regularly attended the meetings), so this set a good

precedent. Bryson also believed that putting the full minutes for all FC meetings on the website was important so that those living away from the community could be made aware of what the FC did on a regular basis.

Well, this last meeting ... I said, first off, I'd like to understand why more people don't come, and that's on the back burner. But I said for those who can't come, why aren't the minutes and the agenda on the web page? [The administrator] says, Well, we put the minutes on the message boards. I said, Listen, as stupid as I am as a boomer, even I know how to go to a website, so if I can't get into the facility, if I'm living in Ontario, I can go on the website, pull up the agenda and the minutes and see what's discussed, and I can still contribute remotely by offering ... But there's nothing on the website that actually says, [so-and-so] is the chair, if you'd like to contact her. [The Administrator] said, That's a good idea. It hasn't been done yet, but I won't go away, so I'll poke [the Administrator] again ... I think there's an opportunity here, and the website is not bad, but most websites [have to be updated]. You just need access to show people what's been done and at least give them the opportunity to participate. And to me, that's money well spent.

Bryson's contention was that for it to be fully useful, FC information needed to be shared as widely and transparently as possible with people both inside and outside the facility. Although he had not encountered any overt opposition from the facility staff or the Administrator in advocating for this, he was aware that some organizational factors that he had absolutely no control over as a FC participant could also help determine when and whether it was actually done. These included the allocation of the time or staff resources required to ensure that the website was kept up to date, as well as facility privacy policies. However, he was fortunate that in his father's facility, standard mechanisms for routinely communicating with all family members (not just those on the FC) via email were already set up and that the Administrator was receptive to discussing other information sharing options.

Other concerns about the need to protect privacy and confidentiality in FC work were more subtle and harder to pin down, although all three family FC participants touched on these issues in one way or another. Linda told me, for example, that she had requested electronic versions of all recent FC meeting minutes to share with me when I interviewed her (in order to provide me with written information about what kind of activities the FC was involved in and how it functioned), but that she was told by the staff liaison person that it would not be possible to share this information with me due to perceived confidentiality concerns – presumably meaning that the names of FC members could not be shared outside the facility. In Linda’s mother’s facility, the staff liaison person circulated the FC agenda and minutes electronically only to those who attended each meeting and who had already signed a formal consent form so that their email address could be used for this purpose. Because not every family member at Linda’s mother’s facility attended FC meetings, they were not provided with the option of having their email addresses used to circulate this information, so they could not be informed about FC meetings in order to solicit wider attendance. Neither the agendas or minutes for FC meetings were on the facility website, for what were cited as confidentiality reasons.

Carol faced a parallel situation in her mother’s facility in that the email addresses of family members were used only for ‘official’ facility business. Therefore, she was informed that the list of family emails could not be used not for sharing FC information. FC meeting times were placed on the monthly recreation calendar. It was also unclear who developed the agendas in advance, or whether members of the FC were even consulted with in this process. Neither she nor others who attended the FC meetings

could obtain electronic versions of the FC minutes from the designated facility staff person. Due to purported privacy issues (according to staff she questioned about it), she had to request hard copies of the minutes from the files of the staff liaison person when she went in to visit the facility. The situations faced by Linda and Carol in terms of accessing FC information were in contrast to Bryson's facility, where as noted above, all family members received regular and ongoing communications about the FC via email (including meeting minutes) without having to sign any specific consent form or go through the staff liaison person.

From the facility standpoint, the FCs were considered in some way to be attached to official procedures in the facilities (although this was admittedly a gray area), so their work had to be documented in a reliable form that provided concrete evidence about their functions. This presumably gave rise to the need to have staff largely responsible for documenting the meeting schedules, agendas and minutes. The staff people I interviewed both said that they were keen to have some publicity information shared about the FC meetings, so as to attract new members and keep existing members coming back. There did not appear to be any official policy barriers towards having FC information (that is, agendas and minutes) routinely sent out to all family members connected to the facility to keep them informed. But, the staff liaison person in Linda's mother's facility said that it would not be appropriate for families to receive electronic information about FC unless they had said explicitly that they wanted to learn more about it. In Carol's mother's facility, the reluctance on the part of staff to share some FC information was taken one step further, in that even electronic information about the FCs was treated with circumspection, but it was not clear why. One challenge around information sharing may

simply be lack of time for some of the staff people involved to manage or coordinate the process. In addition, according to facility staff liaison people, it was certainly necessary to have the FC support or facilitation role officially integrated into someone's job description in order to get routines established and followed through.

The issue of information sharing is further complicated by the facilities' preoccupations with certain privacy/confidentiality obligations, which in fact appeared to be inconsistently or poorly understood when applied to FCs – this will be discussed in more detail in the final part of this chapter. According to one of the FC staff liaison I interviewed, the protocol of having a formal consent form for FC members to receive FC emails was not necessarily linked directly to health system requirements for protection of personal health information, but (in her view at least) a case could theoretically arise where someone who participated in a FC meeting would not want to have their name shared with other residents and families. However, no explanation was offered about why seemingly non-controversial information such as someone's name, which could easily be found out in other ways, might be a confidentiality issue. What might be assumed to be routine open access and public documents related to the FCs is sometimes inexplicably treated as private and potentially in violation of health privacy regulations.

Not surprisingly, the two FC staff liaison persons interviewed also expressed what could be termed a more risk-averse position towards sharing of FC documents arising from professional discourse around how to adhere to institutional procedures and policies. As will be discussed in the final part of Chapter Four, these concerns exist in the health care system due to official legislation and regulations around confidentiality of health information. They therefore inevitably form part of the context of LTC. It may be

that in the interests of preventing any confidential information about residents from being inadvertently shared at FC meetings, facilities and their staff ‘err on the side of caution’, so as not to inadvertently contravene any professional or health system norms. For example, facility staff expressed how important it is to be vigilant about discussions taking place at FC meetings so that privacy concerns are not mistakenly violated by reference to any personal or health-related information about residents. They were mainly concerned that family members might not only share personal information about their own people (which might be worrisome but could not necessarily be prevented), but also probe for information or ask questions about other residents (in terms of diet, medication, care regimes or other resident-specific personal information) in order to understand some aspect of policies or procedures. In their perceived role of overseeing FCs, facility staff believe they have a responsibility to ensure that discussions stay within certain parameters. This is a well-intentioned aim, but possibly could also shut down information sharing that supports FC outreach, activities, recruitment and expansion.

Family critique and facility accountability. Linda, Carol and Bryson each noted successes but also challenges and inconsistencies with how their ideas for improvement as FC participants were ultimately treated by their respective facilities. As described above, there were many ways in which their FCs had provided constructive input that was acted on (to some extent at least) by each facility. However, not surprisingly, each of the FC participants came across limitations or barriers that impinged on their efforts to suggest changes and advocate for facility and system improvement. The reasons for these limitations were sometimes precisely defined by the facilities by reference to their policies and/or the requirements of the larger LTC context, but at other times the reasons

for inaction or weak responses by the facilities were vague and not understood clearly by FC participants. These varied experiences highlighted some facility ambivalence about the extent to which FC members could or should act independently to have non-institutional perspectives put forward regarding official LTC functions, practices and structures that are outside their direct control or knowledge.

As noted earlier in this chapter, both Linda and Bryson described efforts made by FC members in their parents' facilities to improve the family orientation process as well as the materials shared with family when an elder was admitted to a facility. This was successful in Bryson's father's facility, where FC members were invited to provide peer-to-peer orientation tours of the facility to new family members: "So now I'm available if a family member wants to meet with another family member to go through the building, to introduce them or if you have questions that you would not want to ask the administrator or a staff member, you can ask me." However, in Linda's mother's facility, while the FC suggested (at her urging) that something similar be done around peer-to-peer orientation as well as other kinds of outreach by families to families, the suggestions were not accepted. Similar to some of the other ambiguities around privacy and confidentiality, the main reason provided by the facility was that there could be sharing of third-party information that might inadvertently violate regulations.

I'm still trying to advocate [for] this, it would have been really nice to have been met by another family member [when my mother and I first entered the facility]. If somebody had come in and said, Oh, I'm so glad your mum is moving here, we've had such a great experience, these are a few hints, this is what I would do if I were you ... Haven't been able to do that yet I felt it would be really nice to send out some sympathy cards to family members, but we were told we're not allowed to do that because that's a 'privacy' issue. My suggestion of having a family council member contact a new family member personally and speak with them, [also] a 'privacy' issue.

This situation did not seem logical to Linda, as in her view this seemed to be precisely the type of outreach and support that FC members needed to be involved in. Her perception of the facility's response to the FC's request was that it was not, in fact, based on any valid reason. On the other hand, as previously noted, she believed it was important not to dwell on issues that did not appear to have easy solutions due to their embeddedness in larger institutional structures. Carol also identified a similar need for an improved family-centred orientation process in her mother's facility (based on her own and others' experiences of the facility admissions process) and then tried to raise it via her FC, but again with no success.

[They could say to me], would you be willing if there's a family member that is struggling and even if they're just gone through the ropes, but they're struggling and it's a month ... could they contact you? But I've never been asked.

Carol and Linda both described how they provided input on the process and content of facility-run family satisfaction surveys. These were administered by each of their facilities (as well as Bryson's) once per year to family members. These surveys are now commonly used by facilities seeking to improve their family input, in order to fulfill Accreditation Canada quality standards as well as meet the stated and implied family-centric aspects of the provincial LTC program requirements. Somewhat surprisingly, given that they are the main quasi-official tools used by facilities to solicit broad family feedback, the family satisfaction surveys were designed and administered without any FC input. Neither were results of family satisfaction surveys discussed with the FCs in order to provide additional input and analysis. The surveys were under the direction of facility staff. The facilities (according to what Linda, Carol and Bryson shared) appeared not to

be under any obligation to involve the FCs in their design, distribution or analysis except to report on the final results of the surveys to FC members. Carol and Linda both identified problems with the survey process and attempted to give feedback as individuals and/or via their respective FCs to improve them. They each noted that the family surveys (which used a standardized template provided possibly by Accreditation Canada or some other authority) only allowed limited responses, with little room for detailed family comments, and that they were administered somewhat carelessly and selectively by staff.

Carol was particularly concerned that the surveys were not circulated electronically to all family members connected with the facility, so there was no way of knowing the rate of response. To her, this meant that the results of the survey had little value, because they did not specify the number of family members involved and to which sections of the facility their comments applied. To help improve the family satisfaction surveys in her mother's facility, Carol prepared a detailed critique of the family survey form that she shared with staff at a FC meeting, indicating where she believed there was room for improvement. Her detailed and specific suggestions included: stating the deadline for responses; asking what specific part of the facility the family member lived in; providing information about the length of time the family member had lived at the facility; indicating whether family visits took place on weekdays or evenings, whether they knew who the administrator was and if administrator knew the name of family members; and indicating clearly what number of family members the survey responses covered. Her contention was that these responses would provide a more precise picture of what was really going on in the facility. Unfortunately, however, Carol received no formal response on these suggestions and no indication that the family satisfaction could

be changed. Because the FCs were not well attended at her facility and they only took place twice a year, she was unable to foster the critical mass of FC input to have her concerns addressed.

Linda described similar challenges with the quality and scope of the family satisfaction surveys. She ignored early versions of the annual survey, but she then gave detailed individual comments that she believed actually had helped improve subsequent versions, although she was not sure exactly how the survey was handled by facility staff.

The first couple of years, I would take the family survey, and I would look at it Can't answer those questions because I don't know, I'm not there. And I can't go ask my mother, because she can't communicate to me [what she sees happening]. So, the first year, I just threw it out and I didn't do anything. The second year, I filled it out and I put little notes in ... So, then the third year ... I said: This survey is the same one from the last few years, it's just not appropriate. It's just not directing the questions the way it should be. So, I started a document saying, you know, I explained why I couldn't fill it out, but these are my comments based on the categories that you have and maybe these are some questions you might want to ask. The survey this year was much easier to fill out, they changed it.

Bryson said he had little direct knowledge about the family surveys, except that they took place and that the final results or findings were posted on facility bulletin boards.

However, he was mainly interested in the potential of using family surveys to find out what might motivate more family members to get actively involved in FC meetings and activities. In his father's facility, he believed that the potential for more family input was quite favourable, whether via using family surveys or simply talking informally to family members who came to visit.

Another cluster of issues identified by the standpoint participants had to do with the work of FC participants in raising questions and suggestions regarding institutional structures, staffing roles/responsibilities, and accountability mechanisms in the facilities.

Bryson said he was able to offer comments on the skill levels, strengths and weaknesses of staff in his father's facility, which he again attributed to the facility Administrator's 'open door' policy and general receptiveness to family input. For example, when Bryson sometimes observed facility staff doing what he considered to be particularly positive or negative activities around the delivery of care to elders, he was able to go directly to the administrator himself and share his observations of licensed staff. The comments Bryson offered did not normally go through the FC (although he sometimes raised them there), but his own credibility as a key FC member no doubt reinforced his ability to be an informal spokesperson on behalf of families with the facility's senior managers.

I'm doing smile checks here all the time. You can take the pulse of a building like this very quickly, [if] staff are stressed for whatever reason If you don't have good staff or happy staff, I mean ... when I catch somebody doing something good, I thank them. I acknowledge it. Well, by the same token, if they're doing a shitty job, I don't tell them directly but I go to the boss, and say, I'm not going to give you a name here unless it's really bad, but I think maybe you want to pay attention to X. [The Administrator] knows it's 80-20 everywhere, 80% of the people are doing a great job and 20% [laughs].

Bryson had observed many variations in the commitment and attention to care exhibited by many different staff members. At the same time, he was very aware of the effects of staffing shortages in his father's facility due to both lack of human resources in the province as well as the structure of funding models for LTC. He expressed sympathy for the challenges the facility faced with negotiating these broader issues, although he was aware of the lack of in-depth understanding of family members about the facility's constraints. Bryson was strongly concerned that the critical perspectives from a family standpoint not be lost and he strongly encouraged these ideas to be put forward.

So, I'm driving questions to [the Administrator], maybe you'd like to address this at the next FC meeting ... Great! That's what I think other

family members should be doing, driving these bigger issues, not to mention the smaller ones ... Because some people will say to me, "Well, I'm scared to say something, because when I leave, what will they do to my loved one?" I said, I find that really difficult to understand. No one wants to get anyone in trouble here, but by the same token, you are obligated if you think there is something wrong, then you should go to the Administrator and ask, or the charge nurse, or whoever, that you have a concern. The people here are very open, so my experience with everything that I'm not clear about, I just go out and ask and I get an answer.

Linda and Carol expressed similar desires for FC participants to be able to put forward critical issues about the 'philosophy of care' or overall approach to delivering services in each facility, but in different ways. Items they both raised were the difficulty of identifying individual staff, and what they perceived as the lack of clear information about staff roles as well as the facility's overall organizational structure. Other on-going challenges that they noted on behalf of FC participants related to what they perceived as relatively high levels of both managerial and frontline staff turnover. They each expressed confusion about how staff shift changes and rotations were handled due to the fact that (again based on FC feedback) these seemed to cause some disruptions in frontline care. Linda noted: "See that's the problem, not a lot of people know who to go to [to address individual issues]. So ... I asked [at the FC meeting] for a copy of the chain of command type of thing, so we're getting an updated copy of that."

Carol's experience was that there was no organizational chart available for her mother's facility either on the website or posted in the lobby of the building, so she raised this point more than once at FC meetings. Her underlying concern was that the FC's lack of information about institutional structures and roles undermined the ability of members to offer meaningful critique and hold the facilities accountable for quality of elder care.

That's the other thing I've mentioned to [the staff] at family councils, why they cannot put their people up on the website with their name and their

position, and when they do leave, you don't have to say where they've gone, you don't have to say why they've left, but just that people know. 'Cause I didn't find out that [the Care Coordinator] ... she wasn't here maybe a year, and all of a sudden she was gone. And I was shocked when I went ... to speak to her, well, she's no longer here.

In both Carol's and Linda's views, staff changes without clear communications to families not only led to confusion about how the facility functioned, but it also undermined accountability of staff to family members. As Linda stated,

We [the FC] talked about it and I brought this up, not every caregiver is a perfect match for a resident, and I wanted to see a pattern, because some days I would go in, and Mum would be very stressed out, and other days I'd go in, and ... she's in a fantastic mood. So, if there's a pattern of her not being comfortable with one particular caregiver, then she should never have that caregiver ... And I said to them ... all the caregivers need to think, if this was my mother, my father, my husband, my partner, how would I want them treated?

Accordingly, Carol and Linda both encouraged their FCs to do more education about staff roles and the facilities' ways of deploying staff, as well as help identify key leadership staff who could be mobilized as family allies. This strategy was somewhat more successful in the case of Linda's facility, but overall there were mixed results in encouraging greater openness about staff roles and accountability.

One concrete example that Linda shared was that when she first entered her mother's facility, the staff did not wear identification badges, so that it was impossible to know 'who was who' and what their tasks and roles were in relation to her mother's care. Based on these observations and those of other FC participants, her FC lobbied over a period of over two years to have facility staff wear name tags as a way of enhancing families' personal knowledge about and respect for staff (by being able to call them by their names), as well as accountability. Although this new practice was accepted in principle by the facility, it was not able to be rapidly or consistently applied. According to

Linda, the discussion about identifying staff had to be revisited for reasons that she implied had to do with the structure of decision making and authority in the facility.

So they did get the name tags ... it was about a year and a half before they did get the name tags, but then we started noticing, not everybody's wearing their name tags but yet they all have name tags, so that's why it was brought up again ... So, we talked about the name tags again, because some of the staff are not wearing them. We've actually found ... more staff [are] wearing them [now], so it was brought up individually with all the [direct] managers [by the social worker] They all wear name tags now. And we're all saying, it has improved communication with staff because now I can look at somebody and say, "Oh, [name], how nice to see you again!" You can't always remember everybody's name. We're finding that when you call a staff member by their name, they're more receptive and warmer, talking to you.

Linda's FC also requested that certain key staff members be present at meetings to make a brief presentation about their area of work. The FC members wanted them to clarify their specific managerial responsibilities and respond to family questions or concerns about the structures and roles in the facility. Linda believed this initiative was successful both in raising family awareness about the accountability structure of the facility, as well as ensuring more general attention was given to improving individual care. In offering suggestions about how to improve some facility systems, her FC had to negotiate some regulatory concerns on the part of the facility and the larger LTC. These issues were eventually resolved in the favour of families' needs.

One of the things we felt would give accountability would be the fact that we should all know who our loved one's caregiver is for the day. So, I had made the suggestion they have a whiteboard at the nurses' station, as they do at hospitals with the names of her caregivers for today. Or do it in the resident's room above the bed Because in my experience I would up to the desk, "Do you know who Mum's caregiver is today?". "No, I just came on [shift], no, I don't know". Even the LPN for some reason would not know, so you start to wonder, do they not want us to know? So, when I brought this up [at the FC], I was told, "Oh no, you can't do that, because that's a privacy issue". Well, thank goodness another [FC participant] said, "It can't be a privacy issue [because] all the hospitals have whiteboards

and it's in the patients' rooms and it's at the nurse's station, so anybody can read it, so it's not a privacy issue".

Like Linda, Carol expressed concerns that her mother's facility did not regularly update family participants in FC meetings on key staff changes. She noted relatively frequent turnover in managerial staff whom families could approach to discuss individual concerns and complaints about care. She saw this as a major gap in the facility's accountability structure as well as undermining the potential for constructive family input on how the care process was managed and implemented. Related to this, she expressed concerns that items discussed at FCs meetings and apparently agreed upon were often not followed through on by staff.

When you're in [FC] meetings, then you say [to staff], so what are we going to do about this? Don't just let them say it, but ... hold them accountable, say, how are we going to do this, what's our game plan to get this accomplished? [Like], the dietician at the last [FC] meeting said that the menu could be posted on-line, and I figured that was going to be done, but it hasn't [been]. I don't know if they're just extremely busy, or I don't know what the reasons are.

Linda, Bryson and Carol all tried to be as fair as possible to facility staff members and managers in proffering their organizational critiques, as well as be aware of the complex emotional dynamics given that staff were also under stress in many instances. Linda, for example, tried hard to maintain an egalitarian attitude and empathy: "And us as family, we have to put ourselves in the shoes of the staff too. You know, they're being pulled in ten different direction, with all sorts of different families, so we have to be cognitive of that". At both Linda's and Bryson's parents' facilities, the FC participants made efforts to either formally or informally provide thanks either to individual staff or collectively to the facility staff team.

Carol thought from her observations that many frontline care staff were overworked and undertrained at her facility, especially in terms of education around new techniques for helping those with memory loss. She believed that the hierarchical staff structure meant it was hard to implement many suggestions or changes. She also pointed out the extent to which, in her opinion, the actual interactions that took place in the facility were often not consistent with the care philosophy stated on the facility website. Carol often raised this point both in FC meetings and in emails she wrote to staff that documented the apparent contradictions between their actions and the stated ideals on the facility website, for example. Linda and Bryson were also very concerned that more could be done to help their parents with memory loss, and that individual facilities as well as the system as a whole were failing to address these complex needs due to a combination of lack of funding, gaps in staff training, and the need to consider new approaches to care. Bryson noted how little stimulation the environment in his father's facility provided for those with memory loss, in spite of his otherwise very positive view of what happened there.

Because if I walked you through this building, it's very sterile with regards to, how do I put it ... there's no stimulation This place has a lot of artwork, but in the [dementia unit] ... they couldn't have anything on the walls ... I don't know if a dementia patient would get satisfaction from seeing artwork, but I don't think it would hurt. And certainly, for me personally, going back there for two years while my father was there ... And it's not as if we can't afford artwork because we've got it everywhere else in the facility, steal a few and put them back there. It's improved somewhat, but to me You could walk into the room right now, they're sitting in their wheelchairs ... So how is it that you're going to enrich this environment for people at various stages in this dementia trip. I don't know but ... do you give up? I don't know. I don't think you should.

Linda, Carol and Bryson, each in their own way, emphasized that family input via the FC could play a role in facility improvements, and that furthermore, there should be

some facility accountability towards the FC for suggestions or ideas put forward. In general, they were concerned that family input should not be treated as a token exercise led by the facility but as a genuine dialogue between the facility and FCs. Linda's example of the feedback process around staff name tags, for instance, seemed to imply that whereas the facility might agree in principle to various changes, actually getting them implemented and reporting back to FC was a challenge.

In some cases, based on what they described, there seemed to be a strong desire on the part of some FC participants to play a larger role in getting more insights from family members and sharing them with the facilities, through family surveys or other means, rather than rely on the facilities alone to drive these processes. They were concerned that FC input to the facilities about how to improve items like the care philosophy or staff capacities to support elders experiencing memory loss be taken seriously. Useful dialogue about how the facility worked and how to further improve it seemed to have happened more frequently with Bryson's and Linda's FC than with Carol's. For example, in Linda's mother's facility, the FC had facilitated annual sessions for family members to systematically brainstorm ways to improve the facility, then take this feedback in an organized manner back to the facility's management team.

The facility staff people interviewed both voiced support for receiving input from families via FCs. However, from what they said there appeared to be a limited formal obligation on the part of facilities to strengthen their dialogue with and accountability towards FCs and their participants. Whether FC feedback was received and integrated was highly dependent on the enabling circumstances in the facility. From the staff perspective, FCs were seen mainly as a regulatory obligation for family input that, in

spite of best intentions, could often be fulfilled without inviting deeper critical feedback. The ability to listen and respond to FC concerns appeared to be at least partly dependent on both the personal attitudes and professional background of individual staff. Staff expressed strong interest in strengthening the educational component of FC meetings, in order to attract more participation and to be as helpful to family members as possible – the main intent being, perhaps, to ensure that families were well-adapted to facility needs. In their view, education for FCs should involve relatively standard topics or simple fact sharing, similar to what could be easily incorporated into admissions packages or family handbooks.

While both staff liaison people noted the importance of a participatory element in FC meetings, they also expressed concerns that the meetings be constructive and help build family-facility allegiances. One staff person emphasized, in a very well-intentioned way, the need to build a “symbiotic relationship” between FCs and facilities, defined as assisting with public advocacy on behalf of the facility and helping the facility present a good façade to the public. This person noted a general need to distrust media reports about LTC that (in their words) “blow things out of proportion” in cases of abuse. FCs were therefore seen mainly by staff as way of gaining allegiances to protect institutional reputation and providing a counter-narrative to negative media coverage. Furthermore, the same person stated that FCs could help improve services, for the benefit of the facility as a whole, but added almost as an afterthought that FC could be for the benefit of families too.

Bryson, Carol and Linda all hoped that providing critical but well-intentioned input as FC participants and family careworkers about issues in their respective facilities

would help improve care practices and increase dialogue and transparency between family careworkers and facilities. Many of the challenges they encountered, however, are ultimately internal organizational items about which the FC participants normally have little direct knowledge or control, but which provide the context for their family carework and their ability to be effective FC participants. The input provided by FC participants is, in general, intended to help the nursing homes get better at what they do, and thereby protect their loved ones who live there. However, whenever FC members encounter significant institutional barriers to their FC work, they ultimately have to accept the situation as it is and then move on. Due to their lack of involvement in official discourses and policies as FC participants, they have little or no leverage over what happened or how things are done, especially around broader organizational or human resources issues. For the most part, due to their structural location at the margins of the official LTC system, FC participants can usually only hope that some family feedback is taken into consideration by the facility through maintaining positive interpersonal relationships with individual staff.

Policy and Regulatory Texts for Family Councils

The FC experiences of Linda, Carol and Bryson provide numerous glimpses of the formal framework of the LTC system – that is, the extra-local institutional regime (Smith, 2005) consisting of policies, regulations, norms and standards through which LTC facilities across the province are administered and managed. In addition to some key policy texts encountered directly by them, there are many other unseen framework documents or tools that help coordinate (across different sites or locations in a multi-faceted institutional system) family members' daily/nightly experiences of family

carework within the LTC system. This larger institutional construct, which as we have seen is largely unknown to most family members when they first interact with the LTC system, gradually emerges into view through the processes of family carework and FC involvement at the facility level, as noted in Linda's, Bryson's and Carol's accounts.

Whether FC participants completely understand this broader institutional policy framework or not, their interactions with policies, texts, forms and/or professional discourses have many profound effects on their FC experiences. These documents, listed in Appendix B, constitute a set of little known, usually invisible and seldom interrogated but highly relevant institutional guidelines surrounding FCs in Nova Scotia LTC.

Due to the large number of policy and regulatory texts in the formal institutional context surrounding FCs, I analyzed two key texts to understand their implications for the institutional relations arising from FC work. These are: 1) the LTC Program Requirements document used in licensing of LTC facilities; and 2) the provincial Personal Health Information Action (PHIA).

LTC Program Requirements. The LTC Program Requirements are a type of 'boss text', in the sense that FC existence and roles at the present time derive mainly from this key document (Burstow, 2016). Most managerial, administrative and coordination activities within facilities are in some way linked to the DHW LTC Program Requirements document, which, as noted previously, provides the regulatory framework for LTC facility licensing inspections in Nova Scotia conducted annually by DHW. As described in Chapter Two, FCs exist officially at the present time in Nova Scotia only because the 2007 version of the LTC Program Requirements required all newly built nursing homes (i.e. those funded via public-private partnerships in the late 2000s) to

encourage resident and family councils to form and meet regularly. This provision is now mandatory as one of the licensing standards as of 2016.

All three FC participants in the research were aware (to some extent at least) that the LTC Program Requirements provided the official quality standards for nursing homes in the province, as well as constituting the administrative framework for licensing inspections by DHW. Both Linda's mother and Bryson's father were housed in older facilities where they said there was some sporadic FC activity prior to 2015-2016, but it appeared that the FCs became more active in these facilities (with increased staff support and involvement) after that, due to the LTC Program Requirements provision. Carol's mother's facility was a new nursing home built around 2010 and should have had a FC dating from that time, but according to the information that she shared, more impetus occurred there around 2016 as well. As previously noted in Chapter Two, lack of public access to FC files within facilities, as well as very limited public data about facility licensing inspections from DHW at the present time, means there is no way to gauge the extent to which FCs have evolved, exist or are currently active across the LTC sector.

The current published version of the LTC Program Requirements define FCs as "... a forum for families to have a voice in decisions that affect them and their loved ones and to improve the quality of residents' lives" (Government of Nova Scotia, 2019, p. 8). Under Section 7.3, various general roles/responsibilities of FCs are listed. The overall requirement of Section 7.3 is that FCs "... are provided with regular opportunities to meet with management to discuss issues related to the care and well-being of residents and the safety and security of the home" (Government of Nova Scotia, 2019, p. 26). Specific provisions include: close cooperation with the facility resident council as well as a

documented purpose and terms of reference (7.3.1); formal policies and procedures governing the work of the FC must exist (7.3.2); FCs should meet at least twice annually, and families must be notified in advance of meetings and be encouraged to participate (7.3.3); the facility administrator attends at least two FC meetings per year (7.3.4); family members chair the FC meeting “whenever possible” (7.3.5); and minutes are recorded and are “easily accessible for viewing” (7.3.6). Aside from the overall FC definition and the above clauses, there is no other information available from the provincial government about FCs, although it is implied throughout the document that multiple forms of family engagement should be encouraged and supported in LTC.

The existence of Section 7.3 can be viewed as largely positive or constructive, in that it does provide an official regulatory foundation for FCs. Perhaps not surprisingly for this type of regulatory text, however, the section is also vaguely worded and leaves many details about the mechanics of FC functioning to be figured out on a case-by-case basis by facility staff and FC participants. This may account, in part, for some of the ambivalent and contested aspects of FC work described by Bryson, Carol and Linda.

There may, of course, be many advantages, from both the facility and family perspectives, if substantial leeway exists for the structure and functions of FCs to be customized according to local circumstances and priorities. Many specific items about the work and structure of FCs would not easily be included in a brief regulatory document like the LTC Program Requirements, so the specific needs and roles of FCs would likely need to be researched and adapted at the discretion of participants in each facility. This includes items such as the appropriate number of meetings to hold each year, whether staff should routinely chair meetings or not, how many meetings the facility staff

members should attend and what role they should play, how to advertise meetings to family members, what style of educational events are most needed or helpful from the family perspective, and how best to attract and foster regular family leadership and participation.

Nonetheless, the very vagueness of the FC provisions in the LTC Program Requirements can lead to considerable confusion or ambiguity. For example, nothing in Section 7.3 explicitly mentions the need for FC independence, in contrast to how FCs are framed in some other resources and jurisdictions (as noted in Chapter Two). Neither are family needs, viewpoints, priorities and preferences stated as being fundamental to the formation and functioning of FCs. Finally, the LTC Program Requirements do not specify (in any meaningful detail) what type of governance structure or operating mechanism might give preference to family leadership or ownership within FCs. Due to the above gaps and ambiguities, the broad provisions of Section 7.3 are quite open to interpretation by facility staff members involved in forming or running FCs, especially where there is relatively low family involvement.

The lack of precision in how the provisions of Section 7.3 can be interpreted at the facility level, in terms of the roles and responsibilities of FC members as well as facility administrators and staff, comes through quite clearly in the accounts of the FC participants. For example, as we saw, Carol's FC was consistently chaired by senior facility staff who acted to compensate for weak family participation. However, there appeared (in Carol's view) to be little genuine desire on their part to critically explore the factors or issues behind that lack of family participation, or to even question the implications of having senior staff so closely involved. Both Bryson's and Linda's FCs

experienced some successes in increasing the level of FC participation, possibly due to having more meetings per year as well as the emphasis on actively encouraging facility-family dialogue, but in neither case did facility staff deeply question the implications of being the main drivers or facilitators of FC work.

This situation may operate, in the larger scheme of things, to the institution's advantage. The inexactness of Section 7.3 (as well as the absence of other readily available independent resources about FCs) means that basic licensing requirements can be fulfilled without questioning many underlying institutional assumptions or norms, for example, concerning the somewhat 'subordinate' or secondary role family careworkers (and, by extension, FCs). For example, based on the information shared by both FC members and facility staff persons, there did not appear to be many openings for facility workers to examine their largely top-down approach to soliciting and/or maintaining FC engagement. Section 7.3. of the LTC Program Requirements aims to strengthen family involvement and encourage FC formation and functioning. However, because it is quite vague, it may also inadvertently reinforce some prevailing institutional attitudes or practices (as noted in Chapter Two) around the need to manage or establish limits around family involvement via FCs.

Personal Health Information Act. A second key institutional text is the Nova Scotia Personal Health Information Act (PHIA) (Government of Nova Scotia, 2010). Questions or confusion about the privacy and confidentiality of information related to FCs arose several times in interviews with both FC members and facility staff. I was curious to understand to what extent the formal legislative framework for privacy and confidentiality in the health sector actually was related to some of the concrete issues

voiced by research participants. Some sections of the LTC Program Requirements document also reference the PHIA, in terms of the need to respect the privacy and confidentiality of various personal health information encountered in LTC facilities.

The PHIA and its related regulations, along with detailed background and guidance materials produced by the Office of the Information and Privacy Commissioner (OIPC), form the basis for a complex infrastructure surrounding the protection of anything having to do with “information related to the health care sought by or provided to that individual” (Office of the Information and Privacy Commissioner, n.d., p.1). This includes anything concerning an individual’s current health or health history, health care assessments, health treatments including medications, identification of an individual’s health care providers, and an individual’s health card number, test results and/or health registration materials. The PHIA and its regulations are designed to ensure that service providers or ‘custodians’ (in the language of the act) take “reasonable steps to protect the confidentiality of personal health information in its custody as well as the privacy of the individual to whom the information applies” (Office of the Information and Privacy Commissioner, n.d., p.2). It is important to note, however, that the OIPC’s interpretation is that what can be deemed ‘reasonable’ also depends on the type and sensitivity of information.

Strictly speaking, the PHIA applies precisely to protecting *personal* health information, such as the technical assessments, diagnostic notes, professional instructions or test results held in someone’s unique health file either electronically or in printed form. It is worth noting that there are some qualifications and exclusions in the PHIA. According to Section 4 of the PHIA, some items that are not technically concerned with

personal health in the narrow sense might be kept in the same location or filed in conjunction with official health records, and therefore could still be governed by the Act. Section 4.2 of the PHIA makes clear that any information collected or maintained by service providers that do *not* have a direct bearing on individual's personal health care would likely *not* fall under the authority of official privacy regulations.

Because some general challenges around information-sharing for FCs were touched on by all three FC participants and by facility staff, it is important to understand to what extent these situations fall under the PHIA domain and in what ways. There does appear to be some confusion about how the work of FCs intersects with general privacy regulations (like PHIA) that form the institutional backdrop for LTC, including whether or not the PHIA would have any bearing on FC work at all. As recounted by FC participants, quite wide variations exist in protocols and norms for documenting and publicizing FC meetings, as well as how to protect the privacy or confidentiality of FC participants and their deliberations. For example, in Linda's mother's facility, the facility staff liaison person said one reason it was necessary for staff to attend all FC meetings was because family members might inadvertently share confidential health information about either their own family members and/or initiate discussions about the health situation or care regimes of other residents. Apparently in order to maintain extra vigilance about 'privacy', FC participants were asked to sign formal consent forms indicating whether or not they wished to be on the FC mailing list and receive FC minutes. From a common-sense perspective, it might be assumed that they had already automatically given their consent to be included in and then receive this basic information through being at the meeting itself.

The situation around FC information sharing as well as privacy and confidentiality was complicated and somewhat unclear to both FC participants and facility staff. There was limited consistency of practices for general information sharing. At both Carol's and Linda's facilities, privacy concerns were cited by facility staff as underlying their reluctance to send out general notices to all family members to inform them about upcoming FC meetings, to circulate FC agendas or minutes electronically, or to post copies of the FC minutes on the facility website. FC members had some scope to promote and publicize the FC with family members independently as well as offer suggestions how this might be done, but it was easier to obtain and share information about FCs in some facilities than in others. There was certainly lack of consistency in facility interpretation of how official regulations about privacy and confidentiality of health information applied to FCs.

Even though the PHIA was not directly cited by staff members as forming the exact basis for these privacy or confidentiality-related actions on the part of facilities, how these issues are presented and framed by those working within the LTC system seemed to indicate too wide an interpretation of privacy and confidentiality concerns. When looked at closely, the PHIA does not appear to have any direct bearing at all on the types of generalized documentation that is produced through the meetings of voluntary groups like FCs. FCs are not formally part of the health system – they are simply informal entities that are connected to facilities that fall under health system regulations and funding. However, it was extremely difficult for FC participants to counter these claims around the need to protect privacy through curtailing FC information sharing or

discussions, as they themselves were not well informed about what policy frameworks existed and whether or not they applied in FC work.

The apparent need for facility staff to maintain appropriate boundaries around FC information could be an inadvertent side effect of two general preoccupations in the health and LTC systems. First, curtailing or managing information flows can be a way of ensuring that FCs do not overstep professional and procedural boundaries in the institutional setting. The end result, though, is the creation and maintenance of a certain degree of invisibility or imprecision around FC activities and roles. Second, it also serves to restrict (either accidentally or on purpose) the types of critical, comparative information about LTC practices that FC members can share and discuss among themselves either with or without LTC staff present to mediate these interactions. This not only potentially creates recruitment challenges for FCs, but it also ensures that FCs are maintained in a marginal position of knowledge and power in terms of the LTC system. These contradictions and tensions illustrate how official texts and documents can maintain or reinforce the institutional ruling relations surrounding FCs, in spite of a larger system imperative towards improving or enhancing person- or resident-centred care practices.

Chapter Five: Synthesis and Conclusions

Institutional Ruling Relations and Family Councils

As outlined in Chapters One and Two, LTC facilities throughout North America and in Nova Scotia are currently located at a critical juncture. On the one hand, the neo-liberal state has an obligation to provide cost-effective and high quality LTC facilities, in a situation of relatively severe funding and human resource constraints across the health sector requiring greater system efficiencies (Baines & Armstrong, 2015; Armstrong, 2018). On the other hand, there is a societal and research focus on the continued need for various forms of LTC culture change based primarily on relational, humanistic care philosophies, which may not be cheap to provide. As outlined in the survey of background literature presented in Chapter Two, the broader LTC culture change movement (which is now accepted, in theory at least, as the basis for LTC evolution in Nova Scotia) posits that extensive systemic reform of previous hierarchical and bureaucratic forms of facility-based care are required (White-Chu et al., 2009). The culture change movement in LTC also purports to increase the focus on constructive and critical community as well as family involvement in LTC, which has given rise to various techniques for family involvement and engagement, including FCs in LTC facilities (Pillemar et al., 1998). However, when putting these ideas into practice in specific institutional settings (such as in the Nova Scotia LTC system), a diverse cluster of bureaucratic and policy factors as well as institutional power dynamics come into play that impede their full realization (Bambusch & Phinney, 2014).

LTC facilities are part of a much larger health services institutional infrastructure which arguably has a strong tendency (albeit well-intentioned) to control or limit the

nature of family involvement for the sake of bureaucratic efficiency, internal accountability and/or resident safety (Hamann, 2014; Barken & Lowndes, 2017). At the same time, as we have seen, the range of potential functions or roles for FCs as found in the existing background research and grey literature on these groups is extremely diverse, aspirational and ambitious, given that they are part-time and voluntary. The reality is that FCs are themselves varied and multi-faceted entities. Due to this complexity (as well as the complicated lives of the people involved in them), they may not always be an effective counterweight to the bureaucratic 'logic' of the LTC system. The wide variation and broad scope in potential functions and roles for FCs allows for adaptability and flexibility, but according to a critical IE-based reading of the disciplinary discourses, it can also lead to ambiguity and confusion about how FCs should be composed, who should be in charge, and the exact issues they should focus on. The many potential roles and functions of FCs may not, in fact, always be realistic, given challenges of time, knowledge, skills and/or resources on the part of either members or facility staff.

These diverse tensions surrounding FCs (in terms of the interplay of institutionally-centred versus family-oriented perspectives) are clearly reflected in the family standpoint stories of FC work that emerged from this research. These challenges all need to be carefully examined and negotiated if FCs are to provide meaningful alternative perspectives in LTC. This need may become more urgent in future, given that people are entering the LTC system at older ages, with more complex needs, and are therefore less able to advocate on their own behalf. This opens the door to a potentially more urgent role for FCs as independent voices on behalf of resident perspectives and quality of care (Change Foundation, 2017).

Critical Typology of Family Council Roles and Functions

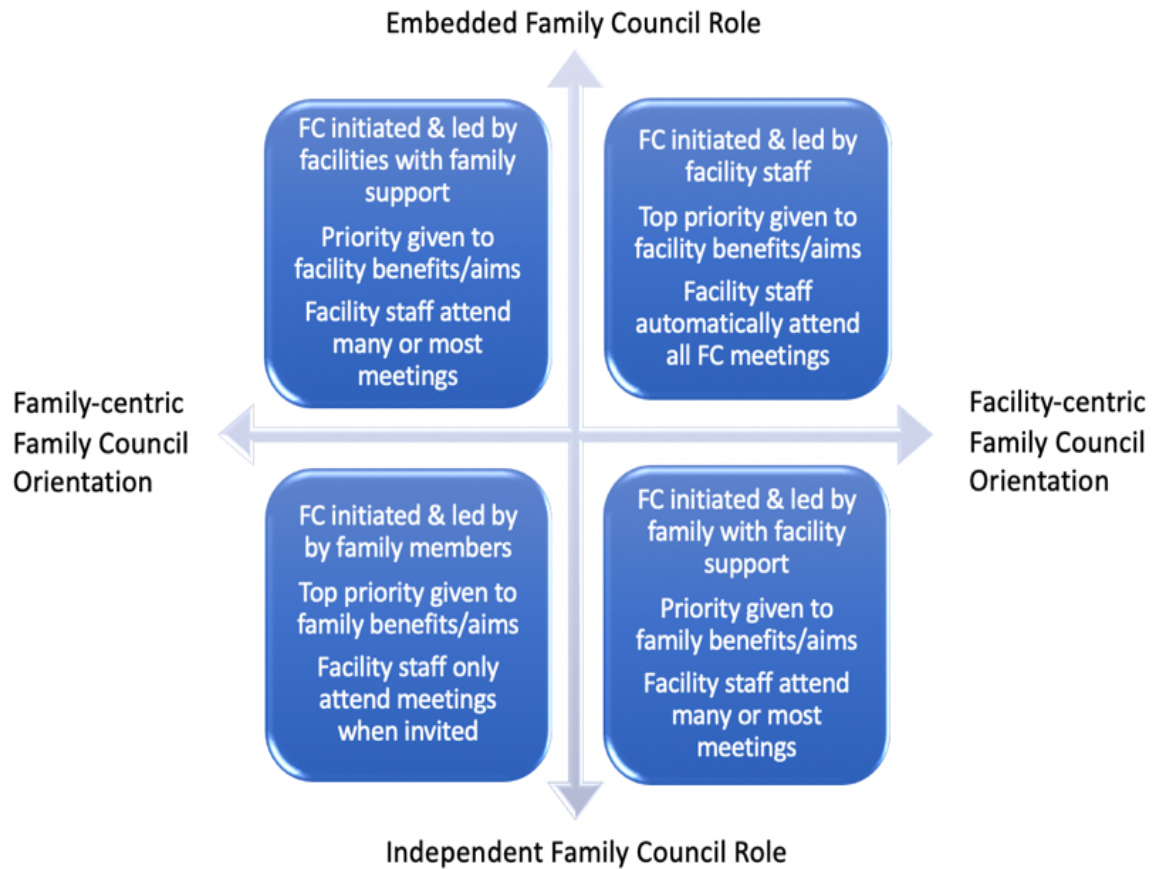
I began this research with the main aim of developing critical insights about the current situation of FCs in the Nova Scotia LTC context. This includes how FCs are being formed and implemented, what family members actually experience as FC participants, and (most importantly) how FC roles are intertwined with and shaped by the overarching institutional regime of LTC. I have tried to describe and unpack some of the institutional ruling relations surrounding FCs, including the complex enabling factors and impediments in the institutional and policy environment surrounding their formation and on-going functioning. To sum up, I present here a brief synthesis derived from my own primary research, combined with both the background information and critical analysis of the policy context. This forms the basis for a FC typology I developed to understand the nature of FCs roles and activities within these complex institutional relations.

In my view, the main contested areas surrounding FCs in LTC are, first, whether FCs are *embedded* or *independent* in terms of their institutional relations, and, second, the extent to which FCs can or should function as *family-centric* versus *facility-centric* entities. The broad characteristics of FCs arising from these categories overlap extensively and are not mutually exclusive. They can be viewed more as a continuum or matrix of issues and options surrounding the social location and socio-political status of FCs in the LTC system. An overview of the typology is shown in Figure 3.

This typology of FCs in LTC is presented here in an exploratory and provisional format that is meant to synthesize the range of issues and ideas arising from this research project in particular. However, it could potentially be adapted for use as a practical assessment tool in one of the two following ways: a) critically analyzing the

characteristics and *modus operandi* of existing FCs, and/or b) helping determine what aspects of the FC role might be actively developed (with corresponding implications for both families and the facilities) in the process of FC formation or support.

Figure 3. Critical Typology of Family Council Roles and Functions



The horizontal axis in the diagram represents one dimension of institutional relations surrounding the FC role, namely whether FCs can or should be embedded in facility structures or fully independent from them. ‘Embedded’ FCs, for the purposes of this analytical tool, can be considered as operating mainly at the behest of facilities and predominantly under the direct authority of staff, with little or no leeway for independent action. This is the situation depicted to a large extent in the description of Carol’s FC. As an example of a strongly embedded FC, Carol’s FC appeared to have been initiated by

staff in order to simply fulfill the minimal standards of Section 7.3 of the LTC Program Requirements. It was consistently chaired, managed or controlled by facility staff and it met relatively infrequently at the staff's initiative only. Carol's own perception was that family members in her mother's facility had little motivation to attend or become involved in the FC due to this situation.

In contrast, 'independent' FCs, as reflected in the resources and definitions proposed by some FC advocacy and support groups (as noted in Chapter Two), are formed and function in such a way that they consistently seek to maintain an arms-length (albeit collaborative or cooperative) stance vis-a-vis official LTC structures. They function with no (or very minimal) interference and control from the surrounding LTC institutional setting. Usually in practice, this means that they are chaired and run primarily or exclusively by family members themselves, and that family members pay a lead role in defining FC objectives. For example, in the case of both Bryson's and Linda's FCs, family members had priority to lead meetings and develop agendas. Although this approach was sometimes modified in practice, it appeared to lead to a somewhat more 'independent' position in relation to the facility, in terms of the FC role and scope of activity.

Because full recognition of the importance of the family standpoint is more likely to be the basis for an independent FC, this model could be viewed as a type of ideal. It may or may not be achievable in every situation due to the challenges of attracting and maintaining the participation of overloaded family careworkers in FCs. However, it might still be worth striving for as it provides families with the ability to share their insights openly and thereby achieve a higher degree of social empowerment, as well as receive

respect from facility staff members regarding the value of FC insights. Any truly independent FC would, of course, need to strive towards collaboration and cooperation with the facility where it operates. At the same time, this should not prevent the FC from being able to openly raise problems regarding policies and care practices as well as staff behaviours or attitudes, without being marginalized by facility structures and staff.

The vertical axis of the diagram represents the second dimension of FC roles and functions, which is whether FCs are family-centric or facility-centric. 'Family-centric' means that FCs exist primarily to put the voices of families first as essential knowledge holders concerning the overall conditions of the facility and the needs of those living there. A fully family-centric FC would ideally provide families with a forum to give voice their concerns and issues. This would not simply be on a personal level, of course, but also concern broader patterns or trends in facility operations. Ideally, family-centric FCs foreground and privilege the family standpoint in all its diversity and complexity. The impetus comes from families and the momentum is sustained primarily by them, as opposed to facility staff. Functionally, family-centric FCs give top priority to family careworker ideas and insights through the way in which meetings are organized and conducted. For example, both Linda's and Bryson's FCs displayed many family-centric features, in the sense that family members apparently took leadership roles at all meetings. Family careworkers also did their own advocacy (to some extent at least) to publicize the value and importance of the FC role in the facility. There appeared to be a moderate amount of family solidarity displayed through the FC, in the sense that family perspectives were understood as standing on their own merits. Families were actively encouraged to share their ideas, to some extent at least. Bryson's FC in particular had a

part of each meeting dedicated to family-only discussions, so that family careworkers could discuss issues among themselves without facility staff members being present.

‘Facility-centric’ FCs, at the other end of the spectrum, are those where the facility’s needs, requirements, policies, procedures, discourses or ‘ways of doing things’ appear to take priority over family voices and perspectives. There may be some token acknowledgement of family priorities and views, especially when there is a need for facilities to ensure some minimal form of family involvement to meet licensing or accreditation standards. In a facility-centric institutional setting, however, the FC role is ‘constructed’ and managed via institutional ruling relations mainly to fulfill LTC system purposes. Hierarchies around staff knowledge and expertise are carefully maintained when families voice their concerns at FC meetings, while insights gained from the family careworker perspective might be actively or passively discouraged by facility leadership. Carol’s FC seemed to be highly facility-centric, in that staff leading those meetings did not encourage families to meet independently and did not share information about FC activities widely enough to broaden the scope of family involvement. The FC attended by Linda also had some facility-centric characteristics, in the sense that privacy and confidentiality provisions appeared to be utilized (whether consciously or unconsciously) by facility staff members to control the flow of information and direct discussions in meetings towards items that fit the facility’s interpretation of the FC’s role and mandate.

When these dimensions are arranged on two axes as shown in Figure 3, a range of complex variations and patterns emerge that provide a useful overview of different FC roles and functions. Again, it is important to emphasize that the four quadrants of the diagram are not necessarily intended to be mutually exclusive. There obviously is

extensive overlap between them which reflects the enormous diversity of how FCs function in the actual world of LTC facilities. Other aspects of institutional relations around FCs not depicted in the diagram would also have to be kept in mind when analyzing FC roles and functions, such as the ways in which the institutional policy framework and key regulatory documents (touched on in the last part of Chapter Four) would come into play in different types of FC arrangements.

Drawing from the accounts of FC participation from the family standpoint as presented in this thesis, the institutional relations surrounding the role of FCs can be clustered within each of the four sections of Figure 3.

Both the upper left category (embedded/family-centric) and the lower right category (independent/facility-centric) for FCs have many similarities, and the situations described for each of Linda's and Bryson's FCs could potentially fit in either area at different times. The initiation and leadership roles for the FCs in both facilities were evidently distributed to some extent among family members and facility staff, with the terms of reference for Bryson's FC at least implying that family leadership was the preferred choice. In both Linda's and Bryson's FC, coordination and administrative tasks were actively shared among FC participants and facility staff to some extent, with agendas developed jointly by families and facilities staff members. However, minutes were taken by facility staff in most cases and then edited and circulated by them. Given the time required to do this type of work, it is not surprising that facility staff would sometimes be more likely play the role of scribes, secretaries and/or communicators on behalf of FCs.

The history and relationships surrounding the FC in Bryson's facility seemed to situate it slightly more in the independent/facility-centric category. Being oriented towards both these aspects is not necessarily a contradiction, but it could give rise to some interesting tensions. His FC was evidently closely aligned with institutional perspectives, as expressed by Bryson's high comfort level with institutional priorities and discourse, as well as his strong concern not to allow individual family members to interject their personal concerns into the FC process. But, somewhat paradoxically, the FC also appeared to have strongly independent ideals and antecedents. In other words, family views were not just tolerated by the facility. Senior staff members also expressed a strong to moderate commitment towards actually listening to and trying to understand their perspectives, as well as encouraging FC members to maintain an independent stance. A further positive development was the focus on wide circulation of FC materials through electronic means to all family members connected with the facility, whether they were active members of the FC or not. The implications of this for the FC, based on Bryson's account, was that it needed to carefully maintain itself in a bridging role between facility and family perspectives, by attempting to keep a foot strongly in both camps, so to speak. The drawback of this, again as reflected in Bryson's own version of events, was that sometimes the facility's institutional norms had to take precedence or be considered first. This occurred when general questions concerning care practices were sometimes sidestepped or deferred due to perceived privacy or confidentiality concerns (some justified and some possibly not).

Linda's FC, while it shared many positive characteristics of Bryson's (such as relatively strong support from senior facility staff members), appeared to fall slightly

more towards the situation of an embedded/family-centric FC. The FC was initiated by family, not the facility, and continued to function with relatively strong levels of family involvement over time. Linda and other family members had put considerable effort into making it a family-friendly space. On the other hand, the facility liaison person for the FC appeared to play a disproportionately active role in managing, guiding or otherwise ensuring that the FC played an appropriate role in the facility. This, as we saw in Linda's account, sometimes gave rise to tensions around who was really in charge. The facility's perspective was that, to be most effective and efficient, the FC had to adhere to proper guidelines and procedures. While Linda herself did not disagree with this and made every effort to ensure that the work of the FC followed proper procedures, she also expressed concerns that the control over information and processes wielded by the staff liaison person potentially inhibited the FC from choosing its own approaches and issues.

The upper right category, that of embedded/facility-centric FCs, appears to depict to a large extent what took place in Carol's FC. As described eloquently in Carol's own account, her FC had been so far initiated, led and managed exclusively by facility staff, to the extreme detriment of genuine family engagement and empowerment. Even family educational events were controlled by staff, and, according to Carol, they were structured in such a way that genuine family participation and learning engagement was impossible. Given the need to pass LTC licensing inspections, facility managers and staff members, evidently with very limited community engagement or facilitation skills, had chosen to ensure that at least the minimal requirements were met, but not in any meaningful way from the family perspective. As reflected in Carol's own stories of trying to mobilize larger family engagement and support around care issues, FC communications were

controlled by facility staff members and the ability of families to mobilize or discuss independently without staff oversight was non-existent. Unfortunately, it is likely that this scenario is found currently in a number of Nova Scotia LTC facilities, due to a lack of facility experience with FCs and inadequate skills and resources that might reinforce the importance of independent family inputs.

Finally, there is the lower left field, which is that of independent/family-centric FCs. None of the (admittedly small) number of FC experiences in Nova Scotia LTC facilities recounted in this research appear to fall completely within this category. Theoretically, this type of FC would be able to meet independently of staff involvement and facility structures and be free to discuss and take positions without facility interference or input – while at the same time having strong awareness of facility norms and values. The background information surveyed in Chapter Two concerning the role of FCs indicates that there are many advantages, from the family standpoint at least, in having FCs fulfill such an independent, critical role which foregrounds family-centric perspectives and knowledge. But, the institutional relations in the current LTC system surrounding FCs may undermine their ability to play this fully independent role, due to the trade-offs and tensions involved. Carol, Bryson and Linda all sought, in one way or another, to encourage their respective FCs to play independent roles and voice family perspectives without undue facility interference. However, as we have seen, the political and social arrangements which provide the framework for the institutional system of LTC may make it very difficult for this ideal to be realized in practice.

Implications for Family Councils in Nova Scotia

There are many potential recommendations arising from the research about the role of FCs in Nova Scotia LTC, that could be targeted at family careworkers as well as LTC system advocates, researchers, policy makers and/or system decision makers. There is sufficient background evidence to show that FCs *do* play a valuable and worthwhile role in LTC. This is true not only in terms of strengthening the relational and community-oriented ‘lifeworld’ within individual LTC facilities (mainly in support of resident well-being), but also by offering independent and critical insights on the systems, structures, ideologies, standards and taken-for-granted discourses found in LTC overall. It is my contention that even when FCs have yet to achieve their full potential (as found in the stories and experiences in this research), they still provide the foundation for focusing community attention towards improving the situation of nursing home residents as well as broader LTC policies and practices. Given the relatively limited amount that is known about FC work in Nova Scotia at the present time, this thesis is intended as a contribution to strengthening the knowledge base and related actions.

Based on the above, the following ideas (in order of importance) should be considered to encourage and support FCs in the Nova Scotia LTC system in future.

1. *Create an arms-length, non-governmental advisory and resource group* (either stand-alone or under the auspices of an existing non-governmental policy analysis, advocacy, activist, service delivery or training agency) systematically compile existing information around the positive benefits of family engagement in LTC and (more specifically) how to promote and strengthen FCs, similar to what is found in some American states and in provinces like

Ontario and British Columbia. This group would function at arms-length from the formal LTC system to advocate independently for the ‘family voice’ or ‘family standpoint’ in LTC, encourage the formation of FCs via outreach and education to families of LTC residents and the general public, provide resources and education to FCs in the province, and continue to lobby with all stakeholders for the autonomous functioning and strategic value of FCs (and the family standpoint) in relation to the LTC system.

2. As part of the mandate and work of the above agency:
 - a. *Develop a on-line clearing house of FC resources or tools for use mainly by FC members in Nova Scotia* and continuously adapt and customize these resources/tools to the Nova Scotia LTC context through dialogue and community outreach as appropriate. This should be done in close consultation with other policy/advocacy groups and all stakeholders or partners in the LTC sector. Resources could also be made available to facility staff involved in supporting/facilitating FCs on request.
 - b. *Provide customized independent training and strategic advice for FC leaders and participants, other family standpoint advocates, and for LTC facility staff (both in person and internet based)* in selected skills in volunteer group development, participatory facilitation, and other organizational techniques to enable formation of FCs around principles of autonomy, empowerment and critical advocacy for the family

standpoint in LTC (similar to training offered by Family Councils Ontario, an independent non-governmental group).

- c. *Develop templates and tools for FCs to use in conducting independent FC-led surveys of family members' needs and concerns in LTC facilities, as well as techniques for how best to communicate these concerns to facility staff and LTC system leaders.*
- d. *Develop an on-going strategy for collecting data about the number, membership, location, activities, and basic outcomes/effects of FCs across the province.*
- e. *Prepare a general guidance note for facilities and FCs regarding the applicability or relevance of PHIA and other privacy and confidentiality norms, regulations and standards to the work of FCs.*
- f. *Develop a Nova Scotia FC manual or handbook for use primarily by FCs under formation or already formed in the province, but also by facility staff involved as partners in the facilitation, encouragement or support of FCs as appropriate. This manual/handbook could be modeled on similar resources already developed for use in other Canadian provinces and elsewhere. It should include self-assessment criteria to allow FC participants and other stakeholders to actively monitor FC evolution and quality over time (in terms of functions and outcomes), and report back the effects or findings from FC work to the support/advocacy agency and the general public.*

3. *Ensure regular public release/updating (at least once per year) of DHW information/statistics collected in relation to Section 7.3 of the LTC Program Requirements, concerning the existence of FCs in Nova Scotia LTC, as part of DHW's evolving process for electronic sharing of LTC licensing inspection reports. This would allow more official empirical data to become available over time regarding the location and number of FCs throughout the province, with the aim of highlighting FCs as an important aspect of LTC.*
4. *Revise/update Section 7.3 of the LTC Program Requirements and/or create an appendix attached to the LTC Program Requirements that sets out more fully for operators and staff of LTC facilities some key principles and provisions to ensure that FCs are formed and function in a fully independent and autonomous manner, while still remaining in a mutually respectful equal partnership with the facility, its governance/management structure and staff members. Section 7.3 should also eventually refer service providers to the specific resources and tools noted under Item #2 above. Specific information or guidelines might address briefly such items as: importance of FC consultation in licensing inspections/audits; standards for quality FC meetings; information sharing procedures; appropriate staff roles and levels of involvement/control; linkages between FCs and management/board accountability structures; and relevance/applicability of various privacy and confidentiality provisions.*
5. *As an adjunct to application of Section 7.3, develop a more detailed set of quality criteria for FCs to be used by DHW licensing inspectors at the facility*

level, which can be posted on public websites and form the basis for on-going analysis of FC structures, functions and roles at the facility level. This would go beyond simply identifying the existence of FCs in LTC facilities, but also help focus attention on the quality of FCs and how to improve/sustain their roles and functions.

6. At a broader level, in order to further strengthen research in or about the LTC system in Nova Scotia led by academics, consultants, DHW and/or the Nova Scotia Health Authority, *develop a strategy and standards for researching the 'family standpoint' as a key socio-political location that is often obscured or marginalized in Nova Scotia LTC research*. This might include, for example, increased use of institutional ethnography and/or other critical ethnographic/qualitative methodologies as part of future LTC research projects, to ensure that the experiences of family careworkers and FC participants are respected and heard in relation to LTC practices and policies.

Concluding Remarks

The main idea behind my research, based on a critical theory and IE approach, is to foreground and give a privileged place to the family standpoint in LTC, as reflected in the role and work of FCs. My own perspective, based on what I have learned through the research as well as on my personal experience as a family careworker in Nova Scotia LTC, is that the family standpoint constitutes a unique and largely unexamined 'marginal' socio-political location of families and their concerns within LTC. This is in direct contrast to official discourses, policies, attitudes and knowledge encountered in bureaucratic accounts and/or documents (as depicted in Figure 1 in Chapter One). I

believe that this perspective has the potential to support both critical and constructive reform of LTC, based on culture change values.

The stories presented by family council members in this research illustrates the ability of FCs to bring forward valuable family experiences, insights and constructive advocacy in LTC. At the same time, family insights and FC roles are strongly influenced by institutional power dynamics and accompanying constraints, disconnections or misunderstandings in the LTC policy landscape. Although families and their concerns are not monolithic, it is still possible to argue forcefully that many family careworkers in LTC have essential knowledge and insights about what happens with elders in LTC, that facility staff do not (Curry et al., 2007; Anderson, 2004; Barken & Lowndes, 2017). Going beyond that, FC members, by virtue of being simultaneously both ‘inside’ and ‘outside’ the institutional norms and discourses surrounding LTC, may also be able to provide valuable external insights into overall system challenges, gaps and needs. Yet, paradoxically, their social and political role within the LTC system is often given short shrift or only offered token recognition – in spite of family-friendly rhetoric that sometimes promises otherwise.

My own personal experiences in LTC as well as my orientation towards social change leads me to want to privilege the voices and knowledge of family members outside official facility discourses. Therefore, my own view is that a truly independent and family-centric FC role would be most interesting and useful to foster at the present time in the Nova Scotia LTC system. Admittedly, not all family members might feel completely comfortable taking an overtly critical stance towards what is happening in LTC facilities and in the system overall. As shared by Carol, Linda and Bryson, doing this

is not in any sense an easy task. There is a lot at stake for those who choose to take issue with practices and policies in the LTC environment, as well as a continued risk of institutional co-optation or capture. LTC is an extremely challenging institutional setting to understand and negotiate as an outsider. Many family members likely will continue to feel disempowered, frustrated and overwhelmed by its complexity. Moreover, when there is an elderly relative in the middle, with complex needs and close emotional attachments, an oppositional or critical stance within the LTC facility setting is often just too fraught and difficult to maintain. It is possible and to be hoped, however, that at least some FCs in Nova Scotia might be able to achieve some of these characteristics – or at least get close enough that the richness and diversity of the family standpoint in LTC will achieve some degree of critical engagement a mutual respect and recognition with the larger institutional setting.

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Appendix A

Recent Family Council Activities in Three Canadian Provinces

Province/Location	Policies/Frameworks/Organizations	Recent Activities and Findings
Ontario	<p>Long Term Care Homes Act (2007) incorporates a provincial Resident Bill of Rights. Resident councils are required under the act and a family council must be formed if it is requested by a family member or someone who is deemed to be a close friend or advocate of any elderly nursing home resident (Change Foundation, 2017). Under the Act, FCs have specific discretionary powers including reviewing licensing and inspection reports, facility budgets, and funding arrangements for LTC facilities (Family Councils Ontario, 2016). However, it is not clear if these powers extend to privately owned service providers that operate under contract to government or are only applicable to directly funded non-profit facilities and government-run residences.</p> <p>Family Councils Ontario (FCO) is a partly government-funded, non-profit research/advocacy organization focused on supporting and improving family councils that has been in existence since the late 1990s. FCO offers a website, webinars, seminars, and other resources and tools for FCs in the province. They emphasize the advocacy role of family councils both at the interpersonal or resident care level and have produced a manual for use by family councils.</p> <p>The Change Foundation (TCF) is an independent, publicly funded health policy think tank formed to advocate and support positive reforms in Ontario’s health care system. TCF conducted a recent multiyear research project on the role of resident and family councils in long term care homes.</p>	<p>Detailed case studies show that FCs play an important role in bringing forward collective concerns about quality of care (Change Foundation, 2016, 2017). Surveyed FC members believe that they are important to the functioning/operation and culture of the home and improving staff-family relationships. However, many facility administrators declined to comment in the survey on the value, role and functions of FCs. Flexibility in the role, structures and functions of FCs was noted as important. Due to cognitive impairment among elders, the functions and roles of resident councils may be variable, indicating a potentially stronger role for FCs to compensate for these challenges. One recommendation from these reports and others is that the sector move towards a ‘co-leadership’ model to foster greater participation of FCs in sector quality improvement (Health Quality Ontario, 2016).</p> <p>The FCO manual emphasizes that FCs can and should go beyond personal support and education, and that diverse and empowering means of family engagement are preferred.</p>
British Columbia	<p>Community Care and Assisted Living Act (2002) supports the formation of FCs. The BC Health website provides detailed information about FCs and recommends an annual opportunity for family members in all facilities in the province to “[e]stablish one or more councils or similar organizations to represent the interests of the persons in care, or their parents or representatives, family members and contact persons, or both” (British Columbia</p>	<p>BC Health publishes FC guidelines on its website that suggest that the focus for these groupings be on communications, working on behalf of resident issues, finding solutions to common problems and working on specific projects that benefit residents. Several regional health authorities in the province have produced detailed FC manuals that</p>

Province/Location	Policies/Frameworks/Organizations	Recent Activities and Findings
	<p>Health, 2018). The provincial Residential Care Policy Manual states that “[h]ealth authorities must support the development of resident/family councils to promote the interests of clients and support the on-going role of family caregivers in residential care facilities” (British Columbia Health, 2017).</p> <p>The Office of the Seniors Advocate is a publicly funded arms-length organization established in 2014 -- the first of its kind in Canada. Although this office has a broader mandate than LTC issues, it has conducted facility level research that includes information about family involvement in LTC facilities.</p> <p>The non-profit publicly funded advocacy group British Columbia Association of Advocates for Care Reform (BCAACR) was one of the first in Canada to lobby for and support the formation of FCs within the context of culture change and LTC facility improvement. It is unclear how active the organization is at this time, as BC Health has taken on direct support for family councils.</p>	<p>provide detailed information for family councils about governance, structure, and organization.</p> <p>The independent Office of the Seniors Advocate conducted a LTC facility survey in 2017 which indicated relatively high levels of family involvement. It recommended that facilities make efforts to foster greater involvement of families and contained a specific section highlighting FCs. It concluded that FCs are an excellent mechanism for family engagement, but that facilities could do a better job ensuring families are informed about them as well as encouraged to become involved.</p> <p>The FC handbook of the BCAACR stresses the benefits of mutual support and family education, plus the importance of both the specialized viewpoint and insights of FCs in improving facility policies/administration and resident well-being. Another potential contribution of FCs can make is towards health service accreditation surveys or assessments done by the facility (Association of Advocates for Care Reform, n.d.)</p>
Alberta	<p>Continuing Care Health Service Standards (2016) was revised by the recently elected NDP government and includes nursing home standards. Section 18 specifically states that LTC facility operators must encourage FCs to be formed, and that operators then have an obligation to respond to any complaints or grievances raised. The Alberta Office of the Seniors Advocate was created in 2016 to provide public independent oversight and accountability for the quality of seniors’ services (including LTC). The Alberta government introduced and passed (as of early November 2017) Bill 22, the Resident and Family Councils Act, which came into effect in spring 2018 (Government of Alberta, 2018).</p>	<p>Bill 22 provides for the roles/responsibilities and accountability of operators towards resident councils and FCs, expanding on what is in the 2016 continuing care standards. The bill implies that the two types of councils be combined into one joint entity, although in practice there may be some flexibility allowed around having separate or mixed groups. It makes it possible for any resident, family member or other interested party to form a council, and it mandates that nursing home operators in the province actively promote and help establish councils.</p>

Province/Location	Policies/Frameworks/Organizations	Recent Activities and Findings
	<p>To assist with Bill 22, a toolkit on the formation of resident councils and FCs was produced jointly by a private health research and service delivery network, Covenant Health, in collaboration with Alberta Health (Covenant Health, 2017). A joint resident/family council is defined broadly as any group of people who want to collaborate to improve residents' lives. Its main role is seen as contributing to more 'successful' nursing home experiences, and its potential effects on policies and building joint understanding in the system are mentioned. The importance of operator accountability to respond to councils' concerns (as proscribed under the standards and Bill 22) is emphasized.</p>	<p>The purpose of a resident/family council under Bill 22: providing a forum for residents and families to discuss ways of maintaining and enhancing quality of life as well as concerns and solutions; presenting requests, concerns and proposed solutions to the facility; developing and participating in projects for the residents' benefit; and offering a network of support and encouragement for the residents and their families. The operator must make a meeting space available and document/respond to any concerns or issues raised by the council. Although it is unclear from the legislation to what extent councils can be involved in licensing inspections, they can have access to inspection reports and may be invited or appointed to provide input to these processes.</p>

Appendix B

Inventory of Texts Surrounding Family Councils in Nova Scotia LTC

<p><u>Nova Scotia -- Provincial Acts, Regulations, Policies, Strategies & Guidelines</u> Homes for Special Care Act (1989) & Regulations Protection for Persons in Care Act (2007) Personal Health Information Act (2013) Personal Directives Act (2010) Occupational Health & Safety Act (amended 2017) Continuing Care Strategy (2006) Long Term Care Policy Manual (various individual sections & effective dates) Adult Protection Policy Manual (2011) Policies -- New & Replaced Long Term Care Beds (2008 service agreements) Challenging Behaviour Program Manual (2013) Nursing Home Maintenance Standard (2013) Scope of Practice of the Continuing Care Assistant in Nova Scotia (2013) Long Term Care Facility Program Requirements (2019) Continuing Care Intake/Assessment/Referral Forms (Single Entry Access-SEA) Licensing Inspection Protocols/Checklists/Reports</p>
<p><u>Other (Joint) Province-Facility</u> Service Provider Agreements (Contracts) with the N.S. Government/NSHA Service Provider Business Plans/Financial Statements</p>
<p><u>Individual Facilities -- Facility Level Documents/Tools/Guidelines</u> Accreditation Canada Standards for Long Term Care Services Accreditation Audit/Inspection Guidelines/Reports Values/Mission Statements/Code of Ethics Privacy/Confidentiality Policy Admissions Package/Forms incl. Resident Financial Agreements Resident/Family Handbook Personal Directives/Do Not Resuscitate/Advance Care Directives Resident Record/Chart including Medication Administration Record (MAR) Interdisciplinary Resident Assessment Guidelines/Procedures (including Oral Health) Resident Background/Preferences Surveys Individual Plan of Care Interdisciplinary Care Conference ('Care Team') Protocol/Minutes/Notes Routine Policy/Procedures (based on provincial guidelines): Complaints, Food Service, Hydration Therapy, Recreation Program, Continuous Quality Improvement, Risk Management/Critical Incident, Infection Prevention/Control, Palliative/End of Life etc Internal Organizational Policies/Procedures: Human Resources, Staff Roles/Responsibilities, Organizational Chart, Staffing Schedules, etc Monthly Newsletter & Recreational Activity Calendar Annual Resident/Family Satisfaction Surveys</p>
<p><u>Family Council Documents/Tools</u> Mission-Vision-Terms of Reference-Membership Criteria Publicity/Information Materials/Agendas/Minutes/Reports/Notes</p>

Appendix C

Certificate of Research Ethics Clearance



University Research Ethics Board (UREB)

Certificate of Research Ethics Clearance

<input checked="" type="checkbox"/> Clearance	<input type="checkbox"/> Secondary Data Clearance	<input type="checkbox"/> Renewal	<input type="checkbox"/> Modification	<input type="checkbox"/> Change to Study Personnel
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Effective Date	October 1, 2018	Expiry Date	September 30, 2019
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File #:	2018-063
Title of project:	The Role of Family Councils in Long Term Care in Nova Scotia
Researcher(s):	Anne Gillies
Supervisor (if applicable):	Janice Keefe
Co-Investigators:	n/a
Version:	1

The University Research Ethics Board (UREB) has reviewed the above named research proposal and confirms that it respects the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* and Mount Saint Vincent University's policies, procedures and guidelines regarding the ethics of research involving human participants. This certificate of research ethics clearance is valid for a period of **one year** from the date of issue.

Researchers are reminded of the following requirements:	
Changes to Protocol	Any changes to approved protocol must be reviewed and approved by the UREB prior to their implementation. Form: REB.FORM.002 Info: REB.SOP.113 Policy: REB.POL.003
Changes to Research Personnel	Any changes to approved persons with access to research data must be reported to the UREB immediately. Form: REB.FORM.002 Info: REB.SOP.113 Policy: REB.POL.003
Annual Renewal	Annual renewals are contingent upon an annual report submitted to the UREB prior to the expiry date as listed above. You may renew up to four times, at which point the file must be closed and a new application submitted for review. Form: REB.FORM.003 Info: REB.SOP.116 Policy: REB.POL.003
Final Report	A final report is due on or before the expiry date. Form: REB.FORM.004 Info: REB.SOP.116 Policy: REB.POL.003
Privacy Breach	Researchers must inform the UREB immediately and submit the Privacy Breach form. The breach will be investigated by the REB and the FOIPOP Officer. Form: REB.FORM.015
Unanticipated Research Event	Researchers must inform the UREB immediately and submit a report to the UREB within seven (7) working days of the event. Form: REB.FORM.008 Info: REB.SOP.115 Policy: REB.POL.003
Adverse Research Event	Researchers must inform the UREB immediately and submit a report to the UREB within two (2) working days of the event. Form: REB.FORM.007 Info: REB.SOP.114 Policy: REB.POL.003

*For more information: <http://www.msvu.ca/ethics>


Daniel Seguin, Chair
 University Research Ethics Board

Appendix D

Research *Aide Memoire* for Family Council Members

Underlying analytic concepts to guide data collection	Topics to cover with standpoint participants (sequence to be adapted as needed)
<p><i>Inquire</i> about the daily activities of standpoint participants, that is, the members of family councils. Maintain this position of enquiry to understand how LTC facilities work in relation to family councils. <i>Learn</i> about the issues, tensions, and contradictions that family council members experience in their lives and in the functions of the family council (i.e. the ‘problematic’ – Smith, 1987, 2002, 2006).</p>	<p>[General background] Tell me about what you do as a family member of someone in LTC What are your main tasks and roles in relation to the person in care? What do you do whenever you visit that person? Are there other tasks you do when you are not visiting the person, that are part of your family support role? [Specific information] Tell me what you do as a member of a family council ... or tell me what you are doing to create a FC ...</p>
<p><i>Examine</i> work practices and processes in organizational and bureaucratic settings in such a way that the researcher "think[s] organizationally" (D. SMITH in DeVAULT & McCOY, 2004, p.758). <i>Orient</i> interviews toward features of social life that link FC members to activities occurring more broadly in the facility and provincial LTC context (social relations).</p>	<p>Give me a picture of what your family council looks like, who is involved, how it functions and what tasks it carries out ... How does it fit within the other functions/tasks and activities of the facility? How do you choose what to work on? What guidance or support, if any, does the FC receive from the facility? What kind of interaction takes place between the FC members and the facility?</p>
<p><i>Investigate</i> the material, empirically observable events of peoples' lives as members of FCs. <i>Listen</i> to people's "stories" of what practices and activities they engage in (DIAMOND in DeVAULT & McCOY, 2004, p.756).</p>	<p>Give me some examples of what the FC has done and/or show me what guidelines, tools, documents or resources it uses ... Can you describe some recent meetings or activities, issues you have been involved in, and/or concerns you have raised as a FC?</p>
<p><i>Refine</i> the research problematic over time through the researcher's immersion in the field. <i>Be</i> attentive to how informants describe the events of their lives. Listen for how people use institutional language and official or authoritative reasoning to explain events. People's accounts might actually be dissonant from what they experience and know.</p>	<p>Can you provide me with some more examples of how the FC has been working in your facility, any key events or activities, anything that you have done that is particularly meaningful or has challenges. Are there challenges or issues you have encountered, successes in your work as a FC member, ways in which the facility deals with the FC that you are not comfortable with, any other issues?</p>
<p><i>Study</i> experiences with FCs in at least two facilities and explore how these may be connected through similar guidelines. <i>Ascertain</i> the implicit and explicit social relations that shape informants' activities.</p>	<p>Can you share with me all the documents or guidelines, notes, memos, minutes or tools that pertain to your work as a FC, or to your work in trying to get a FC started. What is helpful or useful about these documents or guides? What is confusing or challenging? Is there anything missing?</p>
<p><i>Identify</i> the texts people use in their daily activities as FC members and examine how they use them. <i>Find</i> out about how texts organize what informants say and do as FC members (discursive organization).</p>	<p>See above. Can you show me or describe to me how any specific guidelines, policies, tools or documents that relate to your work as a member of a FC (either at the facility level or more broadly)?</p>
<p><i>Focus</i> on how the social location of any FC member informs her/his knowing and consider what the person can say from this position. <i>Develop</i> understandings about how LTC facilities function because this provides insight about social organization and power/ruling relations.</p>	<p>What is your own understanding about the role/function of a FC in your facility, based on what you see happening? How does the facility and the broader LTC system view the FC, are you included, excluded, tolerated, accepted, welcomed, or some combination?</p>
<p><i>Cultivate</i> understandings about the organization of institutional places from participants and texts. Researcher follows up on analytic clues of thread gathered in one interview or observational setting to the other. <i>Acquire</i> understandings about how people use texts. Participants talk about peoples' work practices, and the researcher prepares to dialogue with and/or observe extra-local informants in later stages of fieldwork.</p>	<p>Can you try to describe from your own perspective how you are linked (or not) to the entire facility and the broader LTC system? Are you aware of any similarities or differences with what other people are doing in other facilities? How do you obtain or share information (if any) within your facility, with FCs in other facilities, and/or with provincial LTC officials? [NOTE: Additional cross-cutting analysis will be done by the researcher to synthesis what is happening in different places].</p>

Adapted from Bisailon and Rankin (2013)

Appendix E

List of Questions for Facility Staff

1. Please describe briefly who you are and what you do at your facility.
2. How did the family council get started?
3. What are your main tasks and roles in relation to the family council? How long have you been involved with the family council?
4. What are the regulations, policies and procedures/guidelines that provide a reference point for the family council? Can you give me a short description of each and how they work to guide the family council?
5. How would you describe the work of the family council in your facility? How well does it function? What are its accomplishments and contributions? What are its strong and weak aspects?
6. Overall, how does the family council 'fit into' the nursing home -- what roles does it play, what difference does it make, what are the opportunities and challenges?
7. Any other information you might like to share about the family council?