

**A Critical Analysis of Continuing Care Systems,
Integrated Care Strategies, and Policies: Assessing
the Success of Canada, Denmark, and Australia**

**by
Laura Kadowaki**

B.A. (Health Sciences), Simon Fraser University, 2012

Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Philosophy

in the
Department of Gerontology
Faculty of Arts and Social Sciences

© Laura Kadowaki 2020
SIMON FRASER UNIVERSITY
Summer 2020

Copyright in this work rests with the author. Please ensure that any reproduction or re-use is done in accordance with the relevant national copyright legislation.

Declaration of Committee

Name: **Laura Kadowaki**

Degree: Doctor of Philosophy

Title: A Critical Analysis of Continuing Care Systems, Integrated Care Strategies, and Policies: Assessing the Success of Canada, Denmark, and Australia

Committee: **Chair: Sean Zwagerman**
Associate Professor, English

Andrew Wister
Supervisor
Professor, Gerontology

Barbara Mitchell
Committee Member
Professor, Gerontology

Habib Chaudhury
Committee Member
Professor, Gerontology

Atiya Mahmood
Committee Member
Associate Professor, Gerontology

Nancy Olewiler
Examiner
Professor, School of Public Policy

Margaret Penning
External Examiner
Professor, Sociology
University of Victoria

Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University

or has conducted the research

- c. as a co-investigator, collaborator, or research assistant in a research project approved in advance.

A copy of the approval letter has been filed with the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Simon Fraser University Library
Burnaby, British Columbia, Canada

Update Spring 2016

Abstract

In recent years there has been a call for the development of integrated continuing care systems in Canada. Such systems would provide older adults and informal caregivers with a comprehensive continuum of integrated supports, linking formal and informal health and social care to improve efficiencies. The purpose of this study was to examine how an integrated continuing care system can be developed in BC to address limitations and gaps in service. The study was informed by a critical public policy and a systems approach. A multi-pronged longitudinal methodological strategy was utilized and entailed: 1) Analysis of BC's home and community care system; 2) Document analysis; and 3) Comparative analysis of systems and reforms in other jurisdictions (Ontario, Québec, Nova Scotia, Australia, and Denmark). Data were collected through a) interviews in 2014/15 and 2019/20 with stakeholders in BC and a small number of key informants for each comparison jurisdiction; b) analysis of government policy documents; and c) review of literature and other information sources. Key deficits identified in BC included: lack of a clear vision for home and community care; gaps and fragmentation in the care continuum; lack of investment in home and community care; and lack of supports for informal caregivers. Similar deficits were experienced in many of the comparison jurisdictions, but there also were areas of policy divergence. One of the identified points of tension for integrated care approaches was the fine line between the substitution of services and downloading of responsibilities. A key recommendation for BC is that the lens through which policy is being developed needs to be adjusted and moved away from simply viewing home and community care as substitutes for acute and residential care. Furthermore, the ambiguous position of continuing care in Canada is contributing to the marginalization, medicalization, and underfunding of continuing care systems. It is concluded that a funding model for continuing care needs to be developed at the national level, which has become particularly apparent during the COVID-19 pandemic. Additional recommendations include improving supports for informal caregivers, providing a broader range of community-based supports, shifting care paradigms, and strengthening the integration of services.

Keywords: continuing care systems; long-term care; home care; older adults;
integrated care system; health care policy

Acknowledgements

Thank you to my supervisor (Dr. Andrew Wister), my Supervisory Committee, and the faculty of the Gerontology Department for their guidance and support on my PhD journey.

Thank you to the participants of this study for kindly providing their time and insights for my dissertation research.

Thank you to my family, and especially my husband Daryn Brisson, for their loving support. Finally, thank you to my loyal office assistant Kody who has put in as many hours in the office as I have.



Table of Contents

Declaration of Committee	ii
Ethics Statement	iii
Abstract	iv
Acknowledgements	vi
Table of Contents	vii
List of Tables	xii
List of Figures	xiv
List of Acronyms	xv
Discussion of Terminology	xvii
Chapter 1. Introduction	1
Chapter 2. Literature Review	7
2.1 Conceptualizations of Integrated Care	7
2.2 Key Components of Integrated Care Models	9
2.2.1 Best Practice Framework for Organizing Systems of Continuing/Community Care Services	9
2.2.2 Policy Framework for Integrated Care for Older People	10
2.2.3 Key Components of Integrated Care Models	11
2.3 The Case for Integrated Care	12
2.3.1 Aging in Place	13
2.3.2 Better Care Experiences for Older Adults	14
2.3.3 Efficiency of the Health Care System	15
2.3.4 Cost Savings	16
2.4 Critique of Integrated Care and Substitution Policies	18
2.5 Evidence of the Effectiveness of Integrated Care	20
Chapter 3. Overview of Continuing Care in Canada	26
3.1 Health Care in Canada	26
3.2 Continuing Care in Canada	27
3.2.1 Home Care	28
3.2.2 Assisted Living	30
3.2.3 Long-Term Care Facilities	30
3.2.4 Informal Caregivers	31
3.3 Conclusion	31
Chapter 4. Theoretical Framework and Models	33
4.1 Introduction	33
4.2 A Critical Public Policy Approach	35
4.2.1 Public Policy	35
4.2.2 Critical Public Policy Approach and the Political Economy of Aging	36
4.3 Systems Approaches in Health Care	39
4.3.1 Systems Theories	39

4.3.2	Health Care System Models	42
4.3.3	Frameworks for Comparing Integrated Continuing Care Systems.....	44
4.4	Summary of Theoretical Frameworks and Models	46
Chapter 5.	Methodology.....	47
5.1	Introduction.....	47
5.2	Application of Theoretical Approaches.....	49
5.3	Analysis of the History and Current State of the Home and Community Care System in BC	50
5.3.1	Key Informant Interviews	51
5.3.2	Stakeholder Interviews	51
5.4	Document Analysis of Home and Community Care Policy	53
5.5	Comparative Analysis of Reforms and the Continuing Care Systems and Policy in other Jurisdictions	54
5.6	Ethics	56
Chapter 6.	BC's Home and Community Care System.....	58
6.1	Provincial Health Care Context.....	58
6.1.1	Health Care System Structure and Governance	58
6.1.2	Home and Community Care System.....	59
6.2	Historical Review of Home and Community Care in BC over 1990-2011	62
6.2.1	Home and Community Care, 1990-1999.....	62
6.2.2	Home and Community Care, 2000-2011.....	64
6.3	Home and Community Care Policy Context and Objectives, 2012-2019.....	67
6.3.1	Political and Economic Landscape	68
6.3.2	Key Policy Documents.....	68
6.3.3	Policy Context and Key Events.....	77
6.3.4	Evidence of Impact of Key Reforms.....	87
Chapter 7.	Stakeholders' Perceptions of BC's Home and Community Care System	93
7.1	2014/15 Interviews	93
7.1.1	The Value of Home and Community Care Services.....	93
7.1.2	Current Issues with the Home and Community Care System.....	95
7.1.3	Root Cause: Lack of Funding	106
7.1.4	Root Cause: Lack of Integration of Services	109
7.1.5	Roles of the Non-Profit and Voluntary and Private For-Profit Sectors	116
7.1.6	Contextual Factors Influencing Home and Community Care Reform	118
7.1.7	Vision for the Home and Community Care System	124
7.2	2019 Follow-up Interviews	129
7.2.1	Persistent Challenges for the Home and Community Care System	130
7.2.2	Consequences of Shifting Care to the Community.....	132
7.2.3	Health Human Resource Challenges.....	134
7.2.4	Home and Community Care Reforms	135
7.2.5	Progress Integrating Care for Older Adults	136

7.2.6	Vision for Home and Community Care in BC	138
7.3	Conclusion.....	139
Chapter 8. Critical Analysis of BC’s Home and Community Care System		140
8.1	Assessment of Home and Community Care System	140
8.2	Critical Analysis of Home and Community Care Policy Development in BC.....	142
8.2.1	Vision for Home and Community Care.....	143
8.2.2	Critical Analysis of Gaps and Fragmentation in the Continuum of Care	145
8.2.3	Critical Analysis of Investment in Home and Community Care.....	150
8.2.4	Policies to Support Informal Caregivers.....	152
8.3	Critical Analysis of the Framing of Home and Community Care within Health Care System Discourses	154
8.3.1	Discourses on the Sustainability of the Health Care System.....	156
8.3.2	Discourses on the Purpose of Home and Community Care Services.....	157
8.4	Conclusion.....	158
Chapter 9. The Case of Ontario		160
9.1	Provincial Health Care Context.....	160
9.1.1	Health Care System Structure and Governance	160
9.1.2	Long-Term Care System	161
9.2	Long-Term Care Policy Context and Objectives, 2012-2019	163
9.2.1	Political and Economic Landscape	164
9.2.2	Key Policy Documents.....	164
9.2.3	Policy Context and Key Events.....	166
9.2.4	Evidence of Impact of Key Reforms.....	170
9.2.5	Key Informant Interviews	174
9.3	Critical Analysis of the Case of Ontario.....	178
Chapter 10. The Case of Québec		183
10.1	Provincial Health Care Context.....	183
10.1.1	Health Care System Structure and Governance	183
10.1.2	Long-Term Care System	184
10.2	Long-Term Care Policy Context and Objectives, 2012-2019.....	186
10.2.1	Political and Economic Landscape	187
10.2.2	Key Policy Documents.....	187
10.2.3	Policy Context and Key Events.....	189
10.2.4	Evidence of Impact of Key Reforms.....	192
10.2.5	Key Informant Interviews	195
10.3	Critical Analysis of the Case of Québec.....	198
Chapter 11. The Case of Nova Scotia.....		203
11.1	Provincial Health Care Context.....	203
11.1.1	Health Care System Structure and Governance	203
11.1.2	Continuing Care Structures and Services	204
11.2	Continuing Care Policy Context and Objectives, 2012-2019.....	206

11.2.1	Political and Economic Landscape	207
11.2.2	Key Policy Documents.....	207
11.2.3	Policy Context and Key Events.....	208
11.2.4	Evidence of Impact of Reforms.....	211
11.2.5	Key Informant Interviews	213
11.3	Critical Analysis of the Case of Nova Scotia	216
Chapter 12. The Case of Denmark.....		220
12.1	National Health Care Context	220
12.1.1	Health Care System Structure and Governance	220
12.1.2	Elder Care Structures and Services.....	221
12.2	Elder Care Policy Context and Objectives, 2012-2019.....	224
12.2.1	Political and Economic Landscape	224
12.2.2	Key Policy Documents.....	225
12.2.3	Policy Context and Events.....	226
12.2.4	Evidence of Impact of Key Reforms.....	230
12.2.5	Key Informant Interviews	233
12.3	Critical Analysis of the Case of Denmark	237
Chapter 13. The Case of Australia.....		242
13.1	National Health Care Context	242
13.1.1	Health Care System Structure and Governance	242
13.1.2	Aged Care Structures and Services.....	243
13.2	Aged Care Policy Context and Objectives, 2012-2019.....	246
13.2.1	Political and Economic Landscape	246
13.2.2	Key Policy Documents.....	247
13.2.3	Policy Context and Key Events.....	248
13.2.4	Evidence of Impact of Key Reforms.....	252
13.2.5	Key Informant Interviews	257
13.3	Critical Analysis of the Case of Australia.....	261
Chapter 14. Comparative Analysis of Cases		266
14.1	Policy Convergences and Divergences	267
14.1.1	Vision for Care.....	267
14.1.2	Investment in Continuing Care Services	270
14.1.3	Integrated Continuum of Care.....	272
14.1.4	Policies for Informal Caregivers	278
14.2	Integrated Approaches: Points of Tension	281
14.2.1	Substitution Policies and Downloading of Responsibilities	282
14.2.2	Acute and Continuing Care Services	285
14.2.3	Mainstream and Marginal Services.....	286
14.2.4	Standardization and Individualization.....	287
14.3	Conclusion.....	289
Chapter 15. Discussion of Implications for BC.....		291

15.1	Summary of the Case of BC	291
15.2	Areas for Action in BC	293
15.2.1	Establishing a Vision for Home and Community Care.....	293
15.2.2	Ensuring the Success of Substitution Policies.....	294
15.2.3	Continuing Care Funding.....	301
15.2.4	New Service Paradigms	303
15.3	Context for Future Reforms	304
15.4	Limitations of Study	306
15.5	Future Research Directions	307
15.6	Conclusion.....	307
	References.....	309
	Appendix A INTERLINKS Framework for Long-Term Care	359
	Appendix B Sample Interview Questions	365
	Appendix C Document Analysis Questions	367
	Appendix D Summary of Key BC Policy Documents: 1990-2010.....	368

List of Tables

Table 1 Policy Framework for Integrated Care for Older People.....	10
Table 2 Reviews of Studies of Integrated Care Models for Older Adults.....	21
Table 3 Households Receiving Formal Home Care Services	30
Table 4 Publicly Subsidized Long-Term Care Beds in Canada.....	31
Table 5 Application of Theoretical Frameworks in the Research	50
Table 6 Documents for Analysis.....	53
Table 7 INTERLINKS Framework for Long-Term Care: British Columbia.....	60
Table 8 Summary of Action Areas in An Action Plan to Strengthen Home and Community Care for Seniors	71
Table 9 Summary of Key Findings from Reports from the Seniors Advocate.....	79
Table 10 Contextual Policy Issues over 2012-2019.....	82
Table 11 aICPP Initiatives for Frail Older Adults.....	83
Table 12 Home and Community Care Indicators Part 1.....	141
Table 13 Home and Community Care Indicators Part 2.....	142
Table 14 Acute, Residential, and Community Care Provincial Health Expenditures 2017/18.....	151
Table 15 INTERLINKS Framework for Long-Term Care: Ontario.....	161
Table 16 Ten Steps to Strengthen Home and Community Care	165
Table 17 Contextual Factors Leading up to Patients First Reforms	167
Table 18 Bringing Care Home: Key Themes	168
Table 19 INTERLINKS Framework for Long-Term Care: Québec	185
Table 20 Chez soi: le premier choix – Key Principles	187
Table 21 SAPA and Home Services Budget (\$ Millions).....	201
Table 22 INTERLINKS Framework for Long-Term Care: Nova Scotia.....	204
Table 23 Continuing Care Strategy Actions.....	207
Table 24 Continuing Care Budget (\$ millions)	219
Table 25 INTERLINKS Framework for Long-Term Care: Denmark	222
Table 26 Home Care Commission Recommendations	228
Table 27 INTERLINKS Framework for Long-Term Care: Australia.....	244
Table 28 Key Discussion Papers on Aged Care Reforms.....	248
Table 29 Key Living Longer, Living Better Reforms.....	250
Table 30 Further Aged Care Reform Packages.....	251
Table 31 Residential Aged Care Places and Home Care Packages Places/Recipients	264
Table 32 Government Spending on Aged Care in \$ Billions (% of budget)	264
Table 33 Canadian Programs to Provide IADL Supports.....	274
Table 34 Contributions of Informal Caregivers in Canada and Australia.....	279

Table 35 Available Respite Options by Jurisdiction	281
Table 36 Inadequacy of Home Care in Jurisdictions of Study.....	283
Table 37 Long-Term Care Facility Waitlists 2018/19	284
Table 38 Models for Providing IADL Home Supports.....	297

List of Figures

Figure 1 Model of Integrated Continuing Care System	3
Figure 2 Best Practice Framework for Organizing Systems of Continuing/Community Care Services	10
Figure 3 Theoretical Model of Social Policy and Aging	37
Figure 4 Health Policy Triangle	38
Figure 5 The building blocks of the health system: Aims and attributes	43
Figure 6 Health System Dynamics Framework.....	43
Figure 7 INTERLINKS Framework for Long-Term Care	45
Figure 8 Timeline of Key Events Impacting Home and Community Care Over 2012-2019	85

List of Acronyms

ACAT	Aged Care Assessment Team
ADLs	Activities of Daily Living
AIHW	Australian Institute of Health and Welfare
aIPCC	accelerated Integrated Primary and Community Care
ALC	Alternate Level of Care
BC	British Columbia
BCCPA	British Columbia Care Providers Association
CARES	Community Action and Resources to Empower Seniors
CASI	Community Action for Seniors Independence
CCAC	Community Care Access Centre
CCPA	Canadian Centre for Policy Alternatives
CDC	Consumer-Directed Care
CHSLD	Centre d'hébergement et de soins de longue durée [Residential and Long-term Care Centres]
CHSP	Commonwealth Home Support Program
CHW	Community Health Worker
CIHI	Canadian Institute for Health Information
CISSS	Centres intégrés de santé et de services sociaux [Integrated Health and Social Services Centre]
CIUSSS	Centres intégrés universitaires de santé et de services sociaux [Integrated University Health and Social Services Centre]
CLSC	Centre local de services communautaires [Local Community Service Centres]
CMA	Canadian Medical Association
CSIL	Choices in Supports for Independent Living
CSSS	Centre de santé et de services sociaux [Health and Social Service Centres]
DOH	Department of Health
EÉESAD	Entreprise d'économie sociale en aide à domicile [Domestic Help Social Economy Business]
GDP	Gross Domestic Product
HACC	Home and Community Care
HIP	Home Independence Program
IADLs	Instrumental Activities of Daily Living

IHN	Integrated Health Network
IHSTS	Institute for Health System Transformation and Sustainability
interRAI	International Resident Assessment Instrument
LHIN	Local Health Integration Network
MOH	Ministry of Health
MOHLTC	Ministry of Health and Long-Term Care
MSSS	Ministère de la Santé et des Services sociaux [Ministry of Health and Social Services]
NACA	National Aged Care Alliance
NSHA	Nova Scotia Health Authority
OECD	Organisation for Economic Co-operation and Development
OSA	Office of the Seniors Advocate
PCN	Primary Care Network
PEP	Personal Enablement Program
PRISMA	Programme de recherche pour l'intégration des services de maintien de l'autonomie [Program of Research to Integrate Services for the Maintenance of Autonomy]
RANQ	Regroupement des Aidants Naturels du Québec
RAS	Regional Assessment Services
RCACQS	Royal Commission into Aged Care Quality and Safety
RSIPA	Réseaux de Services Intégrés pour les Personnes Âgées [Integrated Services Networks for the Frail Elderly]
SAPA	Soutien à l'autonomie des personnes âgées [Support for the Autonomy of Seniors]
SCSP	Specialized Community Services Program
WHO	World Health Organization

Discussion of Terminology

Continuing care system and related terms

In Canada, depending on regional preference, the terms continuing care system, home and community care system, and long-term care system are used interchangeably in the literature to refer to a system that provides older adults (and often their caregivers) with a continuum of supports (e.g., long-term care, home care, home support, etc.). This support system allows older adults to maintain their functioning in old age, age in place, and provides specialized facility care when remaining in the community is no longer possible. These “systems” often refer to groupings of these services rather than integrated systems. Long-term care is also sometimes used to refer to care provided in specialized facilities (also known as residential care facilities or nursing homes), while home and community care may be used to refer only to care provided in the community and not in facilities. In this dissertation, when discussing the system in a particular jurisdiction the preferred jurisdictional terms is used (Home and community care system in BC, Long-term care system in Ontario and Québec¹, Continuing care system in Nova Scotia, Elder care system in Denmark, and Aged care system in Australia). However, when speaking more generally about the overarching concept of these services, the term continuing care is used.

Integrated Continuing Care System

The term integrated continuing care system is used to refer to the concept of a system that provides older adults and informal caregivers with a comprehensive continuum of integrated supports, integrating services from the health and social care sectors, and combining supports from formal and informal care sources.

¹ For simplicity, an English term is used for Québec.

Chapter 1.

Introduction

In the 2016 census, for the first time in Canada it was estimated that older adults (age 65+) made up a larger proportion of the population (16.9%) than children under 14 (Statistics Canada, 2017). By the year 2030 it is projected that older adults will comprise between 21-23% of the Canadian population (Statistics Canada, 2019a). While there are many positives facets to the aging experience, and not all older adults are in poor health, aging is associated with declines in health, increased prevalence of chronic diseases, reduced functional abilities, and increased contact with the health care system (e.g., Canadian Institute for Health Information [CIHI], 2011a; Statistics Canada, 2016; Slade, Shrichand, & DiMillo, 2019). In the coming years, it is projected that there will a significant increase in the number of older Canadians requiring formal care:

- The Conference Board of Canada has estimated that by 2026 the number of older Canadians requiring formal and informal care will increase to 2.4 million, and by 2046 will reach 3.3 million (Hermus, Stonebridge, & Edenhoffer, 2015).
- The National Institute on Ageing estimates that by 2050 there will be 120% more older adults requiring home care and 30% fewer close family members (MacDonald, Wolfson, & Hirdes, 2019).

In the future it is expected there will be fewer informal caregivers available and increased reliance on formal care due to increased geographic mobility, declining family sizes, changing work patterns, and increased preferences for formal care (Keefe, 2011).

Rapid population aging has led to concerns about “apocalyptic demography” scenarios in which the older adult population is anticipated to overwhelm the health care system, leading to concerns about the “sustainability” of Canadian health care systems (Gee & Gutman, 2000; Gee, 2002; Chappell & Hollander, 2013). While “apocalyptic” concerns have largely been debunked in the literature as neoliberal attempts to reform and dismantle the welfare state (Gee, 2002), legitimate concerns exist about the ability of the Canadian health care system to adequately serve our older adult population (Wister & Speechley, 2015). Multiple sources have stated that the Canadian health care system is failing to meet the needs of our older adult population, and in particular, the poor way that

the system handles long-term care and chronic diseases has been critiqued (e.g., Canadian Medical Association [CMA], 2013; 2015; 2016; Chappell & Hollander, 2011; Hébert, 2009; Cohen, 2012; Wister, 2011; Wister & Speechley, 2015; National Institute on Ageing, 2019). These sources suggest that the current acute, episodic, highly medicalized, and fragmented approach of the health care system is ill-suited to meet the shifting health care needs of our population. Increasingly, individuals are suffering from multiple chronic and complex medical conditions, requiring care from multiple services and providers, within both the health and social care sectors. However, lack of coordination and access to services hampers the delivery of care to these individuals, a large majority of whom are older adults. As a result, older adults often experience declines in health and utilize more costly health care resources (e.g., hospital care, long-term care), when some could have been treated earlier, and in more appropriate and less costly settings (Chappell & Hollander, 2011; Hébert, 2009; National Institute on Aging, 2019).

The concept of integrated care has increasingly been promoted to improve the performance of health care systems. While there are multiple definitions of integrated care, Kodner and Spreeuwenberg (2002) have offered this comprehensive definition:

Integration is a coherent set of methods and models on the funding, administrative, organisational, service delivery and clinical levels designed to create connectivity, alignment and collaboration within and between the cure and care sectors. The goal of these methods and models is to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems cutting across multiple services, providers and settings. The result of such multi-pronged efforts to promote integration for the benefit of these special patient groups is called 'integrated care'. (p.3)

There are multiple approaches to integrated care and the appropriate approach depends on the policy goals and local context (MacAdam, 2011). Research is required to critically examine different models and strategies of integrated care and their respective efficacy, effectiveness, and feasibility for other settings.

Integrated care system is a term that can be used to describe a model of care that provides coordinated services for special population groups who have ongoing care needs (Chappell & Hollander, 2011; 2013). Recently, there has been a call for the development of integrated continuing care systems as the third key component of the Canadian health care system. Based on key research by Leichsenring, Billings, and Nies

(2013), Chappell and Hollander (2011; 2013), and Hollander and Prince, (2008) the term integrated continuing care system can be understood to refer to a system that:

- provides older adults and informal caregivers with access to a comprehensive continuum of integrated supports (i.e., such as home care, community services, case management, assisted living, long-term care, caregiver supports, and some acute services), integrating services from the health and social care sectors and supports from formal and informal sources;
- has linkages with primary care, acute care, and other social care sectors; and
- coordinates access to the integrated continuum of supports, and when appropriate allows for the substitution of care in the home and community for other more expensive forms of institutional care.

Figure 1 provides a visual representation of an integrated continuing care system. The figure presents continuing care services as a continuum of supports. The arrows illustrate how both formal/informal care and health/social care are integrated into the system. Acute care and primary care are pictured as sectors that overlap with continuing care and have linkages with the continuing care sector as appropriate.

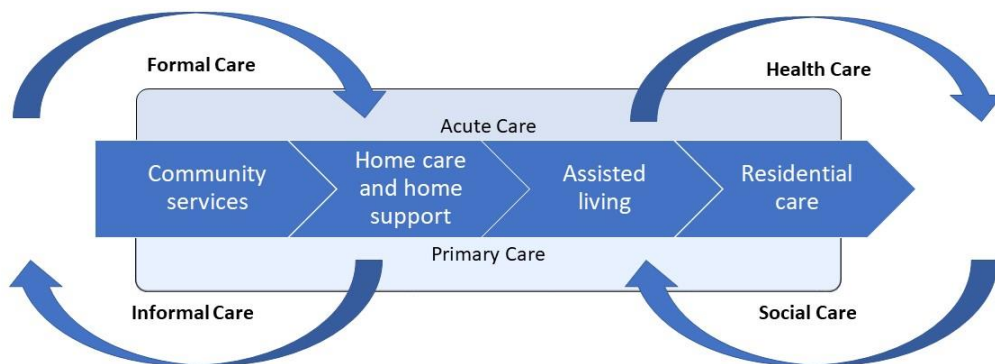


Figure 1 Model of Integrated Continuing Care System

The Standing Senate Committee on Social Affairs, Science and Technology has also recommended the implementation of integrated continuing care systems (Ogilvie & Eggleton, 2012). Similarly, the 2002 *National Report on the Cost-Effectiveness of Home Care* stated the need to shift the policy discourse from home care services to a broader

continuing care system, and suggested that an integrated continuing care system would allow for easier substitution of home care for acute and residential care (Hollander & Chappell, 2002). The CMA (2013) has also endorsed the integration of continuing care services within the health care system. The calls for the development of integrated continuing care systems in Canada reflect the wider international recognition of the need to reform continuing care systems (Kodner, 2004).

In British Columbia (BC), the current home and community care system has been criticized by academics, advocates, and monitoring bodies as failing to meet the needs of the older adult population. Key weaknesses of the system include (e.g., BC Medical Association, 2008; Office of the Auditor General of BC, 2008; Cohen, 2012; BC Office of the Ombudsperson, 2012a; 2012b; Office of the Seniors Advocate [OSA], 2014a):

- Underfunding: Underfunding is a systemic problem resulting in reduced access to home and community care services. Eligibility criteria have become increasingly strict and the basket of available services has shrunk, resulting in inadequate and untimely care for older adults and increased burdens on informal caregivers.
- Difficulties entering and navigating the system: The home and community care system operates in a reactive rather than proactive manner, and older adults often do not access the system until they are in a crisis. Once in the system, navigating home and community care can be a confusing and frustrating experience for older adults and their informal caregivers.
- Lack of integration with other services: The lack of integration between sectors of the health care system (e.g., acute care, primary care, home and community care) creates fragmented and challenging health care experiences for older adults and informal caregivers (as well as health care providers). Poor coordination and lack of communication can result in suboptimal or untimely care being provided.
- System does not offer a comprehensive range of services: The system has been critiqued for not offering the comprehensive range of services required to care for older adults and support informal caregivers. In particular, it has been noted that “non-medical” home supports and other community services required to assist older adults to age in place are lacking.

These challenges and critiques will be discussed in more detail in chapter 6. The need for health care system reform has been recognized in BC and in a 2015 policy paper the BC Ministry of Health (MOH) acknowledged:

Despite many changes over the past 20 years, home and community care services remain organized in large part around eligibility criteria and service

guidelines that limit who may receive services and in what format. Clinical services such as community pharmacy, social work and dietician services are available in some communities, but not others. Other ministries or community agencies may share responsibility for services in some cases. As a result, home and community care services can be complex and restrictive in their coordination and delivery. This creates frustrations for clients trying to navigate the health care system, for caregivers, and for family physicians and other health providers needing to link with community based care.” (BC MOH, 2015a, p.79).

For this dissertation a critical comparative analysis of continuing care systems and policies for older adult populations in Denmark, Australia, and Canada was conducted. Specific focus is placed on how the systems, policies, and experiences from these other jurisdictions are relevant for health care reform in BC. Denmark was chosen for comparison because it is often considered to be the gold standard for care for older adults (Health Council of Canada, 2012). Australia’s aged care system has a strong emphasis on providing care in the community, and significant reforms have recently been introduced (Commonwealth of Australia, 2012a). In Canada, three comparison regions (Québec, Ontario, and Nova Scotia) were chosen, since there has been significant variation across Canada in the development and organization of continuing care systems and policy over time. This dissertation particularly focuses on the integration of services delivered in the home and the community (e.g., home care, home support, community services, etc.), as these services have been positioned as playing essential roles in health care reforms, and increasingly there has been an emphasis on allowing older adults to age in place. A systems approach and critical public policy approach will provide the theoretical underpinnings for this research (see chapter 4 for more details). The findings of this study will be a useful resource for advocates and policy-makers in BC, and also will provide insights for other jurisdictions.

The critical policy analysis will focus on three key areas: 1) the history and current state of the home and community care system and policy in BC; 2) the continuing care systems and policies of other jurisdictions and their experiences of health care reform; and 3) recommendations and potential reforms for BC. The primary overarching research question for this study is: How can an integrated continuing care system, that successfully integrates services delivered in the home and the community, be developed in BC? The study will also include four secondary research questions in order to address the primary research question:

1. What is the history and current state of home and community care services in BC? What progress or retrenchment has been made towards developing an integrated continuing care system in BC since the 1990s?
2. What policies are in place to support the development of an integrated continuing care system for older adults in BC and the other jurisdictions of interest? What are the underlying narratives and frames behind these policies?
3. What components of integrated continuing care systems are present in BC and other Canadian provincial health care systems (Québec, Ontario, and Nova Scotia) and in other progressive countries (Denmark and Australia)? What can we learn for BC from the examples and experiences of health care reform and the progress in developing integrated continuing care systems in the other jurisdictions of interest?
4. What recommendations can be made for BC for developing an integrated continuing care system within the BC policy context?

Chapter 2.

Literature Review

This chapter provides a brief overview of the literature on integrated care. First, conceptualizations of integrated care are reviewed, followed by key frameworks and components of integrated care models for older adults. The rationales for developing integrated care systems for older adults and implementing substitution policies (i.e., policies to substitute lower cost care in the home and community for care in institutions) are described, as well as critiques of substitution policies.

2.1 Conceptualizations of Integrated Care

The fact that there is no common definition for integrated care has been commonly reported in the literature. Indeed, one comprehensive literature review found 175 definitions of integrated care (Armitage, Suter, Oelke & Adair, 2009). A recent scoping review by the World Health Organization [WHO] Regional Office for Europe (2016) identified three primary ways integrated care is defined: 1) process-based definitions that focus on the mechanisms and components of integrated care, 2) user-led definitions that focus on the impacts on the individual, and 3) health system-based definitions that take a systems perspective on integration. A commonality of definitions of integrated care is the focus on the concepts of coordination and collaborations across the continuum of care (Leatt, Pink, & Guerriere, 2000).

The lack of consensus around the definition of integrated care is indicative of a larger issue within the literature – the enormous heterogeneity in what can be considered integrated care. While most integrated care models share certain key features (see next section), the methods and strategies to achieve integration are so varied that it can be difficult to compare interventions or develop frameworks and theories. For this dissertation, the definition of integrated care proposed by Kodner and Spreeuwenberg (2002) (see p.2) is used as the starting point for understanding of the concept of integrated care. It is also important to examine the multiple ways integrated care has been conceptualized to contextualize this dissertation research and understand

the many facets of integrated care. A brief summary of some of the different conceptualizations of integrated care are provided below.

Most conceptualizations of integrated care have focused on the levels and types of integration that can exist between different organizations and stakeholders. Leutz (1999) proposed one of the first conceptualizations of integrated care that included three different levels of integration: linkage (systems where providers operate with appropriate linkages to other systems when needed), coordination (systems where there are structures/individuals in place to coordinate care across the continuum), and integration (systems where resources or services from multiple systems are pooled). Curry and Ham (2010) differentiate between horizontal (involving services or organizations at a similar level of care working together) and vertical integration (occurs when organizations or services at different levels of care work together). The WHO Regional Office for Europe (2016) has identified three types of integrated care models based on the target groups and scale of the models: individual models (coordinate care for high risk individuals), group and disease-specific models (target specific population groups), and population-based models (target the whole population in a region).

Some conceptualizations have focused on the types of strategies used to achieve integrated care. Kodner and Spreeuwenberg (2002) identify five categories of integrated care strategies: funding (division, structure, and flow of funds), clinical (provider practices, standards, and tools), administrative (government regulations and administration), organizational (coordination and collaboration between organizations and programs), and service delivery (delivery and management of services). Reed, Cooks, Childs, and McKormack (2005) recognize that strategies of integration occur at three levels: macro (societal level), mezzo (organizational level), and micro (individual service user). While macro strategies are needed to provide an overall direction for integration and facilitate inter-organizational working, strategies are also needed at the mezzo- and micro-levels to develop effective collaborations and assist in planning and accessing services for clients (Reed et al., 2005).

The conceptualizations of integrated care described above are not mutually exclusive, rather, they provide a series of lenses for examining integrated care models. They emphasize that models vary in the intensity of integration, relationships between care providers, services being linked, target groups and scale, strategies, and level at

which strategies are enacted. These conceptualizations provide a useful starting point for describing and analyzing different integrated care models.

2.2 Key Components of Integrated Care Models

Multiple frameworks have been developed illustrating the best practices and principles of integrated care. These frameworks provide important reference points for examining the components of effective integrated care systems and strategies for integrated care. Two frameworks that are the most relevant to this dissertation are discussed below.

2.2.1 Best Practice Framework for Organizing Systems of Continuing/Community Care Services

The *Best Practice Framework for Organizing Systems of Continuing/Community Care Services* by Hollander and Prince (2008) (see figure 2) was developed from an extensive Canadian study that involved an examination of the continuing care system in place in BC in the early 1990s; a literature review; and interviews with over 270 people on organizing health care delivery for special populations (Hollander & Prince, 2008; Chappell & Hollander, 2013). The framework is composed of three major components: philosophical and policy prerequisites, best practices for organizing a system of continuing/community care, and coordination and linkage mechanisms. This framework was specifically designed to examine continuing/community care systems for older adults, and therefore is extremely relevant for this dissertation.

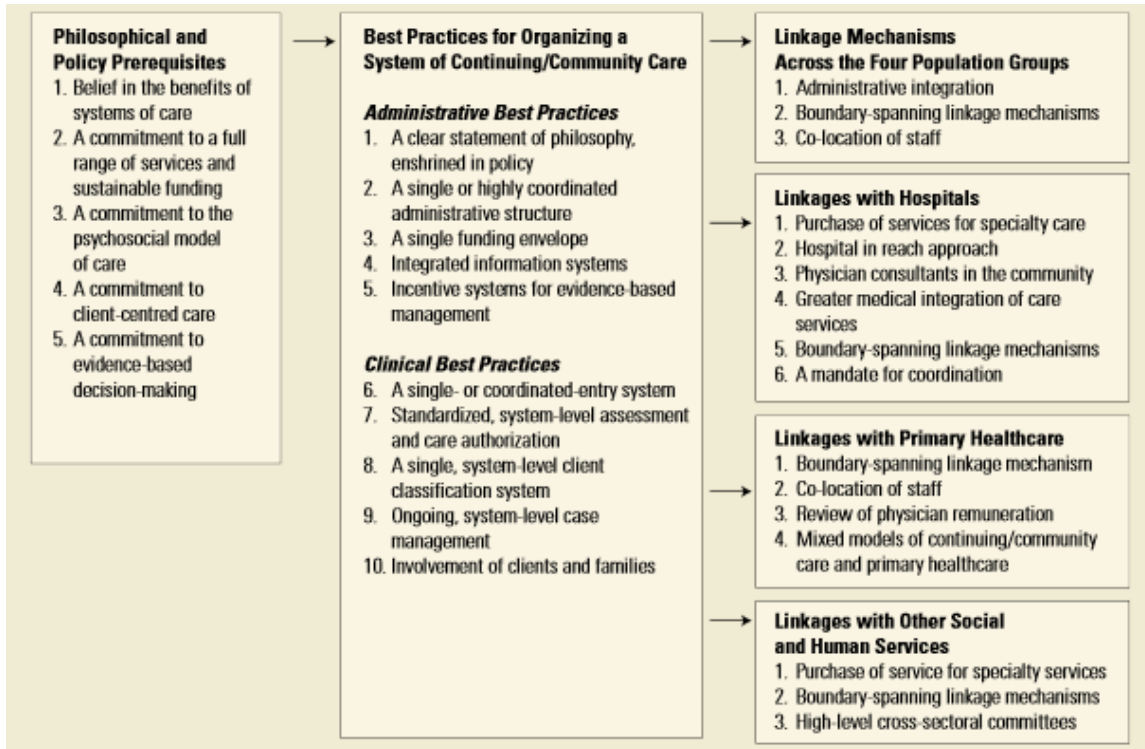


Figure 2 Best Practice Framework for Organizing Systems of Continuing/Community Care Services

Source: Hollander & Prince (2008)

2.2.2 Policy Framework for Integrated Care for Older People

The *Policy Framework for Integrated Care for Older People* was developed by Banks (2004) for the Care and Management of Services for Older People in Europe Network. The policy framework is meant to be a checklist for national and regional governments that wish to integrate services for older adults. It was developed based on the expertise of members and experiences from countries within the network. The framework is unique as it views integrated care systems from the policy perspective. A condensed version of the framework is shown below (table 1).

Table 1 Policy Framework for Integrated Care for Older People

<p>1. Clarifying the vision: A clear vision is in place for integrated care</p>
<p>2. Principles and values: Policy incorporates core set of values</p> <ul style="list-style-type: none"> • Older people are treated as individuals and are in control • Older people's views are central • Access to integrated care should be equitable and according to need • Solutions to integrated care must be sustainable

<p>3. Criteria for operational success: Requirements for a well-operating system are met</p> <ul style="list-style-type: none"> • Flexible and innovative integrated services • Clarity about responsibilities and accountabilities • Appropriately targeted integrated care
<p>4. Coherence with other policies: Integrated care policy must be coherent with policies in other areas</p> <ul style="list-style-type: none"> • Coherent funding systems • Promoting independence and well being • Support to carers • Integrating information
<p>5. Active promotion and incentives: Governments provide incentives and actively promote integrated care</p> <ul style="list-style-type: none"> • Allocating resources • Resourcing integration • Awarding responsibilities to integrate services • Introducing incentives and sanctions • Supporting shared learning • Setting standards for integrated approaches • Providing support to carers
<p>6. Evaluation and monitoring: Core evaluation requirements should be in place</p>
<p>7. Regulation and inspection: Regulation and inspection systems are coordinated</p>
<p>8. Support to implementing policy: Support is provided to implement the policy</p>

Source: Based on Banks (2004)

2.2.3 Key Components of Integrated Care Models

Based on the frameworks described above, and review of additional frameworks of best practices and literature reviews of integrated care for older adults, the following key components of successful integrated care models for older adults were identified:

- Integrated care philosophy (Hollander & Prince, 2008; Banks, 2004; Kirst et al., 2017)
- Supportive organizational culture, leadership, and human resources (Suter et al., 2009; Banks, 2004; Kirst et al., 2017)
- Patient-centeredness (Hollander & Prince, 2008; Suter et al., 2009; Banks, 2004; Wodchis, Dixon, Anderson, & Goodwin, 2015)
- Comprehensive range of services (Hollander & Prince, 2008; Suter et al., 2009; MacAdam, 2008)
- Integrated information systems (Hollander & Prince, 2008; Suter et al., 2009; Banks, 2004)

- Ongoing case management (Hollander & Prince, 2008; Johri, Béland & Bergman, 2003; MacAdam, 2008; Wodchis et al., 2015)
- Single or coordinated entry point (Hollander & Prince, 2008; Johri et al., 2003; Wodchis et al., 2015)
- Standardized assessment (Hollander & Prince, 2008; Suter et al., 2009; Johri et al., 2003)
- Multidisciplinary teams (Suter et al., 2009; MacAdam, 2008; Johri et al., 2003; Wodchis et al., 2015)
- Financial incentives or sanctions (Hollander & Prince, 2008; Suter et al., 2009; Johri et al., 2003; Banks, 2004; Kirst et al., 2017)
- Ability to substitute home-based services (Johri et al., 2003; MacAdam, 2008; Eklund & Wilhelmson, 2009; Béland & Hollander, 2011)

This list helps us to conceptualize what an integrated care system looks like and provides a useful framework of features for examining integrated care models. However, literature on integrated care emphasizes that there is no single perfect model, and the success of a model and integrated care strategies are context dependent (e.g., Kirst et al., 2017; MacAdam, 2011). Therefore, a model could be successful without incorporating all of these components.

2.3 The Case for Integrated Care

Why do people want to develop integrated care systems? Increasingly, integrated care systems are perceived as the preferred way to deliver care to aging populations. The primary logic behind integrated care models for older adults is that they will improve the coordination of services for patients with complex needs and potentially allow for the substitution of lower cost care (e.g., home care) for higher cost care (e.g., long-term care and acute care) (Chappell & Hollander, 2011; 2013; Reed et al., 2005; Leichsenring, 2004). Substitution policies have been strongly promoted in developed countries based on humanitarian (older adults' desire to age in place) and financial reasons (potential for cost savings) (Blank & Burau, 2010).

Based on the literature, there are four principle rationales for developing integrated care systems for older adults and providing care to the community: a) Facilitating aging in place; b) Improving care experiences for older adults; c) Increasing

efficiency of the health care system; and d) Cost-savings for the health care system. While in government policy there often is a heavy emphasis placed on rationales c) and d), it is important to not forget the importance of rationales a) and b). Each of these rationales is described below.

2.3.1 Aging in Place

Aging in place generically refers “to the notion of aging in one’s home and community as long as possible and to delaying any potential relocation to a long-term care setting.” (Bigonnesse & Chaudhury, 2019, p.3). While there is a lack of consensus of what constitutes home and community, this usually is conceptualized as referring to aging in a) one’s own private home and b) supportive housing or a community setting (Bigonnesse & Chaudhury, 2019). A recent survey of Baby Boomers and older adults in four major census metropolitan areas in Canada found 86% of respondents want to age in place (Mustel Group, 2020). Golant (2014) identifies a number of factors that contribute to the desire of older adults to age in place: the high proportion of home owners; high satisfaction with homes; appeal of familiar settings and the status quo; attachment to belongings; pride in their home; fear of loss of identity or relationships; and desire for privacy and control. Research has found that older adults generally prefer to be cared for in their home by family or paid caregivers, while long-term care homes are the least preferred care setting (e.g., Eckert, Morgan, & Swamy, 2004).

Globally, there is significant variety in the amount of resources invested in caring for older adults in the home and community, but recently there has been a shift towards policies to support older adults in the home and community. The two primary reasons for this shift are the belief that older adults wish to age in place and the belief that it is more cost-effective (Blank & Burau, 2010). In 2007, the WHO released *WHO Global Age-Friendly Cities: A Guide* and one of the eight key areas of age-friendly cities identified is community supports and health services. The guide states about home care:

One very consistent theme is the need for a wide range of home support and care services – from help with shopping and/or providing meals to home visits from doctors and other service providers. With few exceptions, the focus group participants want services that would allow them to tend to their health and personal care needs in their own homes. (WHO, 2007a, p.68)

In Canada, it has been recognized that changes to services and policies will be required in order to facilitate aging in place. The Special Senate Committee on Aging reported “Too many older people across the country are not being well served by this continuum of supports to age in place of choice.” (Carstairs & Keon, 2009, p.33). The Committee suggested a comprehensive integrated care system for older adults is required to successfully allow older adults to age in place. Home care and home support are recognized as essential components that should be incorporated into a national integrated care program (Carstairs & Keon, 2009).

2.3.2 Better Care Experiences for Older Adults

In addition to the current aging of the population, Canada has undergone an epidemiological transition, where the leading causes of illness and death have shifted from infectious to chronic diseases. An increasing number of older Canadians are living with complex health conditions, and 20% of Canadians aged 65-74 and 36% aged 85+ have 3 or more chronic conditions (CIHI, 2011b). The leading causes of death are now chronic diseases and as a result about 90% of deaths occur over an extended period of time (Canadian Hospice Palliative Care Association, 2015). Most health care systems are ill-suited to deal with the needs of patients with complex chronic conditions. The CMA (2016) has noted: “Canada’s Medicare system was established to deal largely with acute, episodic care for a relatively young population. Today our system struggles to properly care for patients — many of whom are elderly — managing complex and ongoing health issues.” (p.4).

One of the most important benefits of integrated care for health care users (and informal caregivers) is the provision of a seamless and coordinated care experience (Lloyd & Wait, 2006). A recent comprehensive scoping review of older adults’ perspectives on integrated care models reported older adults wanted integrated care to provide: increased continuity of care; seamless transitions; well-coordinated care; the ability to be involved and informed about their care; and quick access to services (Lawless, Marshall, Mittinty, & Harvey, 2020). The results from the 2019 Commonwealth Fund International Health Policy Survey illustrate some of the current deficits of coordination of care within the Canadian health care system. For example, only 24% of primary care physicians coordinate with home care providers on the needs of patients

and only 43% frequently coordinate care with social services. Improved integration of services was identified by 65% of primary care physicians as the top priority for improving patient quality of care (CIHI, 2020). Integrated care is proposed as a solution that will improve the coordination of care for older adults and other complex populations.

2.3.3 Efficiency of the Health Care System

In many countries the focus of health care systems has shifted from improving quality of care to improving efficiency and generating cost-savings (Blank & Burau, 2010). The drive for efficiency has emphasized better allocation of the health care resources available, and home and community care services have been identified as resources currently not being used to their maximum potential. It has been proposed that home and community care services have the potential to reduce pressures on, and inappropriate utilization of, acute and residential care services.

Alternate level of care (ALC) refers to hospital patients who no longer require acute care but are waiting in hospital beds for alternative placements (CIHI, 2009). ALC has negative impacts both for older adults and the health care system. Acute care is often used as a fallback for older adults, but it is a debilitating environment that coupled with long waits for alternative care can result in declines in the clients' health. ALC also uses up valuable acute care resources and contributes to hospital overcrowding and delays (Walker, 2011). It is expected that the number of older adults in ALC will increase as our population ages, and there are concerns about the impacts this will have on both the health care system and older adults (CIHI, 2012). A report by CIHI (2012) found 54% of older adult ALC patients were waiting for long-term care placement and 18% were waiting for home care. The median number of ALC days for patients waiting for long-term care was 26, and 7 for patients waiting for home care. It seems logical that a strengthened and better coordinated continuing care system would be a component required to decrease the number of ALC bed days in acute care.

In addition to ALC, there is also the issue of the inappropriate and premature placement of older adults into long-term care facilities. A study by CIHI (2017) examining continuing care patients in Ontario, Manitoba, Saskatchewan, Alberta, and BC found that approximately one-third of older adults in long-term care could potentially be living in the community with proper supports (rates varied from 21% in BC and Saskatchewan to

47% in Manitoba). The report proposes that more supports in the community and better alignment and integration of policies and practices in acute, residential, and continuing care would help more older adults to remain at home.

2.3.4 Cost Savings

The quest for cost savings has been a powerful driver of recent health care system reforms. In the 1970s and 1980s studies from the United States suggested that home care was not a cost-effective substitute for residential care (Hollander & Chappell, 2007). However, more recently several Canadian studies have lent support to the argument that home care, home support, and other forms of community-based services can act as cost-effective alternatives to residential care.

One of the first studies on this topic was conducted by Hébert et al. (2001) comparing the costs and disability profiles of a sample of clients receiving home care, intermediate care, and nursing home care. While the study found that home care costs were cheaper regardless of level of disability, after incorporating the societal costs to informal caregivers home care was more expensive than institutional care for people with high levels of disability. Intermediate facilities were found to offer a cost-effective alternative to nursing home care.

Chappell and Hollander have long advocated for integrated continuing care systems and have conducted a number of studies on home care that support this position. Hollander and Tessaro (2001) conducted a natural experiment in 1994 comparing clients in BC in health care units that were impacted and unimpacted by service cuts, and found that clients whose home support had been cut were more likely to die or be admitted to long-term care. The total average costs for those whose home support services were unimpacted were \$20,542 over three years, while for patients whose services had been cut it was \$28,240. Hollander and Chappell led the research team for the *National Evaluation of the Cost-Effectiveness of Home Care* which was a series of 15 studies conducted on home care across Canada (Hollander & Chappell, 2002). Substudy 1 compared the costs of home care versus residential care for clients in BC and found that home care costs were significantly less than residential care (40-75% less) even for the highest needs clients. Substudy 5 built on these findings comparing home care versus residential care in sites in BC and Manitoba and found clients had

similar levels of satisfaction in both settings, and home care was less expensive than residential care even after accounting for the costs of informal care. Substudies 9, 11, 12 and 14 examined home care as a substitution for acute care, and substudies 10 and 13 examined day hospitals as a substitute for acute care. Both types of acute care substitution studies found mixed results (though it should be noted that several of the studies encountered logistical difficulties). Key lessons from these studies included a philosophy of enablement, the need for adequate funding, challenges of implementing new programs, and the need for a comprehensive range of services as a part of an integrated continuing care system. From the national evaluation the authors concluded: “Thus, our findings seem to indicate that in integrated care delivery systems, home care has the potential to be a major force in increasing the cost-effectiveness of the overall health care system.” (Hollander & Chappell, 2002, p. xii).

A 2006 literature review on the cost-effectiveness of continuing care services found there was mixed evidence on the cost-effectiveness of substitution of community care services for institutional or acute services (Hollander Analytical Services Ltd, 2006). While evidence from the 1980s and 1990s suggested that home care was not a cost-effective alternative to facility care, several more recent studies directly comparing the costs of home care to facility care found home care to be cost-effective. Based on a small evidence base it was suggested home support services may delay institutionalization. There was also evidence that some home care programs may be effective in substituting for acute care as early discharge or preventative programs. Literature on the cost-effectiveness of assisted living and supportive housing was limited. An earlier 2003 systematic review by Fraser (2003) on the cost-effectiveness of home care also reported mixed but mostly positive results. In this review (n=11) there were 6 studies that found home care to be less costly than other alternatives, 3 that found it to be more costly, and 2 that were inconclusive.

Two studies from Ontario using a “balance of care” approach also suggest that community services may potentially be a cost-effective alternative to residential care (Williams et al., 2009a; Kuluski, Williams, Berta & Laporte, 2012). In these studies, profiles of different clients waiting for long-term care placement were presented to case managers, and they were asked to design packages of home and community care services if they deemed the client could be safely maintained in the community. The home and community care packages were costed out and if the costs were lower than

long-term care the client was deemed divertible from long-term care. In the first study by Williams et al. (2009a) it was estimated that 37% of clients waiting for long-term care placement could be safely diverted to the community. In the second study by Kuluski et al. (2012) the diversion rate for the city of Thunder Bay was only 8%, however, for the rural Northwestern region around Thunder Bay it was 50%.

Overall, the findings from Canadian studies suggest that home and community care services have the potential to be cost-effective alternatives to institutional care in certain circumstances. The fact that home care is not automatically a cost-effective alternative was emphasized in these studies, and funding needs to be redistributed to home care and other community services so there are adequate resources for system-wide substitution to occur. Indeed, in the study by Kuluski et al. (2012) the majority of people in the rural Northwestern region that could be diverted actually had lower level needs, and it appeared that lack of home and community care resources and fragmentation were causing upward substitution to occur.

2.4 Critique of Integrated Care and Substitution Policies

There are several critiques that can be raised about the logic behind integrated care and substitution policies. First, it is important to note that not all older adults have the desire or ability to age in place. Challenges may arise such as: unaffordable housing; unsuitable dwellings; unmet needs for formal or informal support; social isolation and loneliness; unsafe neighbourhoods and communities; and lack of transportation options (Golant, 2014). In cases where the needs of older adults are too complex or supports are not available, remaining in the home or community can be a maladaptive choice.

Second, the intention behind these models is to provide opportunities to substitute lower cost home and community care services for more costly acute and long-term care; in order for this to occur adequate home and community care resources are required. Historically, home and community care services have been under-resourced in comparison to acute and long-term care (Blank & Burau, 2010), and the extent to which governments are actually willing to invest in the home and community care services required for integrated care models to be successful is unclear. Over the past two decades, while the rhetoric of governments has emphasized providing care in the home,

reforms to home and community care in several Canadian provinces have resulted in rationing of services, tightening of eligibility requirements, reductions in access to home care services (particularly home support), and increased expectations of family/private support (e.g., Penning, Brackley, & Allan, 2006; Duncan & Reutter, 2006; Aronson, 2002). Furthermore, in Canada home care is not insured under the *Canada Health Act*, and there is significant variation in eligibility requirements, baskets of services, and costs across the country (Keefe, Ogilvie, Stevens, MacPherson, & Stoddart, 2014).

Third, one of the key concerns that can be raised about substitution and aging in place policies is that they can lead to downloading of responsibilities onto the individual and informal care sector, particularly when they are being implemented for cost containment purposes and substitution is not accompanied by greater investments in home care (Blank & Burau, 2010). As the provision of home care services is not mandated in the *Canada Health Act*, in many provinces these services fall short and individuals are forced to turn to the private sector or informal care as a supplement. For example, Tousignant, Hébert, Dubuc and Coulombe (2005) estimated that in Québec only 12-16% of home care clients' needs are met by publicly funded services, compared to 75% in long-term care facilities. There is a strong relationship between care setting and who provides care, and the home is a setting where informal care is heavily relied upon and entitlements for care are a matter of debate (Milligan, 2009). Informal care has particular implications for women, as caregiving is usually perceived as part of the taken-for-granted domestic sphere of work that women are "naturally" responsible for. Indeed, while caregiving is usually framed as a choice, the decision to be a caregiver is often the result of gendered and cultural norms, low socioeconomic status, and lack of public support (Hooymans, Browne, Ray, & Richardson, 2002).

Fourth, there is the risk that as home care and other community services are increasingly used to substitute for acute care, the long-term care functions of these services will be lost. It has been well documented that the complexity of clients in the community are increasing and home care is increasingly being used as a substitute for acute care (Johnson, Bacsu, McIntosh, Jeffery, & Novik, 2017). This trend has been ongoing for the past three decades, and in a synthesis report of 45 home care studies conducted between 1997-2001 as a part of the Health Transition Fund, the following caution was offered about using home care as a substitute for acute care:

In sum, concern is warranted about the increasing pressure exerted by hospitals to speed up hospital-to-home transfers. This trend ignores the question as to whether home care should assume the role of a hospital-at-home program at the expense of its mandate as a continuum-of-care program, and if so, the question as to whether the cost of this shift in focus from care to cure makes sense. (Shapiro, 2002, p.13)

Finally, a fifth concern can be raised as to whether integrated care models have proven successful in meeting their intended goals. This concern will be discussed in the section below.

2.5 Evidence of the Effectiveness of Integrated Care

A comprehensive systematic review on integrated care at the system level was conducted by Armitage et al. (2009) reviewing 120 articles and documents on integrated care. From this review, Armitage et al. (2009) concluded that “Very few studies reported on the impact of integration and tended to focus on *perceived benefits* rather than empirically derived outcomes” (p.5). At the system level, the studies that reported on outcomes found conflicting results, with some reporting favourable outcomes and others unfavourable. However, Armitage et al. (2009) noted that there may be better evidence available for integrated care systems for specific populations such as older adults. A more recent scoping review by the WHO Regional Office for Europe (2016) observed that it is difficult to establish causality between integrated care and outcomes due to the multicomponent nature of integrated care strategies, challenges with measuring the success of integrated care, and lack of opportunities for comparison.

Table 2 summarizes six reviews of integrated care models for older adults. The earliest review by Johri et al. (2003) focused on models that integrated acute and long-term care services (n=7) and found 6 of the integrated care interventions were generally able to provide more effective care at a lower cost. A large contributor to the cost-savings were reductions in use of more expensive forms of care (e.g., hospitalizations, long-term care beds, etc.) and substitution of less costly forms of care (e.g., community services). A review by MacAdam (2008) focused on comprehensive models of integrated care (n=7) and 6 of the programs reviewed reported favourable outcomes for at least 2 of the following outcome measures: hospital use, long-term care home use, cost-effectiveness/cost-savings, and patient satisfaction or quality of life. Eklund and Wilhelmson (2009) reviewed integrated care models involving case managers (n=9) and

7 of the studies reported at least one favourable outcome. The most promising results were reported for hospital/institutional days, which half of the studies reported favourable results for. Findings on client and informal caregiver outcome measures were either positive or more frequently no impacts were found. Béland and Hollander (2011) reviewed ongoing comprehensive integrated care models for the frail elderly (n=9) and 7 of the models reported at least one of the following positive outcomes: decreased rates of acute care use, decreased rates of institutionalization, and/or cost-savings. Liljas et al. (2019) reviewed organizational or systemic level integrated care models and the majority of studies reported positive impacts on hospital admissions and readmissions. Findings on length of hospital stay and patient satisfaction were mixed, and no impacts were found for mortality. The largest review (n=29) by Looman, Huijsman and Fabbricotti (2019) examined integrated care models with preventative primary care components and found most studies reported no significant impacts on health care utilization. For the studies that found significant impacts, generally they reported decreases in utilization of hospital care and no consistent findings on institutionalization. There were increases in utilization of other types of care. Findings on cost measures were mixed, and for most studies no significant impacts were reported. For most of the health outcome measures positive impacts, or more frequently no impacts, were observed.

Table 2 Reviews of Studies of Integrated Care Models for Older Adults

Authors & Sample	Study Inclusion Criteria	Key Findings
Johri et al. (2003) (n=7)	a) study used a comparison group; b) program was a community-based intervention for the elderly aimed at improving integration and not disease-specific; c) at least one outcome was reported; and d) study took place after the US National Long Term Care Demonstration.	<ul style="list-style-type: none"> • With the exception of one trial, the interventions were generally able to provide more effective care at a lower cost for older adults. • A large contributor to the cost-savings were reductions in more expensive forms of care and substitution of less costly forms of care. • Several interventions also resulted in improvements in functional ability or delays in functional decline for clients.
MacAdam (2008) (n=7)	a) an integrated care program for older adults; and b) study was a randomized controlled trial or had a comparison group.	<ul style="list-style-type: none"> • Five of the programs resulted in reductions of hospital use, four reductions of long-term care/nursing home use, three cost-effectiveness/cost savings, and five increased client satisfaction or quality of life.

Eklund and Wilhelmson (2009) (n=9)	a) randomized controlled trial of an integrated intervention for community-dwelling older adults; b) intervention involved a case manager; c) study was published between 1997-2007; d) intervention was not disease specific; and e) study was not from Africa, Asia or South America.	<ul style="list-style-type: none"> • Seven of the studies reported at least one favourable outcome, one no differences, and one in favour of the control. • Outcomes measured included client, caregiver, and health service utilization outcomes. The most favourable results were found for length of stay in the hospital/institution. • For a large number of outcomes, no significant differences were found.
Béland and Hollander (2011) (n=9)	a) study provided a good description of the integrated care model; b) there had been a good quality evaluation conducted (assessment of quality was based on a set of scoring criteria); and c) study was published between 1997-2010.	<ul style="list-style-type: none"> • Two of the models reported unfavourable or no difference in outcomes. • The other seven models reported at least one of the following positive outcomes: decreased rates of acute care use, decreased rates of institutionalization, or cost-savings.
Looman, et al. (2019) (n=29)	a) study population was community-dwelling frail older people; b) integrated care model with preventive component based in primary care; c) study included a comparison group; and d) at least one outcome on the effectiveness or cost-effectiveness of the intervention was reported.	<ul style="list-style-type: none"> • The most promising health outcomes were found for well-being, life satisfaction, frailty, and desire for institutionalisation which most studies reported favourable effects for. Most other health outcomes had mixed results. • Most studies found favourable effects for process measures (i.e., goal attainment, empowerment, and care process). • Most studies reported no significant impacts on health care utilization. For those in which there were significant impacts studies generally found decreases in utilization of hospital care but increases in utilization of other types of care. • Three models were cost-effective, two not cost-effective, and four found no significant differences.
Liljas et al. (2019) (n=12)	a) organizational or systemic level integration model; b) study includes comparison group; c) includes objective measures of hospital use or mortality or subjective measures of patient satisfaction; and d) published between 1995-2018.	<ul style="list-style-type: none"> • Two studies reported positive impacts on hospital readmissions and one no impacts. • Three studies reported positive impacts on length of hospital stay and three no impacts. • Six studies reported positive impacts on hospital admissions and three no impacts. • Two studies reported positive impacts on patient satisfaction and three no impacts. • Five studies reported no impacts on mortality.

From the reviews above, it is apparent that the most promising impacts of integrated care models have been reductions in hospital use and to a lesser extent reductions in institutionalization, though the findings have not always been consistent.

Results on the cost-effectiveness of integrated care models have been mixed. There have been some favourable health outcomes reported for older adults, though more frequently no impacts were observed. However, there are a few caveats that should be highlighted with respect to the current evidence on the effectiveness of integrated care initiatives and that might help to explain the lack of consistency of results.

First, a broad range of integrated care interventions were included in the reviews making comparisons among interventions difficult, and the inclusion of such a diverse range of models may be the reason results have been inconsistent. This is particularly apparent in the large review by Looman et al. (2019), which included interventions as simple as a comprehensive geriatric assessment with follow-up to as complex as integrated service delivery networks embedded within the larger health care system. Second, specific to the development of integrated continuing care systems, the three reviews focusing on comprehensive or systemic/organizational level integrated care models found more promising results (MacAdam, 2008; Béland & Hollander, 2011; Liljas et al., 2019). In the review by Béland and Hollander (2011) two successful provincial/state level systems were identified: the BC System and the Arizona Long-Term Care System. A cost minimization analysis of the provision of home care in the BC system operating in the 1980s found home care to be cost-effective even after accounting for costs to informal caregivers. For the Arizona Long-Term Care System, a computer simulation estimated that over 270,000 nursing home days were avoided and approximately \$4.6 million in nursing home costs were saved over a two-year period due to the home and community-based care system. Third, limited evaluation has been conducted of the impacts of integrated care models on process outcomes, outcomes for informal caregivers, psychosocial outcomes, and social care utilization.

In much of the recent literature, the focus has also shifted away from concentrating solely on *if* an integrated care model works, and instead there is increasing attention being paid to *how* and *why* they work in certain contexts (Busetto, Luijckx, & Vrijhoef, 2016). Wodchis et al. (2015) synthesized evidence from seven international case studies of integrated health and social care programs for older adults and people with complex needs. All of the programs resulted in some improvements in user satisfaction and reduced hospitalization or institutionalization rates. Common features of the models included holistic care assessments, multidisciplinary teams, utilization of networks of providers, care planning, care coordination, single point of

entry, involvement of the individual and informal caregivers, and personal contact with a case manager. The authors concluded that there is no single best organizational model for delivering integrated care.

Kirst et al. (2017) conducted a realist review of integrated community-based programs for older adults with complex conditions that used multidisciplinary teams and were long-term programs. Articles had to meet the following criteria: a) evaluative; b) published in English; and c) published in 1980 or later. Of the integrated care programs included in the review (n = 28), 11 were identified as successful, 13 had mixed results, and 4 were unsuccessful. Success of programs was most strongly linked to the development of trusting multidisciplinary relationships (involving collaboration and good communication, knowledge sharing, clear roles, and leadership) and high levels of provider understanding and commitment to the model (positive leadership and organizational culture, flexibility of model, provider incentives, provider expertise and training, and adequate time to build infrastructure). In another scoping review of the literature, Threapleton et al. (2017) reviewed 30 articles on integrated care for frail older adults and identified facilitators and barriers to integrated care. At the macro level factors that might impact initiatives include cultural inertia, health system stability, laws and regulations, and strategic direction. At the meso level factors included funding/finances, organizational leadership, structures of existing services, philosophy/culture, intervention size and complexity, intervention resources, and credibility. Finally, at the micro level factors that might influence initiatives included shared values and understanding, engagement, and communication.

While integrated care systems for older adults do not appear to be the magic bullets that have been hoped for, there is evidence that they can result in positive outcomes under the right circumstances. Benefits of these models can potentially include decreased use of acute care services, decreased rates of institutionalization, cost-savings, increased client satisfaction, and increased quality of life (MacAdam, 2008; Béland & Hollander, 2011; Liljas et al., 2019). It is important to note that integrated care models vary widely in terms of their scope and methods, and therefore also their potential impacts. Broader comprehensive or systemic/organizational level integration models have produced more promising results. At the national/provincial level there has been some evidence of the effectiveness of integrated care models, though the methods of evaluation for these models have been hampered by the large scale of these

interventions. Models that integrate acute and continuing care also appear to produce some promising results, while results of integrated primary care initiatives have been less consistent. It is also important to note that there are benefits to integrated care systems that often are not captured in evaluation studies. For example, allowing older adults to remain in their homes or facilitating seamless transitions through the health care system. Finally, Leutz (1999) one of the early theorists on integrated care pointed out there are costs associated with integration, and when implementing systems it may take time before benefits are fully realized.

Chappell and Hollander highlight in their *Evidence-Based Policy Prescription for an Aging Population* (2011) that the substitution of home-based care for other services is key to the success of most integrated systems for older adults, and this is supported by the findings from the reviews by Johri et al. (2003), MacAdam (2008), Eklund and Wilhelmson (2009), and Béland and Hollander (2011). The research has also identified several other common features of successful integrated care models as described in section 2.2.3. Currently, the evidence and expected benefits of integrated care systems have been strong enough to result in investment into and development of a variety of models for older adults both in Canada and other parts of the world. Integration is especially crucial for continuing care systems as they exist at the nexus of, and must serve as an interface and link between, the health–social care and formal–informal care sectors (Leichsenring et al., 2013). Kodner (2004) writes:

International evidence on the organisation and delivery of LTC more or less suggests that services are poorly coordinated and disjointed, and frequently suffer from less than optimum quality, efficiency, and accountability, as well as difficult to control costs. These problems stem largely from LTC's bifurcated and ambiguous status within traditional health and social care, a complex and difficult situation, which thwarts all-important integration at the administrative, organisational, service delivery, and clinical levels. Serious efforts have been made in various countries to reshape LTC on an ad hoc basis at the nexus of funding, policy and practice. However, with an exponential increase on the horizon in the demand for LTC, growing pressures to contain public expenditures and improve efficiency, and mounting consumerism, these incremental reforms are likely to fall short of what is needed. (p.1)

This description clearly applies to the state of continuing care in Canada as well, and the following chapter discusses continuing care in the Canadian context.

Chapter 3.

Overview of Continuing Care in Canada

This chapter presents a brief overview of Canada's health care system to provide context about the larger system within which continuing care systems operate. Then continuing care systems and core components of these systems in Canada are described.

3.1 Health Care in Canada

The guiding principle for health care in Canada is “universal coverage for medically necessary health care services provided on the basis of need, rather than the ability to pay.” (Health Canada, 2019). The major piece of legislation that governs Canada's health care system is the *Canada Health Act*. This act lays out five basic principles for health care systems: public administration, comprehensiveness, universality, accessibility, and portability (Health Canada, 2019).

The role of the federal government in health care is limited and confined to: setting and administering national principles; funding; providing services to special populations; protection and regulation; and public health (Health Canada, 2019). Provincial and territorial governments have the primary role in providing health care services and are responsible for administering and delivering “medically necessary” health care services. Medically necessary services that are insured under Medicare include physician and hospital services. However, other health care services (e.g., long-term care, home care, dental care, prescription medications, etc.) are not insured under Medicare (Health Canada, 2019). Provinces and territories have the discretion to provide continuing care services as extended health care services that are not insured under Medicare, and thus can set their own terms for provision and fees (Lanoix, 2017).

Primary health care services are the first point of contact for health care systems in Canada and include a wide range of services such as: prevention, treatment of chronic conditions, basic emergency care, referrals to other services, rehabilitation services, primary mental health care, palliative care, etc. Primary health care services are normally provided by physicians on a fee-for-service basis or by other salaried health

professionals (e.g., nurses, allied health, etc.). Secondary health care services provide specialized care in institutional settings and include care delivered in hospitals. Hospitals are usually funded by global budgets (Health Canada, 2019).

Funding for public health care is tax-based and primarily funded by Provincial and Territorial Governments, with an average of 23% of funding coming from Federal Health Transfers (Advisory Panel on Healthcare Innovation, 2015). Total expenditure on health care in 2019 was approximately \$264 billion and accounted for 11.6% of the gross domestic product (GDP). Compared to other developed nations, Canada's health care spending is above average (CIHI, 2019a). Over the past decade Canada's health expenditures generally declined over the period of 2010-2014 due to fiscal restraint, and then begin to grow again over the period of 2014-2019 (CIHI, 2019a). Analysis of health care cost drivers has shown that population aging only contributes to a small amount (0.8%) of the growth in health care spending (CIHI, 2011c). The split between public and private spending has been consistently around 70% public and 30% private, though this varies for each sector of the health care system. For continuing care there is a higher percentage of private spending than most other sectors of the health care system (i.e., hospital care and physician care) (CIHI, 2019a).

3.2 Continuing Care in Canada

As described previously, continuing care services are not insured under Medicare. In 2002 the Royal Commission on the Future of Health Care in Canada recommended that the *Canada Health Act* be extended to cover post-acute, palliative, and mental health home care services (Romanow, 2002). The Senate's Kirby Report also recommended expanding coverage to post-acute and palliative home care a year later (Kirby, 2003). In 2004 a general consensus was reached as a part of the ten year health accord to provide coverage for post-acute, palliative, and mental health home care; however, there has been little follow-up on this commitment (Canadian Health Coalition & Ontario Health Coalition, 2017). Continuing care remains primarily outside the realm of the *Canada Health Act*. It is estimated that Canada spends 1.2% of its GDP on continuing care, which is below the Organization for Economic Co-operation and Development (OECD) average of 1.7%. In comparison to other OECD nations, Canada also spends significantly more on care in facilities (87%) than care in the home and community (13%) (National Institute on Ageing, 2019).

Within the Canadian context, continuing care services (also commonly referred to as long-term care) have been described as (National Institute on Ageing, 2019, p.7):

A range of preventive and responsive care and supports, primarily for older adults, that may include assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) provided by either not-for-profit and for-profit providers, or unpaid caregivers in settings that are not location specific and thus include designated buildings, or in home and community-based settings.

As can be seen in this definition, continuing care services have a different orientation than other health care services, with a focus on the provision of care to assist with ADLs (personal care activities such as bathing, hygiene, toileting, mobility, and eating) and IADLs (activities necessary for daily life such as shopping, transportation, preparing meals, housekeeping, and managing finances).

The provinces and territories, if they choose to provide continuing care, have the responsibility for providing, designing, and funding the services. Usually the delivery of these services takes place through regional health authorities (OECD, 2011). All provinces and territories offer long-term care facilities and home care programs, and many also offer some form of assisted living/supportive housing (Canadian Home Care Association, 2013; Office of the Veterans Ombudsman, 2014). Services are delivered through the public sector or contracted private for-profit or non-profit providers (National Institute on Ageing, 2019). Most jurisdictions use the interRAI (International Resident Assessment Instrument) to assess the needs of clients (National Institute on Ageing, 2019). Non-professional personal support workers (also known by terms such as care aides, health care assistants, community health workers, etc.) provide about 70% of care in the home and 70-80% of care in long-term care facilities (Canadian Home Care Association, 2013; Squires et al., 2015). Below brief descriptions of the major components of continuing care systems in Canada (home care, assisted living, and long-term care facilities) are provided. The role of informal caregivers is also described.

3.2.1 Home Care

An environmental scan of home care in Canada by Johnson et al. (2017) reported that while all provinces have home care programs, these vary in terms of the services available, care coordination, assessments, and costs. They reported there was increasing recognition of the need to increase investments in home care and better

integrate these services within the care continuum. An earlier report by Keefe et al. (2014) provided data on home care services available in Canada. Key findings included:

- All jurisdictions offer homemaking services, except for the territories and BC (BC only offers when necessary for client safety, though some services may be available through community Better at Home programs).
- Personal care services such as ADLs are offered consistently across all provinces, but not the territories.
- Additional services such as cueing, shaving, foot care, skin care, and oral hygiene, are offered by some jurisdictions.
- Home nursing services are offered in all jurisdictions, though they differ in comprehensiveness and level of care. BC offers one of the most comprehensive sets of home nursing services.
- All jurisdictions offer some additional allied health services.
- The most important factors identified by key informants as contributing to wait times were human resource issues, geography, and increasing client complexity.
- All jurisdictions offer assessment, care coordination, and professional services (nursing, occupational therapy, and physiotherapy) free of charge.
- Manitoba, Ontario, Prince Edward Island, and the territories provide all other services free of charge (but there are some service limits and restrictions), while all other jurisdictions have co-payments for homemaking and/or personal care.

Provincial per capita spending on home care varied from a low of \$96.78 to a high of \$302.20. The proportion of total health care spending on home care ranged from 1.6% to 6.4%. BC was the third highest spender on home care in Canada in terms of total annual expenditures; however, BC still had one of the lowest proportions of people receiving home care (second only to Newfoundland).² Over the period of 2006/2007 to 2011/2012 BC and Manitoba were the only jurisdictions that showed a consistent decrease in provision of publicly subsidized home care (Keefe et al., 2014).

More recently, Gilmour (2018a; 2018b) examined data on usage and unmet needs for formal home care services from the 2015/16 Canadian Community Health Survey. Gilmour (2018a) reported that 6.4% of Canadian households had a member

² Financial figures for some jurisdictions are for different years so are not fully comparable

who received formal home care in the past year (see table 3). Only 52% of households reported their home care costs were paid fully by government; 65% for home health (professional care) and 40% for support services. Gilmour (2018b) reported 35% of people with a home care need in the past year had unmet formal home care needs. A higher proportion of people had unmet needs for support services than home health care. The most significant barrier to accessing formal home care was availability of care.

Table 3 Households Receiving Formal Home Care Services

	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NL
% of households receiving formal home care services	4.9	5.9	5.4	5.7	6.7	7.1	7.0	7.8	6.4	6.2

Data from Gilmour (2018a)

3.2.2 Assisted Living

Assisted living is considered a “middle option” between home care and long-term care that provides a combination of housing and health services. A review of assisted living models in Canada by the Office of the Veterans Ombudsman (2014) reported that while assisted living and other similar supportive housing models can be found across Canada, there is variation in the types of housing available, care provided, and whether public subsidy is available. In most cases clients pay for their room and board (either at a publicly subsidized or market rate), while the health care services are paid for publicly.

3.2.3 Long-Term Care Facilities

Currently all provinces offer publicly subsidized care in a long-term care facility, and publicly subsidized beds may be provided in public, non-profit and/or private facilities (Office of the Veterans Ombudsman, 2014). Clients are required to make a co-payment for the cost of their room and board (determined based on income and in some provinces also assets). The availability of publicly subsidized long-term care beds varies significantly across Canada as shown in table 4. Client co-payments also can vary significantly, ranging from a standard daily rate of \$24.72 to \$107 (MacDonald, 2015).

Table 4 Publicly Subsidized Long-Term Care Beds in Canada

	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NL
# of Publicly Subsidized Beds Per 100 People 85+	26.4	26.7	32.5	33.8	29.7	28.8	25.7	32.0	36.3	30.4

Source: Data from Sivananthan, Doupe, & McGregor (2015)

3.2.4 Informal Caregivers

It is important to acknowledge that informal (unpaid) caregivers play a significant role in supporting older adults in Canada. It has been estimated that 80% of care in the home is provided by informal caregivers (Keefe, 2011). Statistics Canada (2018) estimates 1 in 4 Canadians provide informal care to a family member or friend, 36% of whom are providing 10 or more hours of care per week (Turcotte, 2013). All jurisdictions offer in-home respite for informal caregivers, and most also provide respite beds and adult day centres (Canadian Home Care Association, 2013). However, about one-third of informal caregivers have reported they need more help. Financial support and more home care are the most commonly identified forms of help required (Statistics Canada, 2018).

3.3 Conclusion

The decision was made to focus on one province (BC) in this study due to the significant variations among continuing care systems across Canada. Continuing care services have evolved differently in each province and territory, and each system has its own strengths and weaknesses. Within BC, there is a general consensus that changes need to be made to improve the home and community care system, as will be described in chapter 6. BC was a progressive province in the 1980/90s and was moving towards an integrated continuing care model (Chappell & Hollander, 2013), but like many other jurisdictions in recent years there has been significant scrutiny and critique of the home and community care system. However, recently there has been renewed political and research interest in integrated care systems and revitalizing the home and community care sector. This dissertation analyzes home and community care in BC from 1990 to current date and how an integrated continuing care system could be developed. Policies and systems from other jurisdictions are reviewed for comparative purposes. The lessons and findings from this analysis will have some applicability for other provinces

and territories, though as MacAdam (2011) emphasizes, context is key when it comes to integrated care interventions.

Chapter 4.

Theoretical Framework and Models

4.1 Introduction

Due to the multifaceted nature of this dissertation topic, there are a variety of theoretical approaches that could potentially be used to guide the research. After careful weighing of their respective contributions and given that this research focuses on the organization of continuing care systems and continuing care policy, it was decided to use a critical public policy approach combined with a systems approach.³

Health care systems and their components are largely shaped by public policy due to the primacy of the state in providing health care. Therefore, it is essential to understand the public policies behind health care and continuing care systems. For this dissertation, a critical approach to public policy was adopted. A critical public policy approach is informed by the theoretical underpinnings of a public policy approach, but can be differentiated from other approaches by seeking to: 1) elucidate the relationships between policy context, process, and content; 2) explore the ideologies and values underlying the conceptualizations of policy frames, policy discourses, and proposed solutions; and 3) understand how policies are experienced by people in everyday life (Duncan & Reutter, 2006). Critical public policy approaches have their origins in Critical Theory (e.g., see Horkheimer, 1972; Habermas; 1973) and critical theory has been advanced in public policy by theorists such as Forester (1993) and Fischer (2019). A critical policy lens may be informed by a number of theoretical perspectives (e.g., critical gerontology, feminist theory, political economy of aging) and in this dissertation the critical lens primarily draws upon the political economy of aging theory.

Systems approaches provide complementary approaches for examining health care systems and their components. These perspectives have their origins in the *General Systems Theory*, which was introduced by the biologist Ludwig von Bertalanffy to examine the world as a place of organization rather than chaos (Laszlo & Krippner,

³ Both approaches have evolved significantly over time and have been influenced by a range of theorists and generally are not attributed to a specific theorist.

1998). While traditionally associated with hard sciences, general systems theory was strongly influenced by structural functionalism and various social system theories (e.g., see works of Luhmann, Parsons, Weber, Durkheim, etc.) (Friedman & Allen, 2014). The OECD (2017a) has proposed the use of systems approaches for addressing complex public policy problems, noting “Complexity is a core feature of most policy issues today; their components are interrelated in multiple, hard-to-define ways. Yet, governments are ill equipped to deal with complex problems.” (p.3).

As will be described in the sections below, both critical public policy and systems approaches emphasize the need for study of the whole structure, rather than examination of separate parts in isolation. The approaches also embrace the importance of understanding context and multi-method approaches. Theoretical differences exist between the approaches, including epistemology, assumptions, and the nature of inquiry. Systems approaches emerged from the natural sciences and tend to employ analyses of how a system functions. On the other hand, critical public policy approaches (and associated theories such as political economy of aging theory) are associated with critical inquiries. These differences result in some tensions between the two approaches, but also means that each approach has a unique contribution to the dissertation. The critical public policy approach addresses some of the limitations of systems approaches regarding critical analysis and generating deeper understandings of the development of systems, while the systems approach provides specific tools to assist with the analysis of systems. The approaches can be viewed as supplementary and interlocking rather than overlapping approaches that can help to answer different, but related questions. A systems approach can help to investigate questions such as: *Why are certain models of continuing care systems successful? What are common features in successful integrated systems? How do continuing care systems fit within the larger health care system?* While a critical public policy approach can lead to a deeper analysis and help to investigate questions such as: *Why do some jurisdictions provide their citizens with comprehensive continuing care while others do not? What are the values underlying the desire to develop integrated care systems? How can the policy context be influenced to support the development of integrated care systems?* Below, the critical public policy approach is described, followed by systems approaches.

4.2 A Critical Public Policy Approach

4.2.1 Public Policy

Policy can be defined as “Broad statements of goals, objectives, and means that create the framework for activity. Often it takes the form of explicit written documents, but may also be implicit or unwritten.” (Buse, Mays, & Walt, 2005, p.4). Public policy refers to the policies and actions of governments and has been succinctly defined as “anything a government chooses to do or not to do.” (Dye, 2017). Public policy is of the utmost importance to health care systems as the state plays the dominant role in health care in most countries. In addition to government, other actors often involved in the development of health policy include: the private sector, media, the medical profession, and interest groups (Buse et al., 2005). Most public policies fall into one of three categories: regulatory (restrict or control actions of individuals/groups), distributive (provision of services or benefits), or redistributive (alter the distribution of income, wealth, or property in society). Health care involves all three categories of policies, and health care policies can be particularly controversial given their high economic and emotional stakes (Blank & Burau, 2010). Health care policies are dominated by three sometimes competing goals: equity, quality, and cost containment (Blank & Burau, 2010). A variety of policy instruments are available to governments to achieve health care goals, ranging from those involving little or no state intervention to high level interventions. Common policy instruments include: relying on family, voluntary organizations, or the private sector; information and education; subsidy; taxes and user fees; regulation; public enterprises; and direct service provision (Buse et al., 2005).

Policy is developed through a policy cycle process. While there are various conceptualizations of the process, generally the process is seen as including the following stages (Howlett & Giest, 2015):

1. Agenda-setting: Policy problem is identified and placed on the policy agenda
2. Policy formulation: Specific policy options are developed
3. Decision-making: Government decides on a particular policy
4. Policy implementation: Chosen policy is put into action by government

5. Policy evaluation: Outcomes are evaluated by government and society

While the policy cycle is conceptualized as a systematic and linear process, in reality policy-making is more complex and less tidy than this. As a result, this model should be viewed as a framework for understanding, but not an accurate representation of the policy-making process (Howlett & Giest, 2015).

Increasingly, there have been calls for evidence-based policy-making in health care, and there are opposing perspectives on how evidence is used in policy decision-making. The rationalist theory proposes that policy is made through a rational and evidence-based process and the best policy option is adopted. Bounded rationalism is an adaptation of the rationalist theory and proposes that policy-makers intend to make rational decisions, but due to imperfect knowledge often settle for a satisfactory policy option. Incrementalism and pluralism propose that policy usually involves small changes to the status quo and bargaining and adjustments (Bell, 2010). While research has a role in policy-making, it may not be acted upon for various reasons (e.g., finances, practicality). While evidence should be considered in the formulation of health care policy, it is also important to consider the local context (Bell, 2010).

4.2.2 Critical Public Policy Approach and the Political Economy of Aging

In this dissertation, a critical approach to public policy analysis is adopted, informed by political economy of aging theory. Political economy theories have their roots in Marx's class theory and Weber's theory on social stratification (Kail, Quadagno, & Reid-Keene, 2009). While originally political economy theorists focused on class, economics, politics, and ideology, they have expanded their views to consider households, social movements, discourse, intraclass differences, communities, and power relationships (Armstrong, Armstrong & Coburn, 2001). Political economy of aging theory focuses on how social, political, and economic factors impact the distribution of resources and create and reinforce the dependency of older adults within society (Johnson, 1995; Walker, 1981). The theory emphasizes the influence of states and markets, structural factors, social struggle, and power relations on aging policy (Estes, 2001; Kail et al., 2009; Johnson, 1995). Key political economy of aging theorists include Estes (e.g., 2001), Johnson (e.g., 1995), Townsend (e.g., 1981), Minkler (e.g., 1996),

and Walker (e.g., 1981). Retirement, pensions, and income inequality have been key topics for political economy of aging theorists; however, the theory has also been applied to long-term care (e.g., Lynch & Estes, 2001; Townsend, 1981). Estes (2001) developed the *Theoretical Model of Social Policy and Aging* (see figure 3) that illustrates core aspects of the political economy of aging theory (age, class, gender, race/ethnicity, and ideology) and the multilevel nature of the approach (postindustrial capital, the state, sex/gender systems, citizens/public, and medical industrial complex).

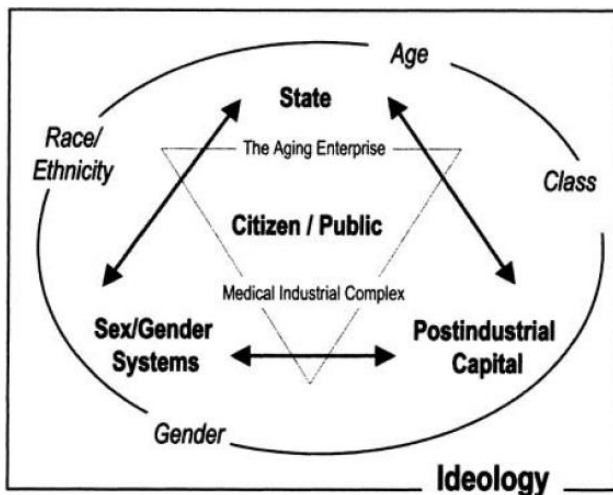


Figure 3 *Theoretical Model of Social Policy and Aging*
Source: Estes (2001)

Regarding health care for older adults and continuing care, the political economy of aging theory draws attention to the following (Armstrong et al., 2001; Williams, Deber, Baranek, & Gildiner, 2001; Lynch & Estes, 2001; Townsend, 1981):

- The tension between the roles of the state to protect the capitalist economy, while at the same time meet the needs of citizens;
- Class, racial, and gender issues in the provision and access to formal and informal care services;
- The commodification and profitization of health care services;
- The dominance of the medical profession and medical institutions;
- The failure to shift resources from hospitals/institutions to the community despite movements for community care;
- The replication of medical and institutional principles in community settings;
- The status of the elderly as economic dependents;

- The impacts of the retrenchment of the welfare state on health care systems; and
- The impacts of care location on responsibility for providing care and rights to care.

The *Health Policy Triangle* (Walt & Gilson, 1994) is a model that was developed specifically to apply political economy theories to the analysis of health care policies. The *Health Policy Triangle* (see figure 4 below) addresses the fact that much health policy research focuses only on the content of reforms and fails to acknowledge the factors that shape the content. The model provides a simplified illustration of the interrelationships between policy content, context, processes, and actors. In particular, the importance of the context is emphasized, including situational (transient or impermanent factors), structural (relatively unchanging elements of society), cultural, and international factors. The role of power is acknowledged as a key element of the policy process. The model can be used to analyze or plan a policy (Buse et al., 2005).

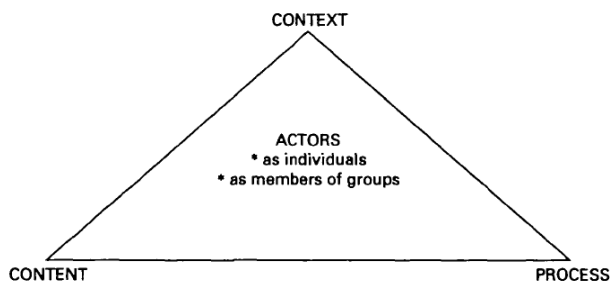


Figure 4 Health Policy Triangle
Source: Walt & Gilson (1994)

Political economy of aging theory provides an overarching critical framework within which this dissertation research is situated, while the *Health Policy Triangle* provides a simplified model for critically analyzing health care policy. In this dissertation, the critical public policy approach is applied primarily for comparative purposes. Comparative public policy analysis involves the systematic investigation of public policy across jurisdictions. It attempts to identify what accounts for patterns in public policy and to question stereotypes and assumptions about policy. Comparative public policy is an ideal way to explore the impacts of different interventions when experiments are not possible, as is usually the case with health care system reforms (Lodge, 2007). The critical public policy approach is utilized in partnership with a systems approach as described below. Health care systems and continuing care systems are complex

systems, and a systems approach and associated models/frameworks provide tools for the analysis of complex systems in systematic and organized ways.

4.3 Systems Approaches in Health Care

4.3.1 Systems Theories

What makes a system a system? Meadows (2008) defines a system as “an interconnected set of elements that is coherently organized in a way that achieves something” (p.11) and identifies elements, interconnections, and function/purpose as the three components that define a system. A health care system “consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health.” (WHO, 2007b, p.2). It has only been in recent years that health care system organization has become an important topic for health research (van Olmen et al., 2012a). In the new millennium we have seen increased emphasis on the performance of health care systems, and also recognition that health care systems are complex systems (van Olmen, Marchal, Van Damme, Kegels & Hill, 2012b; Royal Academy of Engineering, 2017). A health care system does not consist of just a single system, but rather multiple system levels or sub-systems (WHO, 2009; Royal Academy of Engineering, 2017). Health care systems can be described as complex and dynamic with multiple actors, organizations, structures, and stakeholders all interacting within specific social, cultural, political, and economic contexts. The political economy of aging theory examines many of these contextual factors affecting health care systems.

The WHO (2009) has pointed out that in complex systems sometimes even simple interventions fail to achieve their goals due to the characteristics and behaviours of the system they are being implemented within. Some of the common features of complex systems that contribute to these challenges are that complex systems are: self-organizing, constantly changing, tightly linked, governed by feedback, non-linear, history dependent, counter-intuitive, and resistant to change (WHO, 2007b). Continuing care systems are complex systems in their own right, and the health care systems they are embedded in are even more complex. Furthermore, with health care it is often difficult to determine the boundaries of the system and there may be overlaps with other systems (e.g., social welfare). The ways that we think about and analyze these systems need to

acknowledge these complexities, and there are theories and perspectives that have been developed for this purpose. For successful health care reforms to occur:

Successful transformation must take into account the needs of all patients, carers, healthcare professionals and other staff. It requires consistent consideration of every element of the system, the way each element interacts, and the implications of these interactions for the system as a whole – that is, it requires a 'systems' approach. (Royal Academy of Engineering, 2017, p.7)

A systems approach refers broadly to the theories and traditions underlying the study of systems, as well as the methods and organizing frameworks (Best, Clark, Leischow, & Trochim, 2007). The foundation of the systems approach is *General Systems Theory*, which emphasizes focusing on the whole, and examining the interacting and integrated nature of systems. The *General Systems Theory* approach involves: (1) considering the context within which the system is embedded; (2) identifying and describing sub-systems within the whole; (3) examining and attempting to understand the structure, composition, and operations of parts of the sub-systems; and finally (4) refocusing on overall context and integrating all of the perspectives into the whole (Laszlo & Krippner, 1998).

Systems theories are associated with the concepts of complex adaptive systems, complexity science, resilience, and chaos theory (Cordon, 2013; Connelly et al., 2017; Meadows, 2008). Systems theories are also associated with the social-ecological model which is often utilized in environmental gerontology studies. The social-ecological model has its origins in Bronfenbrenner's general ecological model that envisioned the environment as a series of nested systems (Bronfenbrenner, 1994). McLeroy, Bibeau, Steckler and Glanz (1988) developed the social-ecological model as a variation of this model. The social-ecological model consists of a nested model consisting of five levels: interpersonal factors, intrapersonal processes and primary groups, organizational (institutional) factors, community factors, and public policy (McLeroy et al., 1988).

There are multiple frameworks and processes that have been developed to operationalize the systems approach into a concrete method to study health care problems (e.g., see WHO, 2009; Royal Academy of Engineering, 2017; Best et al., 2007; OECD, 2017a). Systems thinking refers to putting the systems approach into practice in order to examine and view the world (Best et al., 2007). Common themes in systems thinking include holism, integration, interconnectedness, organization, perspective

taking, nonlinearity, and constructivism (Best et al., 2007, p.40). Systems thinking requires comprehensively examining potential effects of a system-level intervention and the context in which the intervention would be implemented (WHO, 2009). It involves a variety of approaches and methods, and there is no single right way to approach systems thinking (Best et al., 2007; OECD, 2017a). Systems thinking has been endorsed by the WHO (2009) as a method to analyze and successfully strengthen health care systems. On its potential applications for analyzing long-term care systems, Billings and Leichsenring (2014) write “Systems thinking is particularly useful because it helps identify the mutual interdependencies of stakeholders involved and of given contextual conditions as well as specific patterns of structures and processes in the planning, organising and monitoring of services and facilities.” (p.2).

Systems approaches have been recommended for examining continuing care systems (Chappell & Hollander, 2013), long-term care policy and design (Boiling, 2010), and policy problems related to aging populations (OECD, 2017a). Recently, systems thinking was used as the approach for developing the framework for INTERLINKS, a large-scale European project examining integrated long-term care systems (Billings & Leichsenring, 2014). Systems approaches have been identified as ideal for exploring the complex and multifaceted features of health care in case study and qualitative research (Anaf, Drummond, & Sheppard, 2007). Soft pluralistic approaches that are non-numerical and offer multiple views of the system have been recommended for the study of health care systems (Powell, 2004).

Both continuing care systems and health care systems are complex systems, and continuing care systems also are subsystems that operate within the health care system and the broader social, economic, and political contexts. In this study, examination of health care systems and continuing care systems is guided by general systems theory and systems thinking. The context that each system exists in is considered, the different subsystems and the parts of these subsystems are examined, and then subsequently integrated back into the larger whole. Models, which are a key part of a systems approach, are used to assist in the analysis. The comparative components of this study involve critical assessment of the different systems, contexts, and reforms (see next section for specific models and frameworks for this purpose). The critical public policy approach and political economy of aging theory guide the analysis of the public policies and contextual factors that influence these systems, and can assist in

providing explanations for differences in system design, values, comprehensiveness, and the success or failure of the jurisdictions to adequately provide care for older adults and informal caregivers.

4.3.2 Health Care System Models

Models are a key component of systems approaches and are representations of how reality is perceived by the theorist. Based on systems theory and systems thinking, models have been developed to aid in the analysis of health care systems and interventions in order to critically assess what works, for whom, and under what circumstances. The models discussed below were designed with a systems approach as their theoretical grounding and the intention they be used as tools for systems thinking.

The WHO (2009) has conceptualized a health care system as consisting of six building blocks: service delivery; health workforce; information; medical products, vaccines and technologies; financing; and leadership and governance (see figure 5). System-level interventions are those that affect one or more of the building blocks. Introduction of an integrated care model would primarily affect the service delivery block; however, they also affect the other blocks as well. For example, many integrated care models involve changes in financing structures or increased collaboration between health care workers. The WHO model, however, does not account for the wider context within which health care systems are located – namely the social, cultural, political, and economic contexts. Analyzing the broader context is particularly important when conducting comparative analyses of complex systems, and Kernick (2004) cautions against comparing health care systems without considering their history. Similarly, Blank and Burau (2010) state that health care systems are embedded within wider institutional contexts (e.g., political systems, social structures, social values), and analysis of health care systems should be complemented by analysis of institutional contexts.

The WHO Health System Framework

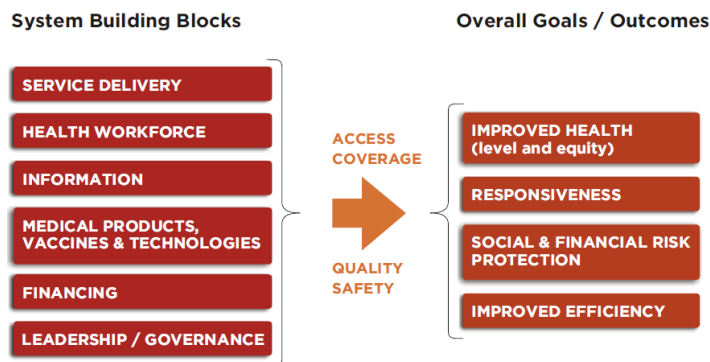


Figure 5 The building blocks of the health system: Aims and attributes
Source: WHO (2009)

van Olmen et al. (2012a) have constructed the *Health System Dynamics Framework* that builds upon the WHO *Building Blocks* model by situating health care systems within the broader contexts of health care delivery. The model consists of 10 elements: goals and outcomes, values and principles, service delivery, the population, the context, leadership and governance, and the organization of resources (finances, human resources, infrastructure and supplies, and knowledge and information) (see figure 6). For each of these elements van Olmen et al. (2012a) describe aspects that could be used in an analysis of a health care system. These aspects are not presented as a list of requirements for analysis, but rather as possible considerations for inclusion.

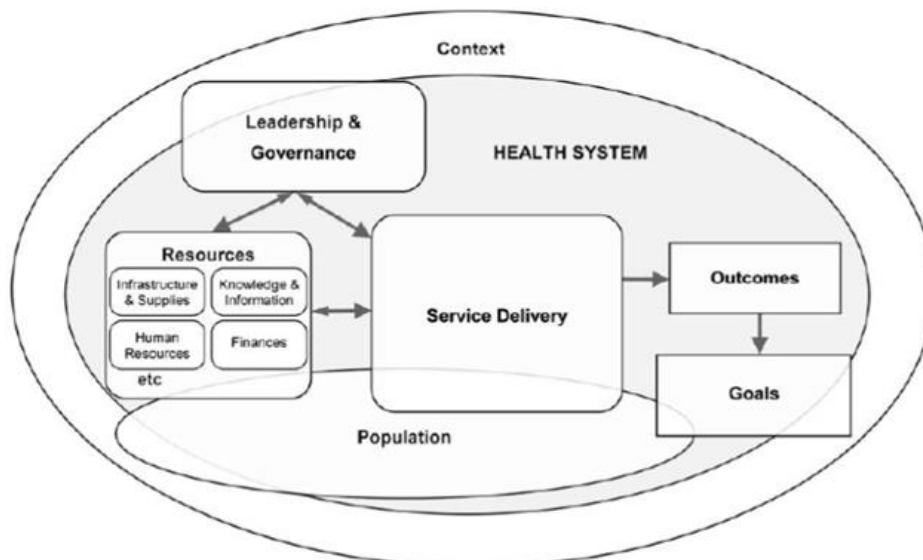


Figure 6 Health System Dynamics Framework
Source: van Olmen et al. (2012a)

Unlike the WHO model, within the *Health System Dynamics Framework* not all elements are viewed as equal, with service delivery as the core axis of the model. As Hollander and Prince (2008) have noted “How systems of care delivery are structured can have a major impact on their relative efficiency and on the quality of care provided to individuals” (p.45). The model also adds additional elements (values and principles, context, and population) to create a comprehensive model that draws on concepts from political economy theories and incorporates social, cultural, political, and economic contexts. As van Olmen et al. (2012a) note, health care systems are open systems that are affected by the broader world. The *Health System Dynamics Framework* is used in this study as a broad theoretical model to guide the examination of the current BC health care system and home and community care system, and also will provide guidance for the analysis of the other jurisdictions.

4.3.3 Frameworks for Comparing Integrated Continuing Care Systems

This study also involves comparative analyses of continuing care systems to identify lessons and recommendations for BC. Early frameworks of integrated care focused on identifying best practices and principles of integrated care (see chapter 2). More recent frameworks have focused on analyzing, comparing, and learning from different integrated care initiatives. These frameworks emphasize the importance of context to the success of integrated care models. Multiple frameworks for comparing integrated care initiatives were reviewed for potential application in this dissertation, and the *INTERLINKS Framework for Long-Term Care* (Billings & Leichsenring, 2014) was deemed the most relevant and is described below. Other comparative frameworks that were reviewed included the *Conceptual Framework for Comparing and Learning from Integrated Care Initiatives* (Calciolari & Ilinca, 2011), the *COMIC Model* (Busetto, Luijkx, & Vrijhoef, 2016), and the *Project INTEGRATE Framework* (Calciolari, González, Goodwin, & Stein, 2016). These frameworks are all comprehensive and incorporate contextual factors into their analyses; however, they were designed generically for chronic care needs while *INTERLINKS* is specific to continuing care systems.

INTERLINKS Framework for Long-Term Care

INTERLINKS was a European Union funded project that took place between 2008-2012 to address methodological challenges in collecting and comparing data on long-term care systems across Europe (Billings & Leichsenring, 2014; Leichsenring et al., 2013). The project involved 13 countries and its goal was to develop methods and tools for describing, analyzing, and comparing long-term care systems, policies, and practices. The project emphasized long-term care as a system with links and interfaces between health-social care and formal-informal care. A systems approach was the underlying theoretical perspective for this project. Through an iterative process involving modelling, review by an expert panel and sounding board, and collection of over 100 practice examples, the *INTERLINKS Framework for Long-Term Care* was developed. The framework places the individual and informal caregivers at the centre, and supports the principles of self-direction, holistic and comprehensive care, and client empowerment. It identifies six themes to consider in an ideal long-term care system (see figure 7 outlining the themes). Additional subthemes were identified for each theme that were then further divided into key issues (see Appendix 1). Validation of the framework occurred through peer review, a national expert panel, and web-based engagement. *INTERLINKS* endorses a pluralist approach to evidence on integrated care, recognizing the range of potentially meaningful evidence and outcomes.

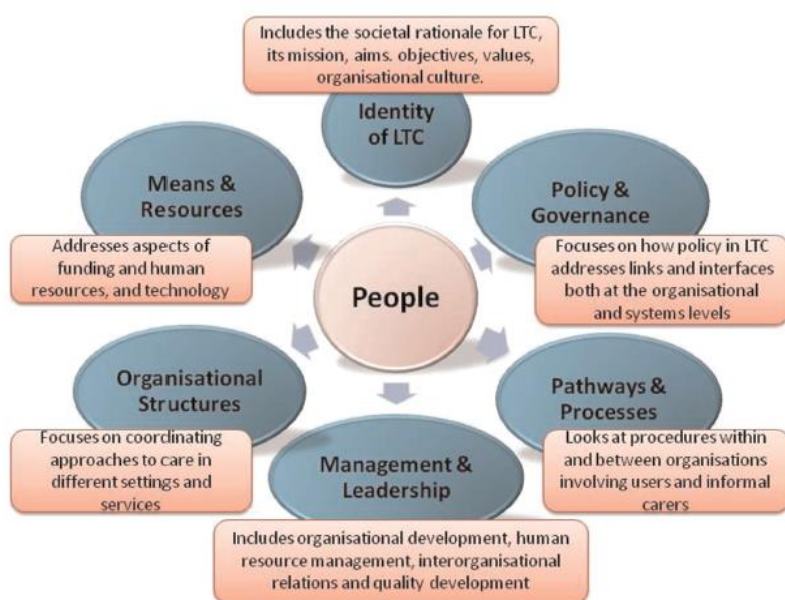


Figure 7 INTERLINKS Framework for Long-Term Care
Source: Billings & Leichsenring (2014)

As the *INTERLINKS Framework* was developed specifically for the study of long-term care systems from a systems perspective, and underwent a rigorous development and validation process, it was chosen for use in this study. The framework can be utilized in two different manners: as a general organizing framework or to examine innovations related to specific themes and subthemes. Further description of how the *INTERLINKS Framework* was used in this study is provided in the next chapter.

4.4 Summary of Theoretical Frameworks and Models

This chapter has introduced the critical public policy approach and a systems approach that will be used as complementary approaches for this study. The political economy of aging theory provides an overarching theoretical framework for situating this research. While there are many models, it is necessary to selectively apply a subset of models that represent the core components of the systems approach used to guide the analysis. The *Health Policy Triangle* model provides a general framework for critically analyzing policies. The *Health Systems Dynamics Framework* provides a general framework for examining health care systems and the context within which continuing care systems are situated. The *INTERLINKS Framework* provides a framework for learning from and comparing continuing care systems. More detail is provided in the next chapter on how these theoretical frameworks and models were utilized in this study.

Chapter 5.

Methodology

5.1 Introduction

This dissertation utilized a unique multi-pronged methodological approach that combined data collected as a part of a preliminary Master's thesis in 2014/15 with additional data collected in 2019/20 for this dissertation. This study design allowed for longitudinal analysis of health care system reform and progress in developing integrated continuing care systems in BC and the other jurisdictions of interest (Ontario, Québec, Nova Scotia, Australia, and Denmark). In a way this can be viewed as pre and post-test design as it allows for analysis of the stated policies and reforms as/before they begin and after they are in progress/completed. As mentioned in the previous chapter, health care systems are complex systems and a systems approach recommends soft pluralistic approaches. Therefore, a multi-pronged approach was considered the best way to understand and examine the complexities of the BC home and community care system and answer the primary research question for this study (How can an integrated continuing care system, that successfully integrates services delivered in the home and the community, be developed in BC?). In order to successfully answer this question, four secondary research questions need to be addressed:

1. What is the history and current state of home and community care services in BC? What progress or retrenchment has been made towards developing an integrated continuing care system in BC since the 1990s?
2. What policies are in place to support the development of an integrated continuing care system for older adults in BC and the other jurisdictions of interest? What are the underlying narratives and frames behind these policies?
3. What components of integrated continuing care systems are present in BC and other Canadian provincial health care systems (Québec, Ontario, and Nova Scotia) and in other progressive countries (Denmark and Australia)? What can we learn for BC from the examples and experiences of health care reform and the progress in developing integrated continuing care systems in the other jurisdictions of interest?

4. What recommendations can be made for BC for developing an integrated continuing care system within the BC policy context?

At the core of this study is a comparative analysis of multiple jurisdictions. This comparative analysis is conducted to provide insights on how an integrated continuing care system for older adults, that emphasizes care in the home and the community, can be successfully developed in BC. In the book *Comparative Health Policy*, Blank and Burau (2010) lay out a case for the importance of comparative analysis in health policy. Currently, many regions are facing the same health policy issues, which include aging populations, changes in medical technology, and rising public expectations and demands. Due to the similarity of issues being faced, combined with the fact there are a limited number of policy options to address these challenges, there is a tendency for global policy convergence. However, diversity still remains in health care policies and their effectiveness due to institutional, historical, cultural, and functional factors. Comparative analysis of policies and systems can provide insights into what does and does not work in other jurisdictions, and as a result deepen our understanding of the issues and potential solutions in our own context (Blank & Burau, 2010).

The cases for comparison that were chosen are Ontario, Québec, Nova Scotia, Australia, and Denmark. While Canada is often perceived as having a single health care system, each province and territory actually has their own health care system and insurance plan guided by the *Canada Health Act*. Therefore, each Canadian province is compared separately in the analysis, though some overarching features are discussed in the comparative analysis. The situations in Denmark and Australia are different; Denmark is a unitary state, while Australia is a federal state but the responsibility for aged care is concentrated primarily at the federal level. All three of the Canadian provinces share similar goals of improving continuing care services and the integration of services but have taken different approaches in pursuit of these goals which will be discussed in more detail in chapters 9, 10, and 11. The jurisdictions for comparison were selected in 2014 and the rationale for selecting each jurisdiction will be briefly described. Ontario was selected since there had been increasing scrutiny and necessary reform of the organization of their home care services in recent years. Québec was selected due to the fact they are internationally known for their integrated service delivery network model and their health and social care services are more closely integrated than in other provinces. Nova Scotia was selected to follow-up on the impacts of a ten-year

Continuing Care Strategy that was nearing completion. Both Australia and Denmark have been highlighted by the Health Council of Canada (2012) as countries from which Canada can learn due to their comprehensive home and community care systems. Denmark was selected because it is often considered to be the gold standard of care for the elderly, and their system has been praised for its movement away from the provision care in institutions. Australia was selected since they were in the process of introducing significant reforms to their aged care system.

This multipronged approach was used to address the primary and secondary research questions for this study and included:

1. Analysis of the history and current state of the home and community care system in BC;
2. Document analysis of home and community care policy; and
3. Comparative analysis of health care reforms and the continuing care systems and policy in other jurisdictions.

Before discussing in detail each of the prongs of this approach, first an overview is provided of how the theoretical frameworks introduced in the previous chapter are applied in this dissertation research.

5.2 Application of Theoretical Approaches

A critical public policy approach and systems approach are complementary approaches utilized in this dissertation. The political economy of aging theory provides an overarching theoretical framework for situating this dissertation research. Table 5 summarizes how specific models/frameworks associated with these approaches relate to the three prongs of this study.

Table 5 Application of Theoretical Frameworks in the Research

Framework	Application	Rationale
Health Systems Dynamics Framework	Overarching framework to guide the analysis of the BC home and community care system and the other jurisdictional systems.	Highlights key health care system elements that should be considered in the analyses: goals and outcomes, values and principles, service delivery, the population, the context, leadership and governance, and the organization of resources (finances, human resources, infrastructure and supplies, and knowledge and information).
Health Policy Triangle	Overarching framework to guide the analysis of BC home and community care policy and policy in other jurisdictions.	Highlights the need to examine not only the policy content, but also to consider the process, actors, and most importantly the context in health policy analysis.
INTERLINKS Framework for Long-Term Care	Organizing framework for describing the continuing care systems from BC and other jurisdictions. Key concepts of the framework informed the development of the guiding questions for the document analysis.	Framework was developed specifically for comparison of long-term care systems and provides a comprehensive framework of themes, subthemes, and key issues.

Content and themes from the *Best Practice Framework for Organizing Systems of Continuing/Community Care Services* (Hollander & Prince, 2008) and *Policy Framework for Integrated Care for Older People* (Banks, 2004) (discussed in chapter 2) will also be drawn on as appropriate to inform the analysis. Next, the three prongs of the research approach are described.

5.3 Analysis of the History and Current State of the Home and Community Care System in BC

This analysis addressed the history of the home and community care system in BC, policies underlying the system, the current state and critiques of the system, and recent reforms and their success in addressing these critiques. The data on the current state of the system and reforms focused on the period over 2012-2019 (the comparative analysis of other jurisdictions focused on the same time period). The reasons this period was chosen were a) the fact several important events and reforms occurred in BC in 2012 and b) to provide context for the 2014/15 interviews. Data was synthesized and critically examined from a variety of sources including: 1) over 30 relevant government policy documents; 2) information from government and other websites pertaining to home and community care; 3) over 40 external policy/research papers related to home

and community care in BC; 4) information from key informants from the BC MOH (2014 and 2019) and Fraser Health Authority (2014); and 5) interviews with community and policy expert stakeholders conducted in 2014/15 and 2019. Chapters 6, 7, and 8 include the data from this analysis. Below, more details are provided on the two types of interviews conducted.

5.3.1 Key Informant Interviews

Key informants from the BC MOH and Fraser Health Authority were interviewed to obtain information on home and community care initiatives and strategies in BC. In 2014, interviews were conducted with 3 employees of the BC MOH and 2 employees at Fraser Health Authority. Each interview lasted approximately 30-60 minutes. In 2019, interview questions were sent to the BC MOH and a written response was received. The BC MOH interview in 2019 was with a different individual than in 2014 due to turnover of positions. Contact information for the BC MOH employees was available on an online public directory of BC government employees. All participants were contacted via e-mail requesting an interview. Other participants were identified through the networks of the researcher and the researcher's supervisor.

5.3.2 Stakeholder Interviews

Sample

Interviews were conducted with community stakeholders (e.g., service providers, advocates, older adults, etc.) and policy expert stakeholders (e.g., academics, researchers, etc.) in 2014/15 (initially for a Master's Thesis) and 2019. During the initial round of interviews in 2014/15, interviews were conducted with 12 community stakeholders and 7 policy expert stakeholders. A total of 16 interviews (2 of the interviews involved multiple stakeholders) were conducted with 19 stakeholders. In 2019, follow-up interviews were conducted with 10 community and policy expert stakeholders, 8 of whom had been interviewed previously in 2014/15. The interviews were halted at 10 as it was perceived saturation had been reached as stakeholders generally reported they thought only limited changes to the home and community care system had occurred.

Interview Data Collection

The 2014/15 community stakeholder interviews were conducted primarily to gain information on the current state of home and community care in BC and ideas for an ideal integrated continuing care system, while the policy expert stakeholder interviews also addressed the policy context in BC and the barriers and facilitators to implementing an integrated continuing care system (see appendix 2 for sample interview questions). Semi-structured interviews were conducted with the stakeholders in-person or by telephone/skype. Stakeholders were interviewed individually, except in two cases, where the stakeholders requested to be interviewed in small groups of two and three people. Each interview lasted approximately 30-60 minutes. The interviews were conducted between July 2014 and January 2015. Purposive sampling was used to ensure stakeholders from a range of regions, backgrounds, and experiences were interviewed. Due to the nature of the interview questions, stakeholders were sought who would be knowledgeable about the home and community care systems, and who would have a higher level of understanding of the system than the general public. All of the stakeholders were familiar with the home and community care system through their employment, volunteering, or research work. Approximately one-third of the sample were also older adults. Several stakeholders were connected to the system through personal experiences (e.g., informal caregivers). Stakeholders were identified through the networks of the researcher and the researcher's supervisor and were contacted via e-mail, requesting an interview. The community stakeholder interviews used a baseline set of questions, focusing on perceptions of the home and community care system in BC, and when appropriate these were adapted to fit the expertise of the person. The policy expert stakeholder interviews used a similar base set of questions, but also explored additional policy-oriented questions. The interviews were audio-recorded and transcribed. The software Nvivo (V.12) was used for the coding of interview data.

In 2019, follow-up interviews were conducted with community and policy expert stakeholders. A base set of questions was used for the interviews focusing on stakeholder's perceptions of changes that had occurred to the home and community care system in the past 3-4 years (see appendix 2). Interviews were conducted over telephone/skype and lasted approximately 30-45 minutes. The interviews were audio-recorded and transcribed and Nvivo (V.12) was used for coding the interview data.

5.4 Document Analysis of Home and Community Care Policy

In order to develop a more in-depth understanding of the policies in the jurisdictions of interest, document analysis was used to investigate the stated policies, goals, and strategies of governments, and the underlying narratives that frame these policies. Document analysis is a systematic, iterative process for analyzing documents and involves selecting, appraising, and synthesizing data from documents. Document analysis incorporates aspects of both content and thematic analysis. It usually begins with an initial reading and qualitative content analysis of the documents (focused on identifying relevant content and passages rather than quantitatively analyzing the content), followed by a more thorough second reading and thematic analysis (Bowen, 2009). Grounded theory and constant comparative analysis are commonly associated with this methodology (Bowen, 2009). Document analysis differs from discourse analysis which is a higher-level approach that focuses more explicitly on the language of documents and its relationship to the social construction of the world (Potter, 2008).

This analysis focused on policy documents from BC produced in recent years. In addition, to provide a comparative perspective, 1-2 documents from each of the other jurisdictions were selected for close reading and documentary analysis. These documents are discussed in the respective chapters on these jurisdictions, as well as the comparative analysis in chapter 14. Table 6 outlines the documents selected for analysis from each jurisdiction. In BC, Ontario, Nova Scotia, and Australia all necessary policy documents were available in English. In Québec and Denmark some documents were available in English, while others were only available in French and Danish respectively. One key document from Québec was professionally translated from French to English.

Table 6 Documents for Analysis

<p>British Columbia Improving Care for B.C. Seniors: An Action Plan (Government of BC, 2012) Setting Priorities for the BC Health System (BC MOH, 2014a) Primary and Community Care in BC: A Strategic Policy Framework (BC MOH, 2015a) An Action Plan to Strengthen Home and Community Care for Seniors (BC MOH, 2017a)</p>
<p>Ontario Patients First: A Roadmap to Strengthen Home and Community Care (Ontario Ministry of Health and Long-term Care, 2015a) Patients First: Action Plan for Healthcare (Ontario Ministry of Health and Long-term Care, 2015b)</p>
<p>Nova Scotia</p>

Continuing Care Strategy for Nova Scotia (Nova Scotia Department of Health, 2006)
<p>Québec Aging and Living Together: At Home, in One's Community, in Québec [<i>English</i>] (Gouvernement du Québec, 2012) Chez soi: le premier choix (Gouvernement du Québec, 2003) [<i>French</i>]</p>
<p>Denmark Social Policy in Denmark [<i>English</i>] (Danish Ministry of Social Affairs and Integration, 2011)</p>
<p>Australia Living Longer. Living Better (Commonwealth of Australia, 2012a) Future reform – an integrated care at home program to support older Australians (Australian Department of Health, 2017b)</p>

Abbott, Shaw, and Elston (2004) identify three approaches that can be used for data extraction in health policy document analysis (overlap often occurs though between these approaches). These include: a) extract the content that is explicitly stated in the documents; b) compare and cross-reference the document with other policies; and c) extract data to answer basic questions about the underlying discourse and ideology of the document. For this document analysis, the approach emphasized purposes a) and c). The document analysis followed a process similar to the constant comparative analysis approach used by Pinto et al. (2012) to analyze equity in Canadian public health standards. For this study, the selected policy documents were first read and coded to identify relevant content and passages based on a series of questions (see appendix 3) that were developed based on the *INTERLINKS Framework for Long-Term Care* and other integrated care frameworks discussed in chapter 2, and shaped more broadly by a critical public policy approach. After the initial reading, a second series of questions was developed (see appendix 3) and a second reading of the documents occurred to more closely analyze the themes that were identified in the documents. Memoing was used throughout this process to capture emerging ideas and concepts.

5.5 Comparative Analysis of Reforms and the Continuing Care Systems and Policy in other Jurisdictions

A longitudinal comparative analysis (focusing on the period of 2012-2019) was conducted investigating the cases of health care reform and progress in developing integrated continuing care systems in other jurisdictions. Usually it takes significant time for reforms to be implemented and effects to be observed, and this unique longitudinal approach allowed for observations and analysis to be made over a significant time period. Inadequate follow-up time has been identified as a potential explanation for why

some integrated care initiatives fail to show results (e.g., Eklund & Wilhelmson, 2009). Five provinces and countries were initially chosen for comparative analysis for the Master's thesis in 2014. Three provinces were chosen from Canada (Québec, Ontario, and Nova Scotia) and two countries were chosen (Denmark and Australia). The primary purpose of these cases is not to provide in-depth case studies of these jurisdictions, but rather to focus on policy convergences and divergences and insights for BC. A chapter is devoted to each jurisdiction (chapters 9-13), followed by a chapter that synthesizes key themes, policy convergences and divergences, and tensions from these cases.

Analysis of each jurisdiction was informed by reviewing relevant: a) government websites and other online information; b) government policy documents; and c) academic and grey literature. Google Translate was used to assist in the translation of some documents and websites from Québec and Denmark. In addition, interviews were conducted with a small number of key informants (e.g., academics, health system employees, etc.) from each jurisdiction to gain further insight into care for older adults. All of the key informants selected had a high level of knowledge about continuing care systems and the policies in their jurisdiction. The interviews were semi-structured and questions were tailored to the specific jurisdiction. Initial interviews were conducted with 1-2 key informants for each jurisdiction in 2014/15 and lasted 30-60 minutes. All of the interviews were conducted via telephone or skype. Key informants were identified through the networks of the researcher and the researcher's supervisor. All key informants were contacted via e-mail requesting an interview.

Follow-up interviews were conducted in 2019/20 in all jurisdictions, with the exception of Nova Scotia as it was perceived that limited changes had occurred from the initial interviews. This allowed a greater focus to be placed on the jurisdictions where more significant reforms had occurred (Ontario and Australia). The follow-up interviews investigated whether stated policies/plans had been implemented, challenges that emerged, perceived impacts of reforms, and continuing challenges and areas for reform. The follow-up interviews were semi-structured and the questions reflected the specific situation in each jurisdiction. A total of 2-3 key informants were interviewed for each jurisdiction. In some cases the informants were the same as in the initial interviews, while in others different informants were interviewed in order to follow-up on specific reforms and developments that had occurred. The interviews lasted 30-60 minutes and were conducted via telephone or skype.

The *Health System Dynamics Framework* and the *Health Policy Triangle* were used as overarching frameworks to guide the critical comparative analysis, while an adapted version of the *INTERLINKS Framework for Long-Term Care* was used as the organizing framework for describing the continuing care systems from BC and other jurisdictions. The themes and subthemes from *INTERLINKS* utilized were selected based on a) the feasibility of obtaining the information and b) selection of the most relevant themes and subthemes. The common integrated care components and frameworks identified in chapter 2 were also taken into consideration for the analysis.

5.6 Ethics

Ethics approval for the already conducted Master's thesis research was obtained from the SFU Office of Research Ethics. Each participant was provided with a consent form explaining the study, and their consent was obtained in writing. For health authority employees, MOH employees, and stakeholders, appropriate organizational approval was sought prior to beginning interviews as required. In some cases, the individual being interviewed was also the appropriate person to approve the interview or they stated no approval was required. No information on the study was withheld from the participants. Participants were sent the interview questions in advance so they could be approved by the participant (and their organization if applicable), and the participant could indicate beforehand or during the interview if there were any questions they did not wish to answer. Individuals being interviewed had the opportunity to stop the interview at any time, decline to answer any questions they did not feel comfortable with, request that a comment be omitted, or request that their entire interview be omitted from the study. The interviews were audio recorded to ensure the participants' thoughts were accurately recorded, and permission was granted to conduct the audio recordings. If a participant was uncomfortable with an audio recording, they could request that their interview not be audio recorded. On the consent form participants could indicate whether they would like to receive a summary of the findings of the study after it is finished. Ethics approval was re-obtained for the dissertation research and the same research protocols were followed as for the initial Master's thesis. For the follow-up interviews, new participants as well as participants who had participated in the initial interviews were asked to sign a new consent form.

The risk to participants in the study was minimal; risk would only potentially occur if there was a breach in confidentiality. To help ensure confidentiality only the researcher had access to the interview data which was stored in a secure manner. Participants were only identified by an interview number for quotations. However, participants were informed that due to the small scope of experts and potential interviewees, and the specific nature of some of the information, there is the potential that an interviewee could be indirectly identified through their comments. As the health authority and BC MOH interviews were meant to provide information specific to the health authority or BC MOH, on the consent form it was noted that information from these interviews would be linked with the specific health authority or the BC MOH.

Chapter 6.

BC's Home and Community Care System

The following three chapters provide information on the home and community care system in BC. This chapter describes the history of the home and community care system from 1990-2011, the current state of the home and community care system today, key policy objectives, and the policy context and recent reforms. The information in this chapter is based on review of relevant websites, government policy documents, and other literature. Information is also presented from key informants from the BC MOH and Fraser Health Authority describing current initiatives to improve seniors' care. Chapter seven summarizes perspectives of stakeholders on the home and community care system in 2014/15 and 2019. Chapter eight provides a critical assessment of the home and community care system and policy in BC. Further discussion of BC's home and community care system and recommendations for developing an integrated continuing care system are discussed in chapters 14 and 15.

6.1 Provincial Health Care Context

6.1.1 Health Care System Structure and Governance

The Province of BC has a universal public health care system that is regulated by the federal *Canada Health Act* and relevant provincial legislation (for more information about the overall health care context in Canada please see Chapter 3). The BC MOH has overall responsibility for health care. Five regional health authorities are responsible for planning and delivering (either directly or through contracts) a range of health care services for individuals requiring care (BC MOH, 2014a). Major programs within the oversight of the health authorities include acute care, long-term care, community care, mental health and substance use, and population health and wellness (Auditor General of BC, 2017). Services by general practitioners are outside of the direct oversight of health authorities and are usually funded directly through the MOH on a fee-for-service basis through the Medical Services Program (Auditor General of BC, 2017). In 2002, the General Practice Services Committee was established to lead primary care reform and the development of full-service family practices (BC MOH, 2015a). This Committee

provides access to funding incentives for primary care reform and is a collaboration mechanism for general practitioners and the BC MOH (Misfeldt et al., 2017). Divisions of Family Practice were also established in 2008 as local networks that allow general practitioners within a region to work together to address local needs and collaborate with other key stakeholders (e.g., health authorities) (BC MOH, 2015a).

Recently, the Provincial Government has proposed the development of Primary Care Networks (PCNs), clinical networks that will incorporate Patient Medical Homes (team-based family practices), health authority services, and community services. Linked to the PCNs will be Specialized Community Services Programs (SCSPs) that will improve the coordination of care for special patient populations, including frail/complex older adults (Institute for Health System Transformation and Sustainability [IHSTS], 2018).

6.1.2 Home and Community Care System

Publicly subsidized home and community care services are intended to: a) help individuals to remain independent in their homes; b) provide care options for those no longer able to remain in their own home; c) provide an alternative to hospital care; and d) provide end-of-life care services (Government of BC, 2020a). Services provided through the home and community care system include home health services (community nursing, community rehabilitation, adult day services, home support, choices in supports for independent living [CSIL]), caregiver respite and relief, end-of-life care, assisted living, group homes, family care homes, short stay services and long-term care facilities⁴ (Government of BC, 2020b). Eligible clients are individuals discharged from acute care, with a life-limiting illness, or requiring care to prevent emergency room/hospital visits or institutionalization (Government of BC, 2020c).

Home and community care services may be delivered directly by the health authority or through contracted private for-profit or not-for-profit providers. Funding for these services is provided by the BC MOH to the health authorities in the form of a global budget (BC MOH, 2015a). While some home and community care services are

⁴ Up until 2019 long-term care facilities in BC were referred to as “residential care;” however, the term was changed to long-term care due to the negative associations with it as a result of the residential school systems that operated in Canada.

free of charge, others require co-payments or means testing (Government of BC, 2020d). Additional services may also be purchased by clients from private providers if desired (BC MOH, 2015a). The *Home and Community Care Policy Manual* sets out provincial requirements for the delivery of services (e.g., fees, determining service needs, accessing services, etc.) (Government of BC, 2020a). Table 7 provides an overview of key components of the home and community care system in BC using an adapted version of the *INTERLINKS Framework*.

Table 7 *INTERLINKS Framework for Long-Term Care: British Columbia*

INTERLINKS Framework for Long-Term Care	
Identity of Long-Term Care	
<i>Values</i>	<ul style="list-style-type: none"> Guiding Principles for Continuing Care and Extended Care: Individuality (Caring and well being, Autonomy and decision-making, Client centred) and Promotion of Health (Partnership, Quality care and services).^a Principles described in the home and community care policy manual include: delivering services in a manner that promotes health, safety, well-being, dignity and independence; collaborative planning; evidence-based services; sustainability; services that supplement rather than replace individual and caregiver efforts; integrated and responsive services; and ensuring safety of clients and staff.^b
Policy and Governance	
<i>Policy</i>	<ul style="list-style-type: none"> See section 6.3 for discussion of home and community care policy in BC.
<i>Governance mechanisms</i>	<ul style="list-style-type: none"> Regional health authorities are responsible for the administration and delivery (either by public or contracted private non-profit or for-profit providers) of home and community care services.^c
Pathways and Processes	
<i>Accessing services</i>	<ul style="list-style-type: none"> Services are accessed through the home and community care office within the health authority. The speed of the initiation of services is based on urgency criteria, with more urgent cases receiving priority.^d Only Fraser Health Authority has a single access line, while the other health authorities have regional/community access lines.
<i>Assessing needs</i>	<ul style="list-style-type: none"> A health professional will conduct a needs assessment, and if the client is eligible creates a care plan with the client and their family/caregivers.^d The interRAI assessment tools are used for home support, assisted living, adult day services, group homes, family care homes and long-term care.^c
<i>Interdisciplinary work</i>	<ul style="list-style-type: none"> The SCSP model once implemented will provide team-based care for complex population groups, including older adults.^e
Organisational Structures	
<i>Nursing and residential care homes</i>	<ul style="list-style-type: none"> Long-term care facilities provide care to complex patients who require access to 24/7 professional care. Clients pay an income-based rate (up to 80% of after-tax income) for hospitality and accommodations.^c
<i>Care within a hospital setting</i>	<ul style="list-style-type: none"> The 48/6 Approach requires screening and assessment of older adults (70+) in the hospital in 6 areas of function. Care plans must be developed within 48 hours of admission and include a discharge or transmission plan.^f

	<ul style="list-style-type: none"> • Since 2013 a series of Home is Best/Home First models have been tested in the health authorities that provide short-term intensive home support services to facilitate discharge from acute care.^g
<i>Transitory care facilities</i>	<ul style="list-style-type: none"> • Short-stay services are available for people who require convalescent care after being discharged from the hospital.^c
<i>Assisted living arrangements</i>	<ul style="list-style-type: none"> • Assisted living facilities provide housing, hospitality, and personal care services to people who are able to live independently and make their own decisions. Clients pay an income-based rate (up to 70% of after-tax income) for hospitality and accommodations.^{b,c}
<i>Formal care in the home and the community</i>	<ul style="list-style-type: none"> • Community nursing and community rehabilitation home care services are provided by professionals (nurses, occupational therapists, or physiotherapists) free of charge.^c • Home support services are provided by community health workers [CHWs] and include assistance with ADLs and may also include safety maintenance activities (meals, housekeeping, or laundry) or delegated nursing and rehabilitation tasks. Clients are required to pay a daily rate for home support services based on their income.^{b,c} 64% of home care clients do not pay a daily rate. For those who pay a daily rate, a client with an income of \$28,000 would pay about 33% of their income for annual home support.^g • The CSIL program is a self-directed care option for eligible home support clients that allows them to manage their own home support services.^c • Adult day services provide social activities, meals, and some health services for up to 7 hours a day. A daily fee of up to \$10/day may be charged.^h
<i>Specialised case or care management centres</i>	<ul style="list-style-type: none"> • The SCSP model once implemented will coordinate and integrate care for complex population groups, including older adults.^e
Means and Resources	
<i>(Shared) funding</i>	<ul style="list-style-type: none"> • Health care in BC is primarily funded through taxation. The Provincial Government provides the majority of the funding, with additional funding (in 2015/16 23%) from the Federal Government through the Canada Health Transfer.ⁱ • In 2018, BC signed a new bilateral agreement with the Federal Government for health care funding that includes \$394 million in targeted funding over 5 years for home and community care. This funding will be targeted towards developing SCSPs and expanding access to palliative and end-of-life care.^j
<i>Enabling, allocating and funding human resources</i>	<ul style="list-style-type: none"> • In BC health care assistants (also known as care aides and CHWs) are estimated to provide 80% of continuing care services. By 2027 BC will need 18,650 new health care assistants. Shortages are already being observed in some communities.^k • BC's health human resource strategy for home and community care involves a three-pronged approach: regularization of casual and part-time staff, targeted recruitment, and training expansion.^l
<i>Supporting informal carers as a resource for LTC</i>	<ul style="list-style-type: none"> • Respite is available through home support, adult day services, or short-stay long-term care beds.^c • Various non-profit organizations offer supports for informal caregivers. Family Caregivers of BC receives funding from the BC MOH to operate a province-wide telephone line and additional online supports.^m

<i>Financial indicators</i>	<ul style="list-style-type: none"> • In 2015/16 health sector spending amounted to 41% of the provincial budget. Long-term care spending amounted to 12% of regional health authority budgets, and community care 8%.ⁱ • 3% of health authority budgets come from patient, resident, and client fees.ⁱ
<i>Role of information technology</i>	<ul style="list-style-type: none"> • Electronic medical records have been adopted by the majority of family physicians. Health authorities also operate their own clinical information systems for primary, acute, and community care. A key issue currently is the need to integrate electronic medical records with clinical information systems. This is complicated by the fact there are multiple electronic medical records and clinical information systems currently in use across the province.ⁿ

Sources: a. BC MOH and Ministry Responsible for Seniors (1999); b. BC MOH (2019a); c. BC MOH (2015a); d. Government of BC (2020e); e. BC MOH (2019b); f. BC Patient & Safety Quality Council (2012); g. OSA (2019a); h. OSA (2015a); i. Auditor General of BC (2017); j. Government of BC (2018a); k. BC Care Providers Association (2018); l. BC MOH (2017a); m. United Way of the Lower Mainland (2016); n. BC MOH (2015b)

6.2 Historical Review of Home and Community Care in BC over 1990-2011

6.2.1 Home and Community Care, 1990-1999

The home and community care system in BC in the 1980s and early 90s was internationally recognized for its effectiveness in providing continuing care to older adults (Hollander, Cherry, MacAdam, Pallan, & Ritter, 2007). The following is a summary of BC's continuing care system at the time as described by Hollander et al. (2007). From 1983 to 1994 a provincial Continuing Care Division was responsible for the administration, policy, and control of home and community care services. Case managers were responsible for assessing clients and developing care plans for them in consultation with their family physician. Clients would be classified into one of five levels of care and regular reassessments were conducted. Services were delivered through three programs: the Long Term Care Program, the Community Home Care Nursing Program, and the Community Rehabilitation Program. Services provided included: family care homes; continuing care facilities; extended care units; meal programs; adult day care centres; group homes; homemaker services; community home care nursing; community rehabilitation; special extended care units; discharge planning units; short stay, assessment, and treatment centres; and quick response teams. With the exception of extended care, special extended care, and discharge planning units, all services were funded by the Continuing Care Division (though some services required co-payments). Over the approximately ten-year period that this system was in place 21 person years per 1,000 older adults were shifted from long-term care to home care (Hollander et al.,

2005). In 1994, the Continuing Care Division model was abandoned and replaced by a regional model. Under the regional model originally there were 52 health entities, but this was reduced to 5 health authorities in 2001 (BC Office of the Ombudsperson, 2012a).

In 1991 the *British Columbia Royal Commission on Health Care and Costs* (Seaton Commission) recommended that care be moved closer to home. An important motivation for this recommendation was the desire to decrease utilization of the acute care system (Government of BC, 1991). (See Appendix 4 for an overview of the findings from this and other key policy documents mentioned in the section). Over 1991-2001 a New Democratic Party Provincial Government was in power, and the 1990s were a period of retrenchment when changes occurred to policy that significantly reduced access to home support. In 1994, due to budget constraints the policy decision was made to focus resources on higher needs clients. This resulted in cuts to lower needs long-term care and home support services, including the discontinuation of services for clients who only required housekeeping services (Hollander & Tessaro, 2001). In addition, housekeeping, meal preparation, and transportation services were significantly scaled back and offered only on an exception basis (Ivanova, 2009). In 1998/99 a review of continuing care services was conducted (Canadian Home Care Association, 2013). In 1999, further home support policy changes were made with the introduction of policy emphasizing providing the greatest number of hours and care to the people with the highest needs (McGrail et al., 2008). This policy also stated the need for the health authorities to work with community stakeholders (e.g., voluntary organizations) to provide services to older adults in the community (BC Office of the Ombudsperson, 2012a). During the 1990s and early 2000s there also were significant cuts to the acute care sector that increased pressures on the home and community care system (surgical and medical innovations also contributed to the increased delivery of care in the community) (Cohen, Murphy, Nutland & Ostry, 2005).

Reports on the restructuring in the 1990s by the Canadian Centre for Policy Alternatives (CCPA) found that reforms during this period had failed to improve continuing care for older adults:

- Analysis of continuing care policy and health service utilization data revealed inadequate funding and services led to reduced access to services for older adults and the emergence of a two-tiered system. Reforms during this period failed to deliver on the promise of providing care closer to home (Vogel, 2000).

- Interviews with clients, staff and other stakeholders revealed that as a result of cuts to the home support system clients experienced poorer health outcomes; increased burdens were placed on informal caregivers; staff experienced poorer training, morale, and teamwork; avoidable use of other health care services occurred; and inequities in access to services based on income increased (Pollack, 2000).

Hollander and Tessaro (2001) conducted a natural experiment in 1994 comparing clients in BC in health care units that were impacted and unimpacted by service cuts, and found clients whose home support had been cut were more likely to die or be admitted to long-term care and had higher health care costs. A related study reported that among clients who had been discharged, 34% reported physical and/or emotional hardship, 29% increased burden on family and friends, and 29% reported becoming more independent (Livadiotakis, 2001).

During the late 1990s interest in assisted living/supportive housing models also grew, and in 1997 a group of municipalities asked the Provincial Government to review supportive housing. In 1999 a report was released that made recommendations for supportive housing in BC, though it did not recommend a specific supportive housing model to be implemented (BC MOH, Ministry Responsible for Seniors and Ministry of Social Development and Economic Security, 1999). Model standards for home and community care services were also developed in 1999 for case management, integrated home health, adult day services, home support, and long-term care (BC MOH and Ministry Responsible for Seniors, 1999).

6.2.2 Home and Community Care, 2000-2011

In 2000, Strategic Directions for Continuing Care Renewal were released in response to the continuing care review. In 2001 the Liberal Party came to power in BC and one of the key commitments made in their election platform was building 5,000 new non-profit long-term and intermediate care beds (BC Liberals, 2001). In 2002, the Provincial Government released a policy paper outlining how they were modernizing the health care system (BC Ministry of Health Planning, 2002). A key component of their modernization plan was their three-year Home and Community Care Strategy. Actions taken to redesign home and community care included:

- Introduction of assisted living as an intermediate level of care.

- Introduction of the BC Palliative Care Benefits Program to provide access to medications and equipment for people receiving palliative care in the home.
- Creation of clear criteria for long-term care access that prioritized those with the most urgent care needs (BC Ministry of Health Planning, 2002).

In 2005, the BC MOH (2005) reported on the successes of the home and community care redesign and stated they had: expanded adult day programs, introduced publicly funded assisted living, enhanced home care and home support, and upgraded or developed 4,142 long-term care, assisted living or supportive housing beds.

In 2005 a Premiers' Council on Aging and Seniors' Issues was formed and in 2006 they published their report on seniors' issues. The report included a vision of a broadened home support program, though it also questioned whether home support services should continue to be delivered as a part of the health care system or be the responsibility of another sector of government (Baird, 2006). In response to this report, in 2007 a seniors' healthy living framework was developed and the Seniors' Healthy Living Secretariat was established within the Ministry of Healthy Living and Sport to implement the framework. One of their assigned tasks was to explore innovative models of delivering "non-medical" home supports (Government of BC, 2007a). A background paper was released on this topic in 2007 (Byrne & Woods, 2007). In 2010, in order to address the identified gap of "non-medical" home supports the BC MOH partnered with the United Way of the Lower Mainland to pilot the CASI (Community Action for Seniors Independence) program (Chomik Consulting & Research Ltd., 2012).

While some progress was made in expanding the continuum of care in the 2000s, this was also a period of increasing scrutiny for the home and community care system, as reports critiquing the system were released by a variety of sources:

- A CCPA report found a significant decline in access to home support in BC as well as a shift in focus to medical care and high needs patients following the restructuring and policy changes in 2001. CHWs were reported to face a number of challenges when providing home support services, including: lack of continuity of care, increasingly complex patients, less time, focus on medicalized care, lack of communication and coordination, and reduction of prevention and maintenance care (Cohen, McLaren, Sharman, Murray, Hughes, & Ostry, 2006)
- In a report by the BC Medical Association (2008) it was recommended that the provincial government increase funding for home and community care,

increase services and ensure they are comprehensive, and develop integrated delivery systems for home and community care.

- A report by the Office of the Auditor General of BC (2008) concluded that the BC MOH had failed in its stewardship role of the home and community care system, and recommended that the MOH develop: a clear strategic direction for home and community care services; better information management strategies; a comprehensive planning framework; and measures to ensure public accountability.
- Another report by the CCPA critiqued the failure of the BC Liberals to deliver on their promise of 5,000 new non-profit long-term care beds, as by 2008 only 3,589 net new assisted living beds had been built. The report also found that over 2001-2007 there was a 30% decrease in access to home support and 11% decrease in access to home care for older adults 75+. The focus of the system was concluded to have shifted to higher needs clients, weakening the preventive care and early intervention functions of the system (Cohen, Tate, & Baumbusch, 2009).

In 2006, the Province of BC also launched the Conversation on Health, a discussion that included 78 meetings and over 12,000 submissions (Government of BC, 2007b). While the consultations were perceived by critics as an attempt to garner support for expansion of private health care, the consultations reaffirmed the importance of a universal health care system and suggested expansions to home care programs (Davidson, 2008). During the consultations many of the issues with home and community care described above were raised, including declining access to services (Government of BC, 2007b).

Research examining health care utilization data in BC over the 1990s and 2000s also confirms declining access to home health and home support over this period. A study by Penning et al. (2006) reported the number of people making home support claims dropped from 13.7 per 1,000 in 1990 to 8.6 per 1,000 in 2000, while the number making home nursing claims changed only slightly. Another study by Brackley and Penning (2009) reported that while more people were dying outside of the hospital, this was not accompanied by a subsequent increase in the provision of home care. McGrail et al. (2008) reported a concentration of home health services in higher needs clients, and a decrease in the number of clients receiving home health services (decline of 30% between 1995/96 and 2004/05). An extensive qualitative research project with CHWs, clients, informal caregivers, and home care managers also confirmed the impacts of changes to home care policy in three key areas: 1) A narrowing scope of services due to the cuts in 1990s and rigid care plans; 2) Challenges with scheduling and increasing

time pressures on CHWs; and 3) Heavy reliance on informal caregivers and lack of support for caregivers (Martin-Matthews, Sims-Gould, & Tong, 2012).

In 2008, in response to the many concerns and complaints, a systemic investigation of the home and community care system was launched by the BC Office of the Ombudsperson (2009) that would have important impacts over the next decade. The first volume of the report, *The Best of Care: Getting it Right for Seniors in British Columbia Part 1* was released in 2009 and focused on three issue areas in long-term care: commitment to care and residents' rights; public information and reporting; and resident and family councils. The second volume of the report was released in 2012 and is described later in the chapter.

The 2000s was a period when reforming primary care and integrating primary and community care became increasingly prominent policy priorities, and some of the changes that provided important foundations for this work over the next decade will be briefly described. A primary care charter was released in 2007 that envisioned a collaborative and community-focused primary care system (BC MOH, 2007). Over 2008-2010 the Integrated Health Networks (IHNs) initiative resulted in the development of 25 IHNs across the five health authorities. The projects all involved establishing multidisciplinary teams/networks to provide care to special patient groups (including the frail elderly). The goal was to provide continuous, coordinated services across the care continuum (BC MOH, 2015a). The BC MOH reported that an evaluation of the IHNs found there were lower hospitalization rates for some clients compared to controls, cost savings were found with some IHNs, and there was improved patient satisfaction and access to primary and community care services (BC MOH, 2015a)

6.3 Home and Community Care Policy Context and Objectives, 2012-2019

The following sections describe the home and community care policy context and policy objectives in BC over 2012-2019. Section 6.3.1 provides a brief overview of the political and economic landscape. Section 6.3.2 describes key policy objectives based on review of relevant policy documents as well as information obtained from interviews with key informants from the BC MOH and a regional health authority. Section 6.3.3 provides description of the policy context and key events based on review of relevant

literature, policy documents, reports, government websites, and other sources. Section 6.3.4 describes in more detail key reforms and evidence of their impact.

6.3.1 Political and Economic Landscape

For the past two decades the political landscape in BC has been dominated by the Liberal Party who were in power over 2001-2017. From 2017 to present the New Democratic Party has been in power. In the 2016 census BC had a population of 4.6 million and 18.3% of the population were older adults (848,990) (Statistics Canada, 2019b). BC has consistently been among the lowest spenders per capita on health care in Canada; provincial per capita spending in 2012 was \$3,745 (second lowest in Canada) and forecast to be \$4,259 in 2019 (the lowest in Canada) (CIHI, 2019b). Analysis of health care spending by McGrail and Ahuja (2017) showed significant growth in per capita health care spending beginning in the mid-90s and then a leveling off around 2008. While spending on hospitals and physicians remained fairly consistent, the proportion of public spending on other institutions (includes long-term care) and other health care (includes home care) decreased while private spending increased. Since 2008, the proportion of public spending on other institutions has decreased from 70% to 56% and for other health care from 85% to 70%. McGrail and Ahuja (2017) suggest that the lack of public investment in building capacity in the long-term care sector, and the shifting of care to the community sector without adequate investments in home care, has resulted in cost-shifting from the public health care system to private costs paid for by patients and families.

6.3.2 Key Policy Documents

The following sections describe key policy objectives in BC over 2012-2019. Information is first described from government policy documents, and then interviews with informants from the BC MOH and Fraser Health Authority.

Government Policy Documents: Integrated Primary and Community Care

Policy documents on integrated primary and community care are described below, as home and community care is stated to be a key component of this vision. Integrating primary and community care has been the major strategic focus for the BC

MOH since the mid-2000s (BC MOH, 2015a). In 2009 the BC MOH developed an Innovation and Change Agenda (2009-2013) with four key themes: health promotion and prevention of chronic disease; integration of primary and community care; high quality hospital services; and innovation, productivity, and efficiency (BC MOH, 2014a). Following the Innovation and Change Agenda, the integration of primary and community care became a regular component of annual BC MOH Service Plans (BC Ministry of Health Services, 2010; BC MOH, 2011; 2012a, 2013a).

In 2014, a new health system strategy paper, *Setting Priorities for the B.C. Health System*, was released (BC MOH, 2014a). This paper established eight priority areas for the health care system: 1) Provide patient-centred care; 2) Prevention and health promotion; 3) Primary and community care; 4) Improve access to specialist services; 5) Access to quality diagnostic services; 6) Access to clinically and cost-effective pharmaceuticals; 7) Review and improve acute care services; and 8) Appropriate residential care. The paper stated there would be targeted funding to support implementation of a provincial system of primary and community care that would provide interprofessional care. It also acknowledged the need to examine the functions of the acute care system and develop closer linkages with the community sector. Regarding residential care, actions focused on developing appropriate long-term care models and quality standards. An accompanying health system strategy implementation paper was also released (BC MOH, 2014b).

In 2015, the BC MOH (2015a) released a cross-sector policy discussion paper *Primary and Community Care in B.C.: A Strategic Policy Framework*. It states:

This is the first time that the Ministry of Health has attempted to capture the significant and sometimes loosely connected initiatives and policy that make up efforts to improve primary care and home and community care, which in many respects have developed as two independent streams. Primary health care—as the foundation of Canada’s health care system—provides a critical entry point of contact to the health care system and serves as the vehicle for ensuring continuity of care across the system. Complementary with this, home and community care provides services designed to help people receive care at home, rather than in a hospital or long-term care facility, and to live as independently as possible in the community. (BC MOH, 2015a, p.1)

The paper built on the 2007 Primary Health Care Charter and refocused and refreshed its vision. It identified three key issues with current service delivery approaches: gaps in

care planning and coordination of services; services unable to proactively respond to the needs of patients; and increased complexity of care in the community due to emphasis on out of hospital care. As a solution, in the paper it is proposed that BC move away from the current system that is dominated by hospitals and towards a proactive, integrated primary and community care system. The overall vision advanced is multidisciplinary teams wrapped around primary care, providing care for people with complex needs in the community. The four guiding principles for this restructuring were: patient-centered, integrated and comprehensive, quality and value for money, and responsible operational and capital investment (BC MOH, 2015a). Policy directions were developed at the practice, organizational, and provincial levels. The policy direction most relevant to home and community care reform was: Systematically and opportunistically establish Linked Community and Residential Care Service Practices for older adults with moderate to complex chronic conditions. This policy direction outlined a multidisciplinary practice model to care for older adults and other special populations. The model would provide comprehensive and longitudinal care and be linked to short-stay services, assisted living, and long-term care services (BC MOH, 2015a). In support of this framework, the BC MOH also released discussion papers on health information management and technology, health human resources, rural health services, and surgical services (BC MOH, 2015b; 2015c; 2015d; 2015e).

No additional strategy papers were released on integrated primary and community care by the New Democratic Party Provincial Government, though it is clear they are continuing on with the objective of integrated primary and community care. Over time the vision of integrated primary and community care has evolved to focus on PCNs and Patient Medical Homes linked to SCSPs (IHSTS, 2018). In the BC MOH (2019b) Service Plan the SCSPs for seniors are described as:

Specialized service for seniors with complex medical conditions and/or frailty will integrate and coordinate all services for this patient population including home support, community-based professional services, community caregiver supports, palliative care, and assisted living. (p.4)

Government Policy Documents: Home and Community Care

Two home and community care action plans were released over 2012-2019 under the Liberal Provincial Government. *Improving Care for B.C. Seniors: An Action*

Plan was developed in 2012 in response to the Ombudsperson’s report (Government of BC, 2012). Six action areas were outlined: concerns and complaints; information; standards and quality management; protection; flexible services; and modernization. In comparison to the recommendations in the Ombudsperson’s reports, the proposed actions in this 10-page plan were much less comprehensive. Under the theme Flexible Services were the proposed actions most relevant to the delivery of services, including a commitment to work with the United Way of the Lower Mainland to expand access to “non-medical” home support services and a commitment to pilot innovative home support models. Under the theme Modernization it was stated that “Over the next two years, the Ministry of Health will work with seniors, health authorities, and care providers to modernize and renew B.C.’s home and community care system.” (Government of BC, 2012, p.8).

An Action Plan to Strengthen Home and Community Care for Seniors was later released in 2017 (BC MOH, 2017a). Table 8 provides an overview of the four action areas in the plan. The action plan included a commitment to provide an additional \$500 million in funding over the next 4 years. It also included a brief health human resource plan in recognition of potential changes due to implementation of the SCSPs and changes in long-term care (BC MOH, 2017a).

Table 8 Summary of Action Areas in An Action Plan to Strengthen Home and Community Care for Seniors

Action Area	Proposed Next Steps
Focus on healthy aging	<ul style="list-style-type: none"> • Develop messaging on healthy aging and self-care. • Provide additional information and support for healthy eating. • Create a seniors section on Health Link BC.
Provide better co-ordinated and integrated community care for seniors with complex medical needs and/or frailty	<ul style="list-style-type: none"> • Develop implementation plan for SCSPs for Seniors that will actively work with primary care, provide comprehensive case management and care coordination, increase home support services and leverage other health professionals, and coordinate access to other health services. • Update a range of home and community care policies.
Work with assisted living residences to implement the new Community Care and Assisted Living Act provisions	<ul style="list-style-type: none"> • Consult with stakeholders and develop new assisted living regulations; educate key stakeholders on these new regulations. • Collect data on the potential new clients for assisted living. • Develop policies on staffing levels, skill mix, and service delivery models in assisted living.

Strengthen role and quality of residential care

- Implement the Residential Care Staffing Review action plan and take steps to ensure staffing levels are adequate to meet a standard of an average of 3.36 direct care hours per day per resident.
- Ensure short-term residential care is integrated into the SCSPs.

Data Source: BC MOH, 2017a

Review of annual BC MOH Service Plans over 2012-2019 also highlights additional policy objectives relevant to home and community care: appointing a Seniors' Advocate; expanding non-medical home supports for seniors; increasing access to home and community care; and increasing direct care hours per day in long-term care (BC MOH, 2013a; 2017b; 2018).

Additional Policy Documents

Two additional action plans relevant to home and community care policy are described below. In 2012, a *Dementia Action Plan* was introduced, outlining actions in three priority areas: 1. Support prevention and early intervention; 2. Ensure quality person-centred dementia care; and 3. Strengthen system capacity and accountability. The recommended actions that pertained to home and community care were increasing the flexibility/options in housing and care models for people who cannot live independently and initiating quality improvement initiatives beginning with long-term care (BC MOH, 2012b). In 2013, an *End-of-Life Care Action Plan* was released that emphasized providing end-of-life care in the home and community. Recommended actions relevant to home and community care included improving the capacity to provide end-of-life care in long-term care facilities/other settings and ensuring access to the BC Palliative Care Benefits Program in long-term care (BC MOH, 2013b). In both action plans, integrated primary and community care was described as an important shift that will improve care for patients (BC MOH, 2012b; 2013b).

Interview-based Information from BC MOH and Fraser Health Authority

Interviews were conducted with informants at the BC MOH and Fraser Health Authority to collect information on current strategic directions and home and community care initiatives. The purpose of these interviews was to collect public information and not information for thematic analysis. Interviews were conducted with three members of the BC MOH and two employees from the Fraser Health Authority in 2014 to learn more about the current status of home and community care in BC. While the experience in

Fraser Health Authority cannot be considered representative of all the regional health authorities in BC, it does provide an example of the progress of integration work in BC. A follow-up interview was conducted with the BC MOH in 2019 (a written response was received) to find out more about the current strategic direction for home and community care and new initiatives.

2014 BC MOH Interview

In 2014 the BC MOH identified the forthcoming *Primary and Community Care* policy paper as a new key document that would capture the vision for home and community care. The *Seniors Action Plan*, *Dementia Action Plan*, and *End-of-Life Care Action Plan* were also referenced as plans that contribute to the overall vision for care for older adults. While long-term care will continue to have a role to play in the future (particularly for higher needs populations), and there may be more opportunities to look at alternative housing options (e.g., expanding assisted living), it was emphasized that community services will be the key moving forward.

The health care system was acknowledged to be a complex system with various structures in place within the system (e.g., legislative, policy, regulations, collective agreements, professional practices, etc.) that can become barriers when trying to integrate services, and integration is a complex task that must be approached on multiple levels. The importance of being very thorough in planning for changes and having a stepwise plan were emphasized. The BC MOH was exploring a number of different areas related to community services including what services should be provided, integration of services, providing team-based care, best use of human resources, and use of technology. When asked specifically about the issue of communication and interoperability between different information systems, this was acknowledged as a significant issue that needed to be addressed. Currently the Provincial Government has requirements for these systems, but does not build them, so the health authorities or health care providers choose which systems they use. The BC MOH was producing a policy paper on this issue.

Regarding a question about ensuring that home care clients with lower level or moderate care needs are adequately cared for, it was acknowledged that this is an issue that many jurisdictions are currently dealing with. It was stated that many patients have

complex needs, and we need to look at having a wide variety of service options available to support them (e.g., occupational therapy, home modifications, etc.). Work is currently being undertaken in the health authorities to provide more of these different types of services and collaborate with community organizations that can provide these types of services. When asked about whether the provincial government was considering the provision of “non-medical” home supports by the health authorities in the future, it was stated that the provincial government had made a decision in the 1990s to phase out these services, and there had not been a change from this position.

Examples of specific steps that have been taken to improve the integration of primary and community care services and strengthen home and community care were provided:

- The Primary and Community Care policy paper is a key step that has brought together many aspects of the different strategy documents over the past 12 years. In addition, there have been conversations with the health authorities, Patients as Partners, and other key stakeholders on integrated primary and community care.
- In 2013 BC held a home care forum with experts from six countries who shared their innovations around home care for older adults.
- Care Management Strategies (the use of interprofessional teams, where the most responsible clinician at the time looks after the needs of the client and assists them in getting the services that they need) and Self-Management Strategies (teaching clients how to manage their own health conditions) were mentioned as important components of current approaches by the health authorities to care for individuals with lower level needs.
- The Better at Home Program was provided as an example of an initiative that seeks to provide services to individuals with lower level needs. The Better at Home program receives its funding from the BC MOH, and even though it is not offered through the health authorities it was perceived that the program has good communication and cooperation with the health care system. It was also stated that currently Better at Home provides a wider range of services (e.g., snow shoveling, home maintenance) than were offered by home support services previously.

2014 Health Authority Interviews

In the interviews conducted with the two Fraser Health employees, both participants stated that home and community care is a very important focus for Fraser

Health. Fraser Health's recent operational review and strategic plan both highlighted opportunities for reduced utilization of acute care resources and increased utilization of long-term care and community care services as alternatives. Programs providing community care resources are exploring ways to increase capacity and efficiencies, in anticipation of increased resources and demand. Some of the key focuses moving forward included integrating health services, improving patient experiences, prevention, and promoting healthy aging. The importance of not losing sight of the patient amidst the various health care system priorities and considering the needs of all people along the health continuum (e.g., frail elderly, healthy individuals, people living with illness, etc.) were emphasized.

A range of examples were provided of initiatives that have been undertaken to improve the integration of primary and community care and care for older adults:

- Work was underway to create and test an interface between the information systems used by home health (PARIS) and acute care (Meditech). There are additional information systems in use (e.g., Procura for home support) that will also need to be integrated with other information systems in the future.
- The concept of care management has been introduced, with the expectation that all of the clinicians in home health should have the ability to develop a care plan and help clients navigate the system. This is a cultural shift to have health professionals thinking from a care management framework and to have clients empowered and involved in their care.
- Unique models of integrated primary and community care have been developed such as the Chilliwack Primary Care Seniors Clinic that provides assessment and comprehensive primary care for older adults with complex health care needs.
- In the major urban centres throughout Fraser Health work has been undertaken to develop health care teams that link community care providers with general practitioners and provide shared care to clients.
- The role of the surveillance nurse was created to monitor clients in the community and provide coaching and proactive check-ins.
- The Community Action and Resources to Empower Seniors (CARES) project has been developed that involves primary care physicians working with well or pre-frail clients to conduct an assessment, create a wellness plan, and link clients to community resources.

- Home is Best is a strategy that was developed by Fraser Health based on the belief that the home is the best environment for the frail and vulnerable populations. When patients are in acute care the approach assumes that they can and will be going home from the hospital, and a specially trained home health liaison assesses them and develops a care plan to get them home. If after their acute episode community supports are not able to meet the client's needs, then a transfer to long-term care will be expedited, but home health tries to wait until the client is home to make this decision because home is a better environment to make this decision in than acute care.
- Outreach nurses based in emergency rooms help link patients with home and community care services, with the intention of preventing hospital admissions.

2019 MOH Follow-Up Interview

In 2019, a follow-up interview was conducted with the BC MOH to find out more about the current strategic direction for home and community care and new initiatives being undertaken in BC. The Provincial Government will be investing over \$1.018 billion over the next 3 years to improve care for older adults, including in primary care, home health, long-term care, assisted living, and respite services. This funding includes \$249 million that will be provided from the Federal Government as a part of the Canada/BC Home and Community Care funding agreement. Some of the specific initiatives currently underway to strengthen home and community care include:

- Creating regulations to expand the number of prescribed services offered in assisted living.
- An investment of \$75 million over 3 years in respite and adult day services.
- Collaboration with the United Way of the Lower Mainland on the Integrated Community-Based Programs for Older Adults with Higher Needs demonstration projects that will scale up innovations/promising practices to help higher needs older adults remain in their own homes.
- Supporting the Seniors Can Move program, an exercise program that helps older adults to strengthen their movement skills.

In addition, work is underway to develop the PCNs and SCSPs. The SCSPs will be integrated programs within the health authority that will provide team-based interdisciplinary care for target patient populations using an integrated care management approach. The target populations include people with complex medical conditions/frailty (e.g., frail older adults). Components of the programs will include information, intake,

urgent response, consultation, referral, assessment, and service provision to complex patients. SCSPs will also coordinate access to specialized services and offer extended hours of service.

6.3.3 Policy Context and Key Events

The period of 2012-2019 began with the release of a major report by the BC Ombudsperson. As described in section 6.2.2 a systemic investigation into the home and community care system was launched in 2008. The first report of the investigation was released in 2009. The more comprehensive second part of the report was released in 2012 (two volumes with 143 findings and 176 recommendations). Some of the issues raised by the Ombudsperson (BC Office of the Ombudsperson, 2012a; 2012b) included:

- Lack of planning and forecasting of needs to determine adequate home and community care funding.
- The need to improve system navigation for the home and community care system.
- Waiting times for assessment of care needs that exceed the two-week timeframe set out in BC MOH policy (usually longer than two weeks and in some cases almost up to a year).
- Lack of accurate reporting by the health authorities on home and community care services provided.
- The need for an evaluation of whether the current home support system is meeting its intended goals.
- Limited availability of home support services and need for a broader range of supports.
- Lack of provincial standards and requirements for home support, assisted living, and long-term care.
- The number of prescribed services assisted living facilities can provide is limited to two, even when the resident is waiting to exit assisted living.
- Lack of enforceable standards for long-term care staffing levels.
- Long wait times for long-term care beds (with average waits ranging from 37 to 93 days depending on the health authority).

Progress by the health authorities and BC MOH on meeting the Ombudsperson's recommendations was slow, and by 2015 only 4 recommendations from the first report and 17 from the second report had been fully implemented (BC Office of the Ombudsperson, 2015a; 2015b). A final update in 2019 reported that 68 of the 176 recommendations from the second report had been completely implemented (BC Office of the Ombudsperson, 2019).

One of the key actions resulting from the Ombudsperson's report was the appointment of a Seniors Advocate in 2014. The Seniors Advocate undertook a province-wide tour upon her appointment and identified 13 key issues, many of which related to home and community care, such as: seniors being unable to continue to live where they want; lack of transportation to medical appointments and support services; lack of home care services and lack of consistency of services across the province; inability to secure a long-term care bed at the right time and in the right place; concerns about the quality of care in long-term care facilities; fragmentation of services; and caregiver burnout (OSA, 2014a). The Seniors Advocate recognized having reliable, provincially standardized data available is crucial for making improvements, and made it her first priority to begin establishing, collecting, and tracking provincial indicators on the key seniors' issues that were identified (OSA, 2014a). The Seniors Advocate has released multiple reports on seniors' care in BC (table 9 provides a summary of relevant reports). Some of the key findings from these reports include:

- Between 5-15% of residents in long-term care could potentially be cared for in the home and community (OSA, 2015c).
- There is a proportion of clients for whom assisted living could potentially be an appropriate service but are ineligible under current regulations (OSA, 2015d).
- Access to adult day services and home support has declined (OSA, 2015a).
- Almost one-third of caregivers are in distress (OSA, 2015a).
- The majority of home support clients (78%) believe home support services are meeting their needs. The most common additional services clients would like to receive are housekeeping (28%) and meal preparation (12%) (OSA, 2016a).
- In a survey of residents of long-term care facilities, many of the challenges identified related to staffing levels and inadequate time for personal care (OSA, 2017b).

- Half of home support clients are at high or very high risk of long-term care placement, yet 86% receive less than 2 hours of home support per day. The cost to subsidize a long-term care bed is \$57,600 annually while 2 hours of daily home support is \$27,740 (OSA, 2019a).

Table 9 Summary of Key Findings from Reports from the Seniors Advocate

Report	Highlights
B.C. Seniors Survey: Bridging the Gaps (OSA, 2015b)	<ul style="list-style-type: none"> • 14% of respondents reported receiving home care/home support in the past year for problems related to aging. • About half of seniors felt they might have to move in the future, most commonly due to health or housing affordability reasons.
Placement, Drugs and Therapy: We Can Do Better (OSA, 2015c)	<ul style="list-style-type: none"> • 5-15% of residents were prematurely admitted to long-term care and could have potentially been cared for in the home and community with the proper supports. BC had a higher prevalence of residents prematurely admitted to long-term care compared to Alberta or Ontario. • In BC in the last 7 days only 12% of long-term care residents had received physiotherapy, 9% occupational therapy, 0.2% speech language therapy, and 22% recreational therapy (generally lower than Ontario and Alberta).
Seniors' Housing in B.C.: Affordable, Appropriate, Available (OSA, 2015d)	<ul style="list-style-type: none"> • 4% of seniors in BC live independently but receive home care services; 3% live in assisted living (of which 20% receive public subsidy); and 4% live in long-term care (of which 90% receive public subsidy). • There is a group of clients for whom assisted living would potentially be appropriate, but under current regulations are ineligible for this service. • Issues about long-term care raised include regional variations in availability, lack of available preferred bed choices, and inappropriate placements. • Recommendations included changing assisted living regulations to allow for a greater range of clients and ensuring all possible options for support in the community have been exhausted before long-term care placement for lower needs clients.
Caregivers in Distress: More Respite Needed (OSA, 2015a)	<ul style="list-style-type: none"> • 54% of caregivers could benefit from respite, but only 7% of clients had used adult day services in the past 7 days and 53% home support. Only 11% had used respite beds in the past year. • Access to adult day services (decrease in clients by 5% over 2011-2014) and home support (rate per 1,000 people aged 75 and up decreased by 7% from 2005/06 to 2013/14) has declined. • Comparison of BC with Alberta found higher levels of caregiver distress (29% vs. 14%), lower percentage of clients who received home support in the last 7 days (53% vs. 65%), and higher complexity of clients in BC (53% vs. 37%). • It was estimated that only 3,700 seniors had used respite beds over 2014/15 while approximately 15,000 could benefit from them. • It was suggested that increasing levels of respite services, introducing more intensive adult day programs, and having dedicated respite facilities would help to better meet the needs of caregivers.

Listening to Your Voice: Home Support Survey Results (OSA, 2016a)	<ul style="list-style-type: none"> • The majority of clients (78%) felt home support services were meeting their needs and home support workers had enough time (80%) to provide them with their care all or most of the time • 63% of clients felt they received care from an appropriate number of regular home support workers • The most common additional services clients would like to receive were housekeeping (28%) and meal preparation (12%).
Making Progress: Placement, Drugs and Therapy Update (OSA, 2016b)	<ul style="list-style-type: none"> • Over 2013/14-2015/16 there were small decreases in the percentage of people in long-term care who could potentially be cared for in other settings. • Over 2013/14-2015/16 there were slight improvements in percentages of residents receiving physiotherapy and recreational therapy, while there was a decline in those receiving occupational therapy.
Caregivers in Distress: A Growing Problem (OSA, 2017a)	<ul style="list-style-type: none"> • The percentage of caregivers in distress increased slightly to 31%. • Access to home support (average hours per day decreased by 5%) and adult day services (hours per client per day decreased by 6%) continued to decline. • Access to respite care increased by 5%. • Participation in CSIL was found to be associated with a significant decrease in risk of caregiver distress (50% decrease). • Recommendations included increasing access to adult day services and home support, increasing awareness and access to CSIL, and developing clusters of respite beds and empowering caregivers.
Every Voice Counts: Office of the Seniors Advocate Residential Care Survey Provincial Results (OSA, 2017b)	<ul style="list-style-type: none"> • Positive aspects of long-term care homes identified by residents included safety and competence of staff. • Many of the negative aspects related to lack of staff and inadequate time for personal care (e.g., toileting, meals) and lack of social connection. • Recommendations included: increasing staffing levels, increasing flexibility in care, increasing activities, improving mealtimes, providing better primary care, providing education to staff to enhance focus on resident emotional wellbeing, fostering greater engagement with families, and conducting follow-up surveys.
Seniors Transportation: Affordable, Appropriate, and Available (OSA, 2018a)	<ul style="list-style-type: none"> • 90% of seniors age 65-69 have a drivers license, but this drops to 79% for those age 75-79 and 61% for those age 80-84. • Other transportation options for seniors include walking, rides from friends/family, public transit, HandyDART, and volunteer driver programs. • A number of recommendations were made to improve transportation options for seniors. It was also recommended that a Community Driver Program be established as a part of the home support system to support frail seniors.
Home Support: We Can Do Better (OSA, 2019a)	<ul style="list-style-type: none"> • 51% of home support clients are at high or very high risk of long-term care placement, yet 86% receive less than 2 hours of home support per day. • The average senior could save \$10,000 per year living in long-term care rather than at home due to the high costs of home support. • The cost to subsidize a long-term care bed is \$57,600 annually while 2 hours of daily home support is \$27,740.

- Qualitative feedback from seniors on home support has identified the following challenges: restrictive and inflexible services, insufficient hours of service, too expensive, lack of continuity, unreliable, and bureaucratic.
- Recommendations were made to improve affordability, create more flexible care plans, examine the role of case management, embed support for family caregivers into care plans, produce a standardized document on home support services, develop a new program for direct client funding, and identify strategies to recruit and retain CHWs.

In addition to the Ombudsperson and Seniors Advocate, other key policy actors involved in bringing attention to the home and community care system during this time included the independent policy think tank the CCPA and the advocacy organization the BC Health Coalition. Key research reports included:

- A report from the CCPA found that within BC, over the past decade there has been a 14% decline in home and community care services for older adults (measured by number of beds available and hours of care provided compared to the population 75 years and older) (Cohen, 2012). Cohen (2012) noted “a decade of underfunding and restructuring has led to a home and community care system that is fragmented, confusing to navigate, and unable to meet seniors’ needs” (p.5), and called on the provincial government to integrate services for older adults.
- A report on home support was released by the BC Health Coalition and Integrated Care Advocacy Group. The current home support system was described by focus group participants as preventing CHWs from providing person-centred care and forming relationships with their clients; not supporting family caregivers; providing reactive and not proactive care; struggling to deal with the increasingly higher level clients; and creating bottle necks due to shortages of case managers (Cohen & Franko, 2015).
- A CCPA report found that over 2001-2016 access to long-term care and assisted living spaces declined by 20% while access to home support declined by 30%. While more clients are now receiving home care visits, clients are receiving fewer visits. The number of long-term care beds in the for-profit sector increased by 42% between 2001-2016 (Longhurst, 2017).

The BC Care Providers Association (BCCPA), an industry organization representing a range of for-profit and non-profit seniors care providers, also released a number of policy papers during this period. Key themes in these papers were the inadequacy of funding and funding models and the role of the private sector in meeting home and community care needs. Some of the key issues highlighted include: addressing ALC; meeting the standard of 3.36 direct care hours in long-term care; the increasing complexity of clients; the need to shift resources from acute care to home and community care; the short

length of home support client visits; limitations on the number of prescribed services in assisted living; and health human resource challenges (BCCPA, 2015; 2017; 2018; 2019a). The BCCPA (2019a) also projects that even if a 15% diversion of clients to the community occurs, by 2041/42, 37,967 new long-term care beds will still be required.

To summarize, based on the various reports described above from the Ombudsperson, Seniors Advocate, and other sources, key home and community care policy issues over 2012-2019 included: declining access to home and community care services; increasing complexity of clients; lack of supports for informal caregivers; staffing levels and quality of care in long-term care; the need for a more comprehensive range of home support services; and the potential for a broader range of clients to be cared for in the home or assisted living. In addition to the home and community care policy issues outlined above, some other contextual policy issues and initiatives during this period are described in table 10.

Table 10 Contextual Policy Issues over 2012-2019

Contextual Policy Issues, 2012-2019
Development of Team-Based Primary Care: Developing team-based primary care has been a consistent objective since the Primary Care Charter in 2007. However, this vision had yet to be fully realized, with pockets of progress across the province but no system-wide change (Misfeldt et al., 2017).
ALC: In 2013/14, 12.6% of hospital days in BC were classified as ALC (Lavergne, 2015). A report by the IHSTS suggested that the most promising interventions to reduce ALC are integrated care systems that integrate primary, home and community, and acute care (Lavergne, 2015). A report by the BCCPA (2015) also estimated that if the number of ALC days could be reduced by 50% this would result in \$200 million in annual savings for the health care system.
Health human resources: Significant health human resource shortages, particularly for health care assistants, have been projected for the home and community care system (BCCPA, 2018). In some communities shortages are already being observed; for example, surveys by SafeCare BC found over 87% of home care and support organizations are always, often, or sometimes understaffed (SafeCare BC, 2017) and 60% of long-term care homes have shortages of workers (SafeCare BC, 2016).
Community-Based Seniors' Services: Beginning in 2015 there was a movement by community-based seniors' services (i.e., non-profit and municipal organizations that provide services to seniors such as senior centres, multiservice non-profit organizations, etc.) to organize themselves and raise awareness about their role in supporting the health and wellbeing of older adults through the Raising the Profile Project (Kadowaki & Cohen, 2017). This work is now being continued by the United Way of the Lower Mainland's Healthy Aging Department (Healthy Aging, 2019a).

However, the priority that dominated the policy agenda was integrated primary and community care, as described in section 6.3.1. Over the period of 2010-2015

bilateral agreements were signed by the BC MOH and health authorities to establish the definitions and vision for an integrated primary and community care system, with the goal of services being delivered in the community by a team wrapped around the family physician (BC MOH, 2015a). Beginning in 2012, \$50 million per year was made available to health authorities for a three-year period for the implementation of accelerated Integrated Primary and Community Care (aIPCC) initiatives (BC MOH, 2015a). In total 20 aIPCC initiatives were launched (McGrail et al., 2019). Table 11 describes the initiatives most relevant to frail older adults.

Table 11 aICPP Initiatives for Frail Older Adults

aICPP Initiatives for Frail Older Adults
Home is Best (Vancouver Coastal Health): Care by an interdisciplinary team and enhanced community-based services are provided to frail seniors to prevent acute care and long-term care admissions.
Home First (Fraser Health, Interior Health, Island Health): Enhanced supports are provided to frail seniors in order to facilitate discharge from the hospital and the provision of care at home.
Care Management Strategy (Vancouver Coastal Health): The strategy focused on improving integration between home health services and primary care through general practitioner case conferencing.
Integrated Accessible Health Services (Northern Health): Primary care homes were implemented for complex patient populations to provide intensive case management and coordination
Frail Senior/Chronic Disease Community Transitions (Vancouver Coastal Health): This initiative utilized interdisciplinary teams to address the transition needs of older adults (70+) who presented at the emergency department

Data source: McGrail et al. (2019)

Later in 2015 a new initiative repositioning health care for older adults was developed at a workshop (BC MOH, 2015f). Health authorities were given the directive from the BC MOH to consult with stakeholders and for local teams to develop new care delivery models for older adults (Hulko, Mirza, & Seeley, 2020). Thirteen prototype Divisions of Family Practice were chosen to develop initiatives that would address access to primary care, reduce emergency department and long-term care utilization, and support robust community care supports (Divisions of Family Practice, 2020). Most recently in 2018, the new Provincial Government announced a primary care strategy that would see investments made into the development of PCNs (networks of primary and community care providers), Urgent Primary Care Centres, and Community Health Centres (Government of BC, 2018b). Currently 20 PCNs have begun implementing their service plans (Doctors of BC, 2020). The Provincial Government has also proposed the

development of the SCSPs that will be linked to the PCNs for several higher needs populations, including older adults.

Over 2012-2019, while home and community care was less prominent on the policy agenda than integrated primary and community care, some reforms were made to the system (see figure 8 on next page).

Steps were taken to address gaps in the home and community care continuum through partnerships with the community-based seniors' services sector, work that began under the Liberal Government and was continued under the New Democratic Party Government. As described previously, in 2010 in response to identified gaps in "non-medical" home supports the CASI pilot project was introduced. CASI was a three-year pilot project of programs providing "non-medical" home support services to seniors in five communities. The project was funded by the BC MOH and managed by the United Way of the Lower Mainland. Based on the positive pilot of CASI, the Provincial Government committed \$15 million for 3 years to implement up to 60 Better at Home programs across the province (Chomik Consulting & Research Ltd., 2012). In 2019, the BC MOH again partnered with the United Way of the Lower Mainland to provide approximately \$4 million dollars annually to fund 2.5-year demonstration projects of Integrated Community-Based Programs for Older Adults with Higher Needs. The programs began in 2020 and are delivered by community-based seniors' services and directly linked to the health care system through referrals, joint planning, and/or resources and support (Healthy Aging, 2019b). These programs include:

- Social prescribing: Primary care physicians develop wellness plans for frail patients and link them to community-based services.
- Caregiver support programs: Programs provide individualized and peer support, education and coaching, and information and linkages to services.
- Therapeutic activation programs for seniors: This model is similar to an adult day service but for lower needs clients (Healthy Aging, 2019b).

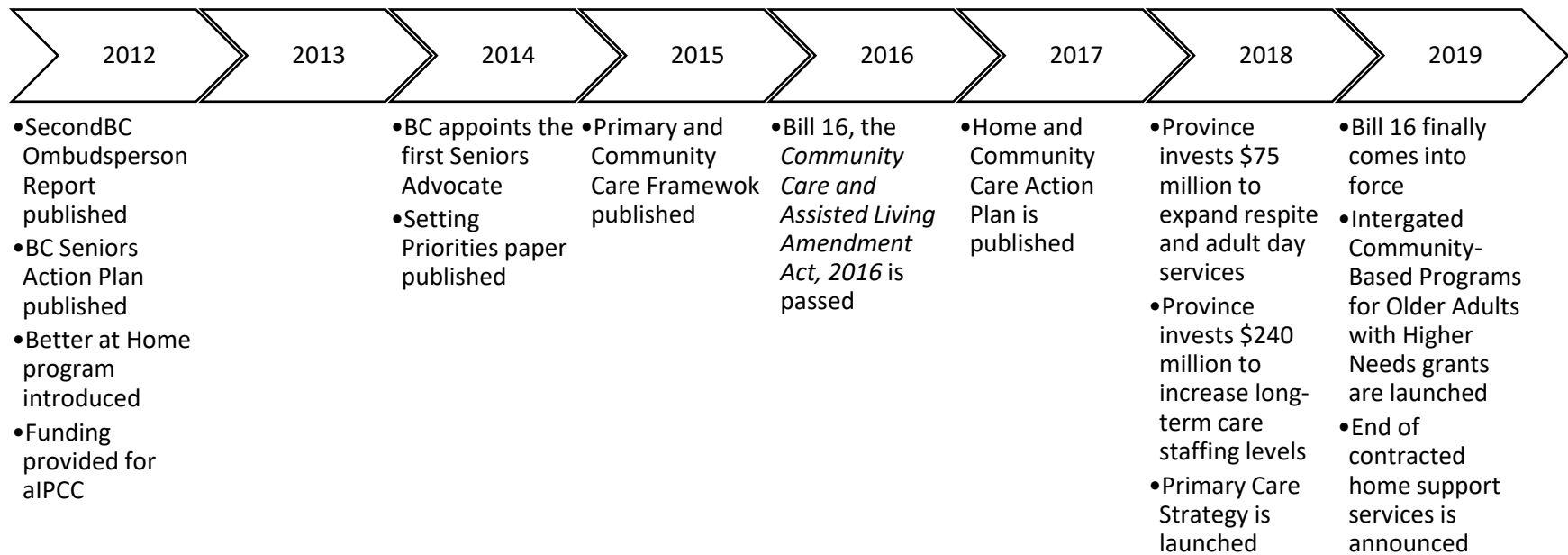


Figure 8 Timeline of Key Events Impacting Home and Community Care Over 2012-2019

In response to critiques from the Ombudsperson, Seniors Advocate, and other sources steps were also taken to expand the scope of assisted living services to accommodate more complex and palliative residents. In 2016, Bill 16 *Community Care and Assisted Living Amendment Act, 2016* was passed (BC Office of the Ombudsperson, 2019). However, it was not until the end of 2019 that the amendments and regulations from Bill 16 finally came into force. These changes removed the restrictions on the number of prescribed services that can be offered and provide increased regulatory oversight over assisted living (Government of BC, 2019).

In 2018 the Provincial Government committed \$75 million over 3 years to expand access to adult day programs and respite services (respite beds and overnight services) – needs that had been highlighted in reports by the Seniors Advocate (Government of BC, 2018c). The Provincial Government also committed \$240 million over 3 years to increase direct care hours to an average of 3.36 hours per resident in long-term care (Government of BC, 2018d). This commitment built on previous work to increase long-term care staffing levels by Liberal Governments. In 2008, the BC MOH had developed a Provincial Residential Care Staffing Framework and in 2009 the target was set at providing an average of 3.36 hours per resident day (BC MOH, 2017b). Since 2010, when long-term care client rates were increased, health authorities had been reinvesting this additional revenue into staffing levels, with slow increases over time to the average hours of direct care. However, these reinvestments were insufficient to bring levels of care up to 3.36 hours (BC MOH, 2017b). In 2017, a Residential Care Staffing Review was conducted, motivated by data from the Seniors Advocate that showed 81% of long-term care facilities were failing to meet the desired 3.36 hours standard (BC MOH, 2017b). The Liberal Government committed to providing funding to increase direct care hours to an average of 3.36 in their home and community care action plan (BC MOH, 2017a), and this policy was carried on by the New Democratic Party. In recognition of current health care assistant shortages and the increased number of workers required to meet the 3.36 hour goal, the Provincial Government also committed funding to create new health care assistant seats (Government of BC, 2018d).

In 2019, it was announced that three of the regional health authorities (Fraser Health Authority, Vancouver Coastal Health Authority, and Island Health Authority) would phase out their current use of contracted home support providers over the next 12 months (Shaw, 2019).

6.3.4 Evidence of Impact of Key Reforms

Over 2012-2019, reforms to the home and community care system in BC were limited in scope. One of the most significant changes occurred outside of the formal home and community care sector, with the introduction of Better at Home programs in 2012. Much of the attention during this period has instead been focused on integrating primary and community care, and some initiatives were developed specifically for frail older adults under aPCC. Since the change in Provincial Government in 2017, some more notable changes occurred in 2018 and 2019, including a commitment to expand adult day services and caregiver respite, increased funding for long-term care staffing, amendments to the Community Care and Assisted Living Act, and the decision to move home support services in-house. As these changes have been of a short duration or are still in progress, there is little information on their impacts. Additionally, the BC MOH has also committed funding for the Integrated Community-Based Programs for Older Adults with Higher Needs demonstration projects. Below, these reforms are described; when available, evaluations or other relevant research that can help to elucidate the impacts/potential impacts of these reforms are also described.

Better at Home

The Better at Home program is funded by the Province of BC, managed by the United Way of the Lower Mainland, and services are delivered by local community organizations. The goal of Better at Home is “to help seniors live longer in their own homes while remaining socially connected to other people in their communities.” (Chomik Consulting & Research Ltd., 2014, p.8). The program provides seven core services: light housekeeping, transportation, friendly visiting, light yardwork, minor home repairs, grocery shopping, and snow shoveling. A mix of staff, contractors, and volunteers provide services. All programs use an income-based sliding scale for fees (Chomik Consulting & Research Ltd., 2014). Currently there are 70 Better at Home programs operating across the province that served 11,787 clients in 2018/19. The most frequently provided services were light housekeeping (51%), friendly visiting (17%), and transportation (12%) (Healthy Aging, 2019a).

Better at Home is based upon the CASI pilot projects. The impact evaluation of CASI included pre-test and post-test interviews with 145 clients, mostly focusing on

client satisfaction. Overall, there were high levels of satisfaction with the service (Chomik Consulting & Research Ltd., 2012). An initial evaluation of Better at Home was conducted by Chomik Consulting & Research Ltd. (2014), focusing on the first 16 programs. The evaluation consisted of formative (stakeholder interviews and surveys) and summative (interviews with 310 program clients) evaluations, with the focus on the formative evaluation. Overall, clients were satisfied with the program and services, and felt the program was making their lives easier, helping them remain in their home, providing peace of mind, and helping with general activities of daily living. In the formative evaluation interviewees believed Better at Home was a viable way to deliver “non-medical” home supports and was having a positive impact on the older adults. Some of the challenges included the need for adequate and sustainable funding; increasing collaboration with community partners and the health care system; difficulties with recruiting/retaining volunteers and contractors; high demand for services and limited capacity; and demand for services outside of the scope of the program (e.g., meal preparation, health care services, etc.) (Chomik Consulting & Research Ltd., 2014).

A second evaluation was conducted in 2017/18 and included surveys, evaluations, and site visits. Overall, older adults, informal caregivers, service providers and volunteers expressed satisfaction with the Better at Home program. However, high levels of service demand were reported, with 74% of staff saying they did not have sufficient funding to meet current demand and 50% of older adults expressing the desire for more services. Multiple theory of change outcomes were measured in the evaluation and the most significant impact reported was for feeling able to stay at home longer (89% of respondents strongly agreed or agreed) (Team Play Consulting Inc. and Shift Collaborative, 2018). Currently an additional evaluation is being undertaken to determine the impacts of Better at Home on health care utilization, quality of life and wellbeing, and cost-effectiveness (PopData BC, 2018).

Integrated Primary and Community Care Initiatives

Over 2012-2019 there were two key primary and community care reform initiatives: integrated primary and community care and aIPCC. An evaluation of the integrated primary and community care work was conducted in 2013, but is not available publicly. However, the evaluation noted that “...there is much more work to be done, including building an information system that will support transformation and developing

a provincial strategy for patient reported measures so that the patient focus is truly incorporated. At this juncture, overall, we find that significant strides have been made in laying the foundation for successful integration.” (Michael Smith Foundation for Health Research, 2013, as cited in BC MOH, 2015a, p.95).

An evaluation of the aIPCC initiatives was conducted by the Centre for Health Services and Policy Research (McGrail et al., 2019). The evaluation utilized a case-control design, with minimum ratios of 1:2 for cases and controls. The analysis of the *Home First/Home is Best* initiatives (cases n=3,670) found no significant changes in costs or differences in health care utilization (emergency department visits and hospitalizations) after the initiative. The analysis of the *Care Management Strategy* initiative also found no significant changes or differences for the cases (n=1,572). For the *Integrated Accessible Health Services* initiative, significant increases in health care utilization and costs were found for the cases compared to controls, though it was noted the trend for cases was decreasing costs and utilization over time (n=4,730). It was suggested that imperfect controls may have contributed to the observed higher costs and service utilization for cases. The *Frail Senior/Chronic Disease Community Transitions* initiative was not analyzed due to lack of a comparison group. Generally, the initiatives targeting older adults were unsuccessful in reducing health care utilization or costs. A key limitation of this evaluation was the evaluators did not receive home and community care data from the BC MOH in time to include it in the analysis, so it is unknown if the initiatives resulted in diversions away from long-term care. Clinical care and quality of life indicators were also outside of the scope of the evaluation, and some health authority staff interviewed believed impacts would have been observed in these areas. The evaluators concluded that the aIPCC initiatives had failed to meet their primary objectives, though there may have been positive impacts outside the scope of the evaluation (McGrail et al., 2019).

More recently, the strategy for integrating primary and community care has turned to the development of PCNs and SCSPs. However, as work on implementation is only in the early stages it is not possible to assess what impacts they will have on care for older adults.

Amendments to the Community Care and Assisted Living Act

In 2016, Bill 16 *Community Care and Assisted Living Amendment Act, 2016* was passed and at the end of 2019 the amendments and regulations finally came into force (Government of BC, 2019). As the amendments only came into force at the end of the study period, there are no data available yet on the impacts of this reform. The BCCPA (2019a) reported that based on projections CIHI provided to the BC MOH, under the status quo it would have been expected that over 2015-2021 there would be a 19% increase in long-term care clients and 20% increase in assisted living clients. However, with Bill 16 and diversion of clients to assisted living, it was estimated that there would be only a 13% increase in long-term care and a 64% increase in assisted living clients. If clients were diverted to both assisted living and home support, then there would be a 13% increase in long-term care clients, 28% increase in home support clients, and 41% increase in assisted living clients. These diversions could result in estimated cost-savings of \$56 million annually (BCCPA, 2019a).

However, there are two caveats that should be made about the potential impacts of Bill 16. First, some research suggests that assisted living clients have higher rates of utilization of other health care services (i.e., acute care) than long-term care clients (e.g., McGregor et al., 2014; Maxwell et al., 2015). It has been suggested that lower levels of education/training for staff and lower staffing levels may reduce the ability of assisted living to act as an appropriate substitute for long-term care, and enhanced staffing may help to reduce/prevent long-term care admission (Maxwell et al., 2013). A recent report on assisted living in BC raised concerns about inadequate staffing levels and clients in assisted living who are already too complex for the setting (Perry, 2020). There has not yet been a funding commitment to raise staffing levels in assisted living. Second, over 2010-2017 only 105 new publicly subsidized assisted living units were built in BC (Longhurst, 2020). The Seniors Advocate also reported there were 870 people waiting for publicly subsidized assisted living in 2019 (OSA, 2019b). The limited assisted living stock limits the diversionary potential of assisted living.

Long-term Care Staffing Levels

In 2018, \$240 million was committed over 3 years to increase direct care hours to an average of 3.36 hours per resident in long-term care (Government of BC, 2018d).

The Seniors Advocate reported that by 2018/19 73% of long-term care facilities had received more funding for direct care. The percentage of long-term care facilities meeting or exceeding the provincial guideline of 3.36 hours doubled from 15% in 2017/18 to 30% in 2018/19 (OSA, 2019b). No evaluations have been conducted yet on the impacts of the increased staffing levels on quality of care in long-term care facilities in BC. However, research generally suggests that quality of care is positively associated with staffing levels (e.g., Murphy, 2006; Boscart et al., 2018).

Expansion of Adult Day Services and Caregiver Respite

In 2018, an additional \$75 million was announced to expand access to adult day services and caregiver respite. These expansions are in the early stages, so it is not yet clear what impacts they will have beyond increasing access to these services. It is worth noting that a previous study from Fraser Health Authority found that attendance at adult day services reduced the risk of institutionalization, and had a dose-response effect (Kelly, Puurveen, & Gill, 2016).

Integrated Community-Based Programs for Older Adults with Higher Needs

The Integrated Community-Based Programs for Older Adults with Higher Needs demonstration projects include three streams: 1) social prescribing, 2) family and friend caregiver supports, and 3) therapeutic activation programs for seniors (Healthy Aging, 2019b). The demonstration projects build upon already existing program models in BC. For the social prescribing stream, projects are encouraged to build upon the CARES model that has been developed by Fraser Health Authority (Healthy Aging, 2019b). A pre- and post-test evaluation of this model on a sample of older adults (n=51) reported 61% of participants had improvements on their frailty scores post-test (Theou et al., 2017). For caregiver support programs, there are already examples of family and friend caregiver support programs operating in some communities across BC. A systematic review of caregiver interventions has found while there are some inconsistencies in the literature, generally there are positive impacts observed for individualized supports (positive effects on depression, burden, stress, and role strain) and caregiver support groups (positive effects on coping ability, knowledge, social support, and reductions of depression) (Lopez Hartmann, Wens, Verhoeven & Remmen, 2012). The therapeutic activation programs for seniors were inspired by mental health programs for seniors

experiencing isolation and depression originally available in the Interior and Island Health Authorities in the early 2000s that were eventually discontinued due to funding cuts (Raising the Profile Project, 2017). The integrated community-based programs for older adults with higher needs were launched in 2020 so no data is available yet on their impacts. A four-part evaluation of the programs is planned, including a summative evaluation, formative evaluation, health care utilization research, and program annual reporting (Healthy Aging, 2019c).

Moving Home Support Services In-house

The main rationale provided for moving home support provision back into the health authorities was to facilitate the provision of integrated team-based care (Shaw, 2019). Research has shown that team-based care is an important component of integrated care (see chapter 2), and this move could potentially help facilitate meeting this aim. It has also been suggested by the BC Government and Service Employees Union (2019) (who will absorb the affected home support workers) that this decision will increase job security and improve care for older adults. On the other hand, the decision to move home support services in-house was strongly opposed by the BCCPA (2019b) as a risky move that does not address core deficits within the home support sector and may complicate staff shortages if workers do not wish to change employers. No information has been released on whether this change is a part of a larger strategy to reform home support in BC.

Chapter 7.

Stakeholders' Perceptions of BC's Home and Community Care System

This chapter describes the findings from the BC stakeholder interviews that were conducted in 2014/15 and 2019. Themes from the 2014/15 interviews are summarized, including key issues with the home and community care system, root causes of these issues, contextual factors, and a vision for the home and community care system. The 2019 follow-up interviews are then described, including continued challenges with the home and community care system and the progress in making reforms.

7.1 2014/15 Interviews

A total of 9 interviews (7 with individuals and 2 with multiple people) were conducted with 12 community stakeholders (service providers, advocates, and older adults) from various regions throughout the province. An additional seven interviews were conducted with individuals with expertise in various home and community care policy areas (e.g., academics, policy researchers, retired health system management). The interviews were semi-structured, with a base set of questions focusing on perceptions of the home and community care system in BC, and also questions tailored to the individual's areas of expertise as appropriate. In the interviews with policy experts, questions were included about specific policy issues and current research on home and community care as appropriate. Below the perspectives of stakeholders on the value of home and community care services, issues with the home and community care system, root causes of current issues, and contextual factors are described.

7.1.1 The Value of Home and Community Care Services

Stakeholders believed that home and community care services are important to provide to older adults and that most older adults would prefer to be cared for in the community. Home and community care services were viewed as contributing to the quality of life of older adults, providing them with benefits such as peace of mind, social activities, and human interaction. Stakeholders also mentioned the benefits that

providing these services can have for caregivers, by easing their burden and providing them with respite. Providing a flexible and full continuum of services to meet the needs of older adults was considered essential for providing true person-centred care.

Stakeholders generally believed that providing services in the community such as home support and adult day services could help delay or prevent hospitalization or institutionalization. The issue of ALC was also discussed, and the current inappropriate use of hospital beds because there are no community services or long-term care placements available for these clients. The inappropriate use of acute care beds (and also some long-term care beds) was considered a bottleneck in the system, and one that can have long-term impacts as stays may last for months or even years. For example, stakeholders commented:

If you had the community supports, for one you might have prevented the hospitalization, or second you would have been able to go from hospital back to the community and avoided the long-term care institutionalization. (PE 1)

People who are in hospital, the ALC waiting for a placement, perhaps many of them could have gone home earlier if there was adequate supports put in place in their homes. Like again the housekeeping or some support and direction, that's sometimes what people need. It's not expensive services necessarily. (CS 7)

The purpose-built building on the North Shore can take up to 30 adult day clients a day, 5 days a week, so they have made a huge impact on the community with their service and provide a bridging to you know, maybe even sidestep institutionalization or at least delay it for a time if somebody can participate in an adult day service. (CS 2)

Some stakeholders provided examples based on experiences of family and clients of how home health services were able to prevent or delay individuals from being institutionalized.

Some stakeholders emphasized the value of integrated continuing care services for effective system planning. In order to plan for the capacity and resource requirements of specific services, it is essential to know what the other components of the health care system are providing. Having an integrated system also allows for funds to be shifted to different areas, and low-cost services to be substituted for high cost ones. The cost savings that could potentially be realized from providing services in the community were discussed by many stakeholders as an important reason to invest more in the home and community care system. Stakeholders stated that in order to decrease costs in other

sectors of the health care system (e.g., acute care) we need to have a strong home and community care system. One stakeholder explained that the cost of acute care would be about \$900 a day compared to \$180 for long-term care (and community care usually would be even less expensive). Another stakeholder noted that research had already been conducted in BC in the past that showed providing minimal levels of support in the home to people with low level needs does result in cost savings through decreased hospitalizations and long-term care facility use. Stakeholders commented:

What you would need to do is find money to put back into preventative care so you could have care for the full range of people. You'd probably get most of that money back if not more, by cost avoidance or through other, through hospitals or long-term care facilities and so on, but that's another whole topic in terms of how you actually realize that money. (PE 2)

I know that it would be helpful to cost those [community] services out. To figure out really how much it does cost to provide the complete package, because I would argue that it's still a lot less than you know what a hospital visit would cost or residential care. (CS 2)

You know my argument has been over and over again that you get the best bang for the buck if you would provide these services. It's not like you are going to save money, but you get the best return for the money that you do spend. (CS 3)

Another stakeholder commented that while they did not feel the evidence was there yet to definitively say it is cost-effective to provide care in the home over other settings, it definitely is cheaper in some areas as there are significant investments and operating costs required to construct and maintain hospitals and long-term care facilities. This stakeholder also mentioned that the cost-effectiveness of an intervention depends on who is eligible for the service, so it is important to target clients appropriately:

You don't ever want to say we're not going to build long-term care facilities because it's too expensive, but if you combine that with people's preference to be cared for in their own home you have a reason to try to make the home-based part of your system as strong as possible. I don't think we are ever going to get to the point where we can keep everybody at home. (PE 7)

7.1.2 Current Issues with the Home and Community Care System

While a comprehensive, properly integrated continuing care system was seen as having a number of potential benefits, the current system was viewed as being far from this ideal. Systemic issues identified by stakeholders included: access to services; gaps

in the continuum of care; increasing complexity of clients; challenges navigating the system; lack of supports for informal caregivers; reactive rather than proactive services and the need to provide person-centred care.

While a number of key issues were identified with the home and community care system in the interviews and will be elaborated upon in the sections below, it is important to note that some people report having very good care experiences with the system in BC. As one stakeholder observed:

I think a lot of these services when they work really well for a family and the individual, or when they get one of the really amazing case managers, things can work in a really seamless way, and families just rave about it. It's when families fall through the cracks – and I think that's a big challenge, just making sure that there aren't as many cracks to fall through and making sure that people don't need to hop around from silo to silo, that those services are wrapped around them in a meaningful way. (CS 4)

Some of the positive features of the system were identified in the interviews, including: the single point of entry; well trained and dedicated staff; public support for the health care system; public engagement and interest in improving the system; initiatives to improve care for high needs patients; the provision of some “non-medical” supports and adult day services; and a single assessment for community and long-term care. For example, stakeholders commented:

Some of the other strengths are that there is sort of one assessment for both community care and institutional care, and a lot of systems don't have that, that's a real strength. (PE 6)

I think the home support workers are pretty well trained. I think everyone has pretty good training. (PE 5)

I think the adult day program is fantastic and that's something that as I've said before we hear again and again from families that we work and that we serve. (CS 4)

However, in general stakeholders were critical of the current system and below key systemic issues identified by stakeholders are described. The issues identified by the stakeholders are reinforced by the literature and research described in chapter 6.

Access to Services

Stakeholders most frequently commented on the issue of access to services. Issues highlighted included declining access to home and community care services, unequal access for some communities, and services not being available at the right time and place. For example, stakeholders stated:

The access has gone down over the last – well for home support it's almost 20 years that the access has gone down. And so it's particularly been a reduction in the basic home support services and the residential care services. (PE 5)

I think there's a lot of barriers based on geographic location, as well, in whether they do or do not have adequate access. (PE 1)

...sometimes they say they offer the service but it's more in name than in actuality. (CS 3)

Home support services are notoriously inadequate. For instance, a friend of mine, her husband came out of the hospital on Friday. He was supposed to get a phone call on Saturday, he never did, and so finally she phoned on Monday and got things going. And then it was set up that they were going to, he was going to be getting a phone call 4 times a day to remind him to take his meds and that didn't happen. It was inconsistent across the board. (CS 7)

Almost every type of home and community care service was mentioned by at least one stakeholder as experiencing shortages. Stakeholders stated that older adults may experience long waitlists, delays in receiving services, or may not receive services due to shortages. Regional variations were perceived as existing between health authorities, and also between communities within the same health authority. Several stakeholders noted that rural and smaller communities were more likely to lack access to services.

Many stakeholders also perceived that services were becoming more difficult to access due to increasingly strict eligibility criteria, and that access to services had been better in the past (particularly for home support). For example, stakeholders observed:

And I think that access to these services as well has very strict criteria. If you don't meet the criteria, if you don't fit in, there's very little room for individual needs. It just makes it much more difficult to access services. (CS 7)

What has happened in BC over the past few years is they've raised the bars for whose eligible. So they get to say 'Oh well yes we give this service,'

but then you have to dig behind that to see whether or not that service has enough funds to provide services to people who need them. (PE 6)

Increasing eligibility requirements were viewed as a mechanism to ration increasingly scarce resources. A stakeholder commented that there is a culture of restriction within the BC MOH and health authorities, where the tendency is to try and restrict and prevent people from being eligible to access community services. Some stakeholders also suggested that the lack of advertising of services and the system being so difficult to navigate were ways of keeping demand for services down. It was mentioned that cuts to home and community care services have more negative impacts on low-income older adults as they are not be able to afford private services. A stakeholder offered this assessment of the care for older adults in BC:

I have a cartoon in my head. It's of an old guy in a wheelchair being left in front of the SPCA, because we know that the animals get better care than the seniors [laughter] you can put that at the end of your report... And what we do, I mean we have people go down and walk the dogs and clean up after the dogs and brush the dogs and there are volunteers who take care of these animals and we can't do this for our seniors. (CS 10)

Reasons suggested by stakeholders for difficulties accessing services included lack of funding, lack of case managers, and changing demographics and health care needs. Stakeholders suggested that more services should be made available, services should be more flexible and fit the needs of the individual, and hours should be extended/made more convenient.

Gaps in the Continuum of Care

Multiple stakeholders mentioned gaps in the continuum of services available. Housekeeping, meal preparation, transportation services, adult day services for lower needs clients, caregiver supports, early dementia care services, and alternative housing options were highlighted as services that are needed to help support people remain in the community. Participants commented that we do not yet have the full spectrum of home and community care services that are necessary to care for our older adult population:

I think actually we need more on our spectrum, right? So not just the importance of home care and home support, but sort of filling out – like right now if you think about a spectrum you've got a few dots, but we don't have the full set of services that we might need. (PE 7)

For our families the big gap that we tend to encounter is about services that go sort of beyond bed and body care, services that relate more to the psychosocial realm. In the 1980s home care really was designed to be more holistic and really focus on medical concerns, but also to be focused on concerns like helping individuals prepare meals, making sure that we're guarding against things like loneliness, and that that isn't what the home care system is reflective of now. And that can be a big challenge. (CS 4)

I think one of the biggest holes in service provision is IADL supports. (PE 1)

“Non-medical” home supports were the most commonly identified gap in the continuum. Meal preparation was discussed by several stakeholders as a current gap, as this service is generally not provided through the home support program and also is not provided through Better at Home. While there are some Meals on Wheels programs available, a couple stakeholders commented they did not provide quality food and were lacking the social component that is so valuable. For example, stakeholders commented:

Food, food, food. It's the most frequent request that I get, food preparation services. (CS 8)

We've heard from people that sometimes all they need help with is meals and meal preparation. It's hard for them to be, to get out shopping or to prepare the meals you know. So sometimes it's just a little bit of encouragement for people to eat because they aren't motivated or they have lost their appetite. (CS 2)

Stakeholders also commented a broader range of housing options need to be available, including more supportive housing and affordable housing for people who require a level of care below assisted living. Some stakeholders also suggested the need to redesign current long-term care home models, and instead consider models such as smaller group care homes. A stakeholder also remarked on the fact creative options needed to be explored to meet the needs of rural and remote communities:

If you live in rural and remote communities then you can't expect some of the services larger urban centres have available for a variety of legitimate reasons, I think. However, we have to be creative and try and ensure those rural and remote communities have ways of accessing those services, telehealth for example or outreach clinics or whatever creative ideas we can think of. (PE 4)

Critiques about gaps in the continuum were linked to the concern that without a full integrated continuum of care available, and without appropriate levels of community-based services, attempts to shift care to the community and delay/prevent hospitalizations and institutionalizations will not be successful.

Increasing Complexity of Clients

The increasing complexity of home and community care clients was mentioned in many interviews as a challenge for the system. Clients were viewed as increasingly complex with higher levels of care needs than in the past. Stakeholders noted the relationship between this issue and constraints imposed on the system due to scarce resources and the fiscal situation. The system's response to these constraints has been to decrease services for the lower needs people and concentrate available resources on higher needs clients. For example, a stakeholder commented:

From the experience I've had because I work mostly with people in the community, I would say any sort of long-term supports for people to stay at home is really challenging. You know there's good access to bathing assistance and medication if they can show need, but when people fall into the more grey area where the need might support their long-term wellbeing but isn't related to their extreme immediate need, they don't have access. (CS 4)

Stakeholders were concerned that not being able to access services might contribute to accelerations in the decline of lower needs clients and result in the need for more costly services in the future. A stakeholder commented on the flaws in the current approach:

The logic is we're looking at the higher care needs people because they have high care needs, we think they are an important group to care for, but we don't have enough money so we're chopping out all of the lower care needs people and hoping that families and community services will look after them...So, what have you done? You've set up a system where people have to hurry up to get sicker and sicker to get care. ... So what happens is you focus on the high care needs people – fine. What happens in 2 or 3 years when there is another bout of fiscal constraint? You've only got so much money. You end up slicing off the lower levels of what you were doing over and over again...And over time as you simply accept fiscal constraints, you end up with a system that's really not a system anymore for the vast majority of seniors. (PE 2)

The result of this approach is a system that only caters to the needs of higher needs people, essentially making it impossible to deliver preventative functions through home and community-based services. Concern was also expressed over the fact that the fundamental philosophy of some services seems to be changing, and services are providing different care than they were originally intended to. For example, adult day services originally had a health promotion focus and helped to promote and maintain the health of clients; now the focus is more on remediation and rehabilitation of clients.

Another concern with the increasing complexity of clients was that staff training and standards of care have not necessarily increased in correspondence with these changes. For example, a stakeholder remarked:

I think the people that are being given access to our services are changing...I mean we can modify, we can change, we can adjust – but we're not being given the support to do that. Our operation procedures are from 1984. (CS 11)

Another participant provided the example that in adult day services the needs of clients have been increasing, but the trend has been to hire more Licensed Practical Nurses rather than Registered Nurses. A similar comment was made about long-term care and the fact there have not been increases in staffing to correspond with the increasing complexity of clients. It was suggested that lack of funding was the reason staff education and standards of care have not increased in accordance with client needs.

Difficulties Navigating the System

Lack of awareness of available home and community care services among the public was mentioned in several interviews as a significant barrier to accessing them:

...the first thing is most of them don't even know that they exist. (CS 5)

Clients, informal caregivers and health professionals were all identified as experiencing difficulties with navigating the home and community care system. Getting into contact with the home and community care system was perceived as being difficult, especially given the roles websites and telephone systems play in imparting information and communication. Stakeholders commented:

I think people don't know what's available and all these services come at them. It's overwhelming. They don't know where to go with it. (CS 4)

I think it's incredibly difficult for older adults to navigate the system and understand who to call, when to call, what to ask for, what's the question to ask, and then who is the right person to ask them. (PE 1)

I think most of the people that actually effectively navigate the system fall into one of two categories: they've got family that can help or they're computer savvy. (CS 8)

Several stakeholders noted that even people working within the health care system (e.g., family physicians) are not always clear about how to navigate the home and community care system and who might be eligible for services.

It was noted that there is a generational difference between the current and future generations of older adults, and the internet is not the preferred method of communication for most older adults currently. Older adults may not have the know-how to successfully navigate websites or may not even have access to a computer. These challenges were noted as particularly being issues in rural areas. Some stakeholders observed that even experienced internet users may encounter difficulties navigating these websites. For example:

No it's not easy to navigate and you go to the website and it's like 'Oh my god.' And I search websites all day long so if I'm having problems I can't imagine what other people are doing. (CS 5)

Being able to strongly advocate for services, or having someone to advocate for you on your behalf was perceived as critical for navigating the system and accessing services:

That's something else that I would say about the accessibility of services, it can be context dependent. It can depend on how strong somebody's self-advocacy skills are. It can depend on what case manager you're calling and if it's a good day or whether you're using the rights words. It really can have a lot of...you can have different outcomes depending on the situation. (CS 4)

Several stakeholders believed case manager shortages and heavy workloads were contributing to the navigation difficulties experienced by clients. Examples were provided of informal caregivers not being able to get in contact with their case manager or case managers not having the time to do timely reassessments and follow-up. Case managers were viewed as a vital part of the home and community care system:

See I believe the kingpin for good community care is a very well trained, well informed case manager. Cause what is the case manager? The case manager is someone who really understands the breadth of needs of seniors and is very informed to the state of resources for those needs. (CS 3)

Strategies that were suggested to make navigating the home and community care system easier included: using direct telephone lines rather than automated systems; providing more help and follow-up from case managers/intake person; training volunteers as system navigators; ensuring services are local and community-centred;

providing written materials in places older adults frequent; providing peer-to-peer support; and collaborations between health and communication sectors (e.g., Emily Carr Health Lab). A common thread among many of these suggestions was the need for more human assistance when navigating the home and community care system.

Lack of Supports for Informal Caregivers

Lack of caregiver supports was considered a major weakness of the home and community care system and was mentioned by almost all stakeholders. Informal caregivers may face psychosocial, physical, financial, and employment challenges as a result of caregiving responsibilities. Informal caregivers were viewed as a very important source of support for clients of the home and community care system. Stakeholders commented:

Well nobody is paying attention at all to the caregivers. (CS 3)

There isn't any support system for informal caregivers. They are doing a lot of the work. They need respite, they need just support you know in a number of different ways. And that's just not part of the system at all. (PE 5)

Stakeholders suggested that the needs of informal caregivers should be fully assessed, services should be targeted towards informal caregivers, and informal caregivers should have more input into the care plans. For example, a stakeholder observed:

The caregivers are not adequately recognized within the system either, as potentially requiring some help themselves or as sort of partners in care for the care recipient. (PE 6)

Some stakeholders highlighted that the strength of caregiver supports seems to vary based on a number of factors, including community, disease or health condition of care recipient, and ethnocultural and linguistic background. For example, a stakeholder who had carried out a focus groups with informal caregivers stated that in Burnaby there seemed to be a well-coordinated support system, while informal caregivers from the North Shore reported less positive experiences. Another stakeholder pointed out that for certain conditions (e.g., Alzheimer's disease) there are a lot of targeted supports for informal caregivers, while for other conditions (e.g., multiple complex conditions) there are not. Some stakeholders also expressed concern that some informal caregivers are not aware of all of the options for care and support available to them.

Two different categories of services were commonly mentioned as being inadequate for supporting informal caregivers. The first were home and community care services that can provide respite to informal caregivers (i.e., adult day services, home support, respite beds), and the second were targeted supports for caregivers (e.g., education, support groups, financial assistance, etc.). Adult day services in particular were highlighted by some stakeholders as being a key form of respite for informal caregivers. A stakeholder commented:

So the adult day program is one form of respite and day programs can be an absolute lifeline for so many caregivers. They're one of the things that I hear the most favourable things about over and over again, the adult day programs. It's not unusual that I talk to caregivers who say you know that the respite through the adult day program is something that has just absolutely saved them. (CS 4)

Stakeholders also remarked that respite may mean different things to different informal caregivers. One stakeholder commented:

I think respite in itself is an area that we need to look at creatively and create a system that is much more responsive to family members. We need to look at the system where we may want to actually allocate some funding to family members, and I know Alberta looked at this where they provided them a lump sum and said we know you need respite, you're the best people to say what type of respite, here's some funding, you can go out and purchase some services if you wish with this funding. So we have to look at it differently and be much more accommodating and flexible in how those respite services are offered to family caregivers. (PE 4)

Another stakeholder commented that another way to view respite is to consider it not a service itself, but rather an outcome of a service.

Supports for informal caregivers was perceived as an area where community organizations and non-profits could potentially take a lead role in providing services. However, it was also noted that currently supports for informal caregivers may be offered by the health authorities and also multiple community and non-profit organizations, and this can contribute to fragmentation as there is no umbrella organization to oversee the coordination of all of these services.

Reactive Rather than Proactive Services

In several interviews, stakeholders observed that services in the home and community care system are reactive rather than proactive and that this needs to change.

The fact that when clients usually get into the home and community care system they are already in crisis was pointed out by several stakeholders. For example:

People that call are already in crisis, that's what we find, so each day that goes by you know things can go south...you know they, they're falling, they're mixing up medications possibly. They need to organize through the pharmacist for the blister packs. They're in pain, they need some pain management maybe. Or incontinent, so they need some support around that, toileting, systems in place so they can get up and down in bed easily and hang on to bars in their home, have a commode maybe right there by the bed if it's necessary, have access and be instructed on wearing depends...So they're in crisis, probably needed help a month ago but they're finally calling you now. (CS 2)

Several stakeholders believed the system needs to be more proactive when dealing with frail older adults and wished to see a system that was more focused on prevention. Some stakeholders believed this could potentially save the system money by addressing certain health issues before they happened:

I think that we have a lot of services that are available, but I think that we wait until people are in dire need...a lot of emergencies I think could—would be prevented, and a lot of these services could be used in a preventive way. (CS 4)

So I would like to see a best practice coming from a wellness and health promotion philosophy, rather than the way it is now, which is putting out fires. (CS 7)

Some stakeholders also noted that there is a population of older adults who are frail but currently too well to qualify for services. These seniors were viewed as falling into a gray area within the home and community care system:

Yeah, I would like to see more preventative work so we don't get to the crisis that we're in and scramble to remediate the crisis. And I think it would save an awful lot of money if we focus on prevention rather than intervention...And it's the seniors that are falling through the gaps—they're, they're too well to come to our services, to access our services, but not well enough to access the community services. So they're right in between. (CS 9)

Need to Provide Person-Centred Care

Stakeholders commented on the need to provide flexible and person-centred services to older adults and informal caregivers. Services were considered by many to

be inflexible and not meeting the needs of individuals, despite the rhetoric around person-centred care from the health care system. In particular, there was concern that strict rules and regulations and the emphasis on system efficiency was compromising the ability of the system to deliver person-centred care. Stakeholders commented:

And I think that comes back to this strict criteria, as I said. Individual needs – it's very hard to meet individual needs when you have to stick to the letter of the law so to speak. (CS 7)

I think if the system would focus on the person instead of the needs of the system – and that's exactly what I see in every little place I volunteer and work in right now, that the system, you have to adjust to fit the system, the system isn't going to fit you. (CS 12)

Stakeholders also expressed concern about the growing impersonal nature of care, due to both the increased use of technology as well as imperatives to increase efficiencies. For example, a stakeholder stated:

I'm a strong believer with seniors we need more high touch, low tech in service. (CS 3)

The theme of person-centred care overlapped with many of the issues discussed in the previous sections. Stakeholders believed the home and community care system could become more person-centred by for example offering a comprehensive continuum of care, providing informal caregivers with flexible respite options, and being designed so anyone can easily navigate through it. A stakeholder commented:

So if we want to be patient-centred then we need to be thinking about the system as a system and not as individual pieces. (PE 7)

It was noted by one stakeholder that providing person-centred care does not necessarily result in the use of more health care resources, as for example with palliative care patients often actually desire less intensive interventions.

7.1.3 Root Cause: Lack of Funding

Throughout the interviews it became apparent that there were two root causes that contributed to many of the issues identified with the home and community care system: lack of funding and lack of integration. Lack of funding was identified as a root cause of problems in almost all of the interviews:

I think the main problem is funding. I mean that's the crux of everything...How can you do more with less? And it just doesn't work, it never has. So yeah, it's a big problem. (CS 9)

I think they're going to have to put more money in. (CS 8)

Weaknesses, the biggest ones: lack of funding... (PE 1)

So you know you could kind of go on where the system is falling short, but I think fundamentally that just relates to does it have enough funding? And is it properly integrated with the rest of the health care system? You could probably put everything else underneath those broad categories. (PE 7)

Lack of funding was viewed as the cause of shortages of services and service gaps. Several stakeholders noted the trend has been to cut home and community care services and funding, while at the same time increasing pressures on the system for care. Stakeholders commented that if the government wished to achieve their goals for the home and community care system and increase care in the community, more funding and resources are required. One stakeholder reflecting on experiences from the past commented:

Back in the 80s or 90s when I think it was the NDP government was in place and they began this 'Closer to home' they called it, where they were going to move patients out of acute care and into the home. Well that was a wonderful idea, it was embraced by those of us who were working in home and community care, but it, the funding never came with the idea. The services were taken out of the hospital and put in the home but there was not adequate funding to sustain that and not adequate funding to improve the services in the community. (CS 7)

Some stakeholders also commented on the tendency of the government to provide short-term funding for pilot projects and noted that in order for real systemic change to occur there needs to be an initial injection of resources into the home and community care system and then funding needs to be sustained at an adequate level.

Stakeholders acknowledged the difficulties related to the current economic climate and that fiscal constraints do exist for the system. However, most did not believe that this was an adequate justification to restrict or not provide home and community care services. Several stakeholders were critical of arguments that additional money could not be made available to improve the home and community care system:

It really is baloney, you know, and the public has bought it. And they always feel, you know it's a shell game, because I was talking to a friend just

yesterday because you want to win electorally, you turn around and say we've cut back a lot, our civil service is now lean, it's much less, but they've contracted it all out, the same work has to get done. (CS 3)

All of this talk about the national financial crisis is disingenuous and people may have their own motives for doing that. The point is, if you look at the national picture – health care as a percentage of GDP – you don't really have a problem. I mean, you may think it's too big, and then that's your view, but in terms of runaway health care costs there's no such thing. (PE 2)

It was explained by several stakeholders that reduction of tax rates at the federal and provincial levels have taken significant amounts of money out of the health care system, so in a way these financial shortages are the governments' own making. While health care may appear to take up an increasingly large portion of government budgets, part of the reason for this is that the total pot of government revenue has been decreasing:

I think the fiscal situation, the reduction in taxes at the beginning of the 2001-2002 when they took a few billion dollars out of the tax system, and the lack of revenues in taking it means that they have very little place to move and we're really limited because of that. And I do think we need to be reducing the rate of growth in health care, to cut spending, but it will only happen when we have a strong community system so that the hospitals are not so heavily used on emergency basis as they are now. (PE 5)

Part of the reason is that they, that they cut taxes. And so they basically lowered the whole pot but they couldn't lower the health care because that was kind of a hard thing to reduce health care costs. (PE 2)

A few stakeholders believed overall levels of health care funding were likely adequate and perceived the funding issue as primarily being related to the division of funds amongst different health care services, with not enough of the funding being invested in home and community care. For example, a stakeholder stated:

I do also believe we probably invest enough money into health care and probably a lot of people won't agree with me on that. I think we need to look at realigning the funding, in the sense of how it's distributed within the health care system, rather than continue to invest. We can't continue to invest at the same extent we do at the moment. And I believe also we've got to look at ways of stopping some services, you know we are very good in the health care system in providing services, providing services, and adding onto those services, and creating new services, but rarely do we look and say well do we need this service, can we, should we stop doing this service? Because it's not necessarily high priority or it's not efficient, but you know, we all have difficulty – and I'll include myself – in that process of saying no, we shouldn't deliver that anymore and because it's not necessary, it's not viable. We really need to look internally and say are we

using the money that currently goes into health care in the best way possible – then determine whether we have enough money or need more investment. (PE 4)

Another stakeholder commented on the fact that in comparison to other OECD countries, the amount Canada spends publicly on health care (70%) versus privately (30%) is actually lower than the norm, and the division between public and private payments is very unusual compared to international standards:

You know our public portion of the total is low by OECD standards, and it's also bizarre by OECD standards because it's almost 100% public for physician or hospital services and only 30 or 40% for public long-term care, and maybe 40 and 50% for public pharmaceuticals, and they scratch their heads, like what? How did you end up with a system like that? (PE 7)

A few stakeholders also raised the question about whether individuals should bear increased responsibility for paying for home and community care services. For example:

You know this points to a big, big question, of how much should the health authority be responsible for you know – the taxpayer's dollars. Do families of seniors have any responsibility? (CS 5)

Whether there is a willingness among government and the public to pay more money to improve the home and community care system was also discussed by several stakeholders, with some of the opinion people would be willing to pay more and others that they would not. One commented on this debate:

I actually think that we need to enter some sort of public discussion about what we as a society expect, because I think you know ultimately these are normative decisions, they're not positive decisions, right? There's not any analysis in the world that would tell you now you have to do x in the home and community care sector. At some point it's going to come down to, well how much are you willing to invest? And if you told me that then maybe we could do lots of research and figure out how you're going to get the biggest bang for your buck for that investment. But the normative decision is still there about how much you're willing to invest, right? (PE 7)

7.1.4 Root Cause: Lack of Integration of Services

Lack of Integration of Home and Community Care Services

The second root cause that emerged for issues within the home and community care system was lack of integration. The general consensus among stakeholders was

that home and community care services were fragmented and poorly integrated with each other, and also with other sectors of the health care system:

Even though there's one telephone number to call, the system is still not integrated. (CS 6)

So the problem is, how can I put it? There is no continuum of care. There is no...it's a patchwork system. (CS 3)

...but basically you know the problem is everyone is siloed. (CS 5)

I believe that BC is worse than a lot of other health care jurisdictions or health authorities or health regions. I think BC is very, very poor at integrating their sectors. They don't talk to each other and it is very siloed. (PE 1)

Stakeholders provided examples of patients being discharged from hospital without their family doctor being notified or supports put in place. Stakeholders also provided examples of patients who were unable to be discharged from hospital because community/long-term care placements were unavailable. These examples illustrated the lack of coordination and communication between the acute, primary, and home and community care sectors:

Well this is really what the whole problem is, I mean the health and social care system has to be all in one. So there's a big gap between hospital care and primary care, I just can't believe how big that gap is. And I spoke to well over 30 different seniors groups a couple of years ago and one of the things they said is you know the primary care doctor doesn't even know when their own patient is being discharged from hospital. (CS 3)

They don't talk to each other, they really don't. The second floor of the hospital is full of people who can't be placed anywhere. (CS 10)

My biggest frustration with regionalization as it has rolled out the past 15 years or more, is I understand to some degree why the acute care to primary physician care integration hasn't really happened, cause primary care doctors are not a part of the health authority and there's not really an obvious mechanism for them working together. Okay, it's not ideal from a patient perspective but I understand how that might happen. I really, really, don't understand the lack of integration between the acute care sector and the home and community care-based services, because they are all owned by the health authority. They have full responsibility for all of those services, so why is it so hard to move things from acute into the community, why does the acute care sector still have so much power within the health care system? (PE 7)

The lack of integration of home and community care services with the rest of the health care system was perceived as compromising the potential gains that can be achieved by investing in home and community care:

They like all of the provinces across the country have caught that home care, community care, that's where the cost savings are. But the problem is they're not integrating it. And as long as they don't integrate it, it's not going to be cost saving. (PE 6)

A stakeholder commented that without integrated funding it makes it difficult to shift resources away from the acute care sector and towards the community in order to provide the resources and funding required for the goal of increased care in the community. At the same time, when the home and community care system is able to relieve some of the pressure on the acute care sector and decrease unnecessary use, without integrated funding these savings will not go back into the home and community care sector.

Difficulties sharing information across the health care system and the fact that there is no single electronic health record was mentioned by several stakeholders. The seamless transfer of information and development of a single electronic health record were viewed as being key to the successful integration of services:

So I mean when the computer systems aren't talking to each other how can you possibly share a care plan or medical information? You know, obviously there are confidentiality concerns and things like that, but a lot of people out there wrongly assume that if they were to walk into a clinic or see some other health professional in the system that that person would have access to you know their information, personal information. (CS 2)

The integration of medical records probably is one of the key factors that has to take place for integration to happen, so that all elements of the health care system wherever they happen to be or what services they are providing, have access to those records. And I think, the majority – not everybody – but the majority of clients would be delighted if that happened because I know they're tired of having to respond to the same questions to different groups of the health care system time and time again. Whereas if you have the integrated system that recorded the visits to the various components of the health care system, if each had access to it, it would save so much time and bother not only for the clients and families, but also for the service providers as well. (PE 4)

A few stakeholders also commented on how different assessments may be used by different clinicians or regions. This can lead to unnecessary repetition of assessments for the client. A stakeholder also commented that the scope of assessments is not broad enough and do not include the input of enough providers (e.g., CHWs).

Several stakeholders remarked on the progress that is being made on integrating health care services in BC. Examples were provided of efforts to improve the integration of primary care such as the integrated primary and community care and aIPCC initiatives, establishing the Divisions of Family Practice, and offering billing incentives to general practitioners for participation in care conferences. It was noted that all of the health authorities are currently engaging in work to improve the integration of services, though progress differs in each. One stakeholder provided the caveat that integration means different things to different people, and so what is labelled as integration may not always be true integration:

...but everybody saw integration kind of in a different way which fit with what they were doing and what they believed in. So some people thought integration is better integration in the hospital stuff, and in BC there's better integration between primary care and home care, and they think that's integration, so you have to be a little careful to figure out what integration people are talking about. It's the flavour of the day. (PE 2)

Lack of integration of home support

Stakeholders specifically highlighted home support services and other “non-medical” supports as being poorly integrated with the health care system. Stakeholders believed that both medical (personal care) and “non-medical” home support services (e.g., meal preparation, housekeeping, laundry, etc.) provided an important role in supporting individuals to remain in their homes:

I really think there are a lot of people with chronic conditions you know who'd manage really effectively in their own home if they had a minimum of home support services, but that is paid for by the government. (CS 3)

I feel that there's a huge importance of non-medical home support services and that's often what can help individuals stay at home longer, which is often the ultimate aim not only for the person whose living with – whether it be dementia or another chronic illness –as well as the caregiver. They often want to keep the other person home as long as they are able to do – not in all cases – so by providing those non-medical services that can often be a way to meet that aim for everybody. (CS 4)

A couple stakeholders stated that the language currently used by government to describe “medical home supports” verse “non-medical home supports” creates a false divide between the services, as both are essential to the health and wellbeing of older adults:

To separate those things and say the health authority deals with things that are medical and the non-medical supports are not in their purview really I think adds to the division of segmentation of these services where as I'm sure you know, there's a multitude of things that impact wellness and they're not all about whether someone comes and changes your dressing, right? (PE 3)

Several stakeholders noted that home support services had been much more comprehensive in the past. In particular, the significant changes and cuts made in the 1990s and 2000s, including the tightening of eligibility requirements and the pulling back of certain services (e.g., housekeeping) were mentioned:

And I just point out that back in the 70s when I worked in home care, we had home support services and home support workers did housekeeping. And it was seen as a very advanced type of service across the country, we were at the top of the heap so to speak for the services that we gave. And then they took away the housekeeping and everything went downhill after that and I'm sure there's research out there about how the service with housekeeping is better at keeping people out of the hospital. (CS 7)

Stakeholders commented on how these changes had impacted the quality of the services. Issues related to service continuity, scheduling, reliability, and lack of personal relationships were also mentioned. Some stakeholders expressed the view that the human nature of the service had been lost:

So that was already, once things were outsourced and the number of minutes were counted per visit, I think it just, I think a little bit of it became like an assembly line of the home support workers. (CS 6)

There's no human contact and I think that's extremely important for older adults – for anyone – but it's older adults who have no other supports. (CS 9)

Stakeholders also observed that CHWs are not normally a part of health care teams, even though they are often the first and most frequent point of contact for the frail elderly. These stakeholders wanted there to be more recognition of the role of the CHW and home support services. For example, they commented:

So it's like, integrating the community health workers as part of the primary care team would seem like such a reasonable – when you think community health workers, those home support workers, they're like the canary in the coalmine. They're going to see something before anybody else does. (PE 7)

I mean they would say that okay there's Meals on Wheels or Better Meals, but the problem with that also is there isn't any community overseeing how this person is doing over time. Because they're not, they're not ill enough and acute enough. And so much of the benefits in terms of quality of life and savings would be dealing with those things before it becomes an emergency visit, hospitalization, and then they have to put in those services. (CS 6)

While overall there was a general consensus among stakeholders that “non-medical” home supports were valuable for older adults, there was not a consensus on who should provide them. Some felt strongly that “non-medical” home support services are important services that contribute to the overall health and wellness of clients and therefore should be considered health services and provided by the health authorities. Having the health authorities provide these services was also viewed as a way of ensuring they are integrated with the health care system. However, other stakeholders mentioned that from the health authority perspective these services are expensive, and therefore given budget considerations it is justifiable for the health authorities to not provide them directly. Providing “non-medical” home supports through non-profit or other organizations was viewed as a viable alternative. Stakeholders expressed their opinions on this debate:

...if the services were strictly provided by the health authority then the expense would be so high for the government, and you know the system, that we wouldn't be able to serve enough people. Providing the services by non-profits or non-professional – if we can call it that – organizations allows us to serve more people, but we run the risk that the people providing those services are not well trained. So, it's kind of a catch-22 almost. (CS 8)

And once they made the division between non-medical and medical it was a disaster. Who is supposed to pick up the pieces for non-medical? The health department will only do the medical part...well you can't separate a human being into two pieces like non-medical part and a medical part. (CS 3)

You know, some jurisdictions are better at uniting the health and social service aspect of things and have some social services that focus for older adults. I don't think that we have that social service focus very much. When we think about social services I think we're thinking about welfare for poorer families and maybe some things for kids, but not about shoveling snow for older people...We're going to have more and more older people in our society who are living alone and actually don't have any blood relatives anywhere near them who even could potentially provide them services, much less permanently do so. So it is going to become I actually think more and more a societal problem. Does it need to be done formally through the health care system? I don't know – probably not. Does the health care system end up paying if you don't provide those services somehow or other? Probably. (PE 7)

Examples of Promising Integration Models and Practices

Stakeholders were asked to provide examples of what they thought were best practices for the integration of services for older adults. Examples from BC included:

- The Mid-Main and Reach Community Health Centres in Vancouver Coastal Health were both provided as examples of community health centres that operate as one-stop shops and are able to provide for a variety of health care needs (e.g., family doctor, nurse, dentists, etc.).
- The work being done by Northern Health to develop primary care homes and transform and wrap services around primary care was also mentioned by a few participants. Primary care initiatives specifically for the frail elderly have been piloted in several cities (Prince George, Fort St. John, and Prince Rupert) where team based primary care was implemented and a single electronic record used by the team for their clients.
- The Home Vive model provides care in the home for the frail elderly through primary care teams that provide home visits.
- In the Interior Health and Island Health there have been pilot projects where CHWs provide team-based care.
- Currently there is a joint project between the University of Northern BC and Northern Health to investigate residents in long-term care who may potentially be able to transition back into the community, and then if feasible to pilot a project to return these residents back to the community.
- An IADL pilot project was implemented through a partnership between the University of Northern BC, Northern Health, the United Way and various local organizations. The project aimed to provide non-medical home supports in Prince George, Fort St. John and Burns Lake to older adults to help them to remain in their homes for as long as possible.

The Hollander and Prince Model discussed in chapter 2 was brought up by a stakeholder as a potential integrated model upon which BC's home and community care system could be based. This model shares many components with, and was influenced by, the continuing care system that was in place in BC in the 1980's and early 1990's. A few other stakeholders believed the system that BC had in place in the 1980's and early 1990's (as described in section 6.2.1) actually was quite good and more integrated than the one that we have today.

Stakeholders also provided examples of innovations from other provinces as well as other countries, including: enhanced adult day services (Alberta and the USA), long-term care insurance (Japan), reablement (Australia), PRISMA (Québec), the Extramural Hospital program (New Brunswick), and care coordination (Ontario). The care offered in Denmark was highlighted in several interviews. Features of Denmark's system that were highlighted were the comprehensive continuum of services, the philosophy of independence, and building capacity in clients to be proactive and in control. A stakeholder remarked:

Well whenever I think about an ideal I think about Denmark. I think about their focus on supporting people to be as healthy as possible and to be as independent as possible. The extent to which they have done a lot of things around housing, and around multidisciplinary team centres that are available to seniors to act as an alternative to acute care and long-term care. That they haven't cut back on the minimal levels of services and services for more moderate people. They do that proactive asking people if they need services. And they provide the services 24/7. All of those pieces seem to me to be really important. (PE 5)

7.1.5 Roles of the Non-Profit and Voluntary and Private For-Profit Sectors

Role of the Non-Profit/Voluntary Sector

Several stakeholders also reflected upon the relationship between the home and community care sector and services offered through the non-profit/voluntary sector. The non-profit/voluntary sector was viewed by several stakeholders as being able to provide essential supports needed by older adults and informal caregivers, and to fill in some of the gaps in the home and community care system. For example:

I think voluntary organizations play a huge role in making sure that not only seniors are able to access the services that are formally available through the government, but filling the gap in terms of the psychosocial. So Better at Home for example is really an example of the voluntary sector coordinating and stepping up, with, with some dollars from government, but to fill that need. There's pretty much not one area where voluntary organizations aren't at the forefront, in terms of seniors and seniors care, whether that be peer counselling or whether that be helping seniors navigate the system. (CS 8)

However, some stakeholders also expressed concern about what they saw as a trend of downloading services from the public sector to the non-profit/voluntary sector:

I think there has been more and more reliance on the voluntary sector to pick up some of the work that's being downloaded from the public care system. (CS 2)

Some stakeholders also raised worries about the sustainability of volunteer programs. It was noted that the current force of volunteers is aging, and there tends to be high turnover with the new generation of volunteers.

Stakeholders generally perceived there were good working relationships between non-profit/voluntary organizations and the health care system, though it was noted that these relationships were often informal and context dependent:

In my experience it's dependent on the individual relationships, so perhaps case manager A has a really good relationship with person B who works in a certain community organization and trust gets built up between them and that can be a really positive working relationship. (CS 4)

It was also noted by a stakeholder that developing trust between non-profits and the health authorities takes time, and lack of trust can be a barrier to co-operation.

Some of the comments that were made about the non-profit/voluntary sector were mentioned specifically in relation to the new Better at Home Program. Stakeholders believed the supports Better at Home is providing are beneficial to older adults. Better at Home was perceived as filling in some of the service gaps in the home and community care system. However, a couple stakeholders expressed concern about the lack of integration of the services with the health care system. It was also noted that there are currently waitlists for services in some communities.

Role of the Private For-Profit Sector

Several stakeholders also discussed the implications of the involvement of the private for-profit sector in the home and community care system. Some expressed concern over the practice of contracting out services to private agencies. These stakeholders believed this results in lower quality care being provided and increased costs. For example:

I think eventually all of this outsourcing is going to break down, and you know because everything is running on a business model. You know it's, one of my friends used to always say 'There's too many MBAs in this world.' And I think you can't run a non-profit health system on a business model. (CS 6)

A few stakeholders believed the private for-profit sector is able to provide good care or provide services to fill in gaps in the home and community care system. While they all supported the public health care system, these stakeholders believed that there should be more co-operation and integration between the public and private systems, and clients should be made aware of all the options available to them. A stakeholder stated:

I think there needs to be opportunities for people, if they desire, to be able to purchase services more readily. I think we always need to be able to support and provide services to those clients who can't afford health care services, no question about that, but in BC and in Canada we have—I believe that all health care services should be free to some extent, but they're not free, we all contribute to them in one way or another. But I do believe that we need to look at ways of creating a more stronger private sector, so that when people have the opportunity to purchase it's available to them and they can decide how they wish to spend their money if they have the money to spend. (PE 4)

7.1.6 Contextual Factors Influencing Home and Community Care Reform

Integration Barriers and Facilitators

In the policy expert interviews, stakeholders were asked about what they perceived as current barriers and facilitators to successful health care integration in BC. Most of the barriers discussed related to the political climate and government at the time, which are discussed in more detail in the next section. Barriers were also identified that related to the provincial vision of integration. Stakeholders generally perceived the integration of primary and community care as a positive step that may result in improved care for clients; however, they also noted flaws in the current approach. Several stakeholders commented on how current integrated primary and community care initiatives seem to be a continuation of primary care reforms rather than truly focused on integration. Some believed that the current reforms were too strongly focused on physicians and the community aspects of these reforms were being neglected. For example, stakeholders stated:

And unfortunately I think there's still more lip service to community care...like it just seems like divisions of family practice got \$3,000 per practicing physician per year to go into a pot to help them work together and community care gets to do everything they do within their existing budgets, right? Like it's a very, it seems from the outside looking in like it's quite an uneven playing field. Somebody – one group gets to innovative

with new money and the other group only with the constraints they are already facing. (PE 7)

Integration of home care and primary care could be a very nice component of a bigger system. You know it would provide good care to the high care needs people, but it really should be a component of a bigger system, not a substitute for a bigger system. (PE 2)

Some stakeholders were skeptical about whether efforts to integrate primary and community care would result in real system change. A stakeholder noted that many of the integration initiatives have been pilot projects or only designed to serve small populations. There was also concern expressed that while current integration efforts may have benefits for higher needs clients, lower needs clients are still left outside of the system.

Stakeholders identified barriers to integration related to the structure of the health care and home and community care systems: siloes and lack of coordination and cooperation between sectors; information systems do not communicate across the whole system; challenges with change management; the dominance of the acute care and primary care sectors over community care; and the culture of the health care system (curative culture and culture of restriction).

A key facilitator that was identified by several stakeholders as necessary for integration, but not viewed as being in place in BC, was mechanisms to facilitate the evaluation and dissemination of new initiatives. Often new initiatives that are introduced are not evaluated and are simply assumed to be efficient or cost-effective. Stakeholders emphasized it is important to build evaluations into pilot projects or reforms from the beginning. Some stakeholders questioned the current capacity of the system to effectively disseminate best practices and successful models. In BC (and Canada as whole) there are many pilot projects and demonstration projects, but few translate into permanent practices or system change. It was also maintained that there is the tendency to reinvent the wheel among the health authorities, and there needs to be closer collaboration so that successful initiatives can be shared and built upon. A stakeholder remarked on the need for health care systems in Canada to become learning systems:

I actually think that the biggest thing that we could take from all of this is just the culture of experimentation and learning and modification, you know. And I try and tell people, particularly when I'm doing knowledge translation things, it's not like we're going to get to a point and say right, that's a great policy and we're done now and I can now ignore home and community care for the next 20 years. Like that's not reality and things are changing, and

you know we could set up a really great system and what's going to happen is there is going to be all sorts of technological innovations and smart homes and all of the other—it's going to change again, right? It's going to make things possible that we can't do now. So, I do really think it's more openness, learning, experimentation. It's more of becoming a learning system rather than becoming a set of policies that we might adopt from somewhere else. (PE 7)

Stakeholders identified facilitators for integration that are present in BC less frequently than the barriers. However, it was observed by some that progress was being made towards integration and there is a general commitment by government and health authorities to integration. Stakeholder noted that currently the health authorities are working on some of the key aspects of integrated systems (e.g., electronic health records, standardized assessment tools). The establishment of the Divisions of Family Practice and other primary care initiatives were also viewed as positive steps that facilitate the provision of more team-based care. It was also predicted that there will be a strong lobby for better health care in BC in the future as the baby boomers age.

Conduciveness of Political Climate for Reforms

In the policy expert interviews, stakeholders were also asked about the political climate at the time and whether they felt it was conducive to change in the home and community care system and an integrated continuing care system in BC. Stakeholders varied in their level of belief in the Provincial Government's commitment to integration and improving home and community care services. Some stakeholders were critical of the leadership by the Provincial Government at the time:

So I think there really has been a lack of leadership in government about interdisciplinary care, integration, and consistent support for it, for anyone other than doctors. (PE 5)

Well to speak frankly I think that we currently have a government whose perspective on health and social and education services is really one that seems dominantly that they are a weight on the economy and that they are you know sucking too much of the dollars or the resources in the economy. I mean they're not viewed as an asset, but they're viewed as a drain on the economy. (PE 3)

Other stakeholders were less critical about the intentions of the government and felt that some progress was being made. However, some of these stakeholders were unsure

whether the current strategy and focus on integrated primary and community care would produce results for older adults:

The current policy world is conducive in the sense that it's more open than it has been, but I still think it's got a bit of a way to go. (PE 7)

I actually think the policy climate in BC is conducive but what's happening is they're going with the wrong model. (PE 2)

Stakeholders acknowledged the political challenges and constraints that exist when trying to reform the health care system, including the difficulties presented by the fiscal situation. Some stakeholders suggested BC needs to increase the involvement of the public in making reforms and shift public perceptions. Stakeholders commented:

I think the biggest problem, definitely from the government's perspective, I think the biggest challenge is public opinion, public knowledge. And I don't—I think where we don't necessarily do a good job is informing or involving the public in what is taking place, why this is taking place, the benefits of what is taking place. So what you have is public opinion, and all politicians have to be somewhat sensitive to public opinion. And I think until we really, truly get the public opinion to change – because everyone believes the acute care hospital is the be all and end all of the health care system. And the acute care hospital is an important element but it's only an element of a health care system. And so we have to do a lot of education around informing and involving the public at large around health care and the appropriate methods and best practices for delivering health care. (PE 4)

People overwhelmingly you know talked about the need for a public health care, the importance of it, to be able to do the same thing, to try and shift the perspective of the province to one that's not seeing health and education and social services as a drain, but actually as a huge you know resource and benefit to the province. So I think that's the biggest, the biggest issue that we're facing, that view. (PE 3)

The issue of timing of reforms was also mentioned, as politicians are sensitive to election cycles and may not want to commit to an action or policy if the gains will take a long time to emerge. It was asserted that it is often easier to ask the federal government for more money or do pilot projects rather than attempt large scale health system change. Finally, the fact was raised by a stakeholder that even when there is strong evidence transmitted to policy-makers, this still may not be enough to prompt action:

Just having evidence alone is not enough. To have trusted and respected messengers that deliver the message to the decision-makers in a way that's kind of non-threatening and informative to them, and then there's a good chance that something will happen. (PE 2)

Stakeholders also discussed the competing interests and influences that exist within society and government in regards to the health care system and the allocation of resources. Perspectives of generational equity were discussed by a stakeholder, and it was observed that some policy-makers and members of the public believe older adults are using up too much of society's resources at the expense of younger generations:

Which to me is a false dichotomy anyways, that you have to make a choice about the priorities of society as a whole. And I don't believe that there aren't the resources to you know give a good quality of life to everyone. It's a question of making decisions about what we think are, what's important. (PE 3)

The influence of neoliberal philosophies and privatization were also discussed by a stakeholder. This stakeholder expressed concern about the power of the privatization lobby and the tendency of the government to suggest privatization as a solution to health care problems, rather than invest money in or look for solutions for the public system:

So because they don't see home care as part of medicine, they're, they're privatizing that more and more. And so despite the rhetoric about home care where that's cheaper, what they're really saying is it's cheaper, and it's going to be even cheaper still to government because we're going to privatize it. (PE 6)

Funding Models to Support Home and Community Care

When the policy experts were asked about funding models for the home and community care system, all stakeholders felt the system should be publicly funded, and services should be available to those who need them. Most felt strongly that services should be publicly funded through tax revenues like other health care services, for both health equity and integration reasons. For example, a stakeholder remarked:

I think the right way to fund home and community care services is the way we fund our health care system. That's tax-based funding. I'm very, very leery of people who start trying to say that we need somehow a different set of funding for this, and sometimes that's I think well-meaning in the sense of what people are saying is maybe we need Social Health Insurance for this, which would be everybody pays in some kind of tax to a dedicated fund that can be used in long-term care. Okay, that's fine but then does that help you with integration of those services into the rest of the publicly funded health care system? (PE 7)

On the issue of co-payments stakeholders had various opinions. For example:

I really think that these things need to be available to people and there shouldn't be these, increasing in the direction of more and more means tests and more and more co-pays. Yeah, I just think they need to be available to people. I think it's a right to have those kinds of services, so I take a bit of a rights-based perspective on that. (PE 3)

You know, people who have a bit more money can pay a bit, people who are poor don't have to pay anything anyways. In fact, it's like 70 or 75% of home care clients never ended up having to pay anything because they were under the limit where you had to start making payments. So I'm not fussy about one way or another. It would be nice if they didn't have co-pays but if they do, you know they should maybe be income-tested, certainly not asset-tested. And it would be nice if you don't have to start paying until you have a reasonably higher level of income. (PE 2)

Several stakeholders commented on the roles of the Federal and Provincial Governments in funding health care. Federal funding is provided through the Canada Health Transfers and Canada Social Transfers, which are blocks of funding, and it is up to the discretion of the provinces to decide how to spend this money. A stakeholder emphasized the importance of how provinces decide to spend this money:

... but in terms of where the money gets spent that's really what provinces do, you know at the provincial level and at the regional level. They make decisions about where to put their money. And so it's not where the money comes from I don't think, it's what you do with the money you get. And that's the real choice. (PE 2)

It was suggested that the Federal Government could play a larger role in paying for continuing care by providing targeted national funding or agreeing to match the funding provided by the provinces. It was also recommended that having appropriate financial incentives in place could be an important contributor to the performance of the system, although it was emphasized these must fit the local context, otherwise they can actually have a negative impact on services and care.

Provincial Strategy for Home and Community Care

Regarding whether BC needs a provincial strategy for continuing care, many stakeholders believed this was necessary and that the BC MOH needs to develop a clearer strategy and vision for seniors' care. These stakeholders believed a strategy would result in a clear focus on providing care in the home and community, increase the consistency of services across the province, and set out goals for in the system. It was emphasized though that just a strategy would not be enough, and several stakeholders

commented on the fact that strategies and rhetoric need to translate into action and funding. For example, stakeholders stated:

So, yes I think there has to be a strategy at all levels of government. And a shift, an understanding, because they talk about it, but I don't really see them moving. (CS 2)

I think that that would be wonderful...I think if that were to go forward it would be important to include the voices of different stakeholders – so seniors kind of broadly speaking as well as community organizations. I think a strategy is great, I also think there needs to be funding behind the strategy to support the implementation, and goals and benchmarks along the way to monitor how successful the strategy is. (CS 4)

Some stakeholders believed that there already are enough strategies and the problem is the implementation and follow-through. A stakeholder provided the example of the Ombudsperson's report and noted while there were over 100 recommendations made, a large proportion of them have not been enacted. Another stakeholder commented on the fact that there are already sufficient strategies in place (e.g., Seniors Action Plan, MOH Service Plans), and the problem is lack of follow through on the strategies rather than not having one:

We often fail miserably by not fully implementing strategies and it taking years and costing many, many dollars to develop because we don't either commit the time to do it or the reallocation of funding or whatever, and the strategy gets lost or changed or whatever. So yeah, it probably does need developing more, but I don't want to see a new strategy, I think we build on the existing work and make it a promoting one. (PE 4)

One stakeholder suggested that we need a broader plan for the province that would address and integrate the broad range of health and social needs.

7.1.7 Vision for the Home and Community Care System

When stakeholders were asked about their visions for the home and community care system in BC, three overarching themes emerged: a system that cares for older adults and informal caregivers; new care philosophies; and an integrated home and community care system. These themes have already been touched on in the previous sections but are summarized below.

System that Cares for Older Adults and Informal Caregivers

Stakeholders wanted a home and community care system that cares for BC's older adult population and provides them with the supports they need to have a good quality of life as they age. For example, a stakeholder commented:

So my vision is that you know people wouldn't be afraid to grow old because of the lack of services, that they would feel confident that they would be provided for by our public system, and not have to rely so much on friends and family and worry about the burden on those people. (CS 2)

Stakeholders recognized the crucial role of informal caregivers and the lack of supports provided to them. They emphasized the need to provide supports to informal caregivers and include them in health care conversations. Stakeholders stated:

We have lots of excellent caregivers, where most of them are family members who are saving the system thousands, millions of dollars but we don't invest much time or resources into supporting the family caregivers who are looking after elderly people in our communities today and that's a huge element. (PE 4)

I would like to see caregivers' needs be attended to. I would like to see caregivers' input into the care plan for care recipients taken more seriously. And I would also like to see the health care system do more both for the older adult and for the caregiver. Instead of just saying, 'Okay are you eligible for services?' but having a conversation with them about what is best for the caregiver and the care recipient, in terms of where the care recipient want to be—and overwhelmingly they will want to be at their own home in the community—and how to make that work taking the community sector into account. (PE 6)

Stakeholders believed the community was the desired care setting for most older adults.

They also believed that older adults should have choice in their care and be able to access a continuum of flexible services:

I think right now a lot of the people that I see just feel like they don't have choice, that they have to go this route because that's the only option. And I think the whole aging in place is actually a great, a really great concept, but people's access to the services to allow them to do that is really lacking so that needs to be improved. (CS 4)

New Care Philosophies

The need to change current care philosophies was emphasized by stakeholders. Recommended revisions included: 1) shifting from reactive care to proactive and preventive care; and 2) changing from rigid and impersonal care to person-centred care.

Stakeholders believed that there needs to be a shift away from the dominant paradigm of providing reactive care in response to crises. This alternative mode of care delivery would include providing care that takes preventive and restorative approaches and shifting resources and focus to the community. Stakeholders believed that these changes would be beneficial both for older adults and the health care system. Early intervention and preventive measures in the community were viewed as having the potential to prevent health care crises and decrease the need for higher cost health care services. For example, stakeholders commented:

I think there could be a stronger focus on prevention. And a few years ago I think we saw that movement, we saw slightly the move towards a more preventative approach. And I hope that the focus will be more on the prevention again. (CS 12)

So, I answer this by saying what the system is I would want for my mother, if my mother needed services now. So I think one thing is that it's responsive, and I mean that in the sense of not having to wait as you hear sometimes now people wait three or four months for an assessment. (PE 7)

Several stakeholders also remarked on the importance of practices that maximize the independence and functional ability of individuals and empower them to participate in their own care:

And I think there's, the emphasis should be on restorative care and preventive care, and not curative. You know people need support for the disability they have, and not fix that disability. We have to change that mindset because people can live with a disability for many, many years if they have the right support. (CS 7)

I think there needs to be more of a focus in people therefore having the capacity to take more control of themselves. (PE 5)

Several stakeholder identified that in order to realize their vision for the home and community care system, there would need to be a shift away from the dominance of the acute care system and investment would need to be made into developing the capacity of the home and community care system. It was suggested that resources may need to

be diverted to home and community care from other parts of the health care system, and home and community care needs to be recognized as an important part of the health care system. A stakeholder stated:

So the fundamental thing before anything can happen is there has to be an agreement it's a legitimate part of – and when I say this I don't mean a component part all in the 'Other Category,' but by itself. If you think about the Canadian health care system what are the major components? Hospitals is one, doctors is one – is continuing care one or isn't it? Because right now it isn't. If they say it should be, then everything else changes because if they say it should be then CIHI starts collecting data on continuing care, provincial governments set in place Assistant Deputy Ministers for continuing care, regional health authorities set up vice-presidents for continuing care, and all of that because it's seen as an important and legitimate part of the system and they need to be able to report on it nationally and to their citizens and everything else. So that's the fundamental step number one and we're still far away from that. (PE 2)

The second shift in philosophies identified by stakeholders was the need to provide person-centred care. Stakeholders noted that currently, clients are made to fit the system, rather than having the system meet the needs of the clients. Stakeholders wished to see a truly person-centred care system that focuses on the needs of the person:

I think that whatever happens it's really imperative that the person be the main focus of how the system focuses. So right now I think that we've got lots of different systems and people move through the different systems and advocate for themselves, rather than the different services being wrapped around the individual. And I think that that's a big question that the health care system is looking at addressing really broadly speaking and in lots of different areas. You know, how are we able to provide the most person-centred care possible? (CS 4)

Person-centred care includes providing timely and appropriate care that respects the clients' wishes; flexible care in recognition of the different needs of individuals; and a system that is easy to navigate. For example, stakeholders commented:

So I really think that an ideal vision of a continuing care system would be a very person-centred approach to care, where persons are able to have their needs met at the right time, in the right setting for them, and in the desired setting of care so the resources are available to meet their needs where they need them, when they need them met. (PE 1)

I'm just trying to think about the people I see and what could improve their situation. I think for most of the people that I see, smoother access to health services, more confidence in where their care is going to go in the long-

term, and more support for their choice whether it be to be in the home or to transition into assisted living or however that might look. I think right now a lot of the people that I see just feel like they don't have choice, that they have to go this route because that's the only option. (CS 8)

I mean the problem in all of this, in saying what is the right system and what is the right formulation of services, is that everybody's needs are very individualized. I might need something for a very short period of time, I might need something for a longer period of time, I might need services now and then need to move into a more supportive arrangement in which case services could disappear for a while. Like it's all – it could be a thousand different things for a thousand different people, right? So in some sense what you need is a system that is flexible and understands what it's trying to achieve. (PE 7)

Finally, the importance of the human aspect of providing care was highlighted:

That people get the services that they actually need, and that they're not treated like – I was going to say cattle, but that's a bit – that they're not treated like things, like an illness. (CS 9)

We've fallen off the rails. The quality of life and quality of care that a person is getting should be the primary driving force of any of these health care services, but it isn't done anymore. (CS 7)

Integrated home and community care system

Stakeholders also wanted better integrated services, with the sectors of the health care system all working together as part of a system rather than in silos:

And that means get everything lined up and you know one thing leads to another, and it's, everybody knows how this should work. And I think people are too busy working in their own little area, too many silos as they say. There's still lots of silos. So I think that you know everybody's got to get together on the same page. (CS 1)

Stakeholders stated the need for the health care system to take a broader view of health and integrate both health and social services. While there was no consensus about whether “non-medical” home support services should be offered directly by the health care system or through non-profit and voluntary organizations, there was the consensus that these services should be integrated and coordinated with the health care system. Several stakeholders commented on the need for better integration with the community-based sector and other social supports:

And the health care system would be an advocate for the older person and they would start trying to link with – not offload – to link with the third sector within the community. (PE 6)

I'd like to see the division between medical and non-medical changed. I'd like to see us integrate multipurpose community centres, seniors centres – their funding is different and that always makes for problems – but that there be some outreach from the health department to them and some way of integrating them a little better. (CS 3)

I think it would be a program that integrated across all aspects of care and supports, so including so called non-medical. You know so really looking at the social determinants of health, frankly which gets even broader which we didn't really get into, but I think all those things are part of providing a continuing care system. And I just said it would be publicly funded and accessible to everybody. And then I think the other, probably and again I said it already, but I think it would have to mobilize and bring together a really wide range of supports and resources from Ministries, health authorities, community agencies, volunteers, you know family members as well. So sort of I guess you could say the collective unified impact of having integrated care over the whole continuum of need and over the continuum of time. (PE 3)

Stakeholders also identified the ability to move information smoothly across the system as a key requirement for any integrated system:

So as the clients move around the system when they get older, it's a smooth process. Data follow them, records and clinical information follow them as they go around. And so we're not recreating, recreating, recreating all the time to try and keep up with what's going on. (PE 4)

Other important components of an integrated system were also highlighted: having a common assessment process that is shared across the continuum; a single electronic health record; the ability to communicate across systems and sectors; the standardized collection and use of data; and system-level case management.

7.2 2019 Follow-up Interviews

A total of 10 follow-up interviews were conducted with community stakeholders (service providers, advocates, and older adults) and individuals with policy expertise in various areas of home and community care (e.g., academics, policy researchers) from across the province. Eight of the interviews were conducted with stakeholders from 2014/15 while two were conducted with new stakeholders. The interviews were semi-

structured, with a base set of questions focusing on perceptions of changes to the home and community care system within the past 3-4 years.

7.2.1 Persistent Challenges for the Home and Community Care System

In the follow-up interviews, stakeholders continued to identify the same challenges that were identified in the 2014/15 interviews. The most frequently discussed issue was access to services. Stakeholders discussed declining access and waitlists for a range of home and community care services:

They don't have enough placements, and they well understand that, but then they're not providing enough support at home. (F 1)

But I would say over the last while in general there's still been as far as I can tell a decline in the level of services that are available in the home and community care system, I expect driven largely by the growth of the population. So I don't think there are certain cuts, I just think the expansion has not continued to keep up with the population expansion. (F 2)

Certainly over the last decade and a half we've also gradually seen a lot of the rehab professions and also other allied health science professions gradually become no longer provided on a publicly funded basis within the home and community care sector. (F 3)

Regarding assisted living and long-term care specifically, one of the stakeholders highlighted how the lack of capital financing to support new developments in the public system has negatively impacted efforts to build capacity. Most of the new assisted living and long-term care capacity has been in the private for-profit sector.

Stakeholders also highlighted continued gaps in the continuum of services for home support services that had been cut in the early 2000s (e.g., meal preparation, housekeeping):

We saw a system, that had, at one point, at least theoretically, included things like housekeeping, food preparation, etc. And really you know, in my personal opinion, those are the things that really enable for our older adults to stay at home effectively. (F 6)

Several stakeholders observed that the Better at Home program had been able to fill some of the gaps in the "non-medical" needs of older adults, though similar to in 2014/15 it was also noted many Better at Home programs are at capacity and the program is not

available in all communities. It was also suggested that there may be higher needs older adults who need more supports than Better at Home provides.

Several stakeholders also expressed concern over the lack of person-centred care. Stakeholders noted how the system is inflexible and focused on time and efficiency rather than providing person-centred care:

Yeah, just go back to a really holistic system that doesn't treat people like tasks, but humans. Maybe I am asking for too much. (F 6)

But if there are more supports...supports that people actually need and want, not what they [the system] decide they need or want. (F 5)

Difficulties navigating the system were also mentioned by stakeholders as a continued challenge, including lack of awareness of services, heavy workloads for case managers, and the complexity of navigating the system. In particular, stakeholders highlighted lack of awareness of services and poor communication as issues. It was noted that this is a concern particularly relevant to isolated seniors, and there are currently some programs from the non-profit and voluntary sector that are trying to help connect older adults with needed services. For example, a stakeholder remarked:

I do think that you know there's some more outreach that is needed to let, you know let people know what's available to them, to connect them to services. I mean obviously there's the advocacy side too for more and more of those services to be made available, but you know I just do think that sometimes they're out there, those services are there, and people just are not aware that they're there. (F 7)

Stakeholders also reiterated that there are issues relating to increasing complexity of clients and the delivery of reactive rather than proactive services:

We have now become almost care facility like places, so the social component and the rehabilitation component is kind of gone. Cause we are not rehabilitation workers and then we are not funded that way either. (F 5)

You know, we can look at examples like Denmark, where there is a great system in place regarding preventive visits to older adults. We can look at what impacts that has had on the overall kind of health care expenditures for older adults. There is some pretty solid evidence to be looking in that direction and we haven't. (F 6)

Lack of funding and the need to change current distributions of funds continued to be identified as an underlying cause for key challenges within the home and community care system:

The need is growing. I mean, we either have to find funds to better support it, get more creative, or we really need to think hard about what impacts will be incurred if we don't address this. (F 6)

And of course resource allocation continues to be a priority right. We look at places in the world like Europe where they invest more in social care than in health care and the quality of life surmounts those reported in Canada – whereas in Canada we invest much more in health care than we do in social care. And so it's those types of paradigm shifts that we continue to make a priority. (F 10)

Some stakeholders perceived the economic climate to be more promising than it had been in the past. However, it was also noted by a couple stakeholders that historic underfunding over the past decade means that any increases in funding will primarily be used to offset the deficits that have accumulated over time.

7.2.2 Consequences of Shifting Care to the Community

While potential consequences of shifting care to the community without adequate resources and supports were discussed in the 2014/15 interviews, concerns about this issue were more apparent in the 2019 interviews. It was acknowledged by several stakeholders that there has been increased recognition by government of the needs of older adults and the desire of older adults to age in place in the home and community. However, the caveat was also provided that this has not yet translated into the full resources and supports necessary for this to successfully occur. Some stakeholders highlighted the strain inadequate resources are putting on older adults and informal caregivers. It was acknowledged that women (who often take the role as primary caregiver) and low-income seniors (who cannot afford to pay for private services) are struggling. Concerns about the downloading of responsibilities onto older adults and informal caregivers were also expressed. For example, stakeholders commented:

I think that there is a really strong feeling from my generation of seniors that you know people do not want to go into the traditional long-term care facility, we would rather have services at home and or in some sort of homelike environment. There's really an interest and willingness to change. There's totally a fear because people see there isn't the services needed

and that people have to pay for it. And I've seen lots and lots of examples of if you have money you're okay, and if you don't have money it's really a challenge. So it's really becoming very two-tiered. (F 4)

Yes. Home is best for THEM, for the system! Not for the people that have to take the brunt of all the work. (F 5)

Providing these things via what still seems to be largely volunteers or overworked staff or overworked and stressed family members, you know, is not really a solution. (F 8)

You know, 15 minutes is not enough time to take your jackets and shoes off, let alone to really kind of attend to what somebody really needs. So, we have been advocating for a long time to increase visit times, because I think it's incredibly important to help people age in place—that is the government's direction. (F 6)

In particular, the continued lack of support for informal caregivers was an area of growing concern. For example, stakeholders commented:

One of the case managers said you know, 'I have never had a call from a senior crying, but I've had lots of calls from caregivers crying on the phone wanting help.' (F 5)

You know if families had more help they might be able to hang onto their loved ones a little longer. (F 1)

Stakeholders discussed how supports for informal caregivers continued to be inadequate and not flexible enough to meet their needs. Stakeholders highlighted the need for greater recognition of the needs of informal caregivers within the health care system. Some stakeholders also commented on the need to critically examine what populations of older adults it is truly feasible and best to care for in the community:

So that would be my concern, that it has not really been driven by the use of evidence or data beyond a reliance on interRAI data to say we have more people in long-term care that could be in assisted living or at home and I think a lot of the RAI data has been highly suspect to be relying on that as your source of truth. (F 3)

Not that [aging a home] is always the best option for everybody either. Because some older adults really benefit from moving into assisted living or long-term care – they benefit from the social interaction, they benefit from the additional care. I think we also can't be blind to the effects that staying at home has for families, because it has impacts on families as well of course, and an incredible gender dimension...But you know, I think we need to look at these things fairly holistically. (F 6)

7.2.3 Health Human Resource Challenges

Health human resource challenges emerged as an additional policy issue that stakeholders discussed much more frequently in 2019. While it was acknowledged challenges existed for the whole home and community care sector, stakeholders in particular brought attention to challenges with staff recruitment/retention and understaffing in long-term care facilities. Stakeholders stated:

The workers are getting burnt out because they are putting too much pressure – and that was at my mother's care facility. There is very little staff and they are burnt out. (F 5)

So, we are in a severe health human resource crisis right now. There are not enough workers to deliver the care that British Columbians need and that is a big problem. (F 6)

So recruitment and retention of care staff is really a challenge right now and will continue to be so. And I think a part of that is the fact is over the last few decades a lot of that work has become increasingly devalued. (F 3)

Poor pay and compensation packages and inadequate/inconvenient hours were suggested as factors contributing to shortages. It was also noted that pay and compensation packages for CHWs are less generous than those for care aides working in long-term care, providing incentives to work in facilities rather than in the community.

Stakeholders also discussed the lack of training and professional development opportunities offered to health care aides and CHWs, which was a particular concern given the increasing complexity of clients. Stakeholders remarked that:

There has really been no provincial approach to professional development and supporting those occupations in the health system. (F 3)

They need to know how to deal with somebody that's hard to handle, and they're not trained. They don't get any of that training and I feel very badly that they don't. (F 1)

The announcement made in 2019 to move all home support services in-house over 2019 and 2020 was also mentioned by a couple stakeholders. One expressed concerns over the potential disruptions this might cause to home support services and continuity of care for clients, as well as the potential negative impacts on workers and private home support providers. The stakeholder commented:

I think that there's a very big likelihood that we have underestimated the challenges that are going to result both in terms of workforce availability but also in terms of continuity of care for seniors. (F 6)

7.2.4 Home and Community Care Reforms

Overall, the general sense of stakeholders was that there had been some pockets of improvements to the home and community care system in recent years, but there have not yet been the types of systemic changes required to truly transform the system. Generally, stakeholders believed more work is needed to ensure the system can meet the needs of older adults and informal caregivers:

Some people do have very good experiences. They got lucky right, but for the most part the system, the way it is, it's not working. Is it worse? I don't know that it's better or worse. (F 5)

I think that there are always bright spots. That being said, are we doing enough and investing enough at present? No. (F 6)

I mean just looking at the access, the access to services you know is continuing to go down, the number of seniors is continuing to go up. (F 4)

Stakeholders were able to identify some areas where they believed improvements has been made to the home and community care system:

- Increased staffing levels for long-term care, which were noted to potentially be improving the quality and intensity of care (though not increasing the number of spaces).
- Clustered care home support models where CHWs have responsibility for a group of clients within a neighbourhood or building.
- Funding to increase access to adult day services and respite services.

Stakeholders also discussed current efforts to expand access to assisted living for older adults with complex needs and palliative care needs (at the time of the interviews the Bill 16 amendments had not yet been brought into force). A couple of stakeholders asserted that while the Seniors Advocate identified a population of older adults currently in long-term care who might be appropriate for assisted living or care in the home, there needs to be careful consideration of what care will be appropriate for these populations. A stakeholder observed:

Already there are a lot of people with complex needs and palliative needs in assisted living, and it is a real challenge looking after them in that environment for a number of reasons: staffing levels, the built environment isn't right – they can't do lifts and there is no wheelchair access. (F 4)

While not a formal part of the home and community care system, stakeholders also described the expansion of Better at Home programs, as well as the investment by Provincial Government in the Integrated Community-Based Programs for Older Adults with Higher Needs as positive steps. Stakeholders from the community-based seniors' services sector believed their sector has an important role to play in supporting older adults, but were also aware of need to maintain a fine balance between capitalizing on the prevention and health promotion supports this sector can provide and not allowing the inappropriate downloading of responsibilities onto the sector:

It's important to make sure that we're not putting ourselves in a position where the province is downloading work and responsibilities because that can severely jeopardize the quality of services that have been provided. (F 10)

7.2.5 Progress Integrating Care for Older Adults

Stakeholders continued to identify integration of services as a problem for the home and community care system, with challenges transitioning patients and information seamlessly across the different sectors. They also noted how further work needs to be done to ensure social care services and “non-medical” home supports are integrated into the care continuum. For example, stakeholders remarked:

I think there is also an effort to you know, to try and coordinate better and integrate better, but I am not sure that I have seen what I would call fundamental changes in that regard. (F 8)

And I think integration is really an important challenge particularly if we are talking about the home support side of things because I don't think most people in the health care sector routinely think of the home support workers as part of the health care team. (F 2)

Some stakeholders commented that progress was being made on improving the integration of care for older adults. It was noted that efforts had been made to strengthen ties with the community-based seniors' services sector. The BC MOH has provided funding for pilot projects for integrated community-based programs for older adults with higher needs (social prescribing, caregiver supports, and therapeutic activation programs

for seniors). Other specific examples of progress in advancing integration were also provided, including:

- Improved coordination of care for people transitioning from hospital to community with some specific health conditions (e.g., stroke, osteoarthritis)
- Progress has been made to link physicians to long-term care services. The shared services committee of the General Practitioners Service Committee and Divisions of Family practice have played an important role in this.
- Team-based care has been expanded and incorporates a broader range of professions (e.g., social workers).

Stakeholders also recognized how changes were often confined to “pockets” of innovation and are not occurring consistently across the province. They provided some examples of successful models for integrating primary and community care that could be more widely disseminated across the province to improve care for older adults (e.g., Specialized Seniors Clinics in Fraser Health Authority, Community Health Centres, and the Home Vive program).

Stakeholders were asked about current progress to implement integrated primary and community care and the potential impacts of this integration on home and community care services and care for older adults. Stakeholders frequently stated that integrated primary and community care had the “potential” to improve care for older adults. Generally though, they did not feel there had been enough progress to determine what the impact would be. For example, stakeholders commented:

Well, I'm a little bit of a 'rose colored glasses' person, so I think there is a lot of potential and I think it could have a really positive impact if people are willing to do things differently. I think that the coordination would mean amazing results for older adults. And maybe aging in place would actually be a real thing. (F 9)

It has a lot of potential, that it could be doing a lot but it's not. The primary care networks is very divorced from what's going on in the health authorities with seniors care still, and that's really a missed opportunity. (F 4)

I sort of feel like yes, in theory, this is a very good move, but I don't know that we are far enough along to say much about it in practice. (F 8)

I think some of the impacts have yet to be felt in community, I think it's more at the service delivery that some of this work is happening at this point. But

with the development of some of this work we should hopefully see some benefits in community, on the ground. (F 10)

Reasons that some stakeholders were skeptical of the benefits that would result from integrated primary and community care reforms included doubts over whether there would be adequate resources to support these reforms and the limited focus on home and community care services. For example, a stakeholder maintained:

They have developed a very aggressive primary and community care reform agenda, unfortunately the focus has been almost entirely on the primary care side. And I think, well I can say you know that there has been very little progress in the community side and the primary care side is much more fully developed in terms of a provincial vision, the different kinds of delivery mechanisms, the provincial infrastructure to support that. (F 4)

7.2.6 Vision for Home and Community Care in BC

There was consensus among most stakeholders that BC is lacking a clear vision for the home and community care system. While some changes have been made to the system, these have been piecemeal and were not seen as being a part of a larger holistic vision or strategy:

In terms of the community care side, it's all kind of been devolved to the health authorities, there's no ministerial lead or leadership or vision or coordination. (F 4)

I can't say I know enough about the current vision to be able to comment on that one way or another – which might be a problem within itself. (F 2)

It's been more tinkering around the edges when we probably need a bit more of a deeper dive into how we do some redesign work. (F 3)

I just don't think that they've got onto this yet and provided us with a vision. (F 7)

Some stakeholders wanted there to be a larger role for service providers, informal caregivers, and older adults in shaping the direction of the home and community care system:

It seems to be ad hoc and piecemeal. It is rather like reactive rather than proactive. And we have given lots of suggestions, but we're not listened to. We don't matter. (F 5)

My sense is that it is a lot of high-level thinking. And I don't feel like there is a lot of on the ground connection to what is happening. I think also what

happens is, the government, they feel that it is too time consuming to engage the community and the solutions that might actually really work. So they take all these other avenues and then eventually come back to the community. (F 9)

It was also suggested there are opportunities to examine and learn from experiences in other jurisdictions:

I think that it does need to be really, really examined and thoroughly and compared to what's going on in other places and look for examples from other places that are doing better. (F 4)

7.3 Conclusion

This chapter summarized key themes from stakeholder interviews in 2014/15 and 2019. The challenges with the home and community care system identified by stakeholders align with the various reports and critiques described in chapter 6. In the 2019 interviews stakeholders perceived that there had been limited reforms to address these issues and also expressed increasing concerns over the potential negative impacts of shifting care to the community when inadequate supports are provided. The following chapter will provide a critical analysis of BC's home and community care system, drawing on the perspectives of stakeholders as well as the material presented in chapter 6. The critical analysis will also include additional evidence and analysis of policy documents.

Chapter 8.

Critical Analysis of BC's Home and Community Care System

As described in chapters 6 and 7, over 2012-2019 reforms to improve the home and community care system in BC were limited. This chapter will assess the overall impact of reforms on the performance of the home and community care system. First, data is provided from the Seniors Advocate to paint an overall picture of the impact of policies and reforms on the home and community care system. Second, the current deficits in home and community care policy in BC are analyzed. This analysis integrates data from the stakeholder interviews with analysis of government policies and/or policy documents. Third, the discourses and underlying values of home and community care policies, that help to explain why some of these deficits have emerged, are discussed.

8.1 Assessment of Home and Community Care System

One of the most important contributions the Seniors Advocate has made to the policy context in BC has been the tracking and collection of data on seniors' care and services. Tables 12 and 13 summarize key indicators using data from the Seniors Advocate's annual *Monitoring Seniors Services* reports. Some of the key findings are:

- There have been fairly consistent annual increases in the number of home support clients, home support hours, professional home care clients, and professional home care visits.
- There has been a modest increase in the number of publicly subsidized long-term care beds (net increase of 1,384 by 2019), while the percentage of older adults placed in a long-term care bed within 30 days has fluctuated.
- There has been a net decrease of 17 publicly subsidized assisted living units over this period, but there has also been a decrease in the waitlist.
- The number of adult day program days of service decreased by 3,288 during this period, while number of clients generally declined until a significant increase in 2018/19.
- The number of respite beds began falling in 2013 but now are back to the same levels as 2012.

- The total number of inpatient ALC days have increased every year (with the exception of 2017/18). Consistently 15-16% of inpatient days for people aged 65-84 and 24-26% of inpatient days for people aged 85 and up have been ALC days.

Table 12 Home and Community Care Indicators Part 1

	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
# of home support clients**	38,837 ^a	40,624 ^c	41,603 ^c	42,465 ^c	44,442 ^c	46,125 ^d	46,833 ^d
# of home support hours**	10,384,951 ^b	11,034,392 ^c	11,194,249 ^c	11,313,620 ^c	11,672,214 ^c	11,999,681 ^d	11,893,201 ^d
# of professional home care clients	80,828 ^c	82,650 ^c	85,333 ^c	87,315 ^c	92,262 ^c	117,906 ^d	120,775 ^d
# of professional home care visits	1,043,436 ^b	1,042,755 ^c	1,090,193 ^c	1,110,648 ^c	1,169,822 ^c	1,456,866 ^d	1,469,863 ^d
% of seniors admitted to long-term care within 30 days	n/a	67% ^c	64% ^d	58% ^d	61% ^d	70% ^d	67% ^d
# of individuals on waitlists for long-term care	n/a	n/a	n/a	1,798 ^d	1,291 ^d	1,379 ^d	1,780 ^d
# of adult day program clients	n/a	6,295 ^c	6,229 ^c	6,271 ^c	6,062 ^c	5,895 ^c	6,509 ^{d*}
# of adult day program days of service	n/a	255,689 ^c	259,612 ^c	261,665 ^c	226,570 ^c	235,427 ^c	252,401 ^d
# of clients on waitlists for adult day programs	n/a	n/a	n/a	n/a	1,245 ^d	1,526 ^d	1,503 ^d
Average personal care hours per client per year in assisted living	n/a	n/a	n/a	n/a	293 ^d	320 ^d	326 ^{d*}
Total # of ALC days	n/a	391,572 ^c	408,867 ^d	420,601 ^d	438,256 ^d	405,919 ^d	445,807 ^d
ALC days as a % of inpatient days by age group	n/a	n/a	15% (65-84) 24% (85+) ^b	15% (65-84) 26% (85+) ^b	16% (65-84) 26% (85+) ^b	15% (65-84) 24% (85+) ^c	16% (65-84) 26% (85+) ^d

Data sources: a. OSA (2016c); b. OSA (2017c); c. OSA (2018b); d. OSA (2019b)

*Totals do not include Northern Health Authority data. **Home support indicators include CSIL clients.

Note: Conflicting data was presented for some years for indicators in different versions of Monitoring Seniors Services reports. In the cases of conflicting data, the data was used from the report that was the most recent and included the most complete data.

Table 13 Home and Community Care Indicators Part 2

	2012	2013	2014	2015	2016	2017	2018	2019
# of publicly subsidized assisted living units	4,389 ^b	4,472 ^b	4,437 ^c	4,430 ^d	4,408 ^d	4,485 ^d	4,432 ^d	4,372 ^d
# of individuals on waitlists for assisted living	n/a	n/a	n/a	943 ^d	918 ^d	750 ^d	804 ^d	870 ^d
# of publicly funded long-term care beds	26,506 ^a	26,921 ^b	27,238 ^c	27,426 ^d	27,423 ^d	27,829 ^d	27,846 ^d	27,890 ^d
# of respite beds	227 ^b	218 ^b	200 ^c	200 ^d	205 ^d	204 ^d	203 ^d	227 ^d

Data sources : a.OSA (2015e); b.OSA (2017c); c. OSA (2018b); d. OSA (2019b)

Note: Conflicting data was presented for some years for indicators in different versions of Monitoring Seniors Services reports. In the cases of conflicting data, the data was used from the report that was the most recent and included the most complete data.

Over 2012-2019, in most areas of the home and community care system there were modest improvements or little change in the availability and timeliness of services. While there has been some scaling up of capacity in the community, increases in home support capacity have been primarily driven by increases in short-stay clients (OSA, 2019b). The data from the Seniors Advocate, evidence from other research and reports (as described in chapter 6), and findings from interviews (as described in chapter 7) suggest there have been limited improvements to the home and community care system, and further reforms are necessary to adequately meet the needs of older adults and informal caregivers. While government has not introduced cuts in recent years and are attempting to address some issues with the home and community care system, they have failed to keep up with the growing needs of the aging population and to implement the changes required to successfully shift care to the community.

8.2 Critical Analysis of Home and Community Care Policy Development in BC

Dye (2017) defines policy as “anything a government chooses to do or not to do.” Arguably the most significant deficits of the home and community care system in BC have emerged over time from what government has neglected to do to ensure the success of policies to move care closer to the community. These deficits include: not developing a clear vision for home and community care; not providing a comprehensive continuum of care; not adequately funding home and community care; and not introducing policies to support informal caregivers. Each of these policy failures is

critically analyzed in the sections below. First, evidence from the stakeholder interviews related to the policy deficit is briefly summarized. Second, additional evidence from analysis of policies and/or policy documents is described. Finally, an integrated assessment and discussion of the implications is presented.

8.2.1 Vision for Home and Community Care

Key Findings from Stakeholder Interviews

In 2014/15 stakeholders identified three overarching themes they wished to see in a vision for home and community care: a system that cares for older adults and informal caregivers; new care philosophies; and an integrated home and community care system. These themes align with the critiques and recommendations of key policy actors over 2012-2019 (e.g., BC Ombudsperson, Seniors Advocate, advocacy groups, etc.) that were described in section 6.3.3. In the 2019 interviews key findings were:

- Stakeholders noted that reforms to date had been largely piecemeal and reactive in nature. They generally did not believe there was a clear vision in place for the home and community care system.
- Stakeholders generally viewed the concept of integrated primary and community as having potential, but some noted the home and community care aspect of this vision has been overlooked.

As will be described in the next section, analysis of policy documents supports these perceptions of the lack of a vision for the home and community care system in BC.

Analysis of Policies

In BC, many of the changes made to-date have been in response to issues highlighted by the Ombudsperson or Seniors Advocate. These policy actors have played pivotal roles in efforts to improve the home and community care system and have been credited with influencing many of the positive changes made in recent years (e.g., amendments to the *Community Care and Assisted Living Act*, increasing funding for adult day services, etc.). This highlights the important role publicly available data plays in affecting change. However, it is not enough to just address individual deficits of the system as they are brought to light. Systems approaches, as well as integrated care theory, emphasizes the importance of considering the interconnections of components within a complex system and engaging in integrated planning.

The two home and community care action plans released over 2012-2019 have not resulted in a clear vision for the home and community care system or contemplation of important philosophical and funding questions. In response to the Ombudsperson's reports, the 2012 action plan (see p.70) focused on mostly minor improvements that required a minimal investment of resources, rather than addressing broader systemic issues. The fact only a modest proportion of the Ombudsperson's recommendations had been addressed by 2019 is indicative of a neglect of home and community care policy. The BC Office of the Ombudsperson (2019) concluded in the final monitoring report:

We are encouraged by the fact that some improvements have been made to seniors' care in the province since our initial report was issued. However, most of the work completed to date has focused on small, incremental changes. As this report highlights, there is clearly significant work ahead to ensure that fundamental changes are made to address the systemic and structural gaps that still exist. (p.4)

The second action plan for home and community care (see p.71) differed from the first as it provided some discussion of a vision of desired care for older adults, though there was little connecting this vision with the policy actions. This plan primarily framed home and community care services as separate components rather than part of a larger system and contained only minimal consideration of home health services.

Home and community care policy has also been neglected in the vision for integrated primary and community care, despite older adults being a key target population for these reforms. This is a particular concern regarding home health services, which have been positioned as playing a significant role in the quest to reduce acute care and long-term care utilization and costs. For example, the eight priority areas for the health care system in *Setting Priorities* (BC MOH, 2014a) included long-term care facilities, but other home and community care services were not identified as priorities and were almost never mentioned in the document.

Assessment and Implications

Data from stakeholder interviews and analysis of key policy documents supports the conclusion that home and community care policy development has been neglected in BC and largely overshadowed by the integrated primary and community care policy agenda. The lack of a vision specifically for home and community care is reflective of the politically subordinate position of these services compared to other "medical" services in

Canada which has been observed by other researchers (e.g., Ceci & Purkis, 2011; Penning & Votova, 2009). Within the broader vision for the health care system, research by Misfeldt et al. (2017) on the development of team-based primary care in BC suggests that besides physicians, other providers have limited opportunities to have their voices heard and influence integrated care policy. The medical profession is the most powerful interest group involved in shaping health care policy (Buse et al., 2005) and is extremely influential due to their dominant role within the health care system, significant autonomy, and key role in allocating health care services (Blank & Burau, 2010). In comparison, most people providing home and community care are working in unregulated professions and may be employed by contracted providers. While an integrated primary and community care system potentially will have benefits for older adults, the preoccupation with the primary care components of the system and neglecting of the home and community care components (and in particular home health) will hinder the effectiveness of such initiatives.

8.2.2 Critical Analysis of Gaps and Fragmentation in the Continuum of Care

Key Findings from Stakeholder Interviews

In the 2014/15 interviews stakeholders identified lack of integration as one of the root causes of many of the problems with the home and community care system. Key findings included:

- Stakeholders emphasized that a comprehensive range of supports are necessary to support older adults to age in the community. Two gaps in the continuum that were highlighted were IADL supports (particularly food preparation and housekeeping) and more housing options.
- Home support services were perceived as being poorly integrated into the continuum of care. Many stakeholders described the cuts to home support that occurred in the 1990s and the negative impact they had on older adults.
- Stakeholders also highlighted the need for services to become more proactive, preventive, and person-centred.
- The home and community care system was perceived as difficult to navigate.
- Home and community care services were also perceived as being poorly integrated with other sectors of the health care system; lack of integrated information systems in particular was emphasized as an issue.

These perceptions align with the historical review of the home and community care system and critiques of the system by key policy actors described in chapter 6. In 2019, stakeholders continued to identify similar issues with the continuum.

Over the course of the study stakeholders were able to identify some reforms that had been made to address gaps and fragmentation in the continuum of care. Stakeholders provided some thoughts for consideration about these reforms:

- Better at Home was perceived as filling some of the gaps for IADL services, though there are waitlists and also services (e.g., meal preparation) that are being provided through neither Better at Home nor the home support program.
- The non-profit and voluntary sector was generally viewed as having the potential to fill some gaps in the continuum, but stakeholders also expressed concerns over the potential for downloading of responsibilities onto this sector and the lack of integration with other services.
- Various examples of initiatives to improve integration of primary, acute, and home and community care were described. However, it was also commented that these usually are “pockets” of innovation and not systemically implemented across the system.
- Stakeholders described some of the challenges that would be associated with caring for more complex clients in assisted living.

Analysis of Policies

There are three gaps in the continuum of care for older adults that government sought to address over 2012-2019: “non-medical” home supports, therapeutic activation programs for seniors, and expanded supports through assisted living.

As described in section 6.3.4, evaluations of Better at Home to-date have produced positive results. A key limitation is that access is limited to the 70 communities that have Better at Home programs in place (rather than the theoretically province-wide access for other home support services). This is not an intrinsic flaw of Better at Home though, as Government could expand the programs to communities currently without access. The BC MOH is currently also funding demonstration projects of therapeutic activation programs for seniors, which if found effective and scaled up across the province would provide another service on the continuum of care for people with lower level care needs. These programs represent an emerging willingness of government to partner with the non-profit sector to provide care to older adults.

Publicly subsidized assisted living has been on the continuum of care since 2002 and compared to many other Canadian provinces is a well-developed model (Office of the Veterans Ombudsman, 2014). However, from the outset questions were raised about the ability of assisted living facilities to meet their goals, and in particular provide a substitute for lower level long-term care clients, as these clients often were beyond the level of care provided (Araki, 2004). Subsequent reports by the BC Office of the Ombudsperson (2012a) and OSA (2015d) have echoed similar concerns. Amendments to the *Community Care and Assisted Living Act* that finally came into force in 2019 will potentially expand the role of assisted living within the continuum of care (see section 6.3.4). However, there has been very little investment into developing new publicly subsidized assisted living stock over the past decade and there are currently waitlists for assisted living (Longhurst, 2020; OSA, 2019b). As these new reforms will expand the potential pool of assisted living clients as well as potentially lengthen their stays, a scaling up of public assisted living capacity will be required in order to capitalize on the enhanced diversionary capabilities of assisted living. A thoughtful approach is needed to ensure that the changes to assisted living do not result in the crowding out of people with lower level care needs as was seen with home support services in BC. There also is the potential that if adequate staffing and other resources are not made available, assisted living will become a setting where clients with high level needs are offloaded and not properly cared for.

To date, efforts to improve functional integration of services on the continuum have been limited primarily to integrated primary and community care initiatives. Initiatives such as aIPCC have not been widely disseminated across the health care system or even in some cases extended beyond the pilot stage (McGrail et al., 2019).

Assessment and Implications

Integrated care research and frameworks emphasize the importance of providing a comprehensive range of services to older adults (see chapter 2). As will be described later in chapter 12, the success of the Danish system has been built upon offering a broad range of housing models and community supports to older adults. Steps have been taken in BC to address some of the gaps and points of fragmentation within the continuum of care; however, deficits remain that will impact the success of substitution policies government is pursuing. In particular, gaps in the home support program were

highlighted by stakeholders and have not been fully addressed by new policies. One of the recommendations from the BC Ombudsperson in their systemic investigation was for the province to conduct a systemic evaluation of the costs and effectiveness of the home support program. No systemic investigation had been conducted by government by 2019 (BC Office of the Ombudsperson, 2019) though the Seniors Advocate has reviewed the home support program. The Seniors Advocate (OSA, 2019a) has recommended broadening the scope of home support services to include both ADL and IADL supports, and notes that greater flexibility is needed when providing care:

... care plans must be sufficiently expansive and flexible to allow the CHW to meet the changing needs of the client and to support the client's family in caring for their loved one. Cleaning, full meal preparation, assisting with telephone orders, laundry, additional bathing, watering plants, and taking out garbage are all types of activities that CHWs should be empowered to do for the client or their caregiver on an as-needed basis. (p.52)

One of the common consequences of reforms to move care to the home is that the conditions under which services are received and accessed change (i.e., government has a responsibility to provide certain types of care in an institution, but this may not be the case in the home) (Williams, Deber, Baranek, & Gildiner, 2001). Services that would be the responsibility of the health care system in an acute care or long-term care setting are no longer publicly subsidized in the home. For example, meals are provided in acute care and long-term care settings in BC, yet the home support program does not provide meal preparation and will only heat up meals. Similarly, most pharmaceuticals and equipment are paid for publicly in acute and long-term care settings but must be paid for out-of-pocket by home health clients (with the exception of palliative care patients). These gaps in services and coverage may create perverse incentives for older adults to enter institutions. The Seniors Advocate (OSA, 2019a) estimated that an older adult with an income of \$27,800 would spend approximately \$10,000 more per year on housing, food, and care if they were living at home and receiving home support than if they were living in a long-term care facility.

Within BC, recent partnerships between government and community-based seniors' services to fill gaps in the care continuum can potentially be viewed in two different ways: 1) as an opportunity to strengthen the health-social care interface and take advantage of the strengths of the community-based sector or 2) as a downloading of responsibilities onto the community sector. One of the key criteria for assessing

whether downloading is occurring is the extent that new responsibilities are accompanied by adequate funding (Duffy, Royer, & Beresford, 2014). In surveys and discussions with municipal governments on downloading in BC, the importance of a) not transferring responsibilities without new funding streams and b) providing stable sources of funding rather than short-term grants have been emphasized (Duffy et al., 2014). For example, in the mid-1990s when government cut IADL supports from the home support program, members of the non-profit and voluntary sector perceived these changes as offloading onto their sector (Hanlon, Rosenberg, & Clasby, 2007). At this time non-profit and voluntary organizations were experiencing significant financial insecurity due to a) reliance on short-term gaming grants for funding and b) the fact grants are managed by gaming commissioners rather than health and social care officials (Hanlon et al., 2007). Currently funding for Better at Home programs is provided directly to the United Way of the Lower Mainland for dispersal to the programs, and funding appears to be reasonably stable (though like other home and community care services demand may outstrip supply and there are waitlists in some communities). In recent years, the BC MOH has demonstrated an increased interest in partnering with community-based seniors' services and going forward it is vital that stable and adequate funding is provided for any services being offered as a result. Consideration also might be given to whether other programs offered by community-based seniors' services (e.g., lunch programs at senior centres, physical activity programs, etc.) should be funded directly through the BC MOH or another stable funding source rather than forced to rely on unstable short-term grants

There are gaps within the continuum that need to be filled, but there is also the need to address sources of fragmentation. One of the most significant points of fragmentation is the lack of integrated information systems. These are an important requirement for integrated care models (as described in chapter 2). While electronic medical records have been implemented for physicians, the lack of interoperability with other information systems is an issue. Another concern is that provision of services from multiple sectors and providers can lead to fragmentation. Facilitating integration between a mix of public and private health and social care services is a formidable task, and while integration can successfully occur this has proven a challenging task in many regions (Blank & Burau, 2010). The development of the PCNs and SCSPs as part of the integrated primary and community care agenda may help to improve coordination and integration for patients with complex needs. Mechanisms are necessary to ensure

services offered by community-based seniors' services are appropriately connected with the formal health care system, and the SCSPs may potentially serve this purpose.

8.2.3 Critical Analysis of Investment in Home and Community Care

Key Findings from Stakeholder Interviews

Stakeholders identified underfunding of the home and community care system as one of the root causes of the system's challenges. Several stakeholders linked underfunding to government tax cuts in the 1990s and 2000s and retrenchment of the welfare state. The impact of government tax cuts on funding for health care systems has been well documented in research (e.g., Evans, 2003; 2008). There was general agreement that more funding is needed for the home and community care system; some stakeholders suggested that overall more health care funding is needed, while others suggested that funding needs to be utilized and allocated in more effective ways. As a result of underfunding, stakeholders described impacts such as declining access to services, increasingly strict eligibility criteria, and downloading of responsibilities onto individuals and their families. These findings are supported by multiple reports in chapter 6 that describe the lack of investment in publicly subsidized home and community care services both to keep up with population demand, as well as to respond to the increased pressures placed on the home and community care system (i.e., services acting as substitutes for acute care). Stakeholders supported public funding for home and community care services, and several highlighted the need for dialogue with the public about home and community care services, and what type of care we as a society wish to provide to older adults and how we will pay for this.

Analysis of Policies

Over 2012-2019 while there were not any major cuts to home and community care funding observed, data from chapter 6 suggests that funding has failed to keep up with the needs of the population. Analysis by McGrail and Ahuja (2017) (see section 6.3.1) demonstrated that the proportion of public spending on long-term care and home care has significantly decreased in BC, suggesting that cost-shifting from the public health care system onto older adults and their families is occurring. Table 14 shows the proportion of provincial health care spending on community care compared to acute and

residential care. Residential and community care accounts for only 16% of total provincial health expenditures, while in contrast acute care accounts for 39%. The division of home and community care funding is 62% for long-term care and 38% for community care, illustrating that care in institutions continues to be prioritized over community care.

Table 14 Acute, Residential, and Community Care Provincial Health Expenditures 2017/18

	\$ (Millions)	% of total budget
Acute Care*	\$7,434	39%
Residential Care*	\$1,986	10%
Community Care*	\$1,227	6%
Total Provincial Health Expenditures**	\$18,922	

*Calculated from 2017/18 budget data from the 2018/19 -2020/21 Service Plans of the 5 regional health authorities.

** From the BC MOH's 2018/19 -2020/21 Service Plan

Assessment and Implications

Interview and financial data on home and community care spending, combined with observed declining access to home and community care services, supports the assessment that there has been insufficient investment in publicly subsidized home and community care services in BC. This is a major deficit of the system that jeopardizes the successfulness of initiatives to move care closer to home. In the Seaton Commission an important caveat was provided about moving care closer to the home for older adults: “Whether home care can be a viable option to institutional care depends largely on the resources that support it.” (Government of BC, 1991, p.32). The power imbalances that exist between the home and community care sector and other sectors of the health care system make successfully advocating for increased funding or shifting funding to the community challenging. Factors contributing to these power imbalances include home and community care services not falling under the umbrella of Medicare; public perceptions of the importance of different health care services; the lower social status of the clientele served by home and community care (i.e., frail elderly); the value placed on these services within the biomedical model; and the power of the staff working in the home and community care sector (i.e., primarily unregulated care providers) versus those working in other settings (i.e., doctors in acute and primary care). As will be described in the comparative analysis in chapter 14, adequately funding home and

community care services is a challenge that is being experienced by many jurisdictions, and lack of investment in home and community care seriously compromises the effectiveness of substitution policies.

Trends of downloading responsibilities onto patients have been observed across Canada as health care systems are undermined by underfunding and the hollowing out of care. Underlying these trends are neoliberal philosophies and the retrenchment of the welfare state (Williams et al., 2001). With home care, in times of fiscal constraint the responsibility, priority, and eligibility of home care clients often is contested (Bjornsdottir, 2013). This was the case in BC in the 1990s when cuts were made to home support services. In Canada, the ambiguous status of home and community care services makes them particularly susceptible to cuts and inadequate funding. Without adequate funding, the danger is that shifting care to the community will continue to be an exercise of downloading responsibilities onto the individual and their family.

8.2.4 Policies to Support Informal Caregivers

Summary of Key Findings from Stakeholder Interviews

In the 2014/15 interviews stakeholders did not believe enough attention was being paid to the needs of informal caregivers in policy. Stakeholders identified two types of supports required: respite (e.g., adult day services, home support) and targeted services for informal caregivers (e.g., financial benefits, support groups, etc.). In the 2019 interviews supports for informal caregivers was perceived as an urgent issue to address, and stakeholders increasingly raised concerns about the negative impacts of substitution policies. Stakeholders described how inadequate home and community care supports lead to a downloading of responsibilities onto informal caregivers (which has implications particularly for women). As will be described in the next sections, these perceptions of a lack of support for informal caregivers are supported by the lack of policies enacted over 2012-2019 and the lack of attention paid to informal caregivers in policy documents.

Analysis of Policies

Examination of government policy documents suggests there has been little consideration given on how to effectively support informal caregivers. Informal

caregivers were almost never mentioned in the home and community care action plans (Government of BC, 2012; BC MOH, 2017a) and integrated primary and community care policy papers (BC MOH, 2014a; 2015a). Even the *Dementia Action Plan*, which mentions informal caregivers quite frequently, contains no recommendations specifically on providing supports to informal caregivers (BC MOH, 2012b). While the policy documents referenced above do outline actions and policies that may potentially improve the experiences of informal caregivers, the omission of policies specifically targeting the needs of caregivers (e.g., providing flexible respite options, introducing financial benefits, providing one-on-one supports) is a significant oversight.

As described in chapter 6, in 2018 and 2019 there were some positive steps taken that suggest a growing awareness of the need to support informal caregivers (i.e., funding for adult day and respite services and caregiver support demonstration projects). However, experts recommend that in order to properly support informal caregivers policies are needed in four key areas: 1) Caregiver recognition and rights; 2) Services for older adults and caregivers; 3) Work-care reconciliation; and 4) Financial support (Cass, Fast, & Yeandle, 2014). Currently informal caregivers' needs are being addressed, but inadequately, in area two. Financially, there are some employment insurance benefits for informal caregivers available at the federal level, as well as tax credits at the provincial and federal levels. However, there are limitations to these benefits: 1) the employment insurance benefits are short-term benefits for caring for a person who is at end-of-life or critically ill/injured, and thus unsuitable for the needs of most informal caregivers of frail older adults; and 2) tax credits are usually non-refundable so only beneficial for people with sufficient taxable income (Fast, 2015). There is an urgent need for a more comprehensive suite of policies to be developed in BC to support informal caregivers, that should include not only the development of policies in the health care sector, but also employment and income policies.

Assessment and Implications

Integrated care frameworks described in chapter 2 emphasize the importance of policies to support informal caregivers. Yet, it is clear caregiver supports have been a neglected policy area in BC. Interviews with stakeholders and analysis of government policy documents and policies (or rather lack thereof) over 2012-2019 support the assessment that informal caregivers have been a neglected policy area in BC, though it

is encouraging that some increased attention has been paid to informal caregivers in recent years. Factors that may potentially contribute to the neglect of informal caregivers include: a) the absence of a powerful lobby group (i.e., unions, professional associations, coalition of organizations, etc.) to promote their interests; b) the gendered nature of caregiving and lower social status of informal caregivers (i.e., women engaging in unpaid labour); c) the significant burdens of care placed on informal caregivers that make self-organizing and self-advocacy challenging; and d) retrenchment of the welfare state and paradigms of family responsibility.

The lack of support for informal caregivers disproportionately affects women due to traditional gendered divisions of labour and ideologies of familism (Hooyman et al., 2002). While caregiving is often positioned as a choice, in reality lack of public services and income are key factors influencing choices to care (Hooyman et al., 2002). Population aging, retrenchment of the welfare state, and embracing the concept of aging in place means that increased reliance on informal caregivers is a common trend in modern societies (Milligan, 2009). The inadequacy of public supports for informal caregivers is not a problem exclusive to BC, as in most liberal welfare states despite the emphasis placed on the role of informal caregivers in rhetoric, explicit support for informal caregivers has been weak (Blank & Burau, 2010). However, there are other jurisdictions that BC can look to that provide a stronger set of supports for informal caregivers, as will be discussed in chapter 14.

8.3 Critical Analysis of the Framing of Home and Community Care within Health Care System Discourses

In the *Setting Priorities* (BC MOH, 2014a) and *Primary and Community Care in BC* (BC MOH, 2015a) policy documents that set the overall vision for the health care system, it is clear that concerns on sustainability are driving these strategies. For example, *Setting Priorities* proposes that the aging population and increasing demands on long-term care and acute care are threatening the sustainability of the health care system. It is explicitly stated that health care spending growth is unsustainable. The current economic challenges are framed as:

Government is challenged on how to meet the increasing costs of the health care system without raising taxes and cutting programs. This is further complicated by the belief of many Canadians that their public health care system should deliver more without requiring them to pay for it. (BC MOH, 2014a, p.13)

In these policy papers developing integrated primary and community care systems that can substitute less expensive care in the community for more expensive care in institutions is advanced as a way to better spend health care money. For example, in *Primary and Community Care in BC* 12 population groups are identified that are currently high users of health care system resources. Older adults make up a significant portion of several of these populations, accounting for 91% of the frail population in residential care, 53% of frail in the community, 93% in the community with high complex conditions, and 76% with palliative needs. The cost per year for a frail older adult living in long-term care is stated to be \$59,210 versus \$20,290 for those living in the community or \$29,690 for those living in the community with high chronic conditions (though these estimations do not include costs to informal caregivers) (BC MOH, 2015a). Both papers frame integrated primary and community care, and in particular care for older adults in the community, as solutions to decrease the demand for acute and long-term care by older adults. For example, the papers state:

It is estimated that frail seniors in the community may be underserved by existing community and support services, which may only hasten the need for high-intensity residential care (BC MOH, 2014a, p.24)

Inadequate or ineffective community care results in an increased demand for acute care services, which is both sub-optimal for patient care and wellbeing and more expensive for the system. (BC MOH, 2015a, p.45)

This same analysis points to the need for community-based, coordinated care that: (a) defers, where possible, the need for residential care; or (b) when residential care is required, facilitates access in a planned manner rather than through a health crisis requiring an emergency visit and inpatient stay in the hospital. (BC MOH, 2015a, p.52)

Consideration of discourse is important as it shapes our perceptions of what the policy problem is, as well as potential policy solutions (Fischer, 2003). The main policy problems in these documents are unsustainable health care spending and increased pressures on institutional care, while the policy solutions are developing integrated primary and community care systems and the substitution of less expensive community care. This narrative reflects global trends where the dominant goals of health care

systems have shifted from equity and access to cost containment. This also is representative of the ideological shift that has occurred in the Western world with the embracing of neoliberal principles (e.g., productivity, efficiency, management, etc.) (Blank & Burau, 2010). This is the overarching narrative within which home and community reforms were being carried out in BC.

While the rhetoric within the home and community care actions plans (Government of BC, 2012; BC MOH, 2017a) does not reflect these sustainability and substitution narratives as strongly, alternative narratives such as the importance of these services for older adults' quality of life or ability to age in place are underdeveloped. The first action plan is framed specifically around responding to the Ombudsperson's reports. The narrative within the second action plan does advance quality of life as a value for delivering home and community care services to older adults (BC MOH, 2017a, p.2):

These specialized services require more than a medical lens. They require shifting how the health system approaches seniors care – and partners with other support systems in seniors' lives – to add a greater focus on enhancing quality of life. Many of the medical conditions experienced by seniors are more about how they live with their conditions, with the highest quality of life possible, rather than a cure.

However, despite some differences in the framing of the policy issue, home health services are still only discussed within the context of integrating primary and community care and the development of SCSPs for older adults.

This analysis of the narratives and framing of home and community care policy elucidates two areas for further scrutiny that will be discussed below: 1) Discourses on the sustainability of the health care system and 2) Discourses on the purpose of home and community care services.

8.3.1 Discourses on the Sustainability of the Health Care System

Within BC, the frames presented on the sustainability of the health care system should be closely scrutinized. In the stakeholder interviews, concerns were raised by some stakeholders about the rhetoric on the sustainability of the health care system. CIHI (2019a) reports that BC spends the second lowest amount per capita on health care in Canada. However, health care spending makes up 43% of the provincial budget (the third highest amount in Canada). Evans (2003), a prominent health economist,

wrote about the relationship between perceptions health care is “crowding out” other programs and tax cuts that have lowered the revenue bases of governments:

But who should pay, and who should get the care? Under public insurance, the burden would fall on taxpayers and the benefits would go to patients. Government expenditure on health care would rise, as would taxation. The claim that such increases would be “unsustainable” boils down to saying that this pattern of burdens and benefits is morally wrong...This moral position does not appear to be widely shared by the Canadian public. Nor can its advocates credibly claim that governments “cannot afford” such increased expenditures, while simultaneously advocating and carrying through substantial cuts to income taxes. (p.22)

As the analysis by McGrail and Ahuja (2017) demonstrated, the proportion of public spending on long-term care and home care has significantly decreased. While it is beyond the scope of this dissertation to conduct an economic analysis on home and community care in BC, what is readily apparent is the fact that there needs to be more discourse on health care spending beyond the simple assertion that it is unsustainable. Policy options to sustainably fund home and community care services should be considered. Are Canadians willing to pay higher taxes for better health care services? Are there other institutions (e.g., corporations) that also could be paying more? Are current allocations of funding for different sectors of the health care system appropriate? What services should we provide to our older adult population? These are questions that together the government, society, and relevant stakeholders should be engaging in discourse on. As was suggested in several of the stakeholder interviews, BC needs to engage with the public to discuss these issues.

8.3.2 Discourses on the Purpose of Home and Community Care Services

Policy discourses on providing care in the home and community have focused mostly on the benefits that will be provided to the health care system if these changes are made, rather than the benefits that will be provided to older adults. Interestingly, the term “aging in place” is only very rarely used in BC policy documents, instead the policy issue is framed as shifting care away from long-term care and acute care to the home and community. This is a notable distinction as the concept of aging in place necessitates providing a broad range of supports to meet the needs of older adults, while the concept of shifting care to the community focuses on meeting the needs of the

health care system. Ceci and Purkis (2011) note how conceptualizations of home care have shifted over time, from a service to support older adults' independence to a cost-effective solution that will save the health care system money and divert people away from institutions. If home health services are perceived primarily as a solution for ills within the broader health care system rather than services for older adults, then the policy neglect and contrary policies on supporting care in the community begin to make more sense. Within BC, the findings from chapters 6 and 7 suggest that home health services are primarily being conceptualized as a cost-effective solution for the health care system. This is evidenced by:

- The increasing complexity of clients and concentration of home care services in higher needs clients.
- Policies introduced in the 1990s and early 2000s to remove lower needs home support clients, restrict access to services, and narrow the scope of these services.
- The downloading of responsibilities onto informal caregivers, lack of supports for informal caregivers, and large proportion of informal caregivers who are in distress.
- The underfunding of home and community care services.
- Rhetoric on home health services in policy documents, and the lack of attention paid to these services beyond their potential to substitute for acute or long-term care.

The ability to substitute lower cost community care for higher cost care in institutions is one of the key benefits of an integrated continuing care system and a worthwhile policy objective to pursue. However, when the motivation to do this is primarily due to the potential utility to the health care system, and as a result inadequate resources are invested and complementary policies are not developed, substitution policies can become exercises in downloading responsibilities onto older adults and their families.

8.4 Conclusion

While some promising steps have been made in BC to improve the home and community care system, review of relevant reports, research and interviews with stakeholders confirm that further reforms are needed to address systemic issues and

ensure the system can meet the needs of older adults and informal caregivers. Home and community care remains a neglected part of the health care system, and further policy development is needed to develop an integrated continuing care system. Key to this is not losing sight of the older adult when developing policies and ensuring that policies first and foremost serve older adults. In the following five chapters, continuing care systems and policies from five other jurisdictions are described. As will be seen in these chapters, all jurisdictions share similar challenges and goals as BC. However, policies, approaches, motivations, and outcomes have differed, and the experiences of other jurisdictions offer both promising policies and cautions. Chapter 14 brings the experiences of all these jurisdictions together to discuss policy convergences and divergences, while chapter 15 discusses recommendations for BC.

Chapter 9.

The Case of Ontario

This chapter provides an analysis of the long-term care system in Ontario over 2012-2019. This analysis was informed by interviews with key informants in Ontario in 2014/15 (n=2) and 2019/20 (n=3), analysis of government policy documents, and review of websites, reports, and other literature on the long-term care system. Section 9.1 describes the health care system and long-term care system. Section 9.2 provides information on the policy context in Ontario and impact of key reforms. Section 9.3 critically analyzes the case of Ontario. Further critical analysis is included in the comparative analysis in chapter 14. Focus is placed on the reforms that occurred before the new Progressive Conservative Government was elected in 2018, as the policies and proposed plans of this government represent significant departures from past policies and are only in the very early stages. (A brief description of their proposed reforms is provided in Section 9.1.1 and some discussion of the potential implications of the proposed policies and reforms is included in Section 9.3).

9.1 Provincial Health Care Context

9.1.1 Health Care System Structure and Governance

Ontario has a universal public health care system that is regulated by the federal *Canada Health Act* and relevant provincial legislation. The Ministry of Health and Long-Term Care (MOHLTC) has overall responsibility for health care, while 14 Local Health Integration Networks (LHINs) fill roles similar to regional health authorities and are responsible for planning and funding health services in their regions and creating agreements with service providers. Organizations within the LHINs' oversight include hospitals, community-based primary care models, home care, long-term care, and community-based services (Cheng, 2018). Since 2017, the LHINs have been directly responsible for providing access to long-term care services. However, until recently these services were accessed through independent Community Care Access Centres (CCACs) operating within the oversight of the LHINs (Government of Ontario, 2017). Primary care providers generally operate independently of the LHINs, though Family

Health Teams (interprofessional care team model) are under their oversight (Peckham, Kreindler, Church, Chatwood, & Marchildon, 2018a). In order to improve the coordination of care for complex patients, the Health Links model was introduced across Ontario beginning in 2012 to form networks of health, social, and community providers (Government of Ontario, n.d.).

In early 2019, the new Provincial Government announced their intention to form Ontario Health Teams (local teams that will incorporate primary care, hospitals, home and community care, long-term care, palliative care, and mental health) and also the development of the super agency Ontario Health that will incorporate certain functions of the LHINs and other provincial agencies (Government of Ontario, 2019a). As of the end of 2019, these changes were only in the very early stages and the responsibility for home and community care remained with the LHINs (Government of Ontario, 2019b).

9.1.2 Long-Term Care System

Long-term care homes and home and community care are the core publicly subsidized services for the care of older adults (Government of Ontario, 2019c; 2019d). Publicly funded community support services and intermediate level housing options (e.g., supportive housing/assisted living) may also be available in some communities, but this is dependent on the presence of local non-profit organizations (Office of the Auditor General of Ontario, 2015a). Intermediate levels of care such as supportive housing have not been well developed as a publicly funded resource for older adults in Ontario (Sinha, 2012). In addition to publicly subsidized long-term care services, there are also numerous private pay services available for those who can afford them. In particular, private pay retirement homes (regulated seniors' residences that can provide a range of combinations of accommodation, support services, and personal care) are a key component of the seniors' care landscape (Government of Ontario, 2019e). Table 15 provides an overview of key aspects of the long-term care system in Ontario using an adapted version of the INTERLINKS Framework.

Table 15 INTERLINKS Framework for Long-Term Care: Ontario

INTERLINKS Framework for Long-Term Care	
Identity of Long-Term Care	
<i>Values</i>	<ul style="list-style-type: none"> The Statement of Home and Community Care Values identifies five core values: Reliable, Accessible, Respectful, Integrated, and Accountable.^a

	<ul style="list-style-type: none"> Long-term care homes should be operated so that older adults “may live with dignity and in security, safety and comfort and have their physical, psychological, social, spiritual and cultural needs adequately met.”^b
Policy and Governance	
<i>Policy</i>	<ul style="list-style-type: none"> See section 9.2 for discussion of long-term care policy in Ontario.
<i>Governance mechanisms</i>	<ul style="list-style-type: none"> LHINs fund and create service agreements with health care organizations/providers in their region.^c This includes long-term care facilities (operated by contracted for-profit, non-profit, or municipal organizations), community support services (provided by non-profit organizations), and home care (provided by contracted non-profit or for-profit providers).^{d, e} Up until 2017, non-profit CCACs were responsible for oversight and contracting of home care services.^c
Pathways and Processes	
<i>Accessing services</i>	<ul style="list-style-type: none"> Home care, long-term care, and certain community support services (supportive housing and adult day services) had a single access point through the CCACs up until 2017, and are now accessed through the LHINs.^{d, f} Other community support services can be accessed independently or through referral from the LHIN.^{d, f}
<i>Assessing needs</i>	<ul style="list-style-type: none"> Care coordinators are responsible for assessing clients using the RAI, developing care plans, and coordinating care.^d The Integrated Assessment Record system allowed care coordinators to share assessment records with support agencies.^d
<i>Interdisciplinary work</i>	<ul style="list-style-type: none"> Multidisciplinary coordinated care plans are developed for complex patients through Health Links.^g
Organisational Structures	
<i>Nursing and residential care homes</i>	<ul style="list-style-type: none"> Long-term care homes provide care for people who require access to 24-hour professional and personal care. Care is provided free of charge, but residents must pay a fee for their room and board.^h Restorative care approaches must be integrated into care in long-term care homes.^b
<i>Care within a hospital setting</i>	<ul style="list-style-type: none"> Several initiatives to improve transitions between care settings and prevent unnecessary hospital admissions have been explored in Ontario including: expanded community paramedicine roles, long-term care nurse-led outreach teams, geriatric emergency medicine nurses, and rapid response nurses.ⁱ Policies such as Home First (ensuring hospital patients return home instead of long-term care), Home at Last (assisting patients without caregivers to return home from acute care) and Waiting at Home (discharging patients from acute care to home with advanced supports to wait for long-term care placement) have been widely adopted.ⁱ
<i>Transitory care facilities</i>	<ul style="list-style-type: none"> The Convalescent Care Program provides beds in long-term care facilities for the support and rehabilitation of patients who have been in the hospital and require additional supports before being discharged to home.ⁱ
<i>Assisted living arrangements</i>	<ul style="list-style-type: none"> Publicly subsidized supportive housing is not widely available but may be accessed in some communities for older adults.^f
<i>Formal care in the home and the community</i>	<ul style="list-style-type: none"> Publicly subsidized home care services include professional care (e.g., physiotherapy, nursing, occupational therapy, etc.), personal care (e.g., washing, eating, toileting, personal hygiene, travel to appointments, etc.), homemaking services (e.g., meals, shopping, cleaning, laundry, bills and banking), and end-of-life care.^j For eligible clients, home care services are provided free of charge.^d

	<ul style="list-style-type: none"> LHINs fund non-profit organizations to provide community support services for older adults such as adult day services, caregiver supports and respite, and meal services. Co-payments may be required to receive these services.^f
<i>Specialised case or care management centres</i>	<ul style="list-style-type: none"> The Health Links model has been developed to improve coordination of care for complex patients, and offers specialized care management through the development of coordinated care plans.ⁱ
Means and Resources	
<i>(Shared) funding</i>	<ul style="list-style-type: none"> Public health care is financed from provincial and federal revenues. In 2016/17 funding from the Federal Government accounted for 25% of public health care funding.^k As part of the 2017 Health Care Agreement with the Federal Government, Ontario will receive \$2.3 billion in targeted funding for home care over the next 10 years.^l
<i>Enabling, allocating and funding human resources</i>	<ul style="list-style-type: none"> There have been growing shortages of personal support workers who provide the bulk of the care in long-term care homes and the home.^m In 2014/15 the MOHLTC began to provide additional funding to CCACs to increase the base wages of personal support workers.^d
<i>Supporting informal carers as a resource for LTC</i>	<ul style="list-style-type: none"> Supporting caregivers was part of the mandate of the CCACs, however, access to supports was limited and included respite in the home (though these hours come out of the home care client's hours) or referral to respite beds or community services.^d In 2018, the non-profit Ontario Caregiver Organization was established (funded by government) to provide information and coordinate the various services for informal caregivers in the community.ⁿ
<i>Financial indicators</i>	<ul style="list-style-type: none"> The health care system in Ontario is the largest source of provincial government spending, accounting for 41% of the budget in 2018/19.^o In the health care budget community programs (home care, mental health and other community programs) account for 10% of the budget and long-term care 7%.^o
<i>Role of information technology</i>	<ul style="list-style-type: none"> Work has been underway since the 2000s to develop an electronic health record. The core projects associated with developing an electronic health record were fully completed in 2017.^p The information platform utilized for home and community care (CHRIS) has been integrated into the clinical viewer and ehealth portal of the electronic health record, allowing other sectors/organizations to view these records.^q

Sources: a. Ontario MOHLTC (2018); b. Long-Term Care Homes Act, 2007; c. Cheng (2018); d. Office of the Auditor General of Ontario (2015a); e. Office of the Auditor General of Ontario (2012a); f. Government of Ontario (2018); g. Government of Ontario (n.d.); h. Government of Ontario (2019d); i. Sinha (2012); j. Government of Ontario (2019c); k. Financial Accountability Office of Ontario (2018); l. Health Canada (2017); m. Ontario Health Coalition (2019); n. Ontario Caregiver Organization (2019); o. Financial Accountability Office of Ontario (2019); p. Office of the Auditor General of Ontario (2018); q. eHealth Ontario (2018)

9.2 Long-Term Care Policy Context and Objectives, 2012-2019

The following sections describe the long-term care policy context and objectives in Ontario over 2012-2019. Section 9.2.1 provides a brief overview of the political and

economic landscape. Section 9.2.2 reviews key government policy documents relevant to long-term care. Section 9.2.3 covers the policy context and key events during this time period. Section 9.2.4 reviews relevant evaluations and evidence on the impact of reforms during this period. Section 9.2.5 provides interview data from key informants on the policy context and reforms during this period.

9.2.1 Political and Economic Landscape

Over 2003-2018, Liberal Governments were in power in Ontario, allowing for a significant period of policy continuity. In the 2016 census, the population of Ontario was 13.4 million and 16.7% of the population (2,251,655) were older adults (Statistics Canada, 2019b). The period of 2011/12 to 2016/17 was a time of fiscal constraint, with health care spending growing by an annual average of 2.2%. A period of increased health care investment followed over 2016/17 to 2018/19 and the annual average growth of health care spending doubled to 4.4% (Financial Accountability Office of Ontario, 2019a). Community programs experienced an average annual spending growth of 5.3% over 2011/12 to 2016-17, and this increased to 7.5% over 2017/18 to 2018/19. Over the same time periods, average annual growth of long-term care spending were 2.2% and 3.2% respectively (Financial Accountability Office of Ontario, 2019a). In 2018, the Progressive Conservative party came to power and committed to balancing the budget, suggesting an upcoming period of economic restraint for the health care system (Financial Accountability Office of Ontario, 2019a).

9.2.2 Key Policy Documents

Over 2012-2019 there were two key policy documents driving overall health care policy in Ontario:

- *Ontario's Action Plan for Health Care* was developed within the context of government concerns about demographic and fiscal challenges. This plan had three goals: 1) Keep Ontario healthy; 2) Faster access and stronger links to family health care; and 3) Providing the right care at the right time and place. Proposed actions relevant to long-term care were prioritizing provision of care as close to home as possible and developing a seniors' strategy (Ontario MOHLTC, 2012). In 2014, an accompanying statement was released on the vision for home and community care, reaffirming its importance to achieving the goal of providing the right care in the right time and place (Ontario MOHLTC, 2014).

- *Patients First: Action Plan for Health Care* built upon the 2012 action plan and identified four action areas: 1) Improving access to the right care; 2) Delivering better coordinated and integrated care in the community; 3) Supporting people and patients to make decisions about their health care; and 4) Making decisions based on value and quality to sustain the health care system. Actions to improve long-term care included: increasing access to home and community care; redeveloping long-term care beds; and improving working conditions and recruitment of personal support workers (Ontario MOHLTC, 2015a).

Following *Patients First*, a complementary ten-step plan for improving home and community care entitled *Patients First: A Roadmap to Strengthen Home and Community Care* was also released (see table 16 for the ten-steps) (Ontario MOHLTC, 2015b). This roadmap included a commitment to increase home and community care funding by 5% annually over the next 3 years (extra \$750 million total) (Ontario MOHLTC, 2015b). At the end of 2015 an additional discussion paper was released with a proposal to make structural changes to the LHINs that would expand their role and amalgamate the CCACs into the LHINs (Ontario MOHLTC, 2015c).

Table 16 Ten Steps to Strengthen Home and Community Care

Ten Steps to Strengthen Home and Community Care
1. Develop a statement of home and community care values
2. Create a levels of care framework
3. Increase funding for home and community care
4. Move forward with bundled care
5. Offer self-directed care
6. Expand caregiver supports
7. Enhanced support for personal support workers
8. More nursing services
9. Provide greater choice for palliative and end-of-life care
10. Develop a capacity plan

Data Source: Ontario MOHLTC (2015b)

Complementing the health care strategies of the Ontario MOHLTC during this time were holistic seniors' strategies published in 2013 and 2017. A comprehensive report was commissioned to inform the development of the first seniors' strategy (Sinha, 2012); however, the strategy adopted only a small number of the recommendations. Some of the actions in the seniors' strategy relevant to long-term care included improving oversight and safety in long-term care homes, increasing personal support

service hours, and increasing house calls and access to acute care at home (Ontario Seniors Secretariat, 2013). In 2017, a new strategy was released to complement the *Patients First* policies. Some of the actions relevant to long-term care included the development of a provincial caregiver organization, scaling up long-term care capacity, and modest expansions to supportive housing (Government of Ontario, 2017).

9.2.3 Policy Context and Key Events

In addition to the Provincial Government and Ontario MOHLTC, many actors were involved in shaping long-term care policy in Ontario over 2012-2019. These included: monitoring agencies; expert panels and working groups; independent think tanks; health care providers and unions; lobby and representative groups; and older adults, caregivers, and the general public.

During the first half of 2012-2019 under *Ontario's Action Plan for Health Care*, long-term care received limited attention on the policy agenda. There were some investments made to expand home care services, but otherwise changes were limited (Government of Ontario, 2014). One noteworthy reform that occurred during this period was the development of Health Links. Health Links were local networks of providers (e.g., hospitals, primary care providers, CCACs, social care services, etc.) introduced in 2012 to integrate and improve the coordination of health and social care services for high needs patients such as older adults (Government of Ontario, 2012). CCACs often took on the lead role within Health Links due to their complementary patient populations and overlapping care objectives (Evans, Grudniewicz, Wodchis & Baker, 2014).

Significant changes to long-term care were made from 2015 onwards as a part of the *Patients First* agenda. Various contextual factors and events contributed to the placement (or prioritizing) of long-term care issues on the policy agenda, and the formulation and implementation of *Patients First* and other new policies. Based on analysis of relevant literature and government sources, table 17 describes some influential policy issues and contextual factors leading up to *Patients First* reforms.

Table 17 Contextual Factors Leading up to Patients First Reforms

Contextual Factors Leading up to Patients First Reforms
Inability of LHINs to fulfill their intended roles: LHINs were not considered to be fully successful in fulfilling their desired integration and planning roles for several reasons, including the lack of clarity/overlap between their role and certain services (e.g., CCACs, the Ministry) and their lack of jurisdiction over several services including primary care (Cheng, 2018).
Policy priority of reducing unnecessary hospital use: Unnecessary hospital use by older adults (ALC and avoidable admissions) was a key policy issue, with two expert reports commissioned by the MOHLTC in 2011; both recommended strengthening home and community care services as part of the solution (Walker, 2011; Avoidable Hospital Advisory Panel, 2011).
Increasing pressures on community services: Increasingly home care services were being reserved for highly complex and/or short-term acute patients due to expectations that hospitals move ALC patients out of hospital beds (Office of the Auditor General of Ontario, 2015b; Ontario Health Coalition, 2015). Policies and practices such as Home First, Home at Last, and Waiting at Home emphasize discharge from acute care to the home (Sinha, 2012).

Arguably though, the CCACs and home care were the most significant policy issue influencing *Patients First* and the series of new policies introduced over 2015-2018. In 2014, the MOHLTC had appointed an Expert Group on Home and Community Care to make recommendations on transforming home and community care (Expert Group on Home and Community Care, 2015). Below, some of the key issues with CCACs and home care in Ontario leading up to *Patients First* are described. These issues were identified from the Expert Group's report as well as reports from monitoring organizations, advocacy and representative groups, and academics.

The first issue was a historical policy issue that while resolved in 2012 resulted in substantial negative attention towards the CCACs. A competitive bidding process was introduced along with the CCACs by the Progressive Conservatives in the 1990s. This system, requiring home care providers to bid on contracts, had long been a subject of critique by advocacy organizations, unions, and academics (e.g., Ontario Health Coalition, 2011; Baranek, Deber & Williams, 2004; CUPE, 2008). The competitive bidding process was never fully workable, due primarily to the significant disruptions caused by contract transitions (Ontario Association of CCAC, 2014). This process was paused in 2008 and then replaced with long-term performance-based contracts in 2012 (Office of the Auditor General of Ontario, 2015a).

A second issue with CCACs was their lack of integration with other health care sectors and challenges coordinating services. CCACs had over 260 contracts for personal care, therapy, and nursing and there were over 800 community support

services (Expert Group on Home and Community Care, 2015). The Expert Group identified the need to better coordinate home and community services, as well as improve the integration of primary and community care (Expert Group on Home and Community Care, 2015). Several independent reports had also brought attention to issues with care coordination for older adults (e.g., Baranek, 2011; The Change Foundation, 2012). Past reports had also questioned the structure and role of CCACs (e.g., Sinha, 2012).

Finally, two additional interrelated issues with the CCACs were a) the requirement that they operate within a set budget that was usually inadequate to meet needs and b) lack of standard service guidelines. Together these issues meant there were no universal entitlements to services and there were significant variations in access. These issues were raised by academics, advocacy groups, and the Auditor General of Ontario (e.g., Williams et al., 2009a; Office of the Auditor General of Ontario, 2015b; Ontario Health Coalition, 2011; 2015). Reports by the Office of the Auditor General of Ontario (e.g., 2010; 2012; 2015a) consistently identified problems with access to home care services due to variations in funding for CCACs, lack of funding and resources, and lack of standard service guidelines.

The Expert Group on Home and Community Care appointed by the MOHLTC released their report *Bringing Care Home* in 2015, identifying five key themes for system change (see table 18). Providing family centred-care that responds to the needs of both the client and the caregiver was the most important theme that emerged in their consultations. The report included 16 recommendations and a Home and Community Care Charter (Expert Group on Home and Community Care, 2015).

Table 18 Bringing Care Home: Key Themes

<p>Provide Family-Centred Care: The needs of the client should be assessed in the care plan. Care needs to be centred around the client and the family. Coordination of care needs to be improved and a single point of contact provided. Greater access to supports for caregivers and particularly respite is needed.</p>
<p>Clarify what services are available: Greater clarity is needed about what services are available and who is eligible, and how eligibility is assessed. A basket of services needs to be explicitly defined. The scope of publicly funded services should be expanded to include a full continuum of necessary supports. Equity is needed between regions regarding funding and available services.</p>
<p>Deliver better coordinated and integrated services: Services and care providers needs to be better coordinated. Greater integration is also needed with primary care and other government services.</p>

More efficient approaches to service delivery: Develop new approaches to service delivery for post-acute clients, clients with functional limitations/chronic conditions, and clients with complex, cross-cutting needs. Maximizing the use of available resources through innovations such as clustered care or delivery in congregate settings, technology, etc.

Increase accountability for performance: Population-based capacity planning and more measuring and reporting on the system is necessary.

Data Source: Expert Group on Home and Community Care (2015)

The MOHLTC released the *Patients First* roadmap (as described in section 9.2.2) in response, which adopted some of their recommendations and focused on functional changes to the home and community care system. While *Bringing Care Home* did not address structural issues related to home and community care (i.e., the future of the CCACs), a special report by the Office of the Auditor General of Ontario (2015b) reinforced the issues with the CCACs, and questioned their role and high administrative costs. The Provincial Government's proposal to transfer the CCACs to the LHINs (Ontario MOHLTC, 2015c) was released soon after this report by the Auditor General and shifted the focus from functional to structural changes.

Bringing Care Home and the *Patients First* roadmap had both emphasized the importance of enhancing supports to informal caregivers. Informal caregivers had also received policy attention from the think tank the Change Foundation who identified informal caregivers as the focus of their 2015-2020 strategic plan (The Change Foundation, 2015). Health Quality Ontario (2015) also released a report that about one-third of informal caregivers of long-stay home care clients experienced distress. In 2017, the Ontario MOHLTC appointed an advisor to develop a report to inform the next steps for strengthening informal caregiver supports. This report recommended a) the implementation of individual, organizational, and system levels supports for informal caregivers and b) the formation of a provincial caregiver organization to coordinate and deliver supports (Beed, 2017). Following this report, the 2017 seniors strategy included the creation of a provincial caregiver organization (Government of Ontario, 2017).

In the 2017 seniors strategy a significant scaling up of long-term care capacity was also proposed through the redevelopment of 30,000 long-term care beds by 2025 and development of 30,000 additional new beds over the next decade (Government of Ontario, 2017). Long-term care capacity had consistently been a policy issue in Ontario (i.e., waitlists and bed shortages, ensuring the right balance of bed types, and redeveloping beds) (Office of the Auditor General of Ontario, 2012b; Long-Term Care

Expert Innovation Panel, 2012). The Financial Accountability Office of Ontario (2019b) reported that over 2012/13 to 2018/19 the waitlist for long-term care increased from 19,615 people to 34,862. The last major long-term care bed redevelopment occurred in the early 2000s, while later governments had avoided increasing long-term care capacity (William et al., 2016). The Ontario Association of Non-Profit Homes and Services for Seniors (2016) estimated that even if 50% of older adults were diverted to the community in coming years, there would still be almost 24,000 people waiting for long-term care beds in 2021. The capacity issues in the long-term care sector were compounded by personal support workers shortages (Ontario Health Coalition, 2019).

9.2.4 Evidence of Impact of Key Reforms

This section contains further descriptions of some of the key reforms that were implemented during the period of 2012-2019 in Ontario: the Health Links, the Patients First Act, reforms from the Patients First Roadmap (levels of care framework, bundled care, and self-directed care), and the establishment of the Ontario Caregivers Organization. In the cases where information is available, evidence on the impact of these reforms and any relevant evaluations have been described. However, the short duration some of these reforms have been in place and the changes in progress under the new Provincial Government meant it was not always possible to obtain information on the impact of these reforms and their current status.

Health Links

A reform relevant to the coordination of care for older adults was the introduction in 2012 of the Health Links. The Health Links were inspired by Accountable Care Organizations, similar network models from other countries, as well as the Northumberland Partners Advancing Transitions in Health Care project in Ontario (Evans et al., 2014; The Change Foundation, 2016). Health Links were implemented with a “low-rules” approach, intended to encourage flexibility, responsiveness to local needs, and bottom-up leadership (Evans et al., 2014). By 2015, 82 Health Links had been established across Ontario, bringing together over 1,800 health, social care, and community organizations to improve care coordination, access to primary care, and patient engagement (Government of Ontario, n.d.). Focus then shifted to implementing the Advanced Health Links Model to improve standardization, performance management

and oversight, redesign the funding model, and promote wider system integration (Government of Ontario, n.d.).

An evaluation of the Health Links by researchers from the Health Systems Performance Research Network found significant variation in the performance of individual Health Links (Mondor, Song, & Wodchis, 2016). This analysis compared selected health indicators for the Health Links target populations between 2012 and 2014. For the target populations there were statistically significant improvements for: total health care costs per patient per month (1% decrease), primary care follow-up after hospitalization (2% increase), and low acuity emergency department visits (10% decrease). There was a statistically significant increase (4%) in overall emergency department visit rates (this increase was also observed in Health Link target population members who were not within a Health Links catchment area). Supplemental examination of health care costs found “the costs associated with care for the complex, high-needs population of Ontario are being shifted away from the acute setting to the community.” (Mondor et al., 2016, p.14). The evaluation estimated that if the Health Links model were spread to all eligible patients it would decrease health care costs by up to \$164 million dollars per year (Mondor et al., 2016). Another evaluation by this research team examined hospital-related outcomes and found no statistically significant differences between Health Links and comparison patients (Mondor, Walker, Bai, & Wodchis, 2017). As of 2018/19, 79,673 complex patients had coordinated care plans (approximately 11.9% of potentially eligible patients) (Health Quality Ontario, 2019).

Patients First Act: Transferring Responsibility for Home and Community Care from the CCACs to the LHINs

In 2016, the Government of Ontario passed the *Patients First Act*, enacting several changes to the structure of health care that had been proposed in the *Patients First* proposal. The most significant change was the transfer of responsibility for home and community care from the CCACs to the LHINs (Sheppard, 2019). A staged transfer of staff and programs from the CCACs to the LHINs took place over May - June 2017 (Ontario MOHLTC, 2017). Key goals of this restructuring included improving the integration of primary and community care, increasing the capacity of the LHINs to coordinate and plan care, and reducing unnecessary bureaucracy and spending (Sheppard, 2019). A SWOT analysis of the policy by Sheppard (2019) identified several

benefits of the policy including that it reduced bureaucracy and improved integration; however, the fact this structural change did not address key issues within the home and community care sector (e.g., capacity, funding) was acknowledged as a weakness. As described previously, further structural changes are in progress under the new Provincial Government, therefore this new structure for services will be changed in the future.

Levels of Care Framework

An expert panel was formed in 2016 to develop the Levels of Care Framework proposed in the *Patients First* roadmap. The Levels of Care Framework was intended to ensure transparency and consistency in the assessment and provision of home and community care. It included 7 levels of care for clients requiring long-term home and community care services, ranging from clients requiring only community support services (Level 1) to above 120 support hours per month (Level 7). The framework emphasizes the need to consider contextual factors (e.g., caregiver capacity, income, medical conditions) when completing assessments and developing care plans. The framework identifies both the individual and their caregivers as partners in care (Levels of Care Expert Panel, 2017).

Bundled Care

Bundled care is an integrated funding approach that provides a group of providers a single payment for care of a patient across care settings (e.g., hospital, home, etc.) (Ontario MOHLTC, 2015b). Several organizations had experimented with bundled care in Ontario prior to its recommended expansion in the *Patients First* roadmap, including St. Joseph's Health Care System and the Toronto CCAC. Promising results from these bundled care projects and a desire to receive better value for money led to the interest in expanding bundled care (Wojtak & Purbhoo, 2015).

As a part of the *Patients First* roadmap, a bundled care pilot project was launched in 2015 to test the approach at six sites for target populations from acute care to post-acute care. Researchers from the Health Systems Performance Research Network were contracted to evaluate the pilot project. The evaluation by Walker, Hall and Wodchis (2019) found the pilots had generally been effective in reducing hospital length of stay, readmissions, and emergency department visits, though results were primarily driven by the projects for cardiac surgery and COPD/CHF patients. The report

recommended moving forward with the surgical bundled care approach, but for the medical bundles cautioned that further work is needed to develop the approach (Walker et al., 2019). A review of the evidence on bundled care by Wojtak and Purbhoo (2015) noted that evidence on the effectiveness of bundled care has primarily been limited to acute and post-acute situations. Government has indicated the Ontario Health Teams will continue implementing bundled care approaches (Government of Ontario, 2019).

Self-Directed Personal Support Services

Another model of integrated funding is self-directed care where an individual is given a budget to procure and manage their own home care services. In 2017, the crown agency Self-Directed Personal Support Services Ontario was established to employ a pool of personal support workers for individuals who wished to receive self-directed care. The intention was to increase access to self-directed care (specifically for older adults) and address some of the concerns about self-directed care from labour and users (i.e., reducing management responsibilities for users) (Dansereau, Hande, & Kelly, 2019). Services were expected to be launched in 2019 (Self-Directed Care Ontario, 2018). However, this new program was criticized by various sources (e.g., unions, caregiver organizations, home care providers), and legally challenged by home care agencies who viewed it as unfair competition. Within this context, in 2018 the new Provincial Government decided to dissolve the organization (Dansereau et al., 2019).

Development of the Ontario Caregiver Organization

The key recommendation from the report on informal caregivers was the development of a provincial caregiver support organization (Beed, 2017). In 2018, the provincially funded non-profit The Ontario Caregiver Organization was established. Their work is focused on enhancing informal caregivers' access to already existing programs and resources; increasing understanding and awareness of needs; and working with informal caregivers, government, and stakeholders to shape policy and programs (Ontario Caregiver Organization, 2018). This organization is only in the very early stages, but one of the actions they have already taken is launching a Caregiver Helpline, which was a priority identified in a survey of over 800 informal caregivers (The Change Foundation, 2020). The new Provincial Government has indicated its continued support for the organization (Ontario Caregiver Organization 2019).

9.2.5 Key Informant Interviews

The interviews with key informants conducted in 2014/15 and 2019/20 played an important role in identifying major long-term care reforms and highlighting relevant literature and policy actors as described in the sections above. This section describes some of the additional insights gained from the key informants on the reforms in Ontario.

In the 2014/15 interviews the CCACs were an important focus of discussion. At the time the structure was that CCACs procured the services for people who require support either in the home or in a long-term care facility, and the services were delivered by contracted non-profits and for-profit agencies. Informants highlighted several issues with these arrangements. The separation from direct delivery was described by both informants as adding an additional layer of complexity and administration. For example, an informant stated:

Well I think the separation from direct delivery actually doesn't make a ton of sense. It kind of adds this layer in the middle and we don't do it for any other health service. (Ontario Interview 1)

Both informants brought up the question of whether it should be the CCAC providing case management or another group such as the provider agency or primary care. Informants also commented that originally when the CCACs had been established a competitive bidding process was in place. The competitive bidding process was eventually frozen and had been discontinued in favour of long-term contracts:

So the structure of the contracts is different, but it's sort of ironic, when they were set up with an absolute mandate to get best price—they don't even do that anymore. So you know not only are they not doing a good job on case coordination, but they're not even ensuring that you know the dollars are competitively allocated on the basis of some metrics. (Ontario Interview 1)

Informants highlighted two groups of actors who had exerted pressure on the provincial government to end the competitive bidding system a) traditional non-profit and small business providers who had difficulty competing in this type of system and b) clients who had experienced disruptions to their care when contracts came up for renewal and changed hands.

Frequent year end budget shortfalls also contributed to negative public perceptions of CCACs. CCACs were challenged by the fact the MOHLTC did not confirm

their budget until about halfway through the year, making it difficult to appropriately plan service levels. As a result, in the last quarter of the year CCACs often had to cut services for people who needed them as they were not allowed to run a deficit. One of the key informants commented on home care services:

So, I think it's a good thing that Ontario has free services – whether they'll be able to continue with that is another whole story – but what they do to manage the budget is basically restrict the service rather than charging fees...Currently there is no income screening, so it's totally based on people's needs. Having said that, it's usually unequal to meet those needs. In other words, the amount of service a person can get is quite limited and that means that often people are having to supplement the services with their own money. (Ontario Interview 2).

Additional issues that were raised with the CCACs included variations in the care offered by CCAC (i.e., hours and services available) and lack of person-centred care. A key informant described the current approach to care:

I find it really bizarre that we've regulated it so tightly that we've gotten very far away from intimate care in someone's house. (Ontario Interview 1)

The Toronto CCAC was provided as an example where a culture change had been implemented and the personal support workers instead of going in with a list of tasks to do, ask clients at the beginning of the visit "What would you like me to do for you today?," and at the end of the visit say "I have (number) minutes left, what else should I do?" This has allowed clients to direct their care based on their current needs and has been very positively received.

The 2014/15 interviews took place before the *Patients First Act* and associated reforms occurred. In the 2019/20 interviews the informants described that an Expert Group on Home and Community Care was formed to make recommendations on how to reform the home and community care system. While the focus of the report had been on functional reforms, the government's main response to this report was to merge the CCACs into the LHINs. Informants commented that due to the short duration the merger had been in place it was difficult to determine its impact, but generally for clients there did not appear to have been much impact. For example, an informant remarked:

And now they are going to be reformed even further, so I don't really know what the impact was, I still hear similar challenges expressed by home care clients and caregivers: that it's confusing to navigate, it's not clear who the point person is, they are not getting the care that they need in their home.

So that's remained a consistent set of problems in the old structure and the new structure. (Ontario Interview 5)

Informants also described additional reforms that occurred in response to the Expert Group report. Bundled care pilot projects were implemented and produced some positive results, though these are most effective for post-acute patients. A Levels of Care Framework was developed, though with the change in Provincial Government it is unclear whether the framework will move forward. The budget for home care also significantly increased, though it was noted was still inadequate to meet the growing demand. A report on caregivers (Beed report) was also published and the Ontario Caregiver Organization was established as a result.

Despite the merging of the CCACs and LHINs, in both the 2014/15 and 2019/20 interviews the integration and coordination of services was viewed as an area needing improvement. In particular there were two challenges identified at both points in time: a) coordinating the large number of home and community care providers and b) integration and reform of primary care services. For example, informants commented:

The biggest weakness in Ontario's program, and I think basically across the country, is that fact that primary care is so badly developed. And to get the physicians to participate in a meaningful way with regard to home and community care services – which basically, they don't even necessarily think is their problem – they really need strong leadership from one of their own. One of their own has to say 'Look, this is what we need to do. (Ontario Interview 2)

So it's quite possible that a person whose got you know a higher acuity could have 3 or 4 different organizations sending staff into their home, not coordinated. (Ontario Interview 1)

Informants did mention some models aimed at integrating services, including family health teams, community health centres, and community service hubs. Key informants also commented on the Health Links model and the more recent vision of Ontario Health Teams. A key informant described the Health Links model as:

Health Links is an approach to better coordinating care for individuals with complex health and social needs – for the top 1-5% of high system users, so high cost users – and not a service delivery model, rather it's just an approach to coordination where patients are identified and brought into the program. They have a meeting with their team or with a care coordinator to develop a coordinated care plan, that is then shared with the broader team as part of the model and when and if they're better they get discharged from the Health Links program. (Ontario Interview 4)

The key informant described how development of coordinated care plans was a key function of the model, and in the early stages some Health Links hired care coordinators specifically to develop the coordinated care plans. Over time as less funding became available, utilizing CCAC or care coordinators from other organizations to develop the coordinated care plans became the norm. Health Links were implemented with a low-rules approach, meaning teams had significant flexibility in implementation of the model:

It allowed for creativity to emerge, it allowed for you know if the Ministry couldn't do something – for example the Ministry constantly promised an IT solution that would allow for the sharing of coordinated care plans for the partners that didn't come – and so organizations that were ready and could benefit from the low-rules were able to develop their own solutions and then try to feed them up to the Ministry to be scaled – spread and scaled across the province. (Ontario Interview 4)

On the other hand, the low-rules approach also meant that each region had a different Health Link model. Later government attempted to increase the standardization of the model through the introduction of the Advanced Health Links model. The proposed Ontario Health Teams share similar aims and principles as the Health Links, representing a new, more formalized iteration of the vision for integrated care. An informant noted that many of the applicants to form the initial Ontario Health Teams were members of Health Links. This informant stated:

And the whole intent of Ontario Health Teams is to really bridge the gap between the various sectors in our health system that people use so this would be things like hospital to community and long-term care and home care and all of those pieces, and the intent is to build an infrastructure around that, that really incentivizes coordinated, integrated care. And so it's different from our previous health reform which is referred to as Health Links, which was sort of voluntary models of integrated care where you know providers were encouraged to work together, encouraged to think outside the sector that they are currently working in, to coordinate care for older adults. Ontario Health Teams, I think there's a greater expectation of providers but also the intention is to merge funding models and governance structures so that it really works as one core system. (Ontario Interview 5)

Regarding the government's new priority of building long-term care beds, informants acknowledged that more long-term care beds are needed in Ontario. However, they also highlighted that long-term care beds are only one part of the solution and commented on the need for integrated planning:

And you can't do anything unless you provide more home care, relief for caregivers, better integration, and better long-term care. And it's not just about building beds, it's really about long-term care services. (Ontario Interview 3)

So I think, if we think about long term care in a broader sense and think, okay, if we have a pool of money to develop long term care spaces, then we have to consider all the different community options that exist, whether it is independent home or an apartment building that happens to have lots of seniors that requires some built in infrastructure, to things like, you know making retirement homes more financially accessible to campuses of care. (Ontario Interview 5)

Informants also remarked on the fact the health care system is still geared towards providing medical care, and a shift needs to occur to better meet the needs of older adults and other complex populations:

I think, when we think about home care we're still, when you talk to home care clients, which I have recently, they still talk about the lack of these instrumental activities of daily living, and how you know they have multiple providers coming into their homes. The focus is really on physical function need, medical needs, and some ADL's like bathing. But a lot of things they need fall outside of that basket and I think we still haven't made the shift (Ontario Interview 5).

And we've had a hospital-based system, acute care-based system and we're good at treating people who are sick. We don't do a very good job with people who are marginalized, so the elderly, even the well elderly, but the frailer and the folks with dementia, children with complex needs, people without homes (Ontario Interview 3)

9.3 Critical Analysis of the Case of Ontario

This section identifies crucial issues embedded in the long-term care policies in Ontario over 2012-2019. It builds upon the material presented in the previous sections and integrates additional document and policy analysis. The analysis reviews the reforms to Ontario's long-term care system against key frameworks and best practices for integrated continuing care described in chapters 2 and 4, as well as the government's stated policy objectives, key policy issues, and historical policies.

The release of the *Patients First* roadmap represented an evolution in policy in Ontario as it acknowledged the need for significant reforms to home and community care. Williams et al. (2016) have noted that historically in Ontario home and community care reforms have been driven by the needs of the health care system. Prior to the

Patients First roadmap, an *Aging at Home Strategy* had been introduced in 2007 that provided \$1.1 billion over four years for community-based services (Peckham, Rudoler, Li, & D'Souza, 2018b). An analysis of the *Aging at Home Strategy* by Peckham et al. (2018b) identified that while originally intended to broadly support initiatives to help older adults to remain in their homes, the vision quickly shifted to reducing the number of ALC clients in acute care. *Ontario's Action Plan for Healthcare* in 2012 also framed providing care as close to home as possible and building capacity in the community primarily as means to reduce patients in ALC (MOHLTC, 2012).

The *Patients First* roadmap placed home and community care at the centre of the policy agenda and framed the sector as not simply a means to decrease pressures on the acute care sector, but rather as a valuable component of the health care system necessary to support older adults and informal caregivers. (Though reducing pressures on acute care was an underlying narrative in the broader *Patients First* reforms). The policy actions in the *Patients First* roadmap were guided by the “need for client and family-centred care.” (Government of Ontario, 2015b, p.5). The *Patients First* roadmap represented a shift in the framing of home and community care as it: 1) defined the policy issue primarily as transforming and strengthening home and community care (rather than preventing unnecessary acute care use); 2) in addition to providing money, proposed reforms to make systemic changes to home and community care services; and 3) explicitly recognized the importance of supporting informal caregivers. Kingdon (1984) suggests opportunities arise and an issue may be put on the policy agenda when the problem, policy, and politics streams coincide. In Ontario, while the proposed policy solution of strengthening home and community care had been an option for some time, a policy window to make significant changes arose due to the factors described in 9.2.3. One of the most important factors was the perception of serious problems with the CCAC model and home care in Ontario.

As a result of *Patients First* and other reforms described in section 9.2, over 2012-2019 steps were taken to further the development of an integrated system in Ontario, including steps to: enhance coordination of care for complex patients; introduce integrated funding models for specific population groups; introduce a standardized framework for care (levels of care framework); and structurally integrate home and community care services with the LHINs. However, one of the critiques of the reforms was they focused too much on structure and not enough on the function of the system

(similar critiques have been made of other structural reforms as will be described in the comparative analysis in chapter 14). Based on review of the reforms to Ontario's long-term care system versus key frameworks for integrated continuing care and the policy issues described in section 9.2, it is apparent that the reforms failed to address several weaknesses of Ontario's long-term care system:

- Gaps continue to exist in the continuum of services available (i.e., supportive housing and community support services are inconsistently available and remain on the margins).
- While person-centred care is acknowledged as important in principle, reforms have not addressed the lack of flexibility and person-centredness of care.
- Structural integration of home and community care with the LHINs does not address the coordination challenges caused by having multiple contracted home care and community support service providers involved in service delivery.
- While the Health Links provided the potential for better coordinated care of complex patients, they only reached a small segment of the population.

Furthermore, there has been a lack of integrated planning in order to maximize the opportunities to provide care as close to home as possible. This was a key observation made by informants as described in section 9.2.5 and will be discussed further here. Despite previous suggestions and evidence that supportive housing could be significantly scaled up to provide an intermediate level of care for older adults in the community (e.g., Sinha, 2012; Williams et al., 2016), this did not emerge as a policy priority. Lum, Williams, Sladek, and Ying (2010) compared the profiles of clients living in supportive housing in Toronto versus those on the waitlist for long-term care homes and found all of the older adults in their sample would potentially be eligible for long-term care placement. However, access to supportive housing is not widely available and waitlists can be up to seven years (Ontario Non-Profit Housing Association, 2016). In the 2017 seniors' action plan, the commitment to enhance supportive housing included only 500 transitional care spaces and 200 new subsidies for affordable housing. On the other hand, the commitment to long-term care was redeveloping 30,000 beds and developing 30,000 new beds (Government of Ontario, 2017). The new Progressive Conservative Government is continuing with the policy of significantly scaling up long-term care bed capacity and has committed to building 15,000 new beds by 2023/24 (Financial Accountability Office of Ontario, 2019a). The scaling up of long-term care seems to be

disconnected from other recent policies and government policy objectives. While there appears to be need for increased long-term care capacity, the significant new investments in building long-term care beds and the lack of investment in supportive housing seem contrary to stated policy objectives. Furthermore, home care budget constraints mean these resources are not being utilized to their full potential. Policy states clients can receive up to 90 hours of personal support per month, but it is rare that hours close to this are provided (Office of the Auditor General of Ontario, 2015a). Community support services have also been largely overlooked in policy despite the identification in research that IADL supports may be important factors for diverting older adults from long-term care (Williams et al., 2016). Williams et al. (2016) state on the challenges of shifting resources to the community and changing entrenched practices:

Seen from the perspective of interests, beds are more than a care setting for older persons; they are also the source of good jobs, sustained departmental budgets and corporate profits, all of which could be negatively impacted by any rebalancing of resources toward the community. (p.32)

This quote encapsulates two common characteristics of complex systems: that they are history dependent and resistant to change. Despite these challenges, integrated planning that takes into account the full continuum of services is essential to develop and effectively utilize long-term care resources. This is a point that has been emphasized in multiple reports (e.g., Sinha, 2012; Expert Group on Home and Community Care, 2015; Williams et al., 2016) and also is a core lesson from systems approaches for dealing with complex systems.

Another important component of an integrated approach is providing support to informal caregivers. The establishment of the Ontario Caregiver Organization represents a first step towards improving supports for informal caregivers. The Beed (2017) report also recommended that organizational level (e.g., identify gaps in programming, expand effective programs, etc.) and system level actions need to be taken (e.g., develop policies to support informal caregivers, educate health care providers on informal caregivers, etc.). There is a need now to move beyond the individual level and develop organizational and system level supports.

Overall, there has been some progress made over 2012-2019 in Ontario in the development of an integrated continuing care system. Steps were taken to improve

integration between sectors, standardize and increase access to services, increase investments in the long-term care system, develop innovative funding models, and recognize and support informal caregivers. However, resources remained unequal to meet needs, and furthermore, fundamental issues with the long-term care system remain unaddressed and thus act as impediments to the policy objectives of integration and bringing care closer to home. Overall, reforms appear to have had little impact on available outcome indicators (Health Quality Ontario, 2019):

- Over 2012/13 to 2018/19 median length of wait for home care services increased from 5 days to 6 days for patients waiting at home, and from 1 to 2 days for patients waiting in the hospital.
- There was little change in overall satisfaction with home care coordination and service providers, with about 75% consistently rating this as excellent or very good over 2013/14 to 2018/19.
- Over 2012/13 to 2018/19 the median length of wait for a long-term care bed decreased from 165 days to 161 days for patients waiting in the community and increased from 77 to 90 days for patients waiting in the hospital.
- The percentage of ALC patients increased from 14.1% in 2012 to 15.5% in 2018.

While it cannot be said the long-term care system was successfully reformed over 2012-2019, some progress was being made. However, more recent developments suggest a significant change in direction for long-term care reforms. In 2018, the Progressive Conservative party came to power and the *Premier's Council on Improving Healthcare and Ending Hallway Medicine* (2019a; 2019b) was established and released two reports. The discourse in these reports frame home care as a means to reduce pressures on acute care. The second report recommended the home care sector be "modernized." Later in 2020, legislation was proposed that would repeal the current *Home Care and Community Services Act* and transfer planning, coordination, and delivery of home and community care to the Ontario Health Teams or other non-profit and for-profit providers. The Ontario Health Coalition (2020) suggest this will contribute to further fragmentation, inconsistencies in services between regions, and privatization. Moving forward, the government has also announced the intention to balance the budget, in which case unless tax revenues increase, the Financial Accountability Office of Ontario (2019a) has estimated health care spending growth will need to be limited to an average of 1.2% annually.

Chapter 10.

The Case of Québec

This chapter provides an analysis of Québec's long-term care system over the period of 2012-2019. This analysis was informed by interviews with key informants conducted in 2014 (n=2) and 2020 (n=2), review and analysis of government policy documents, and review of websites, reports, and other literature. When available the English version of documents were reviewed; some documents in French were also reviewed with Google Translate. An English translation of the key home support policy document *Chez soi: le premier choix* was obtained from a professional translator. Section 10.1 describes the health care context and the long-term care system. Section 10.2 provides information on the policy context in Québec. Section 10.3 critically analyzes the case of Québec.

10.1 Provincial Health Care Context

10.1.1 Health Care System Structure and Governance

Québec has a universal public health care system that is regulated by the federal *Canada Health Act* and relevant provincial legislation. Québec's integrated health and social services system has its roots in the 1971 *Act respecting health services and social services*, and unlike other Canadian provinces Québec has an integrated Ministry of Health and Social Services (MSSS⁵) (MSSS, 2017a). Since the 1970s, Québec has implemented a series of reforms to increase the integration of health and social services. This began with the creation of regional health authorities and local community service centres (CLSC). CLSCs are responsible for providing many frontline health and social services and coordination of care (Jiwani & Fleury, 2011). In 2004, the CLSCs, hospitals, and residential and long-term care centres (CHSLD) were merged into 94 health and social service centres (CSSS) (Wankah et al., 2018a). The CSSS formed agreements with other service providers to form local health and social service networks (Vedel, Monette, Béland, Monette, & Bergman, 2011). In 2015, further consolidation of services

⁵ This chapter utilizes French acronyms that are commonly used by the Provincial Government. The French terms these acronyms are short for are included in the Glossary.

occurred, with the abolishment of the regional health authorities and amalgamation of CSSSs, rehabilitation centres, youth centres, and in some cases university teaching hospitals to form 22 Integrated Health and Social Services Centres (CISSS or CIUSSS if a university teaching hospital is attached)⁶ (Wankah et al., 2018a). Primary health care organizations are not included in the governance structure of the CISSS. Many primary care physicians practice in Family Medicine Groups, which are multidisciplinary, team-based practices (Wankah et al., 2018a)

10.1.2 Long-Term Care System

The Support for the Autonomy of Seniors (SAPA) programs are core publicly subsidized services provided for the care of older adults. SAPA includes needs assessment, home care support services, accommodation services, and other community services. Accommodation services include CHSLD and lower level intermediate resources and family-type resources. (Gouvernement du Québec, 2018; 2020a). These services can be accessed through the local CLSC (Gouvernement du Québec, 2018). Clients who only require domestic help services are referred to domestic help social economy businesses (EÉSAD). The Financial Assistance Program for Domestic Help Services provides subsidies for heavy and light housekeeping services (e.g., laundry, meal preparation, shoveling snow, etc.) obtained from an EÉSAD. Services are subsidized at a basic rate of \$4 of financial assistance per hour (regardless of health or income), and all older adults are eligible for additional assistance (Gouvernement du Québec, 2018). Private pay options are also available, including private CHSLD, seniors' residences, and home care services (MSSS, 2020a).

Québec is well known for the integrated service delivery model developed to deliver care to frail older adults. Indeed, since 2002, implementing integrated services networks for the frail elderly (RSIPA) has been a policy priority (Poirier, Descôteaux, Levesque, & Tourigny, 2013). The RSIPA model consists of 9 components: 1) Local coordination mechanisms; 2) Single entry point; 3) Electronic patient records; 4) Case management; 5) Personalized service plan; 6) An accountable person; 7) Access to geriatric care; 8) Access to a family physician; and 9) Use of a single assessment and

⁶ For simplicity, these are referred to as CISSS throughout.

management tool (Poirier et al., 2013). Table 19 provides an overview of the long-term care system in Québec using an adapted version of the INTERLINKS Framework.

Table 19 INTERLINKS Framework for Long-Term Care: Québec

INTERLINKS Framework for Long-Term Care	
Identity of Long-Term Care	
<i>Values</i>	<ul style="list-style-type: none"> Key principles for home and community care include solidarity, equity, free choice, and neutrality. Individuals should have the right to choose their own living environment.^a
Policy and Governance	
<i>Policy</i>	<ul style="list-style-type: none"> See section 10.2 for discussion of long-term care policy in Québec.
<i>Governance mechanisms</i>	<ul style="list-style-type: none"> The CISSS are the overarching governance structure for health and social care services within regions. CHSLD and CLSCs are a part of CISSS.^b CHSLD may be operated publicly or by contracted private for-profit providers. Home care services are managed through the CLSC and usually offered by public providers, but may also be provided by a contracted service provider (including EÉSAD).^c
Pathways and Processes	
<i>Accessing services</i>	<ul style="list-style-type: none"> Home care and accommodation services are accessed through the local CLSC.^d
<i>Assessing needs</i>	<ul style="list-style-type: none"> Care needs are assessed using the multi-client assessment tool OEMC. This assessment incorporates the Functional Autonomy Measurement System SMAF that measures the level of disability of the client and corresponds this with different profiles indicating service needs.^c
<i>Interdisciplinary working</i>	<ul style="list-style-type: none"> CLSCs deliver much of their care through multidisciplinary teams.^e
Organisational Structures	
<i>Nursing and residential care homes</i>	<ul style="list-style-type: none"> CHSLD provide 24/7 professional care and support services for people who due to loss of functional or psychosocial capacity are no longer able to live on their own.^f Residents are required to make a contribution for their room and board in CHSLD.^g
<i>Care within a hospital setting</i>	<ul style="list-style-type: none"> A provincial approach for care for older adults in the hospital has been developed.^h
<i>Transitory care facilities</i>	<ul style="list-style-type: none"> Short-term geriatric units can provide older adults access to multidisciplinary geriatric assessment and temporary treatment and rehabilitation.^h Days hospitals can provide outpatient interdisciplinary services and may be part of CHSLD.ⁱ
<i>Assisted living arrangements</i>	<ul style="list-style-type: none"> Intermediate resources provide residents with room, board, and some support services. Family-type resources are family care homes that can provide room, board and support to a maximum of 9 people.^d Residents are required to make contributions for their room and board.^j
<i>Formal care in the home and the community</i>	<ul style="list-style-type: none"> Home care support services can be provided on a temporary or long-term basis to assist individuals who are losing their independence and require support to remain in their home. Available services include professional care (e.g., nursing, rehabilitation, nutrition services, etc.), personal care services (e.g., hygiene, dressing, food services, etc.), family caregiver services (e.g.,

	<p>respite) and equipment.^d Home care support services are provided free of charge, though there may be a co-payment for domestic help services.^a</p> <ul style="list-style-type: none"> • Day centres may be available as a part of CHSLD.^l
<i>Specialised case or care management centres</i>	<ul style="list-style-type: none"> • Case management is one of the core components of RSIPA. In 2015, the MSSS developed provincial guidelines for case management.^k
Means and Resources	
<i>(Shared) funding</i>	<ul style="list-style-type: none"> • Health and social care services are financed primarily through taxation. In 2016/17 Québec financed 77% of the provincial health budget, while contributions from the Federal Government accounted for 23%. Under the 2017 health care funding agreement Québec will receive \$2.5 billion from the Federal Government for key priorities, including home care.^l
<i>Enabling, allocating and funding human resources</i>	<ul style="list-style-type: none"> • Recruitment and retention of orderlies and health and social services assistants (who provide the bulk of care in CHSLD and the home) is a policy priority as labour shortages are anticipated in the coming years.^e
<i>Supporting informal carers as a resource for LTC</i>	<ul style="list-style-type: none"> • Family caregiver services are a part of home care support services.^d • The non-profit organization L'Appui national manages a Caregiver Support Fund that was established in 2009 (partially funded by Government of Québec) and 17 regional L'Appui offices receive funding and provide information, training, respite and psychosocial support to informal caregivers.^m
<i>Financial indicators</i>	<ul style="list-style-type: none"> • Health and social services account for 49% of Government spending.ⁿ • In 2011/12 the SAPA program accounted for 9% of health and social service spending. A breakdown of SAPA spending showed 64% of spending was for CHSLDs, 10% intermediate resources, 17% home care, and 9% other services.^o
<i>Role of information technology</i>	<ul style="list-style-type: none"> • The Québec Health Record provides physicians and other authorized health and social service providers access to patient data in six clinical areas: medications, laboratory results, medical imaging, immunizations, allergies and hospitalizations. This record does not include electronic medical records used by family physicians or computerized clinical records used by health and social service providers. Patients can access their health information via the Québec Health Booklet.^p

Sources: a. Canadian Home Care Association (2013); b. Wankah et al. (2018a); c. MSSS (2020a); d. Gouvernement du Québec (2018a); e. Gaumer & Fleury (2008); f. MSSS (2017a); g. Gouvernement du Québec (2020b); h. MSSS (2011); i. MSSS (2009); j. Gouvernement du Québec (2020c); k. MSSS (2015); l. Gouvernement du Québec (2017); m. L'Appui (2020); n. MSSS (2019a); o. Gouvernement du Québec (2013); p. Gouvernement du Québec (2020d)

10.2 Long-Term Care Policy Context and Objectives, 2012-2019

The following sections include discussions on the long-term care policy context and objectives in Québec over 2012-2019. Section 10.2.1 provides a brief overview of the political and economic landscape. Section 10.2.2 reviews key government policy documents relevant to long-term care. Section 10.2.3 covers the policy context and key

events during this time period. Section 10.2.4 reviews relevant evaluations and evidence on the impact of reforms during this period. Section 10.2.5 provides interview data from key informants on the policy context and reforms during this period.

10.2.1 Political and Economic Landscape

Over 2012-2019 four different Provincial Governments were in power in Québec: the Liberals (2003-2012), Parti Québécois (2012-2014), Liberals (2014-2018), and Coalition Avenir Québec (2018-present). In the 2016 census the population of Québec was 8.2 million and 18.3% (1.5 million) of the population were older adults (Statistics Canada, 2019b). Since 2010, and particularly during the period that the Liberal Party were in power, Québec underwent a period of economic austerity (Pineault, 2015). The average annual growth rate of health care spending over 2010-2014 was 2.5% and this increased to 4.6% over 2014-2019. When standardized for age and sex, per capita health care spending by Québec is the second lowest in Canada (CIHI, 2019b).

10.2.2 Key Policy Documents

This section describes key government policy documents over the period of 2012-2019. In addition, the 2003 home support policy *Chez soi: le premier choix* is described, as it is the foundation for home support policy in Québec (Gouvernement du Québec, 2013). When available English versions of documents were reviewed; some additional policy documents are described from translated versions of the documents.

In 2003, Québec's home support policy *Chez soi: le premier choix* was introduced. The policy states: « In respect of the individual's choice, the home will always be considered as the first option, in the early stages of intervention and at all subsequent stages. Home care services should no longer be considered a substitute measure, or as an alternative to residential care or hospitalization. » (Gouvernement du Québec, 2003, p.5). In addition to home as the first choice, the policy also lays out other key principles as described in table 20.

Table 20 *Chez soi: le premier choix* – Key Principles

Home the First Choice Policy – Key Principles
1. Home is always the first option to consider.

2. Prioritizing individual choice.
3. Recognizing informal caregivers as clients, citizens, and partners.
4. A philosophy beyond just offering home support services: <ul style="list-style-type: none"> • Providing services for the individual in the home; • Providing services in the community such as day services, outpatient services, etc.; and • At a societal level providing measures to support housing, transportation, informal caregivers, etc.
5. Receiving care in the home should be financially neutral for the user compared to other settings.

Data Source: Gouvernement du Québec (2003)

Subsequent policy papers have reaffirmed the commitment to providing care in the home. In 2012 under the Liberal Provincial Government the action plan *Aging and living together - At home, in your community, in Québec* was released (Gouvernement du Québec, 2012). The action plan states “Creating conditions that will enable older adults to live at home and within their community for as long as possible is the core concern of this policy and its action plan.” (Gouvernement du Québec, 2012, p.15). The plan outlined 74 actions covering a broad range of areas to support aging in place (e.g., housing, home care, informal caregivers, etc.). Home support was reaffirmed as the cornerstone of supporting older adults to remain at home and \$758 million was to be committed over 5 years for home support services. The policy also committed to investing in residential and accommodation initiatives, having 70% of the RSIPA in place by 2015, working with employers to support work-life family balance, and supporting regional caregiver support groups (Gouvernement du Québec, 2012).

Developing long-term care insurance was a policy priority under the Parti Québécois. In 2013 a white paper proposing the introduction of autonomy insurance was released (Gouvernement du Québec, 2013). Core services covered would have included professional care (nursing, nutritional, rehabilitation, and psychosocial), ADL supports and IADL supports. While it was acknowledged in the white paper that autonomy insurance would require a significant financial investment, it was estimated that it would potentially save \$1.5 billion over the next 15 years compared to maintaining the status quo (Gouvernement du Québec, 2013). The autonomy insurance would have been funded through general tax revenues and operated as a separate autonomy fund to ensure it was used for its intended purposes (Hébert, 2016a).

During the Liberals’ second term in power they released an updated seniors’ action plan for 2018-2023 (though they were removed from power shortly after its

release). This action plan supported the participation of seniors in society, healthy aging in the community, and providing healthy, safe, and welcoming environments. Among the many intervention areas, increasing access to home support and supporting informal caregivers were priority areas (Gouvernement du Québec, 2018b).

The MSSS also released three strategic plans during this time period. The first two strategic plans for 2010-2015 and 2015-2020 shared similar goals for care for older adults, including continuing the implementation of RSIPA and improving and ensuring access to long-term home support (MSSS, 2010; 2017b). The third strategic plan for 2019-2023 reflected the new priorities of the Coalition Avenir Québec, and while increasing access to home support continued to be an objective, new objectives included developing a provincial policy for caregivers, increasing the number of respite homes, and developing 2,600 spaces in seniors housing and alternative living environments by 2023 (MSSS, 2019b).

10.2.3 Policy Context and Key Events

Since the 1970s a series of reforms have occurred in Québec to further the integration of health and social services. This section first discusses the policy context regarding reforms targeting the structural and functional integration of health and social services, and then discusses policy issues related to long-term care services.

The major reform over 2012-2019 was the development of the CISSS that was initiated by the Liberal Provincial Government to further the structural integration of health and social services. This restructuring was controversial and primarily driven by the government. Proponents of the CISSS reforms argued they would improve integration, care provided to clients, and reduce costs. However, during consultations many stakeholders opposed the reforms and questioned the potential benefits of increased structural integration (Quesnel-Vallée & Carter, 2018). Some of the main concerns expressed by policy actors such as stakeholders, scholars, and the Québec Ombudsman included:

- The scale of the CISSS and potential for them to be unmanageable mega-institutions (Le Protecteur du Citoyen, 2014a; Lamarche, Hébert, & Béland, 2014)

- Whether organizations (and particularly social services) would be able to maintain adequate autonomy and representation within the CISSS (Quesnel-Vallée & Carter, 2018)
- The potential that these structures (and their budgets) would be dominated by the medical paradigm (Quesnel-Vallée & Carter, 2018; Le Protecteur du Citoyen, 2014a)

Despite these objections, in 2015 Bill 10 was passed which amalgamated health and social services into CISSS creating 22 overarching regional governance structures for health and social care organizations (Quesnel-Vallée & Carter, 2018).

Over 2012-2019 some progress was made addressing the functional integration of services. Throughout the study period incremental progress occurred to fully implement the RSIPA model as described in section 10.1.2. In the late 1990s and early 2000s two integrated care pilots known as SIPA (Béland et al., 2006) and PRISMA (Hébert et al., 2010), had generated interest in integrated service delivery models for older adults. The PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy) model was the inspiration for the RSIPA model. PRISMA was a coordination level integrated service delivery system for frail older adults that was pilot-tested in the Bois-Francs region and then tested in three locations in the Eastern Townships (Hébert et al., 2010). Since 2002, implementing the RSIPA model had been a priority for the MSSS (Poirier et al., 2013). This work was hindered in the early years by the creation of the CSSS which diverted the focus and efforts of the health care system (Hébert, 2017a). In addition to continued progress to implement RSIPA, other steps to improve the functional integration of services over 2012-2019 included:

- Provincial guidelines for case management were developed (MSSS, 2015).
- The online Québec Health Record (provides access to patient clinical information for providers) and Québec Health Booklet (provides clients access to their health record) became operational (Gouvernement du Québec, 2020d)
- A framework for Family Medicine Groups was introduced to provide financial support and allocate personnel (e.g., social workers, occupational therapists, etc.) to work in these multidisciplinary groups (Wankah et al., 2018a).

The restructuring of health and social care services dominated the policy agenda for much of 2012-2019, and reforms targeting services for older adults were limited. However, during this period various policy actors raised concerns about the state of

long-term care, including the Québec Ombudsman, commissions and committees, health care unions, patient advocacy groups, and academics.

A prominent policy issue has been the declining access to home care services. Despite having a well-established policy for home care, the Québec Ombudsman in 2012 released a special report critiquing home care services. This report highlighted systemic issues such as increasingly strict eligibility criteria, inflexible services, inappropriate limits on service hours, time limits for tasks, regional disparities in applying policy, waits and declining service hours, and lack of support for informal caregivers (Le Protecteur du Citoyen, 2012). Subsequent reports by monitoring bodies continued to reinforce these issues (e.g., Le Protecteur du Citoyen, 2017; 2018; 2019; Auditor General of Québec, 2013; Commissaire À La Santé Et Au Bien-Être, 2016). The independent research institute L'Institut de recherche et d'informations socioéconomiques has also reported the proportion of older adults receiving home care decreased from 15% in 2012/13 to 12% in 2015/16. While the number of users is declining, intensity of the service has been increasing, suggesting a concentration of services for higher needs clients (Hébert, 2017b).

In addition to home care, CHSLDs and informal caregivers also received attention as policy issues. In 2013, the Commission on Health and Social Services was given a mandate to collect information on living conditions in CHSLD. Staffing levels, wait times, and living conditions were identified as key issues in their report (La Commission de la Santé et des Services Sociaux, 2016) as well as reports by other monitoring bodies (Commissaire À La Santé Et Au Bien-Être, 2017; Le Protecteur du Citoyen, 2017; 2018). The Québec Ombudsman also raised concerns about the practice of discharging hospital patients awaiting CHSLD placement to temporary accommodations to decongest hospitals (Le Protecteur du Citoyen, 2014b). In 2018, a patient advocacy group launched a class action lawsuit on the treatment of older adults in CHSLD (Derfel, 2019). L'Appui and the caregiver advocacy organization Regroupement des Aidants Naturels du Québec (RANQ) have advocated for improved supports for informal caregivers and recommended that a provincial interdepartmental committee be formed to develop a caregiver policy (RANQ, 2018; L'Appui, 2015).

Reforms to address policy issues related to home care, CHSLD, and informal caregivers over 2012-2019 were limited. At the beginning of the study period, an attempt

was made by the Parti Québécois Provincial Government to develop a model for financing long-term care services (as described in section 10.2.2). In 2013 the white paper proposing the development of autonomy insurance was released, a parliamentary commission was held, and *Bill 67 Autonomy Insurance Act* was proposed. However, due to the change of provincial government in 2014, Bill 67 was never adopted (Hébert, 2016). Developing a new funding model for long-term care did not re-enter the policy agenda under subsequent provincial governments despite continued pressures on long-term care budgets.

Under the Liberal Provincial Government, the policy agenda was dominated by the CISSS restructuring. Some steps were taken to address concerns about CHSLDs and a committee was set up to review professional-patient ratios through pilot projects, and additional funding was committed to increase staffing levels (FIQ, 2017). The health care system and improving home care emerged as important policy issues in the 2018 election, with most political parties committing to increase funding for home care (e.g., Hendry, 2018; Derfel, 2018). The newly elected Coalition Avenir Québec Government has made several commitments to improve seniors care, including:

- Announcing a \$2.6 billion investment to renovate or rebuild over 2,500 CHSLD spaces using a small cluster approach with units of 12 residents (CBC News, 2019).
- Establishing a Minister Responsible for Seniors and Caregivers and conducting consultations with informal caregivers to support the development of a comprehensive caregiver policy (CMA, 2019).

10.2.4 Evidence of Impact of Key Reforms

The major reform that occurred over 2012-2019 was the development of CISSS. While not targeting care for older adults, this structural reform affected the governance structures for home care and long-term care. Over this period progress also continued to be made on the implementation of the RSIPA model. While there has not been evaluation of these reforms, the evidence behind the PRISMA model and as well experiences with past mergers (CSSS) will be discussed.

Integrated Services Networks for the Frail Elderly (RSIPA)

As described in previous sections, the initial commitment to rollout RSIPA was made in 2002. However, the CSSS reorganization hindered the rollout and implementation of RSIPA due to diversion of attention away from implementing RSIPA (Hébert, 2017a). Some additional challenges that have affected the implementation of RSIPA include: delays in developing a new computerized clinical chart; shortages of funding for case managers; and barriers to implementing the interdisciplinary care plans (MacAdam, 2015; Hébert, 2017a; Breton et al., 2019). Facilitators of the implementation have included: leadership from policy-makers and key stakeholders; supportive government policies and funding; implementation of shared multidisciplinary clinical tools; and allowing flexibility to meet local needs (Wankah, Couturier, Belzile, Gagnon, & Breton, 2018b; Breton et al., 2019; MacAdam, 2015). Despite the challenges, by 2018/19, the implementation of RSIPA had risen to 87% (MSSS, 2019a). It has been observed that some mission drift has occurred in the implementation of RSIPA compared to the original intentions of the PRISMA model (e.g., coordination tables do not routinely include EÉ SAD, community organizations and private providers; not all network providers have access to the computerized clinical record) (Hébert, 2016b).

While so far government measurement has focused on the implementation and not the impact of the RSIPA model, there was extensive evaluation of PRISMA. The PRISMA model consisted of 6 key components: 1) a coordination body, 2) single entry point, 3) case-management, 4) individualized service plans, 5) single assessment instrument, and 6) a computerized clinical chart. The model coordinated the services of a variety of different organizations and service providers, including: CLSCs, family physicians, hospital and rehabilitation services, CHSLDs, voluntary agencies, and social economy agencies. Structures and processes were put into place to allow coordination of care across the continuum (e.g., joint governing boards, service coordination committees, and multidisciplinary teams) (Hébert & The PRISMA Group, 2005). Case managers played a key role in the model and their responsibilities included assessing the clients; planning and implementing services; and coordinating interdisciplinary efforts and services from the network (Veil & Hébert, 2008). Standardized technology and tools developed for the model included individualized service plans, a standardized assessment instrument, and a computerized clinical chart. The SMAF assessment tool used in Québec today was developed for the PRISMA model (Tousignant, Hébert, Dubuc, Simoneau, & Dieleman, 2005).

To evaluate PRISMA a two-wave quasi-experimental design was used that included 1,501 people aged 75 and up who were at risk of functional decline. Participants were followed for either 4 or 2 years (total experimental group n=728; total comparison group n=773). The experimental group experienced lower rates of functional decline and lower hospital and emergency room utilization rates than expected. There also was a decline in unmet needs and increases in levels of client satisfaction and empowerment for the experimental group; however, caregiver burden increased (Hébert et al., 2010). A related study reported the overall costs of the model were cost neutral (Raïche et al., 2008). There also was extensive formative evaluation of the implementation of PRISMA and some of the findings included:

- The implementation of individualized service plans was low and there were issues with the standardization and quality of these plans (Somme, Hébert, Bravo, & Blanchard, 2005).
- Despite some technical issues with the computerized clinical chart, service providers generally found it useful (Morin et al., 2008).
- Organizations differed in the resources they had available to support intensive case management, and some case managers were able to exclusively devote their time in case management, while others had to juggle this with other professional responsibilities (Veil & Hébert, 2008)
- Family physicians generally perceived the impacts of case management positively (Voyer & Hébert, 2008).

Integrated Health and Social Service Centres (CISSS)

In 2015, Bill 10 was passed and 22 CISSSs were formed. These centres are responsible for the governance, and ensuring the delivery of, a wide range of health and social services including acute care, home care, long-term care, rehabilitation, prevention, and other services. They also form strategic partnerships with organizations within their region that are outside of their scope, including primary care and community organizations (Wankah et al., 2018a).

As described in section 10.2.2, CISSS were implemented despite concerns that were expressed by many sources. A letter published by leading scholars from the University of Montréal at the time the reforms were being contemplated stated that:

Scientific evidence has shown that mergers of institutions in the health-care sector do not generate economies of scale, nor do they reduce bureaucracy, and have had little or no effect on the integration of services or an increase in accessibility. (Lamarche, Hébert, & Béland, 2014).

No evaluation has been conducted of the CISSS reform, and it is difficult to evaluate the impact of such large-scale reforms. However, past research on the CSSS reforms suggests there are disadvantages of large institutional mergers. Drawbacks of the 2004 reforms included that the mergers: proceeded slowly and required significant organizational energy; focused more on structural rather than functional integration; increased barriers between frontline providers and decision-makers; and prioritized resources towards acute care services (Demers, 2013; Wankah et al., 2018b; Breton et al., 2019). The Québec Ombudsman also observed that following the 2004 mergers in some regions portions of budgets were reallocated to medical-hospital services (Le Protecteur du Citoyen, 2014b).

10.2.5 Key Informant Interviews

The interviews with key informants conducted in 2014 and 2020 played an important role in identifying the major reforms and highlighting relevant literature and information sources described above. This section describes some of the additional insights that were gained from the key informants on the reforms in Québec.

Québec has a long history of health and social service integration and has a combined Ministry of Health and Social Services. Informants highlighted progress that Québec was making in implementing the RSIPA model that was inspired by the earlier PRISMA demonstration project. Informants highlighted the research evidence behind the model which was described in the previous section. Case management was highlighted as a crucial component of the model:

The main feature of the PRISMA model is the case manager, so the frail older people are referred to one person who is responsible for coordinating all of the services. So I think that it's really putting the client at the centre of the system, in order to facilitate the access to services. (Québec Interview 2)

Informants described how while the decision to implement a PRISMA-inspired model had been made in the early 2000s, the CSSS restructuring delayed the implementation, and as a result it was not until 2010 that full-province-wide implementation began:

One of the problems that delayed the implementation was this reform creating the Health and Social Services Centres. You know it took 3 to 4 years for creating those types of institutions, trying to organize services around those new institutions. So it slowed down the implementation of the functional integration. (Québec Interview 1)

The RSIPA model had some differences from PRISMA, for example, the government developed their own computerized clinical chart. Informants described facilitators of the model implementation that included political will, champions of the model, a strong research base, and flexibility in implementation at the local level (though the importance of maintaining fidelity to the core components of the model was emphasized). Challenges included change management, standardizing case management, the adequacy of funding, and shifting paradigms to working in a coordinated manner. An informant remarked on challenges related to shifting to a coordination model:

So the challenges: that it takes time for coordination, and more than you expect. It's a basic rule that I've observed that has never been contradicted. It takes time.... You have to lose a little bit of your autonomy of management for the profit of the older person. So, it takes time to proceed to this kind of switch. And it's hard. It's not in the management culture to do that. Usually you try to control what happens in your things, not to let other people decide. It's not the way to proceed usually. So this is a challenge." (Québec Interview 2)

The MSSS tracked the implementation rate of the RSIPA model, and by 2014 the average was 74%. In the 2020 interviews, it was noted that implementation was up to an average of 85%, and government planned to develop new indicators to transition from measurement of implementation to impact. Informants also described other progress that had been made in addressing the functional integration of services more broadly, including: the development of standardized guidelines for case management; development of the Québec Health Record; and reforms to promote the delivery of interdisciplinary primary care.

Informants also described the major health and social service restructurings that had occurred in Québec. In 2014 informants described the 2004/5 restructuring that formed the CSSSs. Despite these reforms, it was perceived that challenges still existed with the coordination and continuity of care in Québec. Both informants emphasized that just because services are structurally integrated, does not mean that they are functionally integrated:

The structural merger of those institutions is not synonymous with a functional merger – in other words, just because you are a part of the same institution does not mean that you are coordinating your actions. (Québec Interview 2)

In the 2020 interviews, the 2015 CISSS mergers were discussed, changes that have shifted integration from a local to a regional level. Key informants raised concerns with the 2015 mergers, including that: 1) Structural integration does not result in functional integration; 2) There is limited coordination with organizations outside of these new mega-institutions (i.e., with community organizations, private providers, etc.); and 3) The integration is no longer local. For example, informants commented:

So, since 2015 to now, they are still struggling to reconcile local service centers delivery with regional administration. (Québec Interview 4)

When you merge those programs and services, you reproduce inside the organization, these "silos". And if you don't have a specific plan to integrate and to break down the silo, the silos will still remain. So the silos between home care, hospital care, nursing home, and geriatric services are kept within the organization even if it is part of the same institution. (Québec Interview 3)

Informants also perceived that structural reforms continued to take away focus from the development of the integrated networks for older people and also from other potential actions that could improve seniors care. For example, informants observed:

During those big reforms, the energy of the organization, is to go to mainly to restructuring and redefining positions and benefiting the organization. So, there is much less energy to develop communication and collaboration with the other organizations around. (Québec Interview 3)

We are talking dissolving the administration boards of hundreds of organizations and recreating new organizations with new administrative boards. People have got to meet, and it takes maybe 2-3 years to actually stabilize. So, what we find is that a lot of energy, managerial energy, was redirected to other things apart from most operational programs including integrated care for older adults. (Québec Interview 4)

Informants perceived both in 2014 and 2020 there was a lack of investment in long-term care services in Québec, and in particular the underfunding of home care services was a concern. Concern was expressed about home care budgets being diverted towards other services as a result of the CSSS mergers and later the CISSS mergers. These new institutions were viewed as prioritizing medical services:

So, the point is that, with those very big and large institutions, it's really hospital centered – not only for the priorities but also for the budget. And I don't think it is good for home care and for other type of services. And you have – it's amazing that they are complaining that older people are blocking beds in the hospital, but the problem is not at the hospital. The problem is the insufficiency of home care and there is no other solution. And people cannot continue to live at home because there are no services. (Québec Interview 3)

The lack of investment in home care services was perceived as having hindered the implementation of PRISMA and RSIPA. For example, an informant stated:

And the last point is, there is an important lack of home care. So, we heard sometimes the case manager 'We coordinate a possibility of the services.' (Québec Interview 2)

Informants described how the Parti Québécois government had attempted to introduce long-term care insurance in 2013 to ensure adequate funding for home care services and provide frail older adults with the liberty to choose what type of care they want. Long-term care insurance has been successfully implemented in several other countries (e.g., Japan, Germany). However, a change in provincial government occurred before this could be implemented. An informant commented on the continued urgency to address funding for the long-term care system:

I don't think they [older adults] will agree to go to institutions. And they will require that the services they need are provided in their own home at some point – and it is cheaper. We cannot afford, in fact, to go on the way we are. It is going to block the hospitals, it is going to block the systems, and we have to make a change. But you know, when I look back at Germany, for example, implementing the long-term care insurance has taken 35 years and 10 governments so, I am a bit discouraged. I am not encouraged by that, but we will get there at some point. There is no alternative in my mind. And at the moment the most important issue for Canadians seems to be pharmacare. I am not convinced that it is such a big issue. I think that home care is much more important and has much more consequences than pharmacare. (Québec Interview 3)

10.3 Critical Analysis of the Case of Québec

This section critically analyzes policies in Québec over 2012-2019. First it discusses integration reforms, followed by home support policy and whether Québec has been able to achieve the vision laid out in *Chez soi: le premier choix*. The analysis reviews the

reforms in Québec against key frameworks and best practices for integrated continuing care described in chapters 2 and 4.

A key strength in Québec, as was described in sections 10.2.4 and 10.2.5, is the development of an internationally recognized integrated service delivery model for frail older adults. RSIPA incorporates key components of successful integrated care models for older adults that have been identified in the literature (see chapter 2). In particular, the role of case managers in the model deserves to be highlighted. While many jurisdictions offer case management, often their coordination efforts are siloed. In Québec case managers are involved in coordinating services from a comprehensive network of providers such as home care, community organizations, family physicians, hospitals, rehabilitation services, etc. (MSSS, 2015). Québec has made slow progress on implementing RSIPA, which has now been optimally implemented across almost all the province. The introduction of the CISSS, however, has led to some tensions between the local service delivery networks and regional level organizations. RSIPA was based on the PRISMA model and is a rare Canadian example of a pilot project successfully being disseminated across a health care system. Reviews of the PRISMA literature by Stewart, Georgiou, and Westbrook (2013) and MacAdam (2015) have identified key factors that contributed to the successful adoption and dissemination of the model: 1) The PRISMA pilot was embedded within the health care system and took advantage of structures and processes already in place; 2) the model had strong support from leadership in government, the health and social care system, and academia; and 3) the model was based on a strong evidence-base and had monitoring and evaluation components built in to provide constant feedback.

However, as discussed in section 10.2 the policy agenda over 2012-2019 focused more on structural integration rather than functional integration. Regarding the implications of the CISSS reforms on care for older adults, two potential impact areas that were raised as concerns in sections 10.2.4 and 10.2.5 and should be closely assessed in the future are: 1) whether the change in governance structure results in diversion of the budgets of social care and other non-medical services as was observed in 2004; and 2) how the regional level CISSS are reconciled with the local-level RSIPA networks. A service area both structural and functional integration reforms have generally overlooked are EÉSAD and other community organizations, as they remain outside the CISSS and in RSIPA there has been diminished focus on linkage with these

organizations (Hébert, 2016b). Historically EÉSAD have been viewed by government as sub-contractors and not partners in providing home care (Jetté & Vaillancourt, 2011). The exclusion of EÉSAD is reflective of the marginalized position of domestic help services on the care continuum (as will be described in the comparative analysis in chapter 14 this is also the case in other jurisdictions in Canada).

Chez soi: le premier choix positions home care as the first choice for older adults and not just a substitute for residential and acute care, and also states caregiving should be a voluntary choice. The policy advances a systems approach as it frames home care as one of the components of the broader health and social care system and community that is necessary to facilitate aging in place. Subsequently, complementary policies have been developed (e.g., seniors action plans) or are in progress of being developed to support this goal (e.g., caregiver policy). Increasing access to home support has been a consistent policy priority for governments.

Despite having developed a progressive home support policy and well-designed service model, adequate access to home care services is required to actualize the policy of the home being the first choice for care. This appears to be the main deficit in Québec. As described in sections 10.2.3 and 10.2.5 evidence suggests to-date investments in home care have been inadequate. Indeed, the Québec Ombudsman reported the increases in home care provision between 2014/15 and 2016/17 were well below the targets proposed in the MSSS's strategic plan (Le Protecteur du Citoyen, 2017). Despite recent injections of additional funding for home care by the Coalition Avenir Québec, the Ombudsman has stated about *Chez soi: le premier choix* "However, year after year, institutions fail to live up to the policy's intentions. Too many people do not have access to the services to which they should be entitled, and families become exhausted while awaiting support that never materializes." (Le Protecteur du Citoyen, 2019, p. 92). There also continue to be long waiting lists for CHSLD, and at the end of 2019 there were 3,190 people waiting for placement (MSSS, 2020b).

Declining access to home care has been linked to population aging, government austerity, and increasing pressures on community services due to downsizing of the acute care sector and higher eligibility requirements for CHSLDs (Lavoie, Guberman, & Marier, 2014). Despite the policy statement that home care is not just a substitute for acute care, as observed in section 10.2, there is a problematic power dynamic between

acute and home care, with the needs of the acute care sector heavily prioritized. In addition, Benoit and Perron (2018) observe the tension that exists between the two goals for home care in Québec: support older adults to age in place and decrease costs for government. Under government austerity the latter goal was prioritized, leading to passive privatization of home care services. As seen in table 21, annual increases in the SAPA budget and home services were modest over 2013/14 to 2016/17, with slightly more significant increases from 2017/18 onwards. Despite the policy of home as the first choice, home care services only accounted for 25% of the SAPA budget in 2018/19.

Table 21 SAPA and Home Services Budget (\$ Millions)

	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
Home services (% SAPA Budget)	\$714 (22.4%)	\$763 (23.1%)	\$758 (22.7%)	\$795 (22.9%)	\$883 (23.8%)	\$992 (25%)
Total SAPA Budget (% of MSSS Budget)	\$3,194 (15.5%)	\$3,298 (15.7%)	\$3,338 (15.7%)	\$3,477 (15.9%)	\$3,703 (16.1%)	\$3,966 (16.3%)
Total MSSS Budget	\$20,614	\$21,020	\$21,231	\$21,856	\$22,944	\$24,316

Data Source: Calculated based on MSSS *Home care expenses by program and by region* and *Expenses by program and by region* data obtained from <https://publications.msss.gouv.qc.ca/msss/document-001663/>

The Parti Québécois attempted to address the issue of funding for home care through a proposal to introduce autonomy insurance. Two Commissions in the 2000s (Clair Commission and Menard Commission) had recommended implementing insurance for loss of autonomy (Gouvernement du Québec, 2013). To date, long-term care funding models have received less policy attention than deserved in Canada, despite underfunding consistently being identified as a policy challenge (see chapters 14 and 15 for discussion of the need for a long-term care funding model in Canada).

One promising advancement during this period of study is that informal caregivers were explicitly acknowledged in policy documents and their visibility has been growing. There are several circumstances that have converged to facilitate a policy window for informal caregivers: 1) There is a Caregiver Support Fund, legitimizing the role of the non-profit and community organizations and providing dedicated funding; 2) The presence of umbrella organizations (L'Appui and RANQ) that have created cohesion among caregiver support organizations and have coordinated advocacy efforts; and 3) Caregivers are a policy priority for the Coalition Avenir Québec.

In conclusion, Québec is internationally recognized for their integrated service delivery model for care for older adults. Since 2003, Québec has also had a progressive vision in place of home as the first choice. These are solid foundations to build upon; however, over 2012-2019 there were limited reforms to improve the long-term care system as a whole and fully deliver upon the vision of home as the first choice. There were some increases to home care funding, but the major issue regarding access has yet to be resolved. A challenge to reforms during this period was the lack of continuity in government, with four provincial governments in power over this period, each advancing significantly different policy priorities. In 2019, the Ombudsman reported that organizations had begun introducing new exclusion criteria in response to growing demand, and the MSSS had to release a statement that organizations should stop cutting home care services and meet demand (Le Protecteur du Citoyen, 2019). Whether they will be able to do this will depend heavily on how they prioritize funding, as well as future investments made into home care services. This issue highlights the necessity of funding models for long-term care.

Chapter 11.

The Case of Nova Scotia

This chapter provides an analysis of the continuing care system in Nova Scotia over 2012-2019, focusing on the first half of this period when the most significant reforms occurred. This analysis was informed by interviews with key informants in 2014 (n=2), review and analysis of government policy documents, and review of reports, literature, and other sources. Section 11.1 describes the health care context and the continuing care system. Section 11.2 provides information on the policy context in Nova Scotia and the impact of key reforms. Section 11.3 critically analyzes the case of Nova Scotia. Further critical analysis is included in the comparative analysis in chapter 14.

11.1 Provincial Health Care Context

11.1.1 Health Care System Structure and Governance

Nova Scotia has a universal public health care system that is regulated by the federal *Canada Health Act* and relevant provincial legislation. Responsibilities for health care are split between the Department of Health and Wellness and the Nova Scotia Health Authority (NSHA). There were 9 district health authorities responsible for service delivery prior to 2015, but afterwards these were amalgamated into a single provincial health authority with 4 regional zones. The Department of Health and Wellness has been primarily responsible for policy, planning and funding services; however, in 2016 funding and planning functions for acute care, primary care, mental health, and public health care were transferred to the NSHA. The Department of Health and Wellness retained its responsibilities for continuing care, information technology, and overall funding, policy, and leadership of the health care system (Fierlbeck; 2018, 2019). Due to the rural nature of Nova Scotia, over the past decade the province has developed unique collaborative models for hospitals and primary care in rural areas (collaborative care centres and collaborative emergency centres) (Fierlbeck, 2018).

11.1.2 Continuing Care Structures and Services

Responsibilities for continuing care services are split between the Department of Health and Wellness (funding, policy, and monitoring service providers) and NSHA (assessment, coordination of services, and oversight of service delivery) (Canadian Home Care Association, 2013; Office of the Auditor General of Nova Scotia, 2017). The responsibilities for continuing care assessment, coordination of services, and oversight of service delivery were transferred to the district health authorities in 2009 and are now the responsibility of the NSHA. The core components of Nova Scotia’s continuing care system are long-term care facilities (nursing homes and residential care), home care, rehabilitation, and caregiver respite programs. Co-payments are required for access to most services (Fierlbeck, 2018). Direct funding is also available through the self-managed care program and supportive care program (Nova Scotia Department of Health and Wellness, 2015). Various private pay long-term care facility and home care options are also available (Fierlbeck, 2018). Table 22 provides an overview of the continuing care system in Nova Scotia using an adapted version of the *INTERLINKS Framework*.

Table 22 *INTERLINKS Framework for Long-Term Care: Nova Scotia*

INTERLINKS Framework for Long-Term Care	
Identity of Long-Term Care	
<i>Values</i>	<ul style="list-style-type: none"> • The following is a summary of key principles for home care: <ul style="list-style-type: none"> ○ Most people prefer to remain, and can retain greater independence, at home. ○ Services are provided based on assessed need and risk and prioritize those with greatest need. ○ Services should respect cultural values and autonomy; presume capacity; maintain optimal independence; involve clients and their supporters; assist in accessing other services; and encourage and supplement informal care. ○ Individuals should be treated with kindness, dignity, and respect. ○ Services should be high quality, safe, and effective. ○ The full scope of providers should be utilized. ○ Care in a facility is appropriate when other resources cannot adequately sustain the individual.^a • Key principles for nursing homes include: holistic care; choice and self-determination; respecting privacy; maximizing abilities; flexible scheduling of ADL supports; meaningful relationships; residents and families as partners in care; homelike environments; supportive and safe environments for staff; and use of innovative models of care.^b
Policy and Governance	
<i>Policy</i>	<ul style="list-style-type: none"> • See section 11.2 for discussion of continuing care policy in Nova Scotia.

<i>Governance mechanisms</i>	<ul style="list-style-type: none"> • The Department of Health and Wellness is responsible for funding, policy, and monitoring continuing care service providers. The NSHA is responsible for assessment, care coordination and oversight of service providers.^c • Nursing homes and residential care facilities are usually privately run, with residents receiving public subsidy. Home care services are purchased by the Department of Health and Wellness from private providers.^d
Pathways and Processes	
<i>Accessing services</i>	<ul style="list-style-type: none"> • Continuing care services are accessed by calling a single toll-free number.^e
<i>Assessing needs</i>	<ul style="list-style-type: none"> • Care coordinators use a customized assessment program known as SEAScape that incorporates the RAI assessment tool to assess clients.^f
<i>Interdisciplinary working</i>	<ul style="list-style-type: none"> • Government has been considering the potential establishment of hubs of community care that would provide multidisciplinary care to long-term care facilities and home care clients.^g
Organisational Structures	
<i>Nursing and residential care homes</i>	<ul style="list-style-type: none"> • There are two types of long-term care facilities: nursing homes and residential care facilities. Nursing homes provide care to people with high level needs who require professional and nursing care. Residential care facilities provide personal care, accommodation, and supervision.^e Residential care facilities are often attached to nursing homes.^h Residents of nursing homes and residential care facilities are required to pay for their room and board. Subsidies for accommodation are available for low-income people.^e
<i>Care within a hospital setting</i>	<ul style="list-style-type: none"> • Home First programs provide intensive supports (beyond the regular home care program) to facilitate discharge from hospital or prevent admission to the hospital.^e • Nurse practitioners and paramedics work in some nursing homes to provide alternatives to acute care.ⁱ
<i>Transitory care facilities</i>	<ul style="list-style-type: none"> • Multidisciplinary restorative care programs may be available to provide intensive restorative services to allow seniors in the hospital to return home.^j
<i>Assisted living arrangements</i>	<ul style="list-style-type: none"> • No publicly subsidized assisted living arrangements are currently offered.^k
<i>Formal care in the home and the community</i>	<ul style="list-style-type: none"> • Home care services are available for people with acute, chronic, or palliative needs.^a Available services include home nursing and home support (personal care, housekeeping, meal preparation, respite). There is no charge for home nursing care, but clients may be required to make an income-based co-payment for home support.^e About 20% of home support clients make co-payments.^d • A Self-Managed Care Program is available for people with physical disabilities who want to manage their home support directly.^e • The Supportive Care Program provides eligible individuals with cognitive impairments \$500/month for home support services and up to \$495/year for snow removal.^e • Adult day services and community occupational therapy and physiotherapy are also available.^e
<i>Specialised case or care management centres</i>	<ul style="list-style-type: none"> • Case management (assessment, service planning, care coordination, and monitoring) is the responsibility of health authority care coordinators.^a
Means and Resources	

<i>(Shared) funding</i>	<ul style="list-style-type: none"> Public funding is provided from the federal and provincial governments. In 2012 provincial revenues accounted for 68.5% of public health care funding and federal funding accounted for 31.5%.^d As part of the new federal health funding agreement \$286 million of targeted funding will be provided over 10 years for home and community care and mental health.^l
<i>Enabling, allocating and funding human resources</i>	<ul style="list-style-type: none"> Continuing care assistants provide the majority of care in the home and long-term care facilities; enrollment in programs has been declining since 2010/11.^d Nova Scotia has successfully expanded the role of paramedics to include basic primary care services, providing care in long-term care homes, and support for palliative care patients at home.^d
<i>Supporting informal carers as a resource for LTC</i>	<ul style="list-style-type: none"> Respite beds and respite through the home support program are available.^e The non-profit Caregivers Nova Scotia receives annual funding from the Department of Health and Wellness to provide services such as peer support, education, and practical supports. Support Coordinators are located throughout the province.^m A Caregiver Benefit of \$400/month is available for eligible informal caregivers providing care to low-income care recipients.ⁿ
<i>Financial indicators</i>	<ul style="list-style-type: none"> In 2014, health spending amounted to 15.6% of the provincial GDP. Health spending accounts for 44% of the provincial budget. Continuing care accounts for approximately 20% of the health budget annually.^d In 2017/18 \$265 million was spent on home care and \$575 million on long-term care.^o
<i>Role of information technology</i>	<ul style="list-style-type: none"> Nova Scotia's information technology system consists of three main components: 1) Electronic health records (hospital record system); 2) Electronic medical records (primarily used by primary care physicians, as well as clinics and long-term care facilities); and 3) Personal health records (controlled and accessed by patients). Since 2015, work has been underway to integrate these systems.^d

Sources: a. Nova Scotia Department of Health and Wellness (2018); b. Nova Scotia Department of Health and Wellness (2019); c. Office of the Auditor General of Nova Scotia (2017); d. Fierlbeck (2018); e. Nova Scotia Department of Health and Wellness (2015); f. Canadian Home Care Association (2013); g. Expert Advisory Panel on Long-term Care (2018); h. Curry (2014); i. Government of Nova Scotia, (2010); j. NSHA (2016a); k. Keefe, Dill, Ogilvie & Fancey (2017); l. Health Canada (2018); m. Caregivers Nova Scotia (2014); n. Government of Nova Scotia (2018a); o. NSHA (2019).

11.2 Continuing Care Policy Context and Objectives, 2012-2019

The following sections include discussions on the continuing care policy context and objectives in Nova Scotia over 2012-2019. Section 11.2.1 provides a brief overview of the political and economic landscape. Section 11.2.2 reviews key government policy documents relevant to continuing care. Section 11.2.3 covers the policy context and key reforms during this time period. Section 11.2.4 reviews relevant evaluations and

evidence on the impact of reforms. Section 11.2.5 provides interview data from key informants on the policy context and reforms during this period.

11.2.1 Political and Economic Landscape

Over 2009-2013 the New Democratic Party was in power in Nova Scotia, then from 2013 onwards the Liberal Party has been in power. The population of Nova Scotia was 923,600 in the 2016 census and 19.9% (183,820) of the population are older adults (Statistics Canada, 2019b). Nova Scotia’s economy has traditionally been resource-based and since the 1990s the fiscal environment has significantly declined due to losses in traditional sectors of the economy. An aging population, coupled with economic stagnation and outmigration of the working age population, creates a challenging fiscal situation for governments (Fierlbeck, 2018). Average annual growth in per capita health care spending was higher over 2010-2014 (2.9%) than 2014-2019 (1.7%) (CIHI, 2019b).

11.2.2 Key Policy Documents

This section describes key continuing care policy documents over 2012-2019, as well as the *Continuing Care Strategy for Nova Scotia* published in 2006 that set the policy priorities for continuing care for the following 10 years. The vision of the *Continuing Care Strategy* was “To have every Nova Scotian live well in a place they can call home.” (Nova Scotia Department of Health, 2006, p.4). The main commitment made in the strategy was creating 1,320 new long-term care beds over the next 10 years. The strategy had five action areas: support individuals and families, support community solutions, invest in providers, strengthen continuing care services, and invest in infrastructure (see table 23 for actions in each area). The projected cost for the first four years of the strategy was \$122 million (Nova Scotia Department of Health, 2006).

Table 23 Continuing Care Strategy Actions

Continuing Care Strategy Actions	
1. Support individuals and families:	Develop a caregiver strategy; Improve system navigation; Develop a public awareness strategy
2. Support community solutions:	Develop a transportation strategy; Expand housing options; Expand home repair and adaptation programs; Expand the equipment loan program
3. Invest in providers:	Develop a continuing care human resource strategy; Expand the challenging behaviours program

<p>4. Strengthen the continuing care services: Expand home care, home oxygen, and respite; Develop a provincial palliative care program; Expand home care in facility settings; Expand the role of long-term care; Expand the challenging behaviours program; Deliver primary care in continuing care; Expand ambulatory services in the community; Develop a restorative care program; Provide First Nations care; Improve assessment and classification; Develop standardized case management; Integrate health care system</p>
<p>5. Invest in infrastructure: Develop an infrastructure review strategy; Add to long-term care; Develop an Information Management Strategy; Invest in technology; Develop long-term care funding policies</p>

Data Source: Nova Scotia Department of Health (2006)

In 2015, a discussion paper was released on refreshing the *Continuing Care Strategy* (Government of Nova Scotia, 2015a). The paper identified four potential action areas: living well at home, improving access, supporting caregivers, and improving quality and sustainability. The actions focused on enhancing home and community services. Some of the suggested actions included re-examining current models of home care delivery and financing; broadening available health services in the community; exploring other alternatives to long-term care facilities; and increasing access to home support services. In the paper it was stated that a new 5-year strategy would be released in 2017; however, to-date no new strategy has been released. However, a dementia strategy was released in 2015 (Government of Nova Scotia, 2015b) and a seniors' action plan was released in 2017 though it did not include any actions related to continuing care (Nova Scotia Department of Seniors, 2017).

11.2.3 Policy Context and Key Events

Over 2006-2016 reforms to continuing care in Nova Scotia were guided by the *Continuing Care Strategy*.⁷ The strategy was developed in response to expected pressures from Nova Scotia's aging population. It was formed through input from relevant committees, research and analysis, and public consultations (Government of Nova Scotia, 2008). The focus for the first six years of the strategy was primarily on building long-term care beds, while the remaining years focused on investing in home and community care (Government of Nova Scotia, 2015a). As a result of the strategy, by 2015 approximately \$450 million had been invested in developing new and replacement long-term care beds and \$262 million in expanding programs and services. By 2015

⁷ While many components of the Continuing Care Strategy began being implemented before 2012, this analysis focuses on the whole strategy as a) it was intended to be a cohesive strategy and b) the reforms took time to implement and were being adjusted and improved upon over time.

1,018 new long-term care beds and 898 replacement beds had been built (Government of Nova Scotia, 2015c). A household model of nursing home was developed, and new and replacement beds began to be built using this model in 2009 (Keefe et al., 2017). During the latter half of the strategy the focus shifted to scaling up home care and other community services. Some of the actions taken included:

- The Caregiver Benefit (up to \$400/month) was introduced in 2009. In 2012 the low-income threshold for receiving the benefit was raised to increase its accessibility (Government of Nova Scotia, 2009; 2012a).
- The Supportive Care Program was introduced in 2011 providing eligible clients with cognitive impairments up to \$500/month for home support services and \$495/year for snow removal. Originally clients were required to be low-income, but due to low uptake of the benefit in 2013 this requirement was removed (Government of Nova Scotia, 2015c).
- Community occupational therapy and physiotherapy were introduced, and permanent funding was provided for these programs in 2013 (Government of Nova Scotia, 2015c).
- The self-managed care program, which provides funding to directly hire home support providers, was enhanced. Policy was amended in 2013 to allow participants to delegate management responsibilities to a care manager (Government of Nova Scotia, 2015c)
- Investments were made to increase access to respite, adult day programs, and home care (Government of Nova Scotia, 2015c)
- Expansions were made to in-home palliative care, medications for palliative patients, and integrated palliative care teams (Government of Nova Scotia, 2007)

In addition to the *Continuing Care Strategy*, there was also an acute care strategy (Government of Nova Scotia, 2010) and a palliative care strategy (Government of Nova Scotia, 2014) being implemented over this period. Together these strategies influenced additional changes: placing paramedics in nursing homes to provide emergency care; expansion of the paramedic role to support palliative home care clients; and funding for Home Again style programs that provide intensive supports in the home to facilitate discharge from hospital to home (Government of Nova Scotia, 2011; 2012b; 2015d).

Following the Liberal Party coming to power, in 2015 a report evaluating the success of the *Continuing Care Strategy* was released, highlighting the progress made and making recommendations for further reforms (Government of Nova Scotia, 2015c).

Policy actors such as health care unions, researchers, and representative associations also highlighted the need for further reforms to address key issues, including:

- Health human resource challenges in long-term care and home care organizations (Curry, 2014; Health Association Nova Scotia, 2014).
- Long waitlists for home care and long-term care (Health Association Nova Scotia, 2014; Fancey & Keefe, 2014)
- The need to expand access to and the scope of home care supports available (Health Association Nova Scotia, 2014; Fancey & Keefe, 2014)
- Enhancing the capacity of case managers to coordinate continuing care services, as well as connecting with primary and acute care (Health Association Nova Scotia, 2014; Fancey & Keefe, 2014)

However, after the completion of the Continuing Care Strategy, continuing care policy development was stalled in Nova Scotia and no new strategy has been released to-date. As described in section 11.1.1 consolidation of the district health authorities into the NSHA occurred in 2015, dominating the policy agenda of the Liberal Government. As a result, many other policy priorities (e.g., long-term care) were placed on hold until 2017 (Fierlbeck, 2018). To address long waitlists some additional funding for home care was injected into the system over 2013-2016 (Government of Nova Scotia, 2016) and government policy on long-term care waitlists was changed (Fierlbeck, 2018). Another initiative that government briefly attempted to implement in 2015 was a competitive bidding system for home care services; however, there was a strong pushback against this by home care workers and this attempt was abandoned (Fierlbeck, 2018). The criteria for eligible care recipients for the Caregiver Benefit was also broadened to include people with both very high and high care needs in 2018 (Government of Nova Scotia, 2018b).

When the health authority restructuring began to stabilize, policy attention shifted to quality issues in long-term care facilities. The death of a resident from an infected bedsore in 2018 was a catalyst event prompting government to take action on quality issues (Gorman, 2018). An Expert Advisory Panel on Long Term Care was appointed to make recommendations on how to improve long-term care, focusing primarily on health human resource issues (e.g., staffing mix and levels). However, some recommendations addressed the continuum and organizations of services more broadly, including recommendations to establish hubs of community care that would provide long-term

care facilities and home care providers access to multidisciplinary teams and to convert unused residential care facility beds to rehabilitation or convalescent care beds (Expert Advisory Panel on Long Term Care, 2018). Work is underway to address some of the recommendations made by the panel (Government of Nova Scotia, 2019).

11.2.4 Evidence of Impact of Reforms

This section provides evaluation of three of the components of the *Continuing Care Strategy*: new long-term care beds, expansion of home and community care services, and the Caregiver Benefit. In 2015, the executive summary of an evaluation of the *Continuing Care Strategy* was released that used primarily administrative data to evaluate some aspects of the strategy (Government of Nova Scotia, 2015c).

Continuing Care Strategy: Long-term care beds

The construction and re-development of long-term care beds was undertaken to increase bed capacity, as well as implement a new model of long-term care facility. A total of 1,018 new long-term care beds were built, which fell 302 beds short of the 1,320 commitment. In the evaluation of the *Continuing Care Strategy* it was reported that, while the number of clients placed in long-term care increased by 18% during the strategy, waitlists also increased and there were no significant changes in ALC (Government of Nova Scotia, 2015c). Over 2006-2015 the waitlist for beds doubled from 1,079 to 2,126 (Fierlbeck, 2018). The average waiting time also increased from 169 days in 2006/7 to 333 days in 2014/15 (Government of Nova Scotia, 2015c). An external report produced for the Department of Health and Wellness identified two main factors potentially contributing to the increases to the waitlist. First, clients were being advised by physicians or care coordinators to secure their spot on the waitlist even before they needed this level of care. Half of the clients from the waitlist surveyed would not accept a nursing home bed if one were to become available at the moment. Second, only 57% of the people on the waitlist were receiving home care services and only 25% were receiving intensive services (60+ hours a month). These findings suggested there were issues related to access and awareness of home care services, as well as inappropriate use of the waitlist (Fancey & Keefe, 2014). In response to waitlist issues, government appointed a waitlist oversight committee and changed the rules so if a client refused a placement, they would be removed from the waitlist for three months (Fierlbeck, 2018).

The *Continuing Care Strategy* also resulted in the implementation of a new nursing home model. This model consists of 1) self-contained households of 9-16 residents and 2) increased staffing levels and scope of care (Keefe et al., 2017). A study by Keefe et al. (2015) investigated how the model impacted resident quality of life in a sample of 23 nursing homes. The staffing component of the new model was implemented in two ways 1) for new beds, continuing care assistants were fully responsible for the scope of care (i.e., provided personal care, housekeeping, and food) and 2) for replacement beds, continuing care assistants provided personal care, and worked with other staff to provide housekeeping and food. Residents, informal caregivers and staff from traditional and new model nursing homes were surveyed, and the study found both new nursing home models had positive indirect effects on resident quality of life (effects were mediated by two variables: home-likeness of the facility and relationships with staff) (Keefe et al., 2015). These findings align with a wider evidence base that the physical environment in long-term care settings impacts the well-being of residents (Chaudhury, Cooke, Cowie, & Razaghi, 2018).

Continuing Care Strategy: Enhancing home care and care in the community

The latter half of the *Continuing Care Strategy* focused on home and community care services. The evaluation reported that over 2006/07-2013/14 home care funding increased by 72%. There also was a 38% increase in home support direct service hours and 64% increase in home nursing visits. Growth in the number of hours and visits outpaced growth of clients, suggesting that clients are receiving more care than in the past. However, despite the investments made into home care, 398 clients were on the waitlist for home support at the end of the strategy (Government of Nova Scotia, 2015c) and only 57% of people on the waitlist for nursing homes were receiving home care services (Fancey & Keefe, 2014). As described in section 11.2.3, further funding was injected into the system to help reduce the waitlist. The evaluation included evaluations of four community programs that were developed/enhanced as a part of the strategy:

- **Self-managed Care Program:** The number of clients in the self-managed care program was small (n=146). The program was found to be more cost-effective than regular home support.
- **Community Occupational Therapy and Physiotherapy:** Staff surveyed believed introduction of these services had improved integration and care transitions.

81% of clients examined (n=400) showed improvements in performance and satisfaction for their identified goals.

- Adult Day Programs: Funding was provided to create 400 adult day program spaces; however, no provincial adult day program model was developed. Feedback from clients and informal caregivers showed adult day programs were perceived as a valuable resource, particularly for providing respite.
- Supportive Care Program: Uptake of this program was low and about half of clients also received home support services. A cost analysis suggested it cost about half as much as receiving equivalent care through the home support program, due to the higher costs of agency-managed care.

Continuing Care Strategy: Caregiver Benefit

Between 2009-2013 a total of 2,854 caregivers accessed the Caregiver Benefit (O'Hara, 2014). A retrospective cohort study of the Caregiver Benefit using administrative data from 2009-2012 (n=4,308) reported that receipt of the benefit had protective effects for caregiver distress (OR = 0.59) and client admission to long-term care (OR = 0.48) (Warner, Poss, & McDougall, 2015). Research on the economic sustainability of the program found that providing the caregiver benefit and intensive home care services (100 hours/month) to a client costs approximately \$5,151 per month compared to \$6,002 for long-term care (O'Hara, 2014). Since its introduction, the eligibility criteria for the benefit has been relaxed to allow more people to access the benefit. By 2018 there were 1,979 recipients and it was estimated the expanded eligibility criteria will result in 600 new recipients (Government of Nova Scotia, 2018b). There are plans to further expand the criteria to include care recipients with moderate needs in the future (Government of Nova Scotia, 2018b).

11.2.5 Key Informant Interviews

The interviews with key informants conducted in 2014 played an important role in identifying *Continuing Care Strategy* reforms and highlighting some of the relevant literature and evidence described in the above sections. This section includes additional insights that were gained from the key informants on the reforms in Nova Scotia.

In the 2014 interviews an informant described changes that had been made over the past eight years as a result of the *Continuing Care Strategy*. These included:

- Targeted resources were introduced to the system to add long-term care beds (a proportion of which were replacement beds) and build facilities that utilize a neighbourhood model. The scope of practice of Continuing Care Assistants in these facilities was also expanded.
- Changes were made to the home care system to increase resources and standardize the education of Continuing Care Assistants in the community.
- The Caregiver Benefit and the Supportive Care Program were introduced.
- The Home First model was introduced that focuses on providing acute home care to facilitate discharge from the hospital and prevent readmission.

The informant noted that the increase in long-term care beds had some unintended consequences, as following the scaling up of beds the waitlist almost doubled. The strategy made some positive changes to the continuing care system, but it was difficult to evaluate its success as no ongoing evaluation was built into the strategy:

And well they've done a lot of things which is wonderful. There's lots of things which they haven't done, and so you know you can't really evaluate. They also did not have any ongoing evaluation of the strategy and so that's a bit of a problem. (Nova Scotia Interview 1)

Informants revealed that research had been conducted on the new nursing home models that were implemented (see section 11.2.4 for description of this research). An informant commented on the motivation to develop the new nursing home model and to conduct research on the model in Nova Scotia:

And so there was evidence that the new neighborhood design had positive impact on nursing home clients in other jurisdictions, but there wasn't yet evidence to support within the context of Nova Scotia. (Nova Scotia Interview 2)

One of the deficits of the *Continuing Care Strategy* that was highlighted was government did not follow through on key actions for informal caregivers (development of a Caregiver Strategy and caregiver assessments). An informant commented:

So one of the things that we don't do that some other provinces have started to look at is to have the caregivers be recognized as a client in and of themselves. So even for the caregiver benefit or for any respite services that they may want in providing care, they cannot access that unless there's a file open in the name of their care receiver. (Nova Scotia Interview 1)

However, the Caregiver Benefit was perceived as a positive step forward (though only a small segment is eligible for it). It was also noted the province provides regular funding

to the non-profit Caregivers Nova Scotia to support a regional network of caregiver coordinators. Informants also remarked that a Dementia Strategy was being developed.

Both informants perceived that home care was receiving increased policy attention and improvements had been made to the home care system. For example, the informants stated:

I think in Nova Scotia home care right now is such a priority issue, that I would say we are a work in progress, but very much moving forward. Because we have such a high proportion of seniors in the province, there's a real impetus to focus on issues of home care and nursing home. But as you know from your work, I'm sure, people want to remain at home for as long as possible. (Nova Scotia Interview 2)

Really, they have been putting a lot of effort into home care. I think they have a system that has a lot of good deliverers of services. There's a lot of strong discussion around person-centred care and you know what's optimal for the people living at home. (Nova Scotia Interview 1)

However, one of the informants commented that while access to home care had been expanded, coordination remained an issue:

There's some challenges around coordination and issues of multiple providers coming into the home. And so yeah, it's a really big challenge I think – the expansion of the service has not kept up with coordination to ensure continuity of individuals or staff with the client. (Nova Scotia Interview 1)

Some of the challenges noted with the home care system included continuity of care, coordination of services, staffing, integration with primary and acute care, and expanding available services. An informant remarked:

But every province and jurisdiction are struggling with certain components of home care or grappling with how to – and certainly some provinces with more resources have more capabilities – to provide services, a greater range of services at a lower cost to the client. (Nova Scotia Interview 2)

An informant noted the power imbalance that exists between long-term care and home care:

...all of these little communities want their own nursing home because you know they want, they see the economy, they see the growth by having the building, and home care then has a difficult time trying to compete because it's really in the individual's own home, it's invisible, and so the awareness of the value of home care is kind of lost on the public. I don't think that's

unique to Nova Scotia, but it creates a challenge for the political system trying to support home care because it's so invisible. (Nova Scotia Interview 1)

Both informants commented on the need to continue to move forward with further investments into home and community supports:

I'm sure you've heard the adage 'We can't afford not to.' (Nova Scotia Interview 2)

An informant also remarked that in the past there was a Federal Continuing Care Working Group in the 1990s and early 2000s made up of federal and provincial representatives. Having that opportunity to share experiences and expertise was very valuable:

Just that contact face to face between those directors of continuing care or executive directors or whatever they were called at the branch was really, really valuable. And you know the, at least our province, the small provinces in particular, do miss that because you know we don't have the volume of expertise at the local level and this really provided an opportunity to hear best practices and unfortunately we don't have that anymore. And that would be the kind of structure that I think would be really valuable. (Nova Scotia Interview 2)

11.3 Critical Analysis of the Case of Nova Scotia

This section critically analyzes the impact of the *Continuing Care Strategy* and other reforms in Nova Scotia over 2012-2019. The analysis reviews the reforms in Nova Scotia against key frameworks and best practices for integrated continuing care described in chapters 2 and 4.

The *Continuing Care Strategy* was implemented with the vision of ensuring all people have access to the care options they need and a place to call home (Nova Scotia Department of Health, 2006). An additional underlying rationale was to reduce pressures on hospitals. The strategy was fairly expansive and represented an acknowledgement of the importance of continuing care services. It was originally developed under a Progressive Conservative Minority Government and then implemented under New Democratic Party and Liberal Governments. During its final years under the Liberal Government, attention on the strategy dwindled, as the Liberals had other policy priorities (development of the NSHA). The changes in government resulted in some drift in the strategy in terms of the specific actions implemented, as some key actions were

not implemented (e.g., developing caregiver strategy, developing a provincial model for adult day programs) while other actions implemented were not a part of the original strategy (e.g., introduction of Caregiver Benefit). This highlights the challenges that government turnover poses to implementing long-term strategies.

The strategy resulted in some unexpected outcomes and elucidates some considerations for implementing changes within complex systems. First as described in sections 11.2.4 and 11.2.5, the waitlist for nursing homes significantly rose over the course of the strategy. This increase in waitlists highlights the important role that gatekeepers play in the allocation of health care resources and the challenges of changing historical practices that have become embedded within systems. Second, there was some overlap between newly introduced services and pre-existing services. It was observed that since the scaling up of home care programs use of lower level residential care facilities has been declining and there are unused beds (Expert Advisory Panel on Long Term Care, 2018) highlighting the interconnected nature of continuing care services. In addition, while the Supportive Care Program was originally conceptualized as a self-managed alternative to home support, more than half of the clients also receive home support services (Government of Nova Scotia, 2015b). Third, as described in sections 11.2.3 and 11.2.5, the coordination of the expanded range of services in the home was an issue, and it has been suggested that the case management role needs to be enhanced. While the strategy addressed a broad range of components of the continuing care system, it did not always account for how they would interact or make much progress in facilitating functional integration, and in particular the coordination of continuing care services.

As noted in section 11.2.5, another deficit of the strategy was it did not follow through on key actions for informal caregivers, though a Caregiver Benefit was introduced. Nova Scotia has a unique demographic situation in Canada, with one of the oldest populations and significant population outmigration. This has important implications for the availability of formal and informal caregivers. Despite these facts, the *Continuing Care Strategy* failed to deliver both a human resource strategy and a caregiver strategy. Health human resources were forced back into a prominent position on the policy agenda in 2018 due to the Expert Advisory Panel on Long Term Care (2018). One of the interesting recommendations from the panel that has the potential to

address some health human resource and integration issues is the development of hubs of community care as described in section 11.2.3.

Neoliberal and new public management principles influenced several of the reforms from the *Continuing Care Strategy*, as well as reforms that have been proposed for the future. Some of the new programs had restrictive eligibility criteria for income, thus marking a shift away from universal access (e.g., Caregiver Benefit, Supportive Care Program). Income criteria were utilized as a mechanism for rationing these services, though over time some of the criteria have been relaxed. While sustainability was not prominent in the rhetoric of the *Continuing Care Strategy*, it was identified as a key concern for a refreshed strategy. Policy options proposed to address the sustainability and efficiency of home care services include fairer home support fees and expansion of direct funding programs (e.g., Supportive Care Program) – the former implies increased financial responsibilities for clients and the latter increased management responsibilities. While the Supportive Care Program was found to be more cost-efficient than regular home support, data also suggested that informal caregivers experienced higher levels of distress (though the sample size for this study was small) (Government of Nova Scotia, 2015b). Traditionally, direct funding programs have targeted younger people with significant physical disabilities, and it should be explored whether informal caregivers of older adults with cognitive impairments are empowered by such programs or experience increased burden as a result of management responsibilities. Another policy option to increase home care efficiency that government unsuccessfully attempted to implement was a competitive bidding system (see chapter 14 for further discussion of competition in home care). In Nova Scotia, most nursing home and home care services are delivered by contracted private providers, so the presentation of market-oriented policy options is unsurprising given the history of the system.

Overall, continuing care policy has been neglected, particularly since the Liberal Party came to power. The limited data that is available shows that following completion of the *Continuing Care Strategy* there was a reduced rate of spending growth, reduced provision of home support, and improving but still long waits for nursing homes:

- Since the strategy ended, the number of home support hours provided decreased from 3,170,907 in 2015/16 to 3,063,279 in 2018/19. In comparison, the number of home nursing visits increased from 1,003,492 in 2016/17 to

1,130,155 in 2018/19 (NSHA, 2016b; 2019). Waitlists for home care still existed in 2019 (NSHA, 2019)

- Over 2017-2019 average wait times for nursing home placement from home declined from 222 to 166 days (data on wait times from hospital not available). The waitlist was 1,246 people (this only counts people waiting at home though) (Government of Nova Scotia, 2020).
- As shown in table 24 below, over 2012/13 to 2018/19 the continuing care budget increased by a modest 14%, with the most significant increases occurring over the first half of this period.

Table 24 Continuing Care Budget (\$ millions)

	2012/13	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
Continuing Care Budget	\$727	\$736	\$797	\$820	\$816	\$827	\$842

Data Source: Data obtained from Department of Health and Wellness Annual Accountability Reports for 2012-2013, 2013-2014, 2014-2015, 2015-2016, 2016-2017, 2017-2018, 2018-2019

In conclusion, as a result of the *Continuing Care Strategy* a scaling up of nursing home beds and home and community care services occurred that has better positioned Nova Scotia to meet the needs of its aging population. However, there were limitations to this strategy as described above, and in the evaluation of the strategy (see section 11.2.4) key measures suggest it failed to sufficiently scale up and deliver services in an integrated manner to effectively meet the needs of older adults.

Chapter 12.

The Case of Denmark

This chapter provides an analysis of elder care in Denmark over the period of 2012-2019. This analysis was informed by interviews with key informants conducted in 2014 (n=1) and 2020 (n=2), review of government policy documents, reports, literature, and other sources. A small number of documents in Danish were reviewed using Google Translate. Due to the limitations of such a translation method, only basic information was obtained from these documents, and this data was triangulated with other sources and is only included if it is coherent with narratives and information from other sources. Section 12.1 describes the health care context and the elder care system. Section 12.2 provides information on the policy context and the impact of key reforms. Section 12.3 critically analyzes the case of Denmark. Further analysis is included in the comparative analysis in chapter 14.

12.1 National Health Care Context

12.1.1 Health Care System Structure and Governance

There are three levels of government involved with health care in Denmark: state, regional, and municipal (Danish MOH, 2017a). In 2007, major restructuring occurred, reducing the number of counties to 5 regions and reducing the number of municipalities from 271 to 98. The reforms also shifted some financing and service delivery responsibilities (Andersen & Jensen, 2010). Currently the state is responsible for overall regulation, supervision, planning, and quality monitoring (OECD, 2019a). In the past elder care was a responsibility of various iterations of the Ministry of Social Affairs, but now is the responsibility of the Ministry of Health. The five regional governments are responsible for hospitals, psychiatric care, and general practitioners (Danish MOH, 2017a). Municipalities have the primary responsibility for governance, provision, delivery, and financing of care for the elderly (Danish MOH, 2017a). The 2007 reforms transferred responsibilities for health promotion, prevention, and rehabilitation to the municipalities (Andersen & Jensen, 2010). Health care agreements are negotiated between regions and municipalities every four years and must include policies that

address: hospitalizations and discharge processes, rehabilitation, devices and aids, prevention and health promotion, mental health, and follow-up on adverse events (Rudkjøbing, Strandberg-Larsen, Vrangbaek, Andersen, & Krasnik, 2014). Health care is funded through taxes at the state and municipal levels. Annual financial agreements are negotiated between the state, regions, and municipalities (Danish MOH, 2017a).

12.1.2 Elder Care Structures and Services

Municipalities bear the primary responsibility for elder care services; however, due to their significant autonomy there are variations in the provision of services. Key components of the elder care system include: 1) Preventative measures; 2) Rehabilitation (also known as reablement); 3) Home care (also known as home help); 4) Homes for the elderly (nursing homes, sheltered housing, elderly housing, general elderly homes); and 5) Other interventions (Kvist, 2018). The Danish elder care system emphasizes providing care in the home for as long as possible (WHO Regional Office for Europe, 2019). Since 1987, legislation has been in place banning the construction of conventional nursing homes. However, nursing homes continue to provide care to a proportion of older adults and elderly housing has been developed as an alternative to traditional nursing homes (Kvist, 2014; 2018). Guarantees are in place that waits for nursing homes and elderly housing must not exceed two months (Kvist, 2018). Home care services are the cornerstone of care for older adults and services are available free of charge and provided based on need with no means-test (Danish MOH, 2017a). The Danish elder care system blurs some of the boundaries between home care and homes for the elderly, as care may be delivered by integrated teams (i.e., team of staff may provide care to nursing home residents and also provide care in elderly housing and nursing homes) (Schulz, 2014; Stuart & Weinrich, 2001). Municipalities are also required by law to provide rehabilitation and preventive home visits (Danish MOH, 2017a). Additional private services may be purchased if desired (WHO Regional Office for Europe, 2019). Table 25 provides an overview the Danish elder care system using an adapted version of the *INTERLINKS Framework*.

Table 25 INTERLINKS Framework for Long-Term Care: Denmark

INTERLINKS Framework for Long-Term Care	
Identity of Long-Term Care	
<i>Values</i>	<ul style="list-style-type: none"> The foundational principles of the elder care system are: help to self-help; continuity; self-determination. The system aims to help people stay at home as long as possible (see section 12.2.3 for further discussion of these principles).
Policy and Governance	
<i>Policy</i>	<ul style="list-style-type: none"> See section 12.2 for discussion of the policy context in Denmark
<i>Governance mechanisms</i>	<ul style="list-style-type: none"> Municipalities bear the primary responsibility for elder care. Municipalities are required to establish an elected Seniors Citizens' Council that they must consult with on issues affecting older adults.^a Nursing homes, home care, and day homes may be provided by municipal or approved private providers. By law, older adults must have the choice of receiving home care from municipal providers or a private provider. Municipalities are responsible for oversight of providers.^{b,c}
Pathways and Processes	
<i>Accessing services</i>	<ul style="list-style-type: none"> Services are accessed through the municipality.^a Preventive home visits must be offered annually to vulnerable people aged 65-79 or any person aged 80 and up. These visits provide an opportunity to discuss potential care needs of the older adult and connect them with services.^a
<i>Assessing needs</i>	<ul style="list-style-type: none"> Prior to assessing home care needs, municipalities must offer rehabilitation services.^b Assessments are based on need and performed by municipal case managers.^b There is no national standardized assessment process; however, municipalities have developed a framework for the allocation of care and services based on functional needs known as Common Language.^c
<i>Interdisciplinary working</i>	<ul style="list-style-type: none"> Most elder care staff work in multidisciplinary teams and have regular contact with health care providers. Rehabilitation services are delivered by multidisciplinary teams.^c
Organisational Structures	
<i>Nursing and residential care homes</i>	<ul style="list-style-type: none"> Nursing homes provide care for older adults with the highest level of needs. Professional care is available 24 hours a day. Nursing home residents pay for their room and board, while nursing and health care services are free of charge.^a Traditional style nursing homes are being phased out.^d
<i>Care within a hospital setting</i>	<ul style="list-style-type: none"> Regions and municipalities must have discharge processes in place as a part of their health care agreements. Discharge managers or teams may be employed by hospitals or municipalities. Post-discharge follow-up visits may be offered to patients to assess and provide follow-up care.^c
<i>Transitory care facilities</i>	<ul style="list-style-type: none"> Municipalities may offer intermediate units or nursing home beds for individuals who do not need hospital services but require short-term intensive care or rehabilitation.^a
<i>Assisted living arrangements</i>	<ul style="list-style-type: none"> Sheltered housing (beskyttede boliger) is connected to nursing homes, with some available staff and services.^b

	<ul style="list-style-type: none"> • Elderly housing (plejeboliger) has been developed as the primary alternative to traditional nursing homes. Older adults are tenants in this type of housing and there are permanent staff and service areas attached.^{b,d} • General elderly housing (almene ældreboliger) is adapted to meet the needs of older adults but without permanent staff or service areas (however assistance can still be received through home help).^b
<i>Formal care in the home and the community</i>	<ul style="list-style-type: none"> • Home care (home help) includes personal care (i.e., ADL supports), practical help (i.e., IADL supports), and food services.^{a,c} There are no minimum requirements to receive assistance in the home and 24-hour services are available.^{e,f} Home help services are flexible and consumers may choose to substitute different home help tasks than the ones scheduled.^g Home care is provided free of charge, while a co-payment may be charged for food services or temporary care.^a • Home nursing is available for individuals with a temporary or chronic need, or individuals who are dying.^a • Home care clients may also choose to receive a cash voucher that they can use as a personal budget for home care services.^h • Municipalities must offer rehabilitation services prior to assessing home care needs and when appropriate to improve and maintain a client's functional capacity. Programs usually are 4-12 weeks long.^{b,c} • Day homes (provide the same services as nursing homes, but person goes home at night) and day centres may be available in the community.^c
<i>Specialised case or care management centres</i>	<ul style="list-style-type: none"> • Older adults requiring support receive case management from the municipality. The case manager and service providers work to coordinate services in the home.^{e,f}
Means and Resources	
<i>(Shared) funding</i>	<ul style="list-style-type: none"> • Municipalities receive funding from the state and collect local taxes to finance elder care.^a Public spending accounts for 92.4% of elder care spending.ⁱ • Municipalities make contributions to regional funding based on the utilization of regional health care services by their citizens. This is intended to provide incentives for prevention and to decrease hospital use.^a Hospitals may charge municipalities if discharge is delayed due to waits for services in the community.^f
<i>Enabling, allocating and funding human resources</i>	<ul style="list-style-type: none"> • The elder care workforce is made up primarily of trained social and health helpers/assistants.^c Service delivery is usually integrated, with the same organization providing care and staff shared between multiple settings.^j • It is estimated that by 2025 demand for elder care staff will increase between 17-33% and exceed the available supply.^j
<i>Supporting informal carers as a resource for LTC</i>	<ul style="list-style-type: none"> • Municipalities are required to provide respite services for informal caregivers. Informal caregivers may also apply to be employed by the municipality to provide care to their relative. Training and education programs for caregivers may also be available.^c
<i>Financial indicators</i>	<ul style="list-style-type: none"> • Health care spending amounts to 10.1% of GDP (public funding accounts for 84% of health care spending). Elder care accounts for one-quarter of health care spending.^k • The split of public spending on elder care is 66% for care in the home and 34% for care in institutions.ⁱ

<i>Role of information technology</i>	<ul style="list-style-type: none"> Information technology is extensively used in Denmark. All general practitioners use electronic health records, and records, laboratory tests, referral, and prescriptions can be shared electronically. A web portal allows patients to access their health care information.^a Work has been underway to standardize elder care records through the Common Language platform and to ensure municipal records are integrated with health information technology systems.^l
---------------------------------------	---

Sources: a. Danish MOH (2017a); b. Kvist (2018); c. WHO Regional Office for Europe (2019); d. Kvist (2014); e. Schulz (2010); f. Hansen (2009); g. Rostgaard (2012); h. Campbell & Wagner (2010); i. European Commission (2019); j. Schulz (2014); k. OECD (2019); l. Danish MOH (2018a)

12.2 Elder Care Policy Context and Objectives, 2012-2019

The following sections include discussion of the elder care policy context and objectives in Denmark over 2012-2019. Section 12.2.1 provides a brief overview of the political and economic landscape. Section 12.2.2 describes key government policy documents relevant to elder care over 2012-2019. Section 12.2.3 covers the policy context and key events during this period. Section 12.2.4 reviews relevant evaluations and evidence on the impact of reforms during this period. Section 12.2.5 provides interview data from key informants on the policy context and reforms during this period.

12.2.1 Political and Economic Landscape

At the state level a Social Democrat-led coalition (centre-left) was in power over 2011-2015, while from 2015-mid 2019 a Venstre-led coalition (centre-right) was in power. Universal access to elder care was solidified through legislation in the 1950s and 1960s and continues to receive strong public and political support (Bureau & Dahl, 2013). Many priorities for elderly care (e.g., prevention, rehabilitation, independent living) are shared across political parties and levels of government (Kvist, 2014). Policy changes to elder care tend to be incremental (Greve, 2020a). In 2017, the population of Denmark was 5.8 million and 19.1% of the population were older adults (OECD, 2019a). Denmark is known for its strong financial investment in elder care (2.5% of GDP in 2016) and two-thirds of elder care spending is spent on care in the home (European Commission, 2019). Over 2010-2016, per capita expenditure on elder care increased modestly by 8.5% (Greve, 2020b).

Both the state and municipalities have driven forward various elder care reforms, and at times there are tensions between local autonomy and state control. Municipalities can exert considerable influence on elder care policy individually (as the level of government directly responsible for elder care) and also collectively through the Association of Local Authorities (Burau & Dahl, 2013). The significant municipal autonomy means there is a lack of standardization of services and regional differences in health care outcomes (WHO Regional Office for Europe, 2019; OECD, 2017b).

12.2.2 Key Policy Documents

The following is a review of policy objectives from government policy documents over 2012-2019 (an additional policy document from 2011 on social policy is also described). First relevant policy documents for the health care system are described, and then documents related more specifically to elder care. When available, English versions of policy documents were directly reviewed; some additional policy documents are also described based on a) description of these documents in other English language documents and b) translated versions of the documents.

In 2013, a vision for a coherent health care system was laid out that focused on integration and coordination between primary, acute, and municipal care. The vision emphasized providing care as close to home as possible (Ministeriet for Sundhed og Forebyggelse, 2013). This focus on providing care closer to home is reflected in *The National Action Plan for the Elderly Medical Patient*. This action plan focused on the following key issues: early diagnosis and treatment; strengthening the acute function of home nursing care; increasing competence of home nursing care; addressing hospital overcrowding; increasing hospital outpatient services; improving the coherence of service provision across sectors; improving medication management; and improving continuity of digital information. An allocation of 1.2 billion Danish kroner was provided for these efforts over 2016-2019 (Danish MOH, 2016). In 2016, all levels of government agreed on 8 national goals for the health care system. The goal most relevant to elder care was to strengthen measures for chronically ill and elderly patients, and several acute care indicators were selected for measurement of this goal (Danish MOH, 2018b).

In *Social Policy in Denmark* the Ministry of Social Affairs and Integration (2011) outlines the general framework for social policy in Denmark. This document reaffirms

help to self-help as a principle for the delivery of home care and that the type of housing the elderly live in should not determine what care they are entitled to. Prioritizing prevention, exploring technology solutions, and enhancing independence and the ability of older adults to live active lives are identified as priorities for the future (Danish Ministry of Social Affairs and Integration, 2011). In 2017 a dementia action plan was developed and funding of 470 million Danish kroner was to be allocated over 2016-2019 to support actions in focus areas: 1) early detection, examination and treatment; 2) improving quality of nursing home and rehabilitation care; 3) support and guidance for relatives; 4) dementia-friendly housing and communities; and 5) increasing knowledge and professional skills (Danish MOH, 2017b). In 2018 a policy document on dignity in elder care was published that identified four focus areas for action: self-determination of the elderly; supports for family caregivers; access to the community; and end-of-life (Danish MOH, 2018c). While the framework and direction for elder care is set at the national level, most elder care policy is established by municipalities at the local level. Recent emerging policy priorities have included dignified care, loneliness, informal caregivers, and rehabilitation (Greve, 2020a).

12.2.3 Policy Context and Events

To provide context for policy and reforms over 2012-2019, first a brief description is provided of the key principles of the elder care system, and then some recent developments in the health care system are described. Traditionally, Denmark's elder care policies have followed three key principles that were developed by the Commission on Aging in the 1980s: self-determination (older adults should be able to choose how they are cared for); help to self-help (providing help in ways that activate and encourage the independence of older adults); and continuity (older adults should be able to maintain continuity in their life and remain at home as long as possible) (Hansen, 2009; van der Boom, 2009). More recently, new public management philosophies and the marketisation of care have introduced another key principle into the elder care system: consumer-oriented services. This principle is associated with providing older adults with choice of provider, as well as allowing for the substitution of care tasks and obliging requests of older adults (Dahl, Eskelinen, & Hansen, 2015). In 2002, the Law on Free Choice of Provider was passed, requiring municipalities to provide older adults with the choice to receive publicly funded home care from the municipality or private for-profit

providers. Most municipalities adopted a competition by endorsement model, where the municipality sets costs and quality standards and then will endorse and contract with providers that meet these criteria (Bertelsen & Rostgaard, 2013). The majority of services, however, continue to be delivered by public providers (Rostgaard, 2018).

Regarding older adults and the health care system more broadly, as described in section 12.2.2, hospitals and reducing acute care use by older adults were key policy priorities over 2012-2019. Since the 1990s the number of hospital beds has been declining and there has been substantial pressure to further increase the efficiency of hospitals and move care out of the hospital (OECD, 2019a). Some of the implications of this for elder care have included:

- Increasingly municipalities have been involved in providing intermediate care in prevention and rehabilitation centres or other settings (Campbell & Wagner, 2009; Martinsen, Norlyk, & Lomborg, 2015). More intensive acute home nursing services are also now being delivered in the home (OECD, 2019a).
- There has been increased acknowledgement of the need for better coordination between hospitals, municipalities, and general practitioners (Danish MOH, 2016). It has been observed that integration initiatives often are hospital-centred and focus on how municipalities can prevent hospitalizations and decrease length of stay (Madsen et al., 2019).
- In 2017, the financial penalties that hospitals can impose on municipalities for delays in discharge significantly increased (OECD, 2019a).

Specifically regarding elder care, 2012-2019 began with a court order that had important implications for elder care policy at the municipal level. The court order made it possible for municipalities, based on municipal resources, to reduce the level of public services provided (Bertelsen & Rostgaard, 2013). Some researchers have raised concerns that an unofficial period of retrenchment has been occurring in the Danish system (e.g., Kvist 2014; 2018; Hjelmar & Rostgaard, 2020). Reductions in home care have been observed as the total number of weekly home care hours provided declined by 18% between 2010-2016 (practical help specifically declined by 33%) (Kvist, 2018).

Within these contexts, reforms to elder care have been incremental in nature (Greve, 2020a). The most significant item on the policy agenda was strengthening rehabilitation and prevention paradigms, and this may also be a potential explanation for why reductions in home care utilization were observed (Greve, 2020a). Rehabilitation first entered the elder care system through bottom-up pilot projects and municipal

approaches (Fersch, 2015). Rehabilitation is a multidisciplinary, goal-oriented approach to care that focuses on helping individuals to regain or maintain their capacities (Rostgaard, 2016). A pilot project in the municipality of Fredericia is credited as the inspiration for the current focus on rehabilitation (Bourgon, 2017; Greve, 2020a). In 2009, the Ambient Assisted Living program was launched in Fredericia that provided Everyday Rehabilitation for individuals accessing elder care for the first time and Home Help Training for those already receiving care. The success of the pilot project prompted other municipalities to begin to offer similar programs (Bourgon, 2017). A Home Care Commission was also set up in 2012 that played a key role in the prioritization of rehabilitation and prevention on the national policy agenda. The Commission's report made recommendations to improve home care, focusing on initiating a paradigm shift to rehabilitation and care that will maximize functional abilities and independence (Kvist, 2014). (See table 26 for a summary of the main ideas from the recommendations). Another Elderly Care Commission focusing on nursing homes was also set up in 2012. Its report made 43 recommendations for improving nursing homes, focusing primarily on ways to improve quality of life and standards for care (Kvist, 2014).

Table 26 Home Care Commission Recommendations

Home Care Commission	
1. Shifting Paradigms:	Home care paradigms should focus on improving functional ability.
2. Prevention:	Tools, training, and interventions for prevention need to be strengthened. Preventive home visits should be offered in more targeted and flexible ways.
3. Training and Rehabilitation:	Practices should be standardized and common principles and frameworks for rehabilitation developed. People with both time-limited and long-term rehabilitation needs should be targeted.
4. Supporting Frail Older Adults:	Home care should be targeted towards frail older adults for whom rehabilitation would not be appropriate or who have completed rehabilitation and continue to need services. These services should focus on three quality areas: coherence and coordination, individualization and goal-oriented, and professionally competent staff.
5. Organization and Management of Initiatives:	Coordination and communication between local authorities, care providers, and programs should be improved. Interdisciplinary eligibility assessments and care plans should be developed, and the detailed management of time in care provision limited. Explicit support and financial incentives are needed for rehabilitation.
6. Staff Education and Competencies:	Staff need appropriate education and competencies for new home care tasks.
7. Documentation:	Documentation practices for care plans should be improved and national quality indicators developed. Information technology should be able to share data across municipal and health care services.

- | |
|---|
| <p>8. Digital Technology: The potentials of technology for home care should be explored and the needs of users must be placed at the centre of technology solutions.</p> |
| <p>9. Framework for Social Volunteering: A framework for social volunteering should be developed and municipalities should involve community organizations, associations, and volunteers in initiatives.</p> |

Data Source: Summarized from Kvist (2014)

In response to the Home Care Commission, in 2014 a political Agreement on the Future of Home Care received consensus (Greve, 2020a; OECD, 2019a). The *Act on Social Services* was amended in 2015 to require that all municipalities assess potential home care clients for rehabilitation needs and to offer as appropriate time-limited rehabilitation services to address physical or social needs (Danish MOH, 2016). This new law received broad political support (Greve, 2020a). Motivations for introducing rehabilitation included improving the quality of life of older adults and reducing the need for elder care (Danish MOH, 2016). Also in response to the report, the law on preventive home visits was amended to change the age requirements for home visits (increased to ages 80+ and vulnerable people age 65-80) and allow for alternative visits formats (e.g., group interventions) (Danish MOH, 2016). Recommendations were also made by the Commission on the potentials of technology, and currently as a part of Denmark's digital health strategy actions are being taken to standardize and integrate municipal records into health information systems (Danish MOH, 2018a). A commitment has also been made to use technology to support the elderly, and increasingly municipalities are adopting a range of technologies to assist with delivering elder care (e.g., sensors, electronic pill dispensers, etc.) (Healthcare Denmark, 2019; Danish MOH, 2018c).

Dignity has been an important theme in recent policy documents, and legislation was passed in 2016 to improve dignity in elder care. A total of 1 billion Danish kroner was to be provided each year to support municipalities to develop dignity policies outlining their values and priorities for elder care and implement supporting initiatives. Dignity policies must be developed in partnership with the municipal Senior Citizen Councils and other key stakeholders (Kvist, 2018). Targeted funding was also provided to increase staffing levels in home care, nursing homes, and other elderly housing (Danish MOH, 2019). In addition, as a part of the dementia action plan funding has been provided to support the dignity of people living with dementia, including strengthening adult day centres and establishing counselling and activity centres for people living with dementia and their families (Danish MOH, 2017b).

Over 2012-2019 further marketization of care also occurred. In 2012, amendments to the free choice legislation changed the rules on tendering to facilitate the use of procurement models (competition on price and quality) and free choice vouchers were introduced allowing citizens to directly contract with providers (Bertelsen & Rostgaard, 2013; Rostgaard, 2018). Over 2014-2016 six municipalities participated in a Free Municipality pilot that allowed them to sell supplemental home care services (e.g., gardening, extra meals, snow shoveling, cleaning, etc.) as if they were private for-profit providers. Municipalities had argued that not being allowed to sell supplemental services put them at a competitive disadvantage compared to private for-profit providers. After completion of the pilot, a new Free Municipality scheme was introduced for 2017-2020 that expanded participation to 11 municipalities and will allow for further experimentation with supplemental services (Hjelmar & Rostgaard, 2020).

12.2.4 Evidence of Impact of Key Reforms

This section contains further descriptions of some of the reforms implemented over the 2012-2019: the formalization of rehabilitation as a part of the elder care system; creation of Dignity Policies; and increasing marketization of care. When available, evaluative research is referenced. Due to the language barrier some original research in Danish may have been missed.

Rehabilitation

Since 2015, provision of rehabilitation services had been mandated by law. During their initial assessment for home care services older adults are assessed to determine whether they would benefit from rehabilitation services; if they would, they are referred to rehabilitation services and an individualized plan is developed by a therapist or nurse. Rehabilitation services are typically offered for 8 weeks and implemented by home helpers (Bødker, Langstrup, & Christensen, 2019). Rehabilitation programs may incorporate the following elements: physical training; medication review; nutritional intervention; ADL training; physical aids and home modifications; and measures addressing loneliness (Kvist, 2018).

A key inspiration for the national adoption of rehabilitation was the success of the Ambient Assisted Living program (Everyday Rehabilitation and Home Help Training) in

Fredericia. An evaluation of Everyday Rehabilitation (n=778) reported that: 46% of older adults regained or maintained their capacity for independence; 39% required less care than originally requested; and 85% experienced an increase in quality of life or participation in desired activities (Bourgon, 2017). An external economic evaluation also found after the programs were implemented there were declines in home care service hours used (5% for practical help and 23% for personal care), length of service usage, and average home care costs per person (Bourgon, 2017). Additional research from other municipalities has also produced promising results. A review of evaluations of Danish municipal rehabilitation programs identified eight relevant evaluation studies (six studies used a controlled design). Five of the studies with a controlled design observed reductions in home care utilization. However, the studies did not measure changes in the functional ability of the participants, making it difficult to conclude whether reductions in home care utilization were directly due to the rehabilitation programs (Petersen, Graff, Rostgaard, Kjellberg, & Kjellberg, 2017). One non-controlled pre- and post-test pilot study of a rehabilitation program (n=91) did report that older adults' performance of ADLs improved significantly over time (Winkel, Langeberg & Wæhrens, 2015).

Evidence from municipalities suggests that rehabilitation programs may be reducing the need for home care, with some reporting up to 60% of older adults no longer require home care after rehabilitation (Rostgaard, 2016). However, these reductions in home care use may also be the result of stricter eligibility requirements for care (WHO Regional Office for Europe, 2019; Rostgaard, 2016). Some critiques have been made of rehabilitation programs for their: a) assumption that rehabilitation can restore independence and reduce the need for home care services, which may not be realistic expectations for many older adults (particularly those experiencing an extended trajectory of decline); b) short duration that may be inadequate for many older adults to reach their goals; and c) mismatches between older adults' desires and perceptions of what independence is versus perceptions of workers (Bødker et al., 2019).

Dignity Policies

In 2016 legislation was introduced requiring municipalities develop dignity policies and funding was provided to develop the policies and implement supporting initiatives (Kvist, 2018). Dignity policies were required to address five essential areas: quality of life, self-determination, quality and coordination of care, food and nutrition, and

a dignified death (Danish MOH, 2016). Later, two additional areas were added: relatives and loneliness (Danish MOH, 2019). A variety of initiatives have been funded by the dignity billion, and initiatives to improve quality of life (e.g., investment in rehabilitation programs, establishment of continence clinic, programs for people living with dementia) have been the most significant source of spending (Danish MOH, 2019). One evident outcome of the dignity policies is that the seven essential areas are now objectives on municipal policy agendas.

Increasing Marketization of Care

Marketization of care has been an ongoing process and in 2012 further reforms were made to change the tendering process and introduce free choice vouchers. These reforms were intended to a) increase competition and b) decrease the number of providers to make choice easier to manage and less administratively costly (Bertelsen & Rostgaard, 2013; WHO Regional Office for Europe, 2019). However, the intense competition that resulted caused providers to lower their prices to the point where a series of bankruptcies occurred. Some home care users experienced disruptions of services as a result, and municipalities had to develop emergency procedures to take over service delivery in cases of bankruptcy (Rostgaard, 2018; WHO Regional Office for Europe, 2019). A new law was eventually introduced to reduce the number of bankruptcies and ensure continuity of care (WHO Regional Office for Europe, 2019). Support for the concept of free choice is high, with 70% of home care users reporting it was important in 2015. Over one-third of home care users now receive care from a private for-profit provider, primarily for practical help (Rostgaard, 2018; Bertelsen & Rostgaard, 2013).

Survey research also reveals some concerns about the increased marketization of care (Rostgaard, 2018). A survey of unionized care workers reported those working in the private for-profit sector generally experienced poorer working conditions and were more likely to consider quitting their job. Results from a survey of home care users showed marketization has had little impact on satisfaction with services over time, though there is some evidence that increased attention is being paid to continuity of care as a result of competition (Rostgaard, 2018).

Market principles have also now been introduced into the public sector by allowing municipalities to sell top-up services. An external evaluation of the 2014-2016 free municipality pilot by Hjelmar and Rostgaard (2020) found that within the 6 participating municipalities there was much lower uptake of these services than expected (2% of the target audience). The most frequently purchased extra service was cleaning (90%). Higher prices for municipal services (which appear to have been the result of pressure from state to not undercut pricing) was a key reason for low uptake. The introduction of supplemental services expanded the scheduled hours of work available for care workers, thus potentially creating more attractive working conditions, but also required them to expand their role to include selling supplemental services (Hjelmar & Rostgaard, 2020). Concerns have been raised as to whether allowing the topping up of services is contributing to a diminishment of the comprehensiveness of the public elder care system (Moberg, 2017).

In Denmark marketization has been framed as a means to reduce costs, increase system efficiencies, improve responsiveness and quality of care, and increase choice (Bureau, Zechner, Dahl & Ranci, 2017). However, research highlights some concerns about how well marketization is fulfilling these assumptions. Petersen and Hjelmar (2013) conducted a systematic review of empirical research studies comparing public and private services in Sweden and Denmark (n=18) in three areas: home care, nursing homes, and childcare. Overall, studies did not show positive economic effects (i.e., cost-effectiveness) of home care marketization, though some reported improvements in user satisfaction and perceived quality. The authors noted it is possible markets may not yet be mature enough to produce results, however, they also stated:

Based on the systematic review of documented consequences of marketization within three central welfare areas, we find reasons to be less optimistic than neo-liberalists and public choice advocates about the likely outcomes of marketization reforms within the welfare areas in Scandinavia. (Petersen & Hjelmar, 2013, p.15).

12.2.5 Key Informant Interviews

The interviews with key informants conducted in 2014 and 2020 played a key role in identifying reforms and key policy issues and highlighting relevant literature and information sources described in the sections above.

In the interviews informants described how the elder care system is a universal system that provides care through well trained professionals. While informal caregivers and voluntary organizations have a role in elder care, this is limited, and the expectation is that the state takes the main role in providing care. Key principles underpinning the Danish elder care system include help to self-help, continuity (at home as long as possible), and free choice. An informant described the elder care system as:

So the responsibility for organization, financing and delivery of elder care is placed with the public, which means that informal care provided by relatives is not normally considered the place where elder care takes place. But of course we do also have informal care, we also have volunteers who increasingly have to provide social care in the terms of visiting older people and so on. And we also have involvement of the markets in the sense that in the home care market providers now offer services that are financed by the public – so it's just a matter of consumerism and making sure the older person has the possibility of choosing between providers. The public service model also implies that it's a formalized system in the sense that we have professional care workers who are required to take education and training so that it's considered to be high standard care. (Denmark Interview 1)

Informants described the roles of the state government and municipalities in elder care. Especially since the free choice reforms the state has played an increasing role in elder care, influencing the introduction of market principles and standardization of care. The state exerts influence via funding and legislation. An informant described the use of financial levers by the state:

Every year there are sort of funding negotiations between the national government and the umbrella organization of municipalities, when they negotiate how much money the municipalities get from the central level. And what has happened increasingly is funding becomes, comes with strings attached. (Denmark Interview 2)

Informants described how the 2007 reforms expanded the role of municipalities into disability and rehabilitation services. However, an informant commented on concerns some municipalities have about their expanded roles:

The municipalities have argued that they have many more tasks, like for instance, the whole field of disability has moved from regions and hospitals into municipalities. But they haven't received funds that sort of compensate for that. So, most of the municipalities in Denmark would argue that they had less money due to the fact they have increasing tasks and increasing demand for social services. (Denmark Interview 3)

In the 2020 interviews, both informants also expressed concerns over increased pressures being placed on the elder care system by hospitals. For example, an informant stated:

The other thing I think, which is important, is that the health care system has moved fairly dramatically out of hospitals. And so, there are more and more elderly people discharged from hospital much earlier. Their treatment is being completed outside hospitals. So, what we are also sort of seeing is an increasing medicalization of the field of elderly care. (Denmark Interview 2)

In the 2014 interview the informant commented on preventive visits, which studies have shown help prevent functional decline. However, government was planning to increase the age visits begin at to 80 as many younger people do not require or want the service yet. There is an issue with a large percentage of the population declining the visits:

Maybe it's because they don't need care, but it – there's also the question of whether this is the right way of approaching people and making sure that their care needs are met. (Denmark Interview 1)

Informants also described the spread of rehabilitation throughout Denmark. An informant noted that help to self-help is a traditional principle of the elder care system and rehabilitation represents a more systemic approach to applying this principle. Informants described how even prior to the 2015 law municipalities were utilizing rehabilitation, and implementation of rehabilitation has varied by municipality. An informant commented on both the potential benefits and drawbacks of the rehabilitation approaches being implemented in Denmark:

So, on the one hand there are good thing about increasing functionality of the elderly if they, for instance, are not really able to walk that much or take their own clothes off then there is systematic training actually either keeping their level of functionality or sometimes even improving it. However, the drawback or the less positive aspect of this is that sometimes this principle is misunderstood and very fragile elderly people are actually forced to, quote unquote, forced to do something which actually exhausts them and decreases their quality of life. (Danish Interview 3)

Regarding free choice and the increased marketization of elder care, private for-profit providers were stated to primarily be providing practical care. While it was noted that consumerism was resisted in the 1990s, recent reforms implemented under the banner of free choice have generally been accepted by political parties and the public with little controversy. Increased choice for older adults is a benefit of these reforms,

though it was also noted that choice is constrained by, for example, municipal policies on providers. The main concern that was raised about marketization reforms in both 2014 and 2020 were the costs associated with requiring municipalities to offer a choice of municipal and private provider:

So the concerns are more how this affects sort of the cost-efficiency, in the sense that we have to operate both a municipal system and a private-based system. (Denmark Interview 1)

...some time studies are showing that they [municipalities] use a relatively large amount of time actually administering the marketization. And this is what we would then, in institutional economics, we would call transaction costs. Which means they actually have to approve of companies, they have to ensure that the companies actually provide the care that they are saying they are providing – there is this element of quality control. (Denmark Interview 3)

While in 2014 the informant commented marketization had not caused major disruptions or scandals, in 2020 informants reported there had been concerns over the stability of the market in recent years due to provider bankruptcies:

What we've seen in Denmark, and I don't know if that is part of contracting out, what we have seen in the last 5-6 years is that a lot...not a lot... I think approximately 50 of these private companies have actually gone bankrupt. So that from one day to another, elderly people have not been able to receive the elderly care that they were promised and the municipality then was obliged to do sort of ad hoc caring because they were obliged to actually provide for elderly care when the firms couldn't provide. So that sort of introduces a very problematic element of marketization or of contracting out. (Denmark Interview 3)

But I think what experience has also sort of shown that it is a very volatile market. So that there is a lack of sort of detailed contracts and there's been several cases of providers going bust. And where, you know, municipalities sort of have to pick up the pieces. (Denmark Interview 2)

It was also noted by an informant that having both a municipal and private for-profit system is not conducive to integration.

The role of technology in elder care was discussed by informants. Technologies that were discussed included a) electronic records (though it was noted in 2014 these were not connected to municipal care); b) new assisted living technologies; and c) tools for standardized documentation of services (Common Language). Regarding Common

Language, an informant commented on some concerns about the role this has had in shaping delivery of care:

And there's been, over the years, waves of heated debate about how this sort of system, this catalog of services that comes with time estimates attached, creates some sort of tyranny of time. Where there is more about ticking the boxes and delivering services, particular services, within the time frame rather than being able to relate to a person, to a particular situation in a more holistic way. (Denmark Interview 2)

In the 2020 interviews, some of the challenges for elder care that were identified included: coordination between hospitals and elder care; increasing the availability of nursing homes and elderly housing; shortages of health human resources; and reconciling the tensions between standardization of care and meeting the needs of the individual. An informant also remarked on perceptions of retrenchment:

But there is no doubt that municipalities are short of funds and cutting and cutting and being more and more efficient. If you look at it from a critical perspective, it is really difficult to see that more cuts can be done or more efficiency can be achieved within the elderly care system. (Denmark Interview 3)

12.3 Critical Analysis of the Case of Denmark

The elder care system in Denmark has been internationally recognized for its success in providing care to older adults. The Health Council of Canada (2012) and Canadian Frailty Network (Muscedere et al., 2019) have both suggested that this is a useful system for Canada to examine. This analysis critically reviews Denmark's elder care system against key frameworks and best practices for integrated continuing care, as described in chapters 2 and 4, as well as the government's stated policy objectives, key policy issues, and historical policies.

The elder care system has a well-established identity as a universal system that provides professional care and prioritizes allowing older adults to live "at home for as long as possible." In recent years, reforms to elder care have emphasized the principles of help to self-help and consumer-oriented care. Building on the principle of help to self-help, rehabilitation has shown some promising results. However, as described in sections 12.2.4 and 12.2.5 there have also been some concerns as to whether rehabilitation is being implemented in appropriate ways and also whether it may be

masking retrenchment of the system (see the comparative analysis in chapter 14 for further discussion of reablement). Marketization is also becoming more firmly entrenched in the vision for elder care, driven by rhetoric on “free choice.” In Denmark, marketization of care is viewed more favourably by the public and politicians than in some other countries (Petersen & Hjelm, 2013; Bertelsen & Rostgaard, 2013). However, the introduction of increased competition has created instability in the home care market and additional costs for municipalities. As was described in sections 12.2.4 and 12.2.5, there appears to be little evidence of the cost-effectiveness of competitive market models for home care. The possible public retrenchment of home care also raises concerns about the expansion of the municipal role into providing supplemental services. In the evaluation of the Free Municipality scheme, it was observed the most purchased service was cleaning, which may be the result of municipal policies to restrict public services (Hjelm & Rostgaard, 2020). While to date use of supplemental municipal services has been low, if they become a lucrative source of income for municipalities this could create an incentive to restrict access to these services publicly. Dignity was also an important value in recent elder care policy documents and in policies at the municipal level. Danish research on dignity and care for older adults associates the term with concepts such as preserving individual identity, autonomy, perceptions of worthiness, homelike environments, and relational care (Rehnsfeldt et al., 2014; Høy, Wagner, & Hall, 2007). These concepts align strongly with the overall vision for the elder care system.

In order to actualize “at home as long as possible,” the elder care system in Denmark incorporates several components of successful integrated care systems that have been identified in the literature (see chapter 2): a comprehensive continuum of services in the home and community, care that is delivered by integrated teams, and the ability to substitute a range of home-based services. Denmark is unique even among the Nordic countries as they provide extensive home care services free of charge, including 24/7 home care and services for people with low level needs. While attempting to spread home care resources over a large population of clients could potentially result in poorer care for older adults requiring higher levels of care, this has not been found to be the case (Rostgaard & Szebehely, 2012). A pilot project in the municipality of Skaevinge in the 1980/90s was instrumental in the decision to focus on delivering integrated, community-based health and social care. In Skaevinge, the decision was made to

eliminate the nursing home and instead turn it into a centre for community services and provide care in the home and through community housing options (Wagner, 2001). There are now few traditional nursing homes left in Denmark. In 1987 there were 49,088 people residing in traditional nursing homes (Kvist, 2014). By 2019, this had decreased to 3,337; however, 38,002 people reside in elderly housing and 30,733 in general elderly homes (Statistics Denmark, 2020). Elderly housing blurs the boundaries between nursing homes and assisted living as it can provide high levels of care and has 24/7 staff, but also is designed as housing where older adults are tenants and service areas are separate from the units. These models provide significant flexibility, as the level of care provided can be adjusted as required.

While the continuum of elder care services at the municipal level is well integrated, due to the separation of municipal and regional responsibilities there is some fragmentation between elder care and regional services. Most Danes (66%) believe there needs to be greater coherence between hospitals, general practitioners, and municipal services (Danish MOH, 2018a). Denmark has in place several integrated care components to help ameliorate the challenges posed by fragmentation:

- Health care agreements are negotiated between regions and municipalities and outline processes and expectations for coordination of care and joint working.
- Sophisticated information technology systems allow for communication and sharing of information, referrals, and prescribing. Progress is underway to strengthen the integration of municipal records with health information systems.
- There are financial incentives for coordination and prevention that a) require municipalities to contribute funding to their region based on health care utilization and b) allow hospitals to charge municipalities for delays in discharge.

Regarding financial incentives, questions have arisen about the fairness of this scheme for municipalities and its effectiveness (Rudkjøbing et al., 2012; OECD, 2013). While progress has been made in reducing delayed discharges (OECD, 2019a), such schemes require municipalities to prioritize acute care substitution over other elder care needs. As described in sections 12.2.3 and 12.2.5, there have been increasing pressures placed on municipalities in recent years by the acute care sector, and *The National Action Plan for the Elderly Medical Patient* reinforces caring for patients outside

of the hospital as a top policy priority. Previous chapters described how, in other jurisdictions, diversion of home care funds and crowding out of clients with long-term care needs have been observed due to pressures from the acute care system (see comparative analysis in chapter 14). Denmark differs from other jurisdictions as home care services are more generously resourced (see next paragraph) and have been developed with a strong orientation towards allowing older adults to live at home. However, it will be important to monitor that services substituting for acute care do not marginalize other elder care services.

An integrated and comprehensive continuum of services is not enough to ensure that the needs of older adults are fully met. There also must be adequate funding to provide these services. In Denmark spending on care in the home exceeds spending on institutional care and the policy objective of providing care in the home does not appear to have resulted in a significant downloading of responsibilities onto individuals and families. As described in section 12.2.5, the expectation is that care is provided by the state. Public spending accounts for 92% of spending on elder care (European Commission, 2019) and informal caregivers play only a limited role in providing care. Due to the generous nature of the elder care system, the most frequently reported source of help is tax-funded home care and not informal care (Rostgaard & Szebehely, 2012). In 2016, 13.1% of older adults received home care services (Kvist, 2018). Data from the Survey of Health, Ageing, and Retirement in Europe suggests that in Denmark only 21% of care is provided solely through informal sources (Barczyk & Kredler, 2019). Despite the limited role informal caregivers play in providing care, policy documents in section 12.2.2 and the inclusion of relatives in municipal dignity policies demonstrate that policy attention is still being directed towards their needs.

While Denmark's investment in elder care is quite generous in comparison to other countries, as described in sections 12.2.3 and 12.2.5 in recent years there has been concern retrenchment may be occurring in the system. The reasons for reductions in the provision of home care are not clear, potential explanations include: a) the impact of rehabilitation; b) the introduction of new technologies; c) parliamentary austerity; and d) municipalities being fiscally conservative (Kvist, 2014; 2018; Greve, 2017; 2020a). An additional factor to consider is whether the increased health care responsibilities being placed on municipalities for outpatient, acute home care, and other services may be contributing to the retrenchment of long-term home care services.

In conclusion, it is apparent that the Danish elder care system is both comprehensive and generous. Denmark exemplifies Banks (2004) concept of policy coherence and represents a rare example where the policy objective of providing care in the home for as long as possible is strongly supported by funding and service delivery policies. Review of quality indicators and performance measures suggests that Denmark has a high performing elder care system. In Denmark it is reported that:

- In 2017, average wait time for nursing home placement was 21.7 days (WHO Regional Office for Europe, 2019)
- In 2015, 83% of older adults receiving practical home help and 88% receiving personal home help were satisfied or very satisfied with the care; satisfaction with care in nursing homes was 86% (WHO Regional Office for Europe, 2019)
- The number of ALC days was the lowest among European countries (WHO Regional Office for Europe, 2019)
- Home help recipients receive on average 5.8 hours of personal care and 0.7 hours of practical help per week (Kvist, 2018)

Despite the fact Denmark spends a high proportion of its GDP on long-term care (2.5% in 2016), projections from the European Commission suggest there are low fiscal sustainability risks for the elder care system (European Commission, 2019). Stuart and Weinrich (2001) suggest an important lesson from the Danish system is that home and community-based care can be economically feasible and politically attractive.

Chapter 13.

The Case of Australia

This chapter presents an analysis of the aged care system in Australia over the period of 2012-2019. As the reforms made over this period have been substantial, this chapter focuses on reforms related to service delivery and the continuum of care. This analysis was informed by interviews with key informants in 2014 (n=2) and 2019 (n=3), review and analysis of government policy documents, and review of websites, reports, journal articles, and other literature on the aged care system. Section 13.1 describes the health care context and the aged care system. Section 13.2 provides information on the policy context in Australia and the impact of key reforms. Section 13.3 critically analyzes the case of Australia. Further critical analysis is included in chapter 14.

13.1 National Health Care Context

13.1.1 Health Care System Structure and Governance

In Australia all three levels of government are involved in health care. At the federal level the Commonwealth Government's responsibilities include developing health policy, funding physician services and medicines, providing funding to the states and territories for hospitals, and providing oversight for primary health networks (Australian Institute of Health and Welfare [AIHW], 2018). The Commonwealth is also now fully responsible for the aged care system, though up until recently states and territories shared some responsibility (Australian Department of Health [DOH], 2019). States and territories are responsible for funding and managing public hospitals and some community and public health care services. Local governments are responsible for some community and home-based health services (AIHW, 2018). Since 2015 there have been 31 primary health networks to help coordinate care between general practitioners, other primary health care services, hospitals, and community services (AIHW, 2018).

13.1.2 Aged Care Structures and Services

In Australia legislation (*Home and Community Care Act 1985* and *Aged Care Act 1997*) has clearly established residential aged care, home care, and other home and community care services as core services for older adults (Productivity Commission, 2011a). Up until recently, there were two major public programs providing care to older adults: Aged Care (funded and regulated by the Commonwealth) and Home and Community Care (HACC) (primarily the responsibility of state and territorial governments, but jointly funded with the federal government). HACC provided mainly home support services for individuals with lower level needs, as well as allied health care services. Most HACC providers were community or non-profit organizations, that sometimes relied on volunteers. Aged Care consisted of home care packages (provided older adults with access to a range of services in the home and community) and residential aged care. One lower level home care package was available and two higher intensity packages for individuals eligible for residential care. Residential aged care included high- and low-level care places. Multidisciplinary Aged Care Assessment Teams (ACAT) assessed eligibility for aged care services, while HACC providers assessed eligibility for HACC (Productivity Commission, 2011a; 2011b).

During the 2010s reforms transferred responsibility for all aged care services to the Commonwealth, and HACC and several programs were consolidated into the Commonwealth Home Support Program (CHSP). Currently the aged care system consists of three core components: the CHSP, home care packages, and residential care (Australian DOH, 2019). Home care packages range from Level 1 (basic care - value of \$8,810) to Level 4 (high intensity care - \$51,130) (Australian DOH, 2020). There is no longer a distinction in residential aged care between low- and high-level care places. There are two programs that provide intensive short-term services for older adults: Transition Care and Short-Term Restorative Care. Flexible programs that provide alternatives to mainstream care are available for rural/remote and Aboriginal and Torres Strait Island populations. ACATs continue to assess eligibility for home care packages and residential care, while new standardized Regional Assessment Services (RAS) assess eligibility for CHSP (Australian DOH, 2019). Table 27 provides an overview of key features of Australia's aged care system using an adapted version of the *INTERLINKS Framework*.

Table 27 INTERLINKS Framework for Long-Term Care: Australia

INTERLINKS Framework for Long-Term Care: Australia	
Identity of Long-Term Care	
<i>Values</i>	<ul style="list-style-type: none"> In the <i>Aged Care Act</i>, key objectives for the sector include: promoting high quality of care and accommodation; protecting the health and wellbeing of older adults; targeting services towards people with the greatest need; providing respite for informal carers; facilitating access to services regardless of race, culture, language, economic circumstances or location; encouraging services that are diverse, flexible and responsive; helping recipients to enjoy the same rights as other Australians; planning effectively for the delivery of services; and promoting aging in place.^a In 2015, an <i>Aged Care Sector Statement of Principles</i> was developed for aged care reforms with three overarching themes: empowered consumers and informal carers; flexible and responsive services; and a viable and sustainable system for all.^b
Policy and Governance	
<i>Policy</i>	<ul style="list-style-type: none"> See section 13.2 for discussion of aged care policy.
<i>Governance mechanisms</i>	<ul style="list-style-type: none"> Full responsibility for Aged Care is now consolidated under the Commonwealth Government.^c The Commonwealth regulates the number of publicly funded residential aged care places, short-term restorative care places, and home care packages.^d Residential care, home care packages, and CHSP are provided by approved government, non-profit, and for-profit providers.^c
Pathways and Processes	
<i>Accessing services</i>	<ul style="list-style-type: none"> My Aged Care (contact centre and website) is the single-entry point to access aged care services. Staff members screen clients and if an assessment is necessary, the client is referred to RAS or ACATs.^e
<i>Assessing needs</i>	<ul style="list-style-type: none"> ACATs conduct comprehensive assessments to determine eligibility for home care packages and residential aged care. The CHSP is accessed through RAS.^c The National Screening and Assessment Form is the common tool for assessments.^e
<i>Interdisciplinary working</i>	<ul style="list-style-type: none"> ACATs are multidisciplinary assessment teams.^e Short-term Restorative Care is also offered through multidisciplinary teams.^c
Organisational Structures	
<i>Nursing and residential care homes</i>	<ul style="list-style-type: none"> Residential aged care provides support and accommodation for people who require 24/7 nursing care. Residents are required to pay a basic fee and based on their income and assets a means-tested care fee. Residents also are required to make a means-tested accommodation payment (as a lump sum, daily payment, or combination of both) that contributes to the maintenance of the facility.^c
<i>Care within a hospital setting</i>	<ul style="list-style-type: none"> The hospital system has sub-acute services for older adults (e.g., geriatric evaluation and management, rehabilitation, and psychogeriatric care). There have been pilots of discharge planning for older adults but there is no systematic national approach.^f
<i>Transitory care facilities</i>	<ul style="list-style-type: none"> The Transition Care Programme provides short-term care (up to 12 weeks) in the home or a residential setting for older adults discharged from the hospital.^c

<i>Assisted living arrangements</i>	<ul style="list-style-type: none"> • There are no publicly subsidized assisted living units, but assisted living is available through private providers.^a
<i>Formal care in the home and the community</i>	<ul style="list-style-type: none"> • Home care packages (four levels available) provide a tailored package of personal, support, and clinical care. Government subsidizes the costs of services and clients co-pay a basic daily fee, and if their income is sufficient an income-tested care fee. If a person is receiving a package they do not receive CHSP, as packages can include similar services. A single national queue is used to manage access to home care.^{c,g} • The CHSP provides a range of entry-level supports to help older adults to live at home. Services include personal care, domestic assistance, meals and food services, transportation, home maintenance and modification, individual and group (day centre) social support, nursing, allied health, equipment and other specialized services. Client co-pays are set by the providers and should be in accordance with the principles laid out in the national framework.^c • The Short-Term Restorative Care program provides goal-oriented, multidisciplinary care and services for up to eight weeks in the home or residential care to improve the functioning and independence of older adults and prevent the need for higher care.^c
<i>Specialised case or care management centres</i>	<ul style="list-style-type: none"> • Case management is provided for home care packages which provide access to a range of personal, support, and clinical care services.^c
Means and Resources	
<i>(Shared) funding</i>	<ul style="list-style-type: none"> • Funding for aged care is separate from the health care system and primarily funded through taxes, though most services also require co-payments.^c • CHSP are funded by government grants to CHSP providers. Home care packages are allocated to consumers who may select their own provider and care is delivered as consumer-directed care. In residential care subsidies to providers are determined using the Aged Care Funding Instrument that assesses the care needs of the client.^c
<i>Enabling, allocating and funding human resources</i>	<ul style="list-style-type: none"> • Research suggests there are considerable challenges for the aged care workforce, including recruitment and retention, poor pay, and casualization of labour.^h Since 2002 governments have attempted to address human resource issues in aged care.^d
<i>Supporting informal carers as a resource for LTC</i>	<ul style="list-style-type: none"> • Australia has a National Carer Recognition Act and in 2011 a National Carer Strategy was developed.ⁱ • The Fair Work Act provides carers the right to request flexible working arrangements.ⁱ • In-home, host family, centre-based (residential and adult day), community access (individual or group social outings) and cottage (overnight respite in a small house) respite can be accessed via the CHSP.^c • Financial support is available via the Carer Allowance and Carer Payment.^a The Carer Payment is income and asset-tested and equivalent to a social security pension.^j • The Carer Gateway (online platform and telephone line) is a national one-stop shop for carers, and is part of the new Integrated Carer Support Service that is being developed to provide access to services such as counselling, education, etc.^k

<i>Financial indicators</i>	<ul style="list-style-type: none"> • In 2014/15 aged care spending amounted to 0.9% of Australia's GDP.^g • In 2018/19 \$19.9 billion was spent on Aged Care; 66% of this was spent on residential aged care, 13% on home care, 17% on basic supports at home, 3% on flexible and short-term aged care, and 3% on other.^c • In 2017/18 consumer contributions accounted for 9% of CHSP costs, 6% of home care costs, and 27% of residential care costs.^l
<i>Role of information technology</i>	<ul style="list-style-type: none"> • My Health Record is an online health record that can be accessed by clients and health care providers.^m • My Aged Care includes a central client record with information on assessments and services provided.^d

Sources: a. Productivity Commission (2011a); b. Aged Care Sector Committee (2015); c. Australian DOH (2019); d. Australian DOH (2017a); e. Australian DOH (2018a); f. Duckett (2017); g. Royal Commission into Aged Care Quality and Safety [RCACQS] (2019a); h. Australian DOH (2018b); i. Commonwealth of Australia (2011); j. Australian Department of Social Services (DSS) (2016a); k. Australian DSS (2019); l. Aged Care Financing Authority (2019); m. AIHW (2018)

13.2 Aged Care Policy Context and Objectives, 2012-2019

The following sections include information on the aged care policy context and objectives over 2012-2019. Section 13.2.1 provides a brief overview of the political and economic landscape. Section 13.2.2 describes key government policy documents relevant to aged care. Section 13.2.3 covers the policy context and key events over this time period. Section 13.2.4 reviews evaluations and evidence on the impact of reforms. Section 13.2.5 provides interview data from key informants on the policy context and reforms during this period.

13.2.1 Political and Economic Landscape

Over 2010-2013 the Labour Party was in power as a minority government. From 2013-present the Liberal–National Coalition has had successive majority governments. While the reforms to the aged care system were initiated by the Labour Party, reforms continued to be implemented and built upon by the Liberal-National Coalition. In the past the responsibility for aged care was divided between the Commonwealth (i.e., home care packages and residential care) and the state and territory governments (i.e., HACC). In 2009, the National Health and Hospitals Reform Commission released a report recommending that all policy and funding responsibilities for aged care be transferred to the Commonwealth (Commonwealth of Australia, 2009). In 2011 it was agreed in the National Health Reform Agreement that the Commonwealth would assume full responsibility for policy and funding of HACC (though the transfer of responsibility in

the state of Victoria occurred in 2015 and in Western Australia in 2018) (Australian DOH, 2017a; RCACQS, 2019a). The agreement also assigned the lead responsibility for primary care to the Commonwealth, increased Commonwealth contributions to hospital funding, and established Medicare Locals (later evolved into Primary Health Networks) to improve coordination between acute, primary, and aged care (Council of Australian Governments, 2011; AIHW, 2018).

In the 2016 census the population was 23.4 million and 15.7% (3.7 million) of the population were older adults (Australian Bureau of Statistics, 2019). Over 2012/13 to 2018/19 spending on aged care increased by 27% from approximately \$15 billion to \$20 billion. Spending on home care and support increased by 34% and residential aged care by 24% (AIHW, 2020).

13.2.2 Key Policy Documents

This section describes some of the key government policy documents related to aged care over 2012-2019. In 2012, a major package of reforms was introduced by the Federal Government known as *Living Longer, Living Better*. Below some of the key proposed reforms are listed:

- Helping people to stay at home: Providing more home care packages; introducing consumer-directed care (CDC); fairer means-testing; creating the CHSP which would combine HACC and several other service programs
- Delivering better residential aged care: Building more residential aged care facilities; reforming means-testing and the Aged Care Funding Instrument
- Strengthening the aged care workforce
- Measures to support informal carers, people living with dementia, consumers, and diverse Australians
- Building a system for the future: Developing an Aged Care Gateway as a single point of entry for aged care services and information

The reform package committed \$3.7 billion over 5 years to fund a range of initiatives, with over \$3 billion of the funding to come from changes to means testing and residential care funding, and redirection of aged care funds (i.e., from residential care to home care) (Commonwealth of Australia, 2012a). Since the *Living Longer, Living Better* reforms several discussion papers have been released describing further proposed reforms to

the aged care system and carer supports. Four of the most relevant discussion papers are summarized in table 28.

Table 28 Key Discussion Papers on Aged Care Reforms

Discussion Paper	Summary of Key Points
Increasing Choice in Home Care – Stage 1 Discussion Paper (Australian DSS, 2016b)	In 2015, the <i>Increasing Choice for Home Care</i> reforms were proposed: 1) allocating funding for home care packages to the consumer rather than the provider and 2) integrating the CHSP and home care packages into a single program. The discussion paper focused on reform 1), and as a result of this reform consumers will be able to choose an approved provider. My Aged Care will manage a prioritization process to allocate packages to consumers. The approval process for becoming a provider will also be simplified.
Delivering an integrated carer support service: A draft model for the delivery of carer support services (Australian DSS, 2016c)	The proposed integrated carer support service model would include a national infrastructure and services (i.e., telephone and online services), with regional hubs coordinating services delivered by local providers (i.e., respite, face-to-face services). The model would include a centralized carer record. The model would bring together already existing carer services as well as introduce new services.
Future reform – an integrated care at home program to support older Australians (Australian DOH, 2017b)	Additional policy options for further home care reforms are discussed: developing an integrated assessment model for home care; introducing a higher level home care package/changing the mix of home care packages; changing the mix of individual and block funding for home care; embedding wellness and reablement approaches into assessments; ensuring consistency and fairness of fees; and providing supports to ensure consumers can make informed choices. Any reforms would need to be implemented within existing aged care budgets.
Streamlined Consumer Assessment for Aged Care (Australian DOH, 2018a)	This discussion paper sought feedback on the development of an integrated assessment service that would combine RAS and ACATs. The integrated assessment model would provide an appropriate level of assessment for the person’s care needs, and expedited access would be offered for short-term use of a single service (e.g., transportation). Assessors will use wellness and reablement approaches.

13.2.3 Policy Context and Key Events

Over 2012-2019 significant reforms to the aged care system have been in progress in Australia. To provide context for why these reforms have occurred, some historical trends in aged care should be highlighted:

- Over the past four decades there have been persistent challenges in the aged care system and over 35 major reviews have been conducted and various reforms implemented.

- Since the 1980s the marketization and individualization of aged care has gradually been occurring.
- Since the 1980s steps have been taken to rebalance care and move care closer to home (RCACQS, 2019a).

Within this context, in 2010 the Commonwealth established a Productivity Commission Inquiry into the aged care system due to concerns about population aging, perceived inequities in financing based on care setting, and challenges accessing care (Hughes, 2011). In 2011 the Commission released their report *Caring for Older Australians* and identified key issues with:

- Services: Problems with access and awareness; lack of choice; lack of continuity; lack of incentives for restorative care, rehabilitation, and maintenance; difficulties accessing other health services; challenges navigating the system
- Funding: Inconsistent and inequitable co-payments for different services; inadequate reimbursements for services; and
- Excessive regulations, labour shortages, and variations in quality (Productivity Commission, 2011a; 2011b).

The report made 58 recommendations to improve aged care. Some of the key recommendations included: introducing a Gateway responsible for information, needs assessments, and care coordination; providing flexible service entitlements that are tailored to people's needs; increasing the number of community care packages; removal of limits on the number of packages and residential care places; and improving the interface between aged care and health (Productivity Commission, 2011a).

The consolidation of responsibility for aged care under the Commonwealth in 2011 had increased the capacity of government to make sweeping changes to the aged care system in response to the Productivity Commission (RCACQS, 2019a). However, it was not just government driving aged care reforms forward; reforms were supported by a broad range of stakeholders. One particularly influential policy actor was the National Aged Care Alliance (NACA) that represents a range of service providers, professional associations, unions, and advocacy groups. They have released three influential blueprints on aged care (NACA, 2009; 2012; 2015) and following the Productivity Report, government worked with them to set up working groups to inform the aged care reforms (Senate Community Affairs Committee Secretariat, 2013). In addition, other complementary policy priorities had already been adopted by government through the

Carers Strategy (Commonwealth of Australia, 2011) and the National Health Reform Agreement (Council of Australian Governments, 2011).

The aged care package of reforms *Living Longer, Living Better* was passed into law in 2013 (see section 13.2.2). Many of the Productivity Commission's recommendations were supported by government, though less aggressive approaches were adopted for means-testing, increasing competition, and managing supply of services (Commonwealth of Australia, 2012b). While there was a change in government before all the reforms were implemented, the Liberal-National Coalition Government continued with most of the proposed reforms (see table 29 for a summary of major reforms implemented).

Table 29 Key *Living Longer, Living Better* Reforms

Key <i>Living Longer, Living Better</i> Reforms
<ul style="list-style-type: none">• The My Aged Care Gateway (contact centre and website) was established in 2013 as the single entry-point to the aged care system.• RAS were established, and RAS and ACAT assessments were nationally standardized and access was moved to the My Aged Care Gateway.• The distinction between low- and high-level residential care was removed.• A standardized income-tested care fee was introduced for home care and combined income and asset means-testing in residential care. Annual and lifetime caps on contributions were introduced. Changes were also made to accommodation payments in residential care.• Home care packages were expanded to four levels and the number of packages available was increased. The target is for the number of home care packages to increase by 80,000 by 2021/22. Over 2013-2015 CDC was phased in for all packages.• The CHSP was phased in beginning in 2015 and consolidated the HACC Program with the National Respite for Carers Program, Day Therapy Centres Program, and Assistance with Care and Housing for the Aged Program.• CHSP providers are required to incorporate wellness and reablement approaches into their services.• The short-term restorative care program was introduced in 2016, providing time-limited restorative home support to people living in the community.• A Workforce Compact was introduced to address human resource issues. Originally the compact focused on a scheme for increasing the wages of aged care workers; however, due to low uptake of the scheme funds were diverted to other workforce initiatives.

Data sources: Australian DSS (2015); Australian DOH (2017a)

Following the *Living Longer, Living Better* Reforms, the vision for aged care in Australia continued to be advanced through the following documents:

- In 2015 a discussion paper on a second set of reforms *Increasing Choice in Home Care* was released (described previously in table 28).

- An Aged Care Roadmap was developed by the government appointed Aged Care Sector Committee that identified priorities for further developing a “consumer driven, market based, sustainable aged care system” (Aged Care Sector Committee, 2016, p.3).
- In 2017 a legislated review of the *Living Longer, Living Better* aged care reforms made recommendations for further reforms. An important conclusion of the review was there is growing demand for high-level home care and meeting these demands will require a higher level of investment by government (Australian DOH, 2017a).

In 2017 and 2018 two further packages of reforms were implemented: *Increasing Choice in Home Care* and *More Choices for a Longer Life* (see table 30 for brief descriptions). In 2018 an Aged Care Workforce Strategy was also released (Australian DOH, 2018b).

Table 30 Further Aged Care Reform Packages

Further Aged Care Reform Packages	
2017: Increasing Choice in Home Care Reforms	<ul style="list-style-type: none"> • A national process was introduced to assign home care packages to consumers instead of providers. • Originally it was also proposed that the CHSP and home care packages be amalgamated into a single program in 2018; however, this has been delayed til 2022.
2018: More Choices for a Longer Life Reforms	<ul style="list-style-type: none"> • This package of reforms addressed some of the recommendations from the legislated review and roadmap. • Reforms included trials of aged care navigator services; trials of a reablement-focused assessment model for the CHSP; and creation of an integrated assessment force by 2020.

Data sources: Australian DOH (2017a); RCACQS (2019a); Australian DOH (2018a)

Despite the reforms made to the aged care system, problems persisted and in 2018 a Royal Commission into Aged Care Quality and Safety was established. An interim report was released in 2019 and the findings suggest that challenges still exist including: long wait times to access home care packages (mean waiting time for a level 4 package is 22 months); poor quality of residential care; limited usefulness of My Aged Care and lack of face-to-face help; lack of information on providers and assistance with coordinating care; and challenges attracting and retaining staff (RCACQS, 2019a). At the end of 2019, the Royal Commission (RCACQS, 2019b) released a discussion paper on redesigning aged care for stakeholder feedback. The Royal Commission will release their full report and recommendations sometime in 2020.

In tandem with reforms to the aged care sector, there have also been reforms to supports for informal carers. In the 2015/16 budget the Commonwealth committed funds for an Integrated Plan for Carer Support Services. The first stage of the plan, the Carer Gateway, was launched in 2015 as a one-stop shop for information for caregivers (website and national contact centre) (Australian DSS, 2016c). The second stage is developing a model of Integrated Carer Support Services as described in table 28. The new model is being implemented in two stages: 1) Over 2018/19 new peer support, counselling, coaching, and educational resources were rolled out on the Carer Gateway and 2) Beginning in 2020 carer support services will be accessed through the network of regional Carer Gateway providers (Australian DSS, 2019).

13.2.4 Evidence of Impact of Key Reforms

Despite the significant reforms to the aged care system over 2012-2019, the findings of the 2017 legislated review (Australian DOH, 2017a) and 2019 interim report from the Royal Commission (RCACQS, 2019a), suggest that further work is required to reform the aged care system. Below four of the major reforms are described in more detail: home care package reforms, reablement approaches, My Aged Care Gateway, and Integrated Carer Support Services. The Commonwealth Government contracted researchers to assess and collect feedback on these reforms, primarily via surveys, consultations, and interviews, and the findings are described below. However, most of the evaluations conducted have been formative rather than summative. When available, evaluation data from additional sources is also included.

Home Care Package Reforms

As described in section 13.2.3, significant changes were made to the home care package program, including the introduction of: a) four levels of home care packages; b) CDC; and c) home care packages being assigned to the consumer rather than provider. CDC is “an approach to the planning and management of care, which provides consumers and their carers power to influence the design and delivery of the services they receive, including what services are delivered, and where and when they are delivered.” (KPMG, 2015, p.4). While in some CDC models full responsibility is handed to the consumer for managing their budget and care, research suggests that many consumers do not desire this full responsibility (Ottmann, Allen, & Feldman, 2013). The

CDC models implemented in Australia are conservative and place limited administrative responsibilities on consumers (Low, Chilko, Gresham, Barter, & Brodaty, 2012).

An initial trial of CDC home care packages (n=500) and respite (n=200) was conducted prior to the reforms and evaluated by KPMG (2012). Key findings from the mixed methods evaluation included:

- The predominate model of CDC utilized by providers was offering increased choice of services to consumers, while continuing to oversee most of the management and coordination.
- Generally, consumers reported higher levels of life satisfaction with CDC models. However, no statistically significant differences in wellbeing were found between CDC and comparison clients.
- Older adults requiring higher levels of care and carers were more interested in being involved in management of their supports and had higher levels of life satisfaction with the model.

The Commonwealth Government also contracted several firms to conduct additional research (primarily formative in nature) on the home care packages reforms. National Seniors Australia (an advocacy organization) commissioned an online survey on the reforms. Qualitative research has also been conducted on the reforms. Some of the key findings on the reforms have been:

- Providers generally accepted the CDC model but expressed concerns over the increased workload required for administration and care plans; implementation challenges; and the need to adapt business practices (KPMG, 2015; AMR, 2018; TNS, 2016).
- Level 1 and 2 home care packages were difficult to fill, as Level 1 packages in particular overlapped with CHSP services (KPMG, 2015).
- Consumers' choice of services was limited by their own personal knowledge and the information provided by the provider. Consumers most frequently exerted control over when care was delivered and by whom (KPMG, 2015).
- Concerns were expressed over the challenges CDC presents for vulnerable clients (KPMG, 2015; Phillipson, Low & Dreyfus, 2019; McCallum & Rees, 2017).
- Consumers generally had positive perceptions of CDC and the *Increasing Choice* reforms (AMR, 2018; TNS, 2016; McCallum & Rees, 2017).
- Most consumers do not fully understand the concept, options available, and potential consequences of CDC decisions. There is a lack of tools and resources to support older adults and informal carers in their new role (Day et al., 2018; Gill et al., 2017; 2018; Phillipson et al., 2019).

- Only half of consumers expressed confidence in the ability of the system to provide them with choice of home care provider. Reasons for lack of confidence included lack of capacity and availability of providers in some regions and lack of support for decision-making by consumers (McCallum & Rees, 2017).

The findings from these research studies were also generally supported by the findings of the 2017 legislated review (Australian DOH, 2017a). An additional quantitative research study found no statistically significant differences in quality of life between CDC and traditional home care clients (n=136) (Bulamu et al., 2017). Regarding the impact on the market, the Aged Care Financing Authority (2019) reports there has been a significant increase in the number of home care providers and price competition; while this has resulted in declines in costs, there are some concerns about market stability.

Reablement Approaches

As a complement to the already existing Transition Care Program, a Short-Term Restorative Care program was introduced in 2016 and reablement approaches are now being trialed in CHSP assessments. The Short-Term Restorative Care program provides up to eight weeks of restorative home support to people living in the community (Australian DOH, 2019). Access to this program is limited, and over 2018/19 only 2,543 Australians received this service (Australian DOH, 2019). The reablement model being trialed for the CHSP involves active assessments of clients, where clients demonstrate how they undertake tasks, and a 10-12 week period of reablement is provided (Australian DOH, 2020). In addition, it has also been mandated that home care and home support services begin to incorporate wellness and reablement approaches into their assessments and care (Australian Association of Gerontology, 2019).

Prior to the reforms, reablement approaches were already well established in two Australian states: Victoria (the Active Service Model) and Western Australia (Home Independence Program [HIP] and Personal Enablement Program [PEP]) (Australian Association of Gerontology, 2019). Further description is provided of the HIP and PEP programs as they were rigorously evaluated and influenced the interest in reablement approaches. HIP (for older adults in the community) and PEP (for older adults discharged from acute care) were developed by the home care provider Silver Chain as short-term, goal-oriented, tailored home care services that promote independence. A successful pilot and trial of the programs resulted in HIP and PEP being funded as a part

of HACC across Western Australia over 2004-2018 (Australian Association of Gerontology, 2019). A randomized controlled trial (n=750) compared HIP to usual home care services and found HIP clients were significantly less likely to require ongoing personal care services (Lewin et al., 2013). A retrospective cohort study also found clients who received HIP and PEP were less likely to use HACC services over the first 3 years and median cost savings over 5 years amounted to approximately \$12,500 per client (Lewin, Alfonso, & Alan, 2013). A subsidiary of Silver Chain, Access Care Network Australia, also developed the active assessment approach that the ongoing CHSP reablement focused assessment trials are based on. Access Care Network Australia is assisting with the training of RAS teams for the CHSP trial. An external evaluation is currently being conducted of these trials (Australian Association of Gerontology, 2019).

Research has also been conducted on the general use of reablement and wellness approaches in home-based services. In 2017, an external review by NOUS (2019) reported that while there was strong support for wellness and reablement approaches, they are not yet consistently embedded in aged care services. Some challenges to the implementation of wellness and reablement approaches include that funding arrangements do not incentivize provision (e.g., desire to receive funding to provide ongoing care) and consumers may resist the approach and removal of services (NOUS, 2019). A survey of CHSP service providers (n=1,025) by the Australian DOH (2018c) reported 55% of providers believed wellness and reablement approaches were improving the independence of clients and decreasing the need for ongoing services.

My Aged Care Gateway

My Aged Care Gateway was launched in 2013 as a national single-entry point to the aged care system. In 2015 a central client record, national screening and assessment form, assessment services, and online portals were introduced (AMR, 2016). AMR (2016; 2017) was contracted to evaluate My Aged Care and collected baseline data in 2015 and follow-up data in two waves (early 2016 and 2016/17). The follow-up data in the first wave consisted of survey data from the general public (n=3,429), service providers (n=300), assessors (n=176), and health care professionals (n=151), as well as data from focus groups and interviews. Key findings from the first wave included:

- Only one-quarter of the public were aware of the My Aged Care contact centre and one-fifth the website.
- Care recipients were generally satisfied with the contact centre and website (though informal carers provided lower satisfaction ratings).
- Service providers, RAS assessors, and ACAT assessors had low satisfaction levels with the contact centre and website (both well below 50%).
- Clients who had received an assessment were satisfied with the process. However, service providers and assessors expressed low levels of satisfaction, primarily due to the lack of reliable client information provided.
- Over half of service providers believed that My Aged Care had increased their workload (AMR, 2016).

In the second wave, moderate improvements in satisfaction were observed for most measures, particularly for service providers and RAS assessors. However, for ACAT assessors satisfaction remained low with only 36% satisfied with the contact centre and 25% satisfied with the supports provided for conducting assessments (AMR, 2017). An independent survey of informal carers (n=84) in the state of New South Wales reported low rates of utilization of My Aged Care Gateway for information on respite services, with only 11% having used the contact centre and 25% the website (Phillipson et al., 2019).

The legislated review (Australian DOH, 2017a) and Royal Commission (RCACQS, 2019a) both identified key areas for improvement for My Aged Care, including: improving interoperability with other information technology systems (i.e., health care); improving the usefulness of the contact centre; providing face-to-face supports; increasing public knowledge of My Aged Care; ensuring information available is consistent and up-to-date; and simplifying screening and assessment processes for certain services. In the Royal Commission's Interim Report it was concluded "Seven years after its introduction, My Aged Care is not delivering the vision the Productivity Commission outlined of seamlessly allowing people to navigate the aged care system." (RCACQS, 2019a, p.130). In their discussion paper on redesigning aged care services, one of the suggested changes is making face-to-face supports the cornerstone of access, with support from the website and contact centre (RCACQS, 2019b).

Integrated Carer Support Services

In 2015, the Carer Gateway was launched and currently work is in progress to develop Integrated Carer Support Services. This will eventually lead to a regional

network of providers that will allow informal carers to access in-person counselling, peer support and coaching; emergency respite; tailored financial packages; and carer support planning (Australian DSS, 2019). While the Carer Gateway has been operating for several years, no evaluations of it were identified and the other reforms are only in the early stages. Consultations with stakeholders have resulted in broad overarching support for the proposed Integrated Carer Support Services (Australian DSS, 2017).

13.2.5 Key Informant Interviews

The interviews with key informants conducted in 2014 and 2019 played a key role in identifying major aged care reforms and highlighting relevant literature and reports described above. This section describes some of the additional insights that were gained from the key informants on the aged care reforms.

In the 2014 interviews poor coordination and integration between HACC, aged care, and health care was described as a major weakness of the aged care system:

Well I think probably the main improvement I'd like to see is just a much better transition between the HACC and the Home Care Packages. (Australia Interview 1)

But that's been a criticism of our Aged Care system always – it's hard to navigate, hard to understand, difficult to get information. (Australia Interview 2)

I think that we do need to have integrated health and aged care, because very often it's health challenges result in functional impairment and then disability. And I think it's a pretty artificial distinction to think of them as being separate. (Australia Interview 2)

The *Living Longer, Living Better* reforms which were in the early stages of implementation in 2014 were generally perceived positively, though informants stated that they did not go far enough in some areas or were missing key components. For example, an informant stated:

I just don't think they went far enough. I think there should be a single service system if you like, where people can get the graduated care they need depending on their need and circumstances. (Australia Interview 1)

Four key areas where further reforms were perceived as required were: 1) further integrating Aged Care with HACC; 2) improving the integration of health and aged care

(including integration with primary care and integration of electronic records); 3) further reforms to ensure adequate and sustainable funding for aged care; and 4) strengthening of reablement and preventive functions of the system.

In 2019, integration and coordination of services was still perceived as poor. Navigation of the aged care system remained difficult and complex. On the My Aged Care Gateway informants commented:

So, in theory, it should be good that there's a single access point for any services that they need. But in practice, it's very difficult to navigate the website. (Australia Interview 4)

It doesn't provide people with that local level of knowledge that they need about which providers are good and who is in their area. It doesn't create the relationships that people need to make informed decisions. (Australia Interview 5)

Informants commented that currently system navigators are being trialed to address some of the challenges with navigating the system.

The introduction of CDC was perceived as having added to the challenges of navigating the system. While the idea of providing increased choice to consumers was positive, informants commented on the lack of supports provided to consumers for selecting a provider and deciding what types of services to receive. For example:

There is no support for decision making even for people with cognitive difficulties. It has become a marketing exercise rather than a supported informed decision-making process. (Australia Interview 3)

So really in terms of providing that consumer choice around different sorts of services, we haven't really provided enough information. And providers have not provided enough information for people to be able to make an informed choice between services either. A lot of information that is available is available online. So, if you are not a savvy consumer who is able to do a lot of research, that's a problem. (Australia Interview 5)

Informants noted that lack of availability of providers and services in some communities constrains the choices of individuals. Informants also commented on the challenges CDC presented for home care providers, including less stable funding; increased casualization of the workforce; and challenges adapting business models (particularly for smaller businesses). A couple of the informants also commented on how the focus of CDC has missed the importance of the relational aspects of care:

A big negative I think, is that what we've seen a change in the perception of care. So, consumer-directed care really, in Australia, has seen care conceptualized as an exchange of tasks – you know people need things done. And it is has failed really to see carers and the relational work that is needed. (Australia Interview 5)

Consumer-directed care is meant to be that the older person can choose how the money that is allocated to them by the government is spent – choose providers. So, although that is designed to empower consumers, it actually sometimes has some unintended consequences. One of which is that it used to be slightly more of a family-centered or relationship-centered approach. (Australia Interview 4)

Addressing funding issues and ensuring the sustainability of the aged care system were described as key motivators for the Productivity Commission Inquiry. In both 2014 and 2019, informants commented that there were long wait lists for home care packages, funding for residential care is inadequate for the case-mix of clients, and current funding incentives (e.g., ongoing service provision contracts) do not align with reablement and wellness approaches. In the 2014 interviews informants had described how there was not equal access to services due to rationing and varying regional policies on provision of services:

There isn't necessary equality of access. So there are a certain number of Home Care Packages allocated, so it's not a – what's the word – it's rationed. So there are certain number of nursing home beds and a certain number of home care packages allocated to a particular region. (Australia Interview 1)

What you had in different parts of the country for a certain level of assessed need, people would receive quite different levels of support. (Australia Interview 2)

The fact that service places were assigned to a specific provider could cause hardship for older adults and informal carers. An informant related that some informal carers felt that they could not move to another region because of fear of their family member losing their home care package. In 2019, despite reforms to assign home care packages to consumers rather than providers, the rationing of home care packages remained an issue. For example, an informant observed:

We've seen people, particularly at level 3 and level 4 packages, waiting despite their eligibility for care for well over 12 months to receive any kind of support following their assessment of eligibility. So, we have people that are essentially dying while they are waiting to receive any support because of the underfunding of the system at that end. And those that aren't dying

are essentially also, you know, deteriorating in their health condition and likely to be using health services and being hospitalized and all of those things because of their deteriorating state. So these are people that the system assessed as having complex needs at home. (Australia Interview 5)

Informants also commented on the embedding of reablement and wellness approaches in home support. In 2014, informants described how reablement programs already existed in the states of Victoria (Active Service Model) and Western Australia (HIP and PEP) (as described in section 13.2.4). Regarding the current progress on implementing reablement, in 2019 it was noted by an informant that because the Commonwealth wants to implement a national approach the programs in Victoria and Western Australia are no longer operating. While the Commonwealth wants providers to use reablement approaches, they have not yet developed a clear model, though there is currently a trial of a reablement assessment approach. An informant asserted:

It seems that the Commonwealth is keen to be seen to be implementing reablement. But it's really a bit lost about how to do it, especially given the current separation of home support services and home care packages. (Australia Interview 3)

Informants also remarked on how the reforms have impacted informal carers. While Australia has a variety of financial, workplace, psychosocial, and respite supports for carers, these have not been properly integrated with aged care services. The separation of the My Aged Care and Carer Gateways was highlighted as an issue, with these two systems operating in parallel to each other. Informants stated:

There is a real problem with the way that we have established one gateway for all the people and now another gateway for their carers. So, the lack of understanding of the interdependency of the dyad is another example of the systems not seeing care as essentially relational. So, the new integrated carer gateway system is the only place in which a carer's needs are assessed. (Australia Interview 5)

But they [informal carers] are not a client in their own right. There's been a subtle shift away from seeing them as somebody who may also have needs. (Australia Interview 4)

It was also noted by an informant that under the new CDC model, care recipients may not perceive services that provide respite to carers (e.g., adult day services) as high priority when selecting the care they want to receive.

13.3 Critical Analysis of the Case of Australia

Australia's Aged Care System has been recommended by the Health Council of Canada as a system from which Canada can learn due to their well-developed home and community care sector (Health Council of Canada, 2012). This section critically analyzes the aged care system and recent reforms. It should be noted that significant aged care reforms are still ongoing and some of the reforms described in this chapter are works in progress, therefore further analysis of the reforms when they are complete would be beneficial. The analysis reviews the aged care system against key frameworks and best practices for integrated continuing care as described in chapters 2 and 4, as well as the government's stated policy objectives and key policy issues.

The Productivity Commission Inquiry was instrumental in establishing the vision for aged care over 2012-2019. Hughes (2011) has noted the Productivity Commission perceives subjects through an economic lens and is an agency that reports to government primarily on microeconomic reforms. This orientation was reflected in the Commission's report, as well as the *Living Longer, Living Better* package of reforms which describe their aims as:

Our plan is to create a flexible and seamless system that provides older Australians with more choice, more control and easier access to a full range of services, where they want it and when they need it. In planning this reform we have taken account of the needs of consumers, the business imperatives of providers and the Government's commitment to ensure the best possible systems and support for the future. (Commonwealth of Australia, 2012a, p.29).

Concerns about sustainability were a key motivation for the reforms. Aged care policy issues, and in particular improving home care, were conceptualized as policy problems requiring market solutions. Increasing "consumer choice" was heavily referenced in recent policy documents as a rationale for reforms (e.g., Commonwealth of Australia, 2012a; Australian DSS, 2016b). Underlying recent home care reforms have been new public management principles. Generally, reforms have been positively perceived by consumers. However, as described in sections 13.2.4 and 13.2.5, CDC has added an additional layer of complexity to the system and it is not apparent that CDC is significantly improving care for older adults. Additional responsibilities have now been placed onto older adults and informal carers that they may be ill-equipped to deal with.

The recent discussion paper from the Royal Commission questions the current approach to aged care reforms (RCACQS, 2019b, p.3):

The aged care sector is not, and is unlikely to ever be, a fully efficient market. The direction of current reforms puts too much faith in market forces and consumer choice as the primary driver of improvement in the aged care system.

This suggests limitations of the current vision for aged care are being recognized, and new approaches may be considered for future reforms. For example, in section 13.2.5 informants suggested reforms should focus more on relational aspects of care.

As a result of the Productivity Commission both structural and functional reforms were implemented over 2012-2019 to introduce key components of successful integrated care models (see chapter 2 and 4) (e.g., development of the My Aged Care Gateway, consolidation of programs into the CHSP, standardization of assessment processes). However, it was observed in sections 13.2.4 and 13.2.5 that one of the major challenges remaining is the complexity and difficulty of navigating the aged care system. Currently trials of aged care navigators are underway; however, from an integrated care perspective it seems questionable whether having so many actors involved in navigating the system (aged care navigators, the aged care gateway and assessors, and home care case managers) will produce seamless and well-coordinated experiences. In integrated care literature (see chapter 2), case management is highlighted as an important component of successful systems, and an alternative to the current approach would be to consider an enhanced case management role. In addition, while some progress is being made to improve the integration of aged care services, the health-aged care and formal-informal care interfaces remain largely unaddressed. This is particularly apparent regarding the development of My Aged Care Gateway, which has potential to facilitate integration, but in practice has several flaws as described in sections 13.2.4 and 13.2.5. These flaws suggest that it is disconnected from a) the Carer Gateway, b) the health care system (Aged Care Record is not integrated with My Health Record), and c) local knowledge of services and providers. Stakeholders have also critiqued the proposed Integrated Carer Support Services model for 1) lack of integration with aged care services and 2) planned respite not being a component of the model as it is accessed through My Aged Care (Australian DSS, 2017). These disconnects replicate current institutional siloes, as a) aged care is operated and funded separately from the

health care system and b) aged care is the responsibility of the Department of Health while informal carers are the responsibility of the Department of Social Services.

A broad range of home and community-based services can be accessed through home care packages and the CHSP, including IADL supports and social supports, providing the potential for the substitution of lower cost community services for higher cost residential care. Since the 1980s providing care in the home has been prioritized in the vision for aged care (RCACQS, 2019a). Providing support to informal carers is also a well-established social policy priority that has been reinforced through passage of the National Carer Recognition Act, 2010 and the National Carer Strategy (Commonwealth of Australia, 2011). Australia has developed a diverse range of respite options and supports. However, in 2015 35% of informal carers reported unmet needs and 31% of carers with unmet needs experienced psychological distress (Temple & Dow, 2018). The Carer Gateway may facilitate access to services, but more needs to be done to support informal carers. Over the past two decades progress has also been made introducing reablement into the care continuum, and Australia is considered an international leader in this area. Reablement programs provide the potential for substitution of short-term intensive services in the place of long-term services. This aligns well with government's sustainability objectives. Australia has seen some success with reablement models, as described in section 13.2.4, however, has yet to implement a definitive model for the CHSP (see comparative analysis in chapter 14 for more discussion of reablement).

Australia is taking steps to rebalance aged care services to better align with the policy priority of allowing older adults to stay at home. A significant scaling up of home care packages is underway, and research suggests a shift is occurring in the usage of aged care services:

- A review of service utilization trends over 2008/9 to 2015/16 found admissions to residential care declined from 24 to 20 per 1,000 people aged 65+, while home care admissions increased from 8 to 12 per 1,000 (Khadka et al., 2019).
- As access to home care packages has increased, there has been a slight decline in residential care occupancy rates. The average occupancy rate has fallen from 92.4% in 2015/16 to 90.3% in 2017/18 (Aged Care Financing Authority, 2019).
- Between 2008/09 to 2017/18 admissions to residential aged care increased by 4%, and home care by 130% (AIHW, 2019).

There has been some success with efforts to rebalance the availability of aged care services which are tightly controlled by government. As seen in table 31, particularly since the *Increasing Choice in Home Care* reforms the number of home care packages available has significantly increased.

Table 31 Residential Aged Care Places and Home Care Packages Places/Recipients

	2014	2015	2016	2017	2018	2019
Operational residential care places	189,283	195,953	199,449	204,335	207,142	213,397
Operational home care places/recipients*	66,954	73,550	79,819	71,423	91,847	106,707

*In 2017 the measure changed from places assigned to providers to packages assigned to recipients.

Data sources: Reports on Government Services 2015, 2016, 2017, 2018, 2019, 2020. Aged care services chapters. <https://www.pc.gov.au/research/ongoing/report-on-government-services>

However, as highlighted in sections 13.2.3 and 13.2.5 a major stumbling block for substitution policies is inadequate investment in home care and the strict rationing of home care packages. While government policy has increased the availability of home care packages, demand still far outstrips supply. In 2018, 91,847 Australians were receiving home care packages, while the waitlist exceeded 120,000 (RCACQS, 2019a). The Royal Commission has stated on the supply issues in aged care:

Understandably, waiting for aged care services that are in limited supply has become a focal point in criticism of the current system. The unclear measures of waiting and the need to wait for assessment, approval, allocation and service delivery has created a dysfunctional arrangement in which some people are waiting years to access services. Others wait long periods to receive less than what they need or, in some cases, nothing at all. This is clearly unsafe, especially as many die while waiting. (RCACQS, 2019a, p.151)

Despite increases in home care and support spending, as the table below shows, these services still make up less than a third of the aged care budget.

Table 32 Government Spending on Aged Care in \$ Billions (% of budget)

	2013/14	2014/15	2015/16	2016/17	2017/18	2018/19
Home care and support	\$3.8 (26%)	\$4.1 (26%)	\$4.3 (26%)	\$4.4 (25%)	\$5.1 (28%)	\$5.9 (29%)
Residential care	\$10.0 (68%)	\$10.8 (68%)	\$11.5 (68%)	\$12.1 (70%)	\$12.4 (67%)	\$13.2 (66%)
Other services	\$1.0 (7%)	\$0.9 (6%)	\$1.1 (7%)	\$0.9 (5%)	\$0.9 (5%)	\$1.0 (5%)

Total Aged Care Spending	\$14.8	\$15.8	\$16.8	\$17.4	\$18.4	\$20.1
---------------------------------	--------	--------	--------	--------	--------	--------

Data source: Reports on Government Services 2015, 2016, 2017, 2018, 2019, 2020. Aged care services chapters. <https://www.pc.gov.au/research/ongoing/report-on-government-services>

Currently 67% of older adults waiting for a home care package are eligible for residential care (Australian DOH, 2020). The undersupply of home care packages creates a perverse incentive for older adults to enter residential aged care earlier than necessary, which is more expensive than receiving a level 3 or 4 home care package (RCACQS, 2019a). Jorgensen et al. (2018) have found that every hour of home care per week received by a high-needs user is associated with a 6% lower risk of residential care placement. An additional study by Visvanathan et al. (2019) found individuals who waited more than 6 months for a home care package had a 20% excess risk of death and 10% higher risk of entering residential care compared to those who waited less than 30 days. From a systems perspective, additional challenges also exist for achieving the optimal balance of home care services. As described in sections 13.2.3 and 13.2.4, there is the need to consider improvements to the mix of home care packages and potentially introduce a higher level of home care package. Health human resource capacity has also been identified as a potential challenge for further expansions of home care (Australian DOH, 2017a).

In conclusion, aged care occupied a prominent place on the policy agenda over 2012-2019, and further reforms are planned. Reforms have sought to improve the integration of aged care services and address some of the challenges caused by the previous bifurcated government responsibilities for aged care. However, the complexity of the system remains a weakness, and reforms such as CDC have introduced additional complexity into the system. A significant scaling up of home care services is in progress, marking a step towards actualizing the policy objective of allowing older adults to stay at home. Informal carers also were a prominent issue on the policy agenda; however, reforms have continued to perpetuate the divide between formal and informal care. Reforms have also exposed the limitations of market-based mechanisms to improve home care. It is clear that while progress is being made in Australia, further work is required.

Chapter 14.

Comparative Analysis of Cases

In chapters 6-8, key challenges for the home and community care system in BC were described. As was apparent in chapters 9-13, similar challenges are being faced by other countries and jurisdictions. This chapter provides a comparative analysis of the experiences of BC and the five comparison jurisdictions (Ontario, Québec, Nova Scotia, Denmark, and Australia). With the exception of Australia and Ontario, reforms over 2012-2019 targeting continuing care were limited and changes represented incremental advancements from past policies. The purpose of this analysis is to identify policy convergences, divergences, and tensions, viewed through the lens of how these experiences can inform BC's home and community care system. To begin with, some of the general policy issues faced by the jurisdictions are summarized:

- Governments are trying to control rising health care costs and are increasingly concerned about sustainability. Health care systems are seeking ways to increase the efficiency of services and reduce costs.
- Continuing care systems are operating at capacity in most areas and struggling to meet the needs of aging populations and increasingly complex clients.
- Jurisdictions are attempting to develop approaches to allow older adults to remain at home as long as possible. Providing care in the home has also been recognized as a means to potentially reduce costs in other sectors.
- Providers are seeking ways to provide care that is flexible and individualized.
- Health human resource shortages are predicted for the coming years in all jurisdictions.
- There is increasing attention being paid towards how to improve quality of care and quality of life in long-term care facilities.
- Jurisdictions are seeking ways to improve the integration between continuing care and the acute and primary care sectors.
- Increasing pressures are being placed on informal caregivers and there is growing recognition of their needs.

In this chapter, first themes and policy convergences and divergences are discussed in the key areas where deficiencies were noted for the BC home and

community care system in chapter 8. This discussion highlights reforms and policies over the period of 2012-2019, but also considers pre-existing policies and components of the continuing care systems as appropriate. Second, tensions that have emerged with integrated care approaches are discussed, including the success or lack thereof of substitution policies.

14.1 Policy Convergences and Divergences

14.1.1 Vision for Care

Policy Objectives Related to Care at Home

In all jurisdictions, allowing older adults to live at home or providing care in the home when possible is a main policy objective. In Denmark, caring for older adults in the home is the most firmly entrenched and “at home as long as possible” has been the aim of the elder care system since the 1980s (Hansen, 2009). In the other jurisdictions, embedding of this principle into policy has been more recent and sometimes overlaps with the priority of moving acute care to the community. There have been some subtle differences in the framing of this policy objective in other jurisdictions in recent years:

- BC: In BC’s home and community care actions plans (Government of BC 2012; BC MOH, 2017a) providing care in the home is implied as part of the vision rather than explicitly identified as a primary objective. Within broader health policy documents, rhetoric has focused on shifting care to the home and community for cost containment purposes (BC MOH, 2014a; 2015a). (see section 8.3 for more in-depth discussion).
- Québec: Québec’s home support policy describes home support as “the first choice” and this policy has been incorporated into broader aging in place policies (Gouvernement du Québec, 2003). Policy explicitly states that home care should not just be viewed as a substitute for residential and acute care (Gouvernement du Québec, 2003; 2012).
- Ontario: In the *Patients First* vision the broad objective of reforms to community care is “delivering better coordinated and integrated care in the community, closer to home” (Ontario MOHLTC, 2015a). In the accompanying roadmap for home and community care, the objective is “Everyone who has needs that can be reasonably met in the home or community will receive support to do so.” (Ontario MOHLTC, 2015b).
- Nova Scotia: Nova Scotia’s vision for continuing care is for older adults to be able to “live well in a place they can call home” and this applies to both private homes as well as nursing homes (Nova Scotia Department of Health, 2006).

- Australia: In the *Living Longer, Living Better* reforms the policy objective is to allow older adults to “stay at home” (Commonwealth of Australia, 2012a)

In the English language policy documents selected for analysis, sustainability and rising health care costs, increasing pressures on acute and long-term care, aging populations, and preferences of older adults were common rationales for providing care in the home. The potential value of home and community care services as substitutes for other forms of care (i.e., long-term care and acute care) was most explicit in the case of BC as described in chapter 8, but also was referenced in the other Canadian and Australian policy documents. Ceci and Purkis (2011) have observed that in Canada home care has been conceptualized as a cost-effective alternative for institutional care and primarily promoted based on its utility to the health care system. Today this is reflected in policy documents but also in policies and programs that will be described later in sections 14.1.2 and 14.2.2.

Surprisingly, none of the policy documents from jurisdictions where English is the primary language relate objectives of providing care in the home to the concept of “aging in place” though most acknowledge the preference of older adults to live at home. The only mention of “aging in place” is in a BC document to refer to “aging in place and home care/monitoring services and technologies” (BC MOH, 2014a, p.4). Québec does not use the term aging in place but does situate their home support policy within the broader context of community and societal supports for older adults. This reflects the close relationship between health and social care policy in Québec, which are the responsibility of a combined Ministry of Health and Social Services.

Conceptualizations of Older Adults and Informal Caregivers

Review of policy documents and policies reveals divergences in how older adults are conceptualized in the different jurisdictions. In both Australia and Denmark conceptualizations have emerged of older adults as a) consumers and b) active participants in their care. As will be describe in the next section, reforms have been introduced to provide consumers with choice of providers in Australia and Denmark. Conceptualization of older adults as “consumers” are linked to both the individualization of care and the marketization of care (Burau, Theobald, & Blank, 2007). Reablement has also shifted conceptualizations of older adults, from passive recipients to active participants in their care. In comparison, in Canada older adults have been primarily

conceptualized as care recipients. For example, in Ontario's roadmap for home and community care older adults are referred to either as "clients" or "patients."

As described in chapter 8 informal caregivers have been mostly invisible in government policy documents in BC. There was greater policy attention towards the needs of informal caregivers in the other Canadian cases, as they were consistently discussed in policy documents. In Canadian policy documents, informal caregivers were recognized primarily as a resource for care, with rhetoric framing support for informal caregivers as necessary in order to allow them to continue caring. In the Australian policy documents rhetoric has further formalized the role of informal caregivers, comparing them to paid workers "Like any member of the workforce, these carers sometimes need to take a break and need to take care of themselves." (Commonwealth of Australia, 2012a, p.7). There were other secondary conceptualizations of informal caregivers in some policy documents – as clients in their own right and/or partners in care. This was explicitly stated in documents from Québec and Nova Scotia. In Denmark, while informal caregivers play a much more limited role in providing care, they are an emerging policy area and all municipalities are required to consider their needs in dignity policies. The language in Danish policy documents reinforces that informal caregivers should not have a primary role in providing care, as for example in the Dementia Action Plan (Danish MOH, 2017b) they are referred to as "relatives."

Marketization of Care

All of the jurisdictions utilized private (non-profit and for-profit) providers to some extent to deliver publicly subsidized services. It is important to note that in Australia and Denmark there has historically been higher acceptance of a market role in providing care compared to the Canadian cases. This is reflective of the fact that in Canada there is generally no private for-profit provision of health care services insured under Medicare. However, continuing care generally falls outside of the umbrella of Medicare so there is market involvement in the sector, though this is strongly opposed by some key policy actors and segments of the public.

In the jurisdictions of study new public management approaches are becoming further entrenched in visions for elder care. Since the 1980s, within the context of dissatisfaction with the state and adoption of neoliberal philosophies, new public management principles have been turned to in many jurisdictions as policy solutions to

address perceived health system inefficiencies. Generally, such reforms have been difficult to implement and have not produced compelling evidence of their benefits (Buse et al., 2005). In the cases of study increasing competition among home care providers was explored as a policy option through two types of competition: a) competition for clients (Australia and Denmark) and b) competition for home care contracts (Ontario and Nova Scotia). Competition for clients was implemented under the banner of “free choice” in Denmark and “increasing choice” in Australia. To-date there has been little evidence that competition is improving home care for older adults in these jurisdictions, and concerns have been expressed over the administrative costs of these reforms and stability of markets. In Canada, reforms requiring competition for home care contracts have been fraught with political and logistical problems. The competitive bidding system that was in place in Ontario up until 2012 was strongly criticized due to disruptions to care and bankruptcies, and as a result this system was paused and then officially ended in 2012. In Nova Scotia plans to implement a competitive bidding system were quickly abandoned after pushback from workers. The experiences in these jurisdictions do not provide a compelling case for competition as a means to improve home care, and in Canada such reforms are clearly not viewed as acceptable by key stakeholders.

A mixed economy of providers (whether competition is involved or not) can present challenges for the integration of services (Blank & Burau, 2010). For privacy, governance, and other reasons a mixed economy of care may present barriers for integrated approaches such as sharing information with private organizations; providing multidisciplinary care; incentivizing the provision of certain types of care (reablement); and coordinating providers in the home. Interestingly, BC diverged from the other jurisdictions as in 2019 government announced they would end contracts with private non-profit and for-profit home support providers and instead offer all home support services publicly in order to facilitate the provision of team-based care.

14.1.2 Investment in Continuing Care Services

Welfare State and Funding for Continuing Care

To provide context for the different investments in continuing care by jurisdictions, some distinctions between the welfare states in Denmark, Australia, and Canada should be described. Scandinavian welfare policies have typically emphasized

promoting labour force participation, gender equality, and offering comprehensive social services. Australia and Canada, on the other hand, have more strongly embraced neoliberal policies. A key impact of such policies has been the erosion of the universality of services, with greater selectivity when providing services (Esping-Andersen, 1996). Within continuing care systems, these differences among welfare states have manifested as:

- Denmark: The state is expected to be the primary provider of care, though family still plays a role. Denmark provides universal access to a comprehensive range of services in the home and community free of charge.
- Australia: Family plays a key role in providing care. The number of residential aged care places and home care packages available are planned and tightly rationed by government. Services require a basic, income-tested, and/or asset-tested fee.
- Canada: Family plays a key role in providing care. Eligibility policies and budgets are used to ration services. Home nursing services are offered free of charge, while in most provinces an income-tested or basic fee is required to access other services.

The use of means-testing for home care in the Canadian cases (excluding Ontario) and Australia is an important distinction from Denmark. Denmark provides home care services free of charge to ensure universal access for people who need it. It is not clear in Australia and the Canadian cases how many older adults might be forgoing care because of the cost, but Canadian research suggests cost is a contributing factor for 1/5 people with unmet home care needs (Gilmour, 2018b). However, as the case of Ontario (where all home care services are free of charge) shows, services being free is not enough to ensure access if the system is unequal to meet the demand.

All of the jurisdictions publicly fund their continuing care systems through tax-based financing. Both Denmark and Australia have national legislation that establishes an entitlement to publicly funded continuing care services, while in Canada continuing care is not included in national legislation (*Canada Health Act*). As a result, continuing care has an ambiguous status in the Canadian welfare state and within current funding models. Despite aging populations and expected significant increases in demand for continuing care services, funding models received almost no policy attention in the Canadian cases (with the exception of Québec). Another difference is that in Denmark

and Australia funding for continuing care and health care are distinct from each other and held by different levels of government.

Providing adequate funding for continuing care systems was a policy issue to some extent in all of the cases, but most noticeably in Australia and the Canadian cases. Over 2012-2019 all jurisdictions reported increasing levels of spending on continuing care services. While data and research to assess the adequacy of funding in some jurisdictions was limited, various policies and indicators (e.g., declining number of home support hours, higher eligibility requirements, long waitlists, etc.) suggest that spending is not keeping up with the increased demands of aging populations (see section 14.2.1 for more details). Long-term care facilities were also experiencing funding pressures, leading to quality of care and staffing level issues in several of these jurisdictions. In Denmark there also was retrenchment of home care services reported, though it was unclear if this was related to underfunding.

Denmark is often considered to be a gold standard of care for older adults and there were some clear divergences between the funding patterns in Denmark and the other jurisdictions:

- Denmark spends 2.5% of its GDP on elder care (European Commission, 2019), in comparison Canada spends 1.2% (National Institute on Ageing, 2019) and Australia spends 0.9% (RCACQS, 2019a)
- In Denmark 66% of elder care spending is on home care, while 34% is spent on residential care (European Commission, 2019); the other cases had roughly opposite distributions of spending.

14.1.3 Integrated Continuum of Care

Continuum of Care

Traditionally, long-term care facilities have been at the core of continuing care systems, and this was the case in all jurisdictions except for Denmark which has primarily phased out traditional style nursing homes and replaced them with elderly housing alternatives. A unique aspect of elder care policy in Denmark is the principle that entitlement to care should not be dependent on where you live. In some of the Canadian cases there was a trend of developing more homelike, small pod style long-term care homes (i.e., in Nova Scotia and there are plans to build them in Québec). In

North America, such models have been strongly inspired by the Green House model from the United States (Rabig, Thomas, Kane, Cutler, & McAlilly, 2006).

BC (assisted living), Québec (intermediate resources), Denmark (elderly housing), and Ontario (supportive housing) all offer publicly subsidized assisted living style models where residents are tenants and able to access various hospitality and care services. Denmark's elderly housing model offers an enriched range of services and provides similar levels of care and staffing as traditional nursing homes, but is regulated as housing (Daatland, Høyland & Otnes, 2015). A key divergence is that Denmark's model can provide a range of levels of care and has mostly succeeded in replacing nursing homes, while in BC, Ontario, and Québec they primarily act as a supplement for lower level clients and delay the need for nursing home care. Publicly subsidized assisted living was not a core component of the care continuum for older adults in Australia or Nova Scotia. A factor that may contribute to this divergence is the presence of lower level residential care facilities that may be viewed as filling a similar role (i.e., in Nova Scotia there are lower level residential care facilities, while in Australia up until recently distinctions were made between low- and high-level residential care places).

In all of the jurisdictions home care is a core publicly subsidized service. While personal care services are consistently available, there are divergences regarding whether IADL supports are incorporated in home care programs. IADL supports are most extensively available in Denmark and Australia, which both offer a broad range of supports as described in chapters 12 and 13. Continuing care in these jurisdiction has evolved differently than in Canada, with a greater degree of separation from the health care system and in an environment less firmly entrenched in the biomedical model. This appears to have influenced the services that are available to older adults.

The role of the state in providing IADL supports is contested in many provinces in Canada. All of the cases offered some publicly subsidized IADL supports (e.g., housekeeping, meal preparation) through their home support programs, with Ontario providing the most extensive range. BC had the most restrictive criteria as housekeeping, meal preparation and laundry services are only available if they are for "safety maintenance" purposes. Government funded programs outside or on the margins of the formal continuing care system have been developed to provide additional IADL supports in BC, Québec, and Ontario, while Nova Scotia provides direct funding to

access these services from private providers (see table 33). The introduction of the IADL programs in BC and Nova Scotia have been recent developments. In BC, Better at Home programs have a standardized model and are managed under the umbrella of the United Way of the Lower Mainland, while in the other cases providers operate independently. Key limitations of such arrangements include 1) IADL services are usually excluded from larger coordination mechanisms and case management and 2) IADL services may be inconsistently available across the province. Québec has had some success coordinating with these organizations through their RSIPA model; however, more recent reforms have compromised this coordination.

Table 33 Canadian Programs to Provide IADL Supports

	Better at Home (BC)	Community Support Services (Ontario)	Financial Assistance Program for Domestic Help Services (Québec)	Supportive Care Program (Nova Scotia)
Providers	Local non-profit organizations	Local non-profit or for-profit organizations	Domestic help social economy business (EÉSAD)	Non-profit or for-profit providers
Funding model	Government funds the program; Co-payment may be required	LHINs fund programs; Co-payment may be required	Subsidy provided to clients at a basic hourly rate; Co-payment may be required	Direct funding to client to contract with providers
Point of access for services	Direct access via provider	Direct access via provider	Direct access via provider if only domestic help services are required	Direct access via provider
Assessment of eligibility	Provider	Provider	Provider if only domestic help services are required	Continuing Care Coordinator
Target population	Older adults	People with home and community care needs	Subsidy can be received by anybody, regardless of income or health	People with cognitive impairments

In both Denmark and Australia there have been significant investments over the past decade in developing reablement approaches. Reablement aligns with policy priorities related to promoting independence; participation in activities that matter; person-centred care; recognizing the expertise of individuals; individuals as resources; integration and multidisciplinary care delivery; and cost containment (Aspinal, Glasby, Rostgaard, Tuntland, & Westendorp, 2016). In Canada, reablement paradigms have generally not taken root, though there have been some limited approaches implemented

for certain services (e.g., Ontario uses “restorative” approaches in long-term care homes, Nova Scotia has some restorative programs for transition from hospital to home). The lack of uptake in Canada is somewhat surprising given concerns about health care sustainability and the appeals of reablement: the potential to improve the functional abilities of older adults while at the same time reducing their need for ongoing home care services. The acute care substitution orientation of home care in Canada, and diminishing orientation towards prevention and maintenance, may contribute to the lack of development of reablement approaches in Canada.

While reablement holds promise, the experiences with reablement in Denmark and Australia have elucidated some important considerations regarding adopting and implementing reablement approaches. First, in both jurisdictions it has been observed that while policy-makers and care providers are enthusiastic about reablement approaches, older adults may have trouble adapting to reablement paradigms. Second, concerns have been expressed in Denmark that reablement approaches may be applied too aggressively and promote unrealistic expectations for older adults. If guided strongly by cost-saving motivations, there is the danger that reablement could be used as a guise for reducing or denying access to services. Third, in both jurisdictions there is variety in the reablement approaches being adopted due to lack of a defined model. There is a need for evidence-based models to be designed and adopted.

Integrated Planning

The experiences of the jurisdictions in this study also emphasize the need to engage in integrated planning when developing integrated continuing care systems. A defining characteristic of complex systems is that a change in one part of the system will often result in unexpected impacts on other parts of the system. This is a consideration that has also been advanced by other researchers (e.g., Wister, 2011; Williams et al. 2009a; 2016; Kuluski et al., 2012). Experiences from the cases reinforce the importance of systems perspectives and suggest that it is important to consider the impacts reforms to one component of continuing care systems will have on the rest of the system. From review of the cases some general considerations for planning include:

- Scaling up of home care services may result in declining demand for long-term care beds. As beds are a physical resource, consideration needs to be given

to how to make use of these resources if demand declines (e.g., in Denmark some nursing homes were turned into integrated service centres).

- In Denmark, it has been a combination of both expansive home care services and housing models that has facilitated the shift away from nursing homes.
- Before making significant investments into building new long-term care infrastructure, the adequacy of other alternatives should be assessed. Research suggests intensive home care services or assisted living can in some cases act as alternatives, yet in most jurisdictions these services are not being utilized to their full potential.
- As more services are provided in the home and community rather than institutions, there will be a greater need for supports for informal caregivers and respite care.
- Movement of care outside of the hospital places increased pressures on home and community care services. This can cause home care programs to prioritize acute functions at the expense of other clients.
- Gatekeepers and direct service providers play roles in the allocation and delivery of services. As service paradigms change, the behaviours and education of people working within the system need to change too.
- As the ability to care for older adults in the home and community increases, only the most complex older adults will enter long-term care facilities meaning there will be an increase in the intensity of care provided in these facilities. This has implications for staffing requirements.
- Health human resource shortages emerged as a current or anticipated system pressure in all of the jurisdictions. Expansion of home care requires additional staffing resources; the push to improve quality of care in long-term care facilities also requires additional staffing.

Integrated Service Delivery Approaches

While all of the jurisdictions recognized integration as a policy priority, they have differed in their approaches to the integration of continuing care services. Below, convergences and divergences in the development of various components of integrated service delivery models are described:

- Single entry point: All of the jurisdictions have a single-entry point for services, though the scale of these entry points varied (i.e., at the national level in Australia versus municipal level in Denmark).
- Integrated information systems: A common challenge with information systems has been ensuring the interoperability of the systems used by various

sectors and fully integrating continuing care into electronic information systems.

- Standardized Assessment: All of the Canadian jurisdictions used standardized assessment tools (interRAI or OMEC). In Australia, the National Screening and Assessment Form is the common tool for assessments, though there are separate assessment forces for CHSP and home care packages (but the intention is to combine these forces). Reablement plays a role in assessments in both Denmark and Australia.
- Multidisciplinary teams: In Québec and Denmark home care staff often work in multidisciplinary settings. Multidisciplinary teams were also used to deliver some specialized programs (e.g., reablement, ACAT assessments) in jurisdictions.
- Acute and transitional care: All of the jurisdictions had transitional models in place to facilitate discharge from the hospital to the home (e.g., convalescent care, intermediate units, day hospitals and restorative care programs). Within Canada, variations of the Home First philosophy (provision of intensive home care to facilitate discharge from the hospital to the home) were in place in BC, Nova Scotia, and Ontario. Initiatives to facilitate vertical linkages between hospital and continuing care were common.

In terms of the coordination and delivery of care, jurisdictions used coordination and linkage models for care for frail older adults. The most well-defined coordination model was RSIPA in Québec. This model emphasizes the case management role and coordinates care for frail older adults across a range of health and social care services. In comparison, the other Canadian jurisdictions have hybrid linkage/coordination models with limited functional integration and coordination mostly confined to continuing care services, though various integrated care initiatives have sought to strengthen linkages between sectors. An integration initiative that was implemented system-wide was the Health Links in Ontario that attempted to improve the coordination of care for higher needs populations through the development of coordinated care plans. Both the PRISMA model and Health Links faced some common challenges in their attempts to facilitate multi-sectoral collaboration: a) developing shared electronic records and b) obtaining the resources required for a dedicated case management/care coordinator role. In Ontario and BC new integrated care models are being developed that will integrate care from multiple sectors. There is ambiguity regarding what these models will look like in practice, but the aim is to have integrated governance and budgets and offer multidisciplinary and coordinated care.

Québec and Ontario also implemented large-scale structural reforms during the period of study to improve the integration of services (Nova Scotia also underwent structural reforms, though continuing care was only affected minimally). As was outlined in the chapter on Québec, there does not appear to be a strong evidence base that large-scale structural reforms improve coordination of care. Structural reforms absorb a significant amount of organizational and management energy and it may take a few years for the changes to stabilize. Similarly, in Ontario it was critiqued that the home and community care reforms implemented focused too much on the structural reforms. Structural integration does not necessarily result in the breaking down of siloes between sectors of the health care system. This is not to say that structural integration cannot have benefits, but rather that it should be accompanied by functional integration. As was seen in these jurisdictions, structural reforms also sidelined other policy priorities.

In Denmark, elder care services are connected through integrated service centres and team-based provision of care. This is a unique model that breaks down the siloes between home care, elderly housing, and nursing homes. In Nova Scotia, government is considering introducing hubs of community care that would share some similarities with the Danish model but be a much more conservative version. In Australia, home care packages provide older adults with access to a tailored range of services in the home and community and case management is provided by the home care provider (however case management is not available beyond home care packages). In Denmark and Australia, the division of government responsibilities for continuing care and other health care sectors presents a challenge for the integration of services for frail older adults. Denmark appears to have had more success in ameliorating this divide through mechanisms such as health care agreements and coordinated discharge processes.

14.1.4 Policies for Informal Caregivers

Reliance on Informal Caregivers

Strengthening supports for informal caregivers is essential, however, the question also should be asked: To what extent will it be appropriate and feasible to rely on informal caregivers to support our older adult populations in the future? A recent Canadian analysis reported given growing older adult populations and anticipated declining availability of informal caregivers (families having fewer children), informal

caregivers would need to increase their efforts by 40% in order to meet the needs of frail older adults in the future (MacDonald et al., 2019). The paper concluded:

While there are sizable costs ahead for the public sector, the findings from this paper suggest that a major concern is the sustainability of unpaid care provision – without which there would be major impacts on public sector costs and/or a significant increase in unmet care needs. (MacDonald et al., p.7)

In addition, caregiving can have negative consequences on the finances, labour force participation, and mental and physical health of caregivers (Turcotte, 2013).

In the Canadian cases and Australia, policy has explicitly (through statements of principles and policies) and/or implicitly (through limitations on the provision of home care services) emphasized that home care should act as a supplement to informal care rather than replace it. In Canada 98% of older adults receiving publicly funded home care have an informal caregiver (CIHI, 2010), while 80% of Australians receiving care in the community have an informal caregiver (Productivity Commission, 2011a). A Canadian study reported that 51% of people receiving in-home care received informal care only, 15% formal care only, and 33% a mix (Lee & Penning, 2019). Table 34 provides additional data on the contributions of informal caregivers.

Table 34 Contributions of Informal Caregivers in Canada and Australia

Contributions of Informal Caregivers in Canada and Australia
<ul style="list-style-type: none">• It is estimated that 80% of care in the home in Canada is provided by informal caregivers (Keefe, 2011).• The economic contributions of informal caregivers aged 45+ in Canada are estimated to be \$25-26 billion (Hollander, Liu, & Chappell, 2009)• Employed caregivers in Canada provide the care equivalent to 1.2 million full-time workers (Fast, Lero, DeMarco, Ferreira, & Eales, 2014).• Contributions of informal caregivers in Australia have been estimated to be \$60.3 billion (Deloitte, 2015).

In contrast, in Denmark care for older adults is primarily viewed as the responsibility of the state and not the family (van der Boom, 2009). As a result, the role of informal caregivers is more limited than in most other developed countries. Data from the Survey of Health, Ageing, and Retirement in Europe suggests that in Denmark 21% of care is provided informally, 15% as formal home care only, 37% as a mix, and 27% in nursing homes (Barczyk & Kredler, 2019). OECD indicators also suggest that Denmark is one of the countries with the lowest rates of daily care provision by informal

caregivers, though it is important to note there is still a proportion of the population who are providing regular daily care (OECD, 2019b).

Part of the impetus of investing in elder care in Denmark was because it was viewed as strengthening the country's labour supply and promoting gender equality (Stuart & Weinrich, 2001). The impacts of caregiving on labour force participation are heavily gendered. Research on the Canadian labour market has found women are 73% more likely to leave the labour market due to caregiving responsibilities, and 5 times more likely to engage in part-time work (Smith, Cawley, Williams, & Mustard, 2020). An economic analysis on caregiving in Canada reported that at the lowest levels of caregiving intensity there was a net gain to government due to reduced health care costs (\$4.4 billion), but at the highest level a net loss occurs (\$641 million) mostly due to reduced labour force participation (Jacobs et al., 2013). A recent study comparing the impacts of informal caring in Canada, the UK, and Sweden (a Scandinavian welfare state that is similar to Denmark in terms of its generosity of formal care services) found informal caregivers in Canada and the UK were more likely to not be working, while those in Sweden were more likely to work part-time. (Stanfors, Jacobs, & Nielsen, 2019).

Supports for Informal Caregivers

Recognition and development of supports for informal caregivers in Canada has been slow. This is particularly apparent in BC, but also in the other Canadian cases as well. In the latter portion of the decade informal caregivers began to occupy more prominent spaces on policy agendas (e.g., work to develop a caregiver policy in Québec, the Beed report in Ontario). In contrast to Canada, in Australia supporting informal caregivers has long been a cornerstone of social policy. Australia was the only jurisdiction with a comprehensive strategy for informal caregivers (Commonwealth of Australia, 2011). The development of the Carer Gateway in Australia also recognizes informal caregivers as recipients of services in their own right (though this is detached from the aged care system). Howe (2002) notes in Australia there are three factors that have contributed to the policy objective of supporting informal caregivers: 1) recognition by government of their contributions to delaying residential care admission; 2) the status and influence of caregiver support organizations as providers of HACC (now CHSP) services which increased their voice and political profile; and 3) strong support for the principle of intergenerational reciprocity within communities. The second factor appears

to be a divergence from the Canadian experience. With the exception of respite, supports for informal caregivers are generally not integrated into formal continuing care systems in Canada or afforded the same status as other services. Usually they are delivered by non-profit and community organizations that receive funding from government but operate on the margins of the system. Both Québec and Nova Scotia have developed networks of regional caregiver support organizations, while in BC and Ontario caregiver support organizations operate mostly independently.

In all of the jurisdictions respite services were available though they differed in terms of their availability and scope (see table 35). Australia and Denmark offer respite options that provide alternatives to facility-based respite: host family and cottage respite in small homelike environments (Australia) and day homes that provide the same care as a nursing home, but the older adult goes home at night (Denmark). Cottage respite in Australia is preferred over institutional respite due to its more homelike setting, and has been estimated by informal caregivers to delay placement in residential aged care by an average of 16 months (Harkin, O'Connor, Birch, & Poulos, 2020).

Table 35 Available Respite Options by Jurisdiction

Australia	Denmark	BC	Ontario	Québec	Nova Scotia
In-home, Host family, Centre-based (residential and adult day), Community access (social programs), Cottage respite	In-home, Day homes, Day centres	In-home, Facility, Adult day services	In-home, Facility, Adult day services	In-home, Facility, Adult day services	In-home, Facility, Adult day services

Various community psychosocial, educational, and information services also are available in each jurisdiction, often through non-profit organizations. Divergences existed as to whether there were financial supports. Means-tested financial supports were available in both Australia and Nova Scotia. Australia offers both a Carer Allowance and Payment, and it is estimated that almost 80% of primary carers receive the allowance and about 30% the payment (AIHW, 2015). In Denmark it is possible for municipalities to hire informal caregivers in certain circumstances.

14.2 Integrated Approaches: Points of Tension

Analysis of BC and the comparison cases highlighted four interrelated points of tension in the development of integrated continuing care models that will be discussed

below: substitution policies and downloading of responsibilities; acute and continuing care services; mainstream and marginal services; and the standardization and individualization of care.

14.2.1 Substitution Policies and Downloading of Responsibilities

It is clear that a fine line exists between acceptable substitution of care in the home and the community and the downloading of responsibilities. This tension is reflective of the two at times conflicting objectives of substitution policies: cost containment and facilitating aging in place. All of the jurisdictions of study are currently pursuing substitution policies designed to substitute lower cost care in the home for higher cost care in institutions (residential care or acute care), though only Denmark has been able to successfully realize this objective with limited downloading of responsibilities onto individuals and their families. It is important to note there are limitations to the substitution ability of home care services, and there will likely always be older adults who will require more intensive care in a specialized setting. In Denmark, while there is sometimes the perception that everyone is being cared for in their own home, there is a significant population of older adults who live in elderly housing that provides a high level of care. Therefore, careful consideration needs to be afforded to whom substitution policies are appropriate for.

A key limitation of efforts to assess the success of substitution policies is the lack of data on basic aspects of continuing care systems in jurisdictions (e.g., waitlists, home care spending, total hours of care provided, etc.), and when data was available it often was not consistently collected to allow for comparisons over time. Overall, the data that is available paints a picture of the general inadequacy of substitution policies in Australia and the Canadian jurisdictions. Below relevant evidence related to home care access and informal caregivers described in previous chapters is summarized.

Evidence suggests home care services are not being used to their maximum potential to allow people to remain at home for as long as possible, thus limiting the success of substitution policies in Australia and the Canadian cases (see table 36). In each of these jurisdictions over the study period there were at least one of the following limitations for home care: a) long waitlists; b) declining access to home support; c) a significant portion of older adults waiting for long-term care placement were not receiving

any home care; d) unjustified reductions of home care services due to budget constraints; e) hours of home care offered were well below the amount required for long-term care substitution; and f) the scope of available services were not broad enough. In addition, in Australia, BC, and Ontario high rates of distress were reported for primary informal caregivers. Canadian research has also reported 30% of regular informal caregivers experience 5 or more symptoms of psychological distress (Turcotte, 2013).

Table 36 Inadequacy of Home Care in Jurisdictions of Study

Inadequacy of Home Care in Jurisdictions of Study
<p>BC</p> <ul style="list-style-type: none"> • Multiple sources have reported a need for a more expansive range of home support services. • The majority of clients at high or very high risk of long-term care placement receive less than 2 hours of home support per day. • Over 2001-2016 access to home support declined by 30%.
<p>Ontario</p> <ul style="list-style-type: none"> • Most clients do not receive close to the maximum number of personal support hours available. • Home care budgets are often unequal to meet needs, resulting in arbitrary reductions of services.
<p>Québec</p> <ul style="list-style-type: none"> • The Québec Ombudsman has characterized institutions as failing to live up to Québec's policy on home support. • New exclusion criteria have been introduced due to inability to keep up with demand. • The MSSS has failed to meet its targets for increasing home support hours. • The proportion of older adults receiving home care declined from 15% in 2012/13 to 12% in 2015/16.
<p>Nova Scotia</p> <ul style="list-style-type: none"> • 43% of people on the waitlist for long-term care were not receiving home care services. • The total number of home support hours provided has declined since 2015/16. • Access to a broader range of home care services is required.
<p>Australia</p> <ul style="list-style-type: none"> • While access to home care packages has been increasing, in 2019 120,000 people were waiting for home care packages. The average waiting time for a level 4 home care package was 22 months.

The impacts of downloading responsibilities onto older adults and informal care caregivers was an important theme in the BC stakeholder interviews in chapter 7 and the implications were described in detail in the BC case. When adequate services are not available in the home and community, older adults must turn to informal care or private pay care (if they can afford it) to fill the gaps or be placed in a long-term care facility prematurely. It is not just home care, however, that contributes to the success of substitution policies. Other services such as adult day services and respite also

contribute, though data to assess the adequacy of their availability (or lack thereof) is much more difficult to obtain.

In Denmark, a combination of housing and home care has been used to divert people from traditional nursing homes, and less than 3,400 people now live in traditional nursing homes (Statistics Denmark, 2020). In Australia, as described in chapter 13, evidence suggests that there is currently some rebalancing of care occurring, with declining admissions to residential aged care and increasing admissions to home care. The main challenge to substitution policies in Australia appears to be adequate funding for home care packages. In the Canadian cases evidence suggests concerns over both home care funding and in some cases the comprehensiveness of services available (particularly IADL supports). A notable divergence exists among the Canadian cases for long-care placement waitlists compared to population size. BC and Québec both have lower ratios of publicly subsidized beds per 100 people aged 85+ than Ontario and Nova Scotia (Sivananthan et al., 2015), yet also have substantially smaller long-term care waitlists relative to their population sizes (see table 37). Further study is required to explain these differences; however, this may imply greater inadequacy of home and community services in Ontario and Nova Scotia.

Table 37 Long-Term Care Facility Waitlists 2018/19

	BC	Ontario	Québec	Nova Scotia
Long-Term Care Facility Waitlist	1,780 ^a	34,862 ^b	3,190 ^c	1,246 ^d
Older Adult Population 85+^e	109,195	301,075	188,685	21,645

Note: Waitlist information from Nova Scotia only includes those waiting from home and not those waiting in hospital, therefore the total waitlist is larger than indicated in the table.

Data Sources: a. OSA (2019a); b. Financial Accountability Office of Ontario (2019b); c. MSSS (2020b); d. Government of Nova Scotia (2020); e. Statistics Canada (2019b)

Much of the success of substitution policies is clearly dependent on funding to provide the services, which as described in section 14.1.3 is still heavily weighted towards institutions. Why have governments failed to adequately support substitution policies? Lynch and Estes (2001) examined the underdevelopment of community-based services in the United States and highlighted several factors that would also be relevant for these cases: the lack of power of actors and providers involved in long-term care; inequities in the burden of informal care (i.e., burden falls heavily on low-income minority women); services are often provided by community and non-profit organizations; government resistance to responsibility for disability care; and powerful lobbies that

support the status quo (i.e., for-profit care providers). Support for substitution policies by governments also has been inconsistent, varying based on the political priorities and fiscal policies of the governments in power.

14.2.2 Acute and Continuing Care Services

A second point of tension was the tension between acute and continuing care services. Continuing care services are facing pressures due to historical hospital downsizing, increased use of outpatient care, and policies to discharge patients as quickly as possible (e.g., Ostry, 2006; OECD, 2019a). As noted in 14.1.1, in policy documents narratives emphasize the utility of continuing care services for decreasing costs in the acute care sector. Integrated care strategies and initiatives such as Home First philosophies, transitional and restorative care programs, and financial sanctions are being utilized to facilitate vertical integration and relieve pressures on acute care systems. Research by Peckham, Morton-Chang, Williams and Miller (2018c) elucidates some of the challenges with intersectoral collaboration and implementing a broader rebalancing of care from the acute to community-based sector: diverging worldviews on care; power imbalances (i.e., acute sector attracts the policy attention and funding); and lack of cohesion and capacity of the community-based sector.

Ceci (2012) notes that in the current economic climate the home care sector must choose to prioritize certain clients over others. With acute care substitution, the potential is that within the context of already stretched thin budgets, acute substitution services will be prioritized over those that meet the long-term needs of older adults. Williams et al. (2009b) have cautioned about the need to protect community-based care from erosion by other parts of the health care system. This concern is particularly relevant for the Canadian cases, where home care has evolved with a strong acute care substitution function (Shapiro, 2002). The medicalization of home care has been a trend since the 1980s, reflective of the dominance of the biomedical model within Canadian health care systems (e.g., Penning et al., 2006; Penning & Votova, 2009; Binney, Estes, & Ingman, 1990). More recently funding in the 2004 Health Accords specifically for post-acute, palliative, and mental health home care further entrenched the medical nature of home care in Canada (Motiwala, Flood, Coyte & Laporte, 2005). This was apparent in BC as described in chapter 8, where evidence has amassed that increasingly the home support program is being used to support short-term clients from the acute sector. In

Ontario, it was also reported that increasing pressures were being placed on home care by post-acute clients. These trends can be linked to changing conceptualizations of the purpose of home care services, and these two jurisdictions had the clearest framing in policy documents of home care as a substitute for acute care. Pressures are also being placed on long-term care facilities as reported in Québec. Another challenge for the Canadian cases is continuing care funding comes from the same overall budget as other health care services, and thus must compete with acute care for funding. In the case of Québec, it was observed that when the governance and budgets of hospitals, long-term care facilities, and home care were integrated into CSSS, in some cases funding for home care and other social services were diverted away for medical uses.

In contrast to the Canadian cases, in Denmark and Australia there is separation between acute and continuing care governance, services, and budgets. As a result, elder care and aged care systems have evolved in environments less influenced by the biomedical model. However, tensions have also been observed between acute and continuing care in Denmark and Australia (e.g., Cameron et al., 2010; Rudkjøbing et al., 2012), though the separation of governance means the tension may play out between levels of government.

Continuing care services have a valid role to play in reducing pressures on the acute care system; however, this should not compromise the provision of care to other clients. Key questions that should be asked of vertical integrated care approaches are: What sector is paying for this benefit? Are gains from the benefit being shared fairly? If continuing care services are expected to act as substitutes, then there must be corresponding increases to budgets and savings should be re-invested in continuing care. Furthermore, consideration also must be given to the ability of staff to address the needs of acute clients in the community.

14.2.3 Mainstream and Marginal Services

A third point of tension regards the extent to which IADL supports and supports for caregivers should be integrated into formal continuing care systems. While there was consensus among the jurisdictions that these supports should be available to some extent, there were divergences regarding how they should be provided as described in sections 14.1.2 and 14.1.4. Some of the supports are provided directly through the

public continuing care system (i.e., housekeeping, respite), but others are provided on the margins of the system through other social service programs or non-profit and voluntary organizations that are fully or partially funded by government. Furthermore, partnerships with the non-profit and voluntary sector are increasingly being proposed as policy options for supporting the provision of care to frail older adults. There are strengths to the involvement of non-profit and voluntary organizations: these organizations may be better suited to meet local and cultural needs; their approaches to service provision (i.e., social models of care) may be more appropriate; and the cost may be less expensive for government. However, often these services are poorly funded and treated more as add-ons than essential services. Four issues that must be resolved regarding the involvement of the non-profit and voluntary sector are: 1) ensuring these services are properly coordinated with the continuing care system; 2) ensuring these organizations have adequate and stable funding so downloading does not occur onto this sector; 3) establishing boundaries for what types of services these organizations should be providing; and 4) determining how to increase equity of access to these services (i.e., should access to transportation services be dependent on whether there is a local non-profit organization offering them, or should government take an active role in ensuring equitable access across regions?).

14.2.4 Standardization and Individualization

A final source of tension is between the standardization and individualization of processes and care. Developing integrated care models necessitates a level of standardization (e.g., standardized assessments and care authorization, information systems, program delivery, etc.). Standardization can be viewed as an asset for logistical and fairness reasons, though it should not impede a system's ability to meet the needs of individuals. Several jurisdictions introduced reforms to standardize assessments and the general basket of services available, and these were generally viewed positively to ensure fairness. However, the increasing standardization of care delivery – where care is delivered as specific planned and timed tasks the individual is entitled to (e.g., 30-minute bath once a week) – was identified as a concern in several jurisdictions. In Denmark the term “tyranny of time” has been used to describe this policy issue (Bureau & Dahl, 2013). Standardization aligns well with cost containment objectives, as it also allows for strict cost control of the care that is being delivered. Dyck

and England (2012) observe a distinction exists between caring about (relational and emotional care) and caring for (task-oriented physical care). Under current paradigms, care is becoming increasingly task-oriented. In the jurisdictions of study concerns were expressed over the focus on time management in home care tasks (e.g., Denmark, BC, Québec), lack of person-centred care (e.g., BC, Ontario), and lack of attention to the relational aspects of care (e.g., BC, Australia).

On the other hand, being able to provide individualized and person-centred care is a core component of successful integrated care models (see chapter 2). Rhetoric increasingly emphasizes terms such as choice, flexibility, and person-centred when describing the type of care that should be provided to older adults. For example, in both BC and Ontario the concept of patient-centred care features prominently in policy documents. However, actualizing such principles has proven to be challenging, particularly within the context of cost containment imperatives. Consumer choice also is a prominent principle in both Australian and Danish policy, related to the marketization of care as described previously.

In Australia, CDC reforms were introduced to provide choice of services and some aspects of delivery in home care packages. While there have been problems with CDC in Australia (see chapter 13), it provides an interesting case study of an attempt to expand choice to the whole population of home care users. The experience in Australia highlights several considerations about such models: a) while older adults appreciate the idea of choice, they often do not desire a significant role in managing their care; b) older adults (particularly vulnerable older adults) and informal caregivers need to be supported to make choices so their burden does not increase in such models; c) the most important choices for older adults entail who delivers care (continuity) and when; and d) choices are constrained by a number of factors (e.g., knowledge of consumers, information from providers, availability of services). In contrast, in Denmark flexibility is provided by allowing consumers to substitute home support services during visits. While consumer choice has not been embraced in Canadian policy, self-directed care programs were a target of reforms in Nova Scotia and Ontario.

The models described above position individualization as emerging from “consumer choice;” however, there are limitations to consumer choice. Regarding the logic of consumer choice in home care, Ceci and Purkis (2009) note how logics of choice

assume clients are individualized, rational decision-makers when in reality this is not the case. Another source from which the individualization of care can potentially emerge, particularly for frail older adults who may have limited decision-making abilities, is through the empowering of care providers in the home and allowing them to work with the client and exercise their judgement when providing care.

14.3 Conclusion

The sections above describe some of the key policy divergences and convergences in the jurisdictions of study, and also some of the institutional, historical, and contextual factors that have contributed to these. Reforms over 2012-2019 generally appear to have produced limited improvements to continuing care systems, though some promising trends and policies were observed (e.g., development of structures to coordinate supports for informal caregivers, introduction of reablement approaches, increased funding for continuing care, etc.). Some of the barriers to transformative changes during this period observed included: a) an overreliance on market reforms to improve home care; b) conflicting priorities of governments (i.e., improving care and cost-containment); c) lack of policy attention and vision for reforms; d) government austerity; and e) turnover of governments and subsequent lack of follow-through on reforms.

Based on consideration of the available data on continuing care funding, access to home care, utilization of long-term care facilities, and reliance on informal care, it is apparent that there are deficits to current approaches to substitution policies and to meeting policy objectives related to allowing older adults to live at home. The findings suggest the need to develop coherent sets of policies to support the objective of allowing older adults to live at home. These policy neglects, as described above in various sections, can be linked to power imbalances and the dominance of biomedical paradigms, lack of commitment to gender equality, marketization agendas, cost containment imperatives, and retrenchment of the welfare state. They also point to the lack of systems perspectives on continuing care. Denmark is often considered to be a “gold standard” for elder care and some important contrasts between Denmark and the other jurisdictions were identified regarding the welfare state, perspectives on caring for older adults, funding, and the continuum of care. The next chapter discusses the

implications for BC of this comparative analysis and the experiences of the jurisdictions of study.

Chapter 15.

Discussion of Implications for BC

This final chapter briefly summarizes the case of BC presented in this dissertation. It then describes key action areas for BC's home and community care system in order to move towards an integrated continuing care system. Finally, it concludes with some reflections on the current context for health care reforms.

15.1 Summary of the Case of BC

In 1991, the Seaton Commission proposed guidelines for the public health care system in BC, the first of which was "Closer to Home: Medically necessary services must be provided in, or as near to, the patient's place of residence as is consistent with quality and cost-effective health care." (Government of BC, 1991, p.6). Shifting care from institutions to the community has since emerged as a consistent policy goal for the health care system. Almost 30 years later, BC has a health care system that has made strides towards providing care closer to home for older adults. However, as described in chapters 6 and 7, in BC the policies that have been introduced (or not introduced) over the past three decades have failed to produce an integrated continuing care system. Conceptualizations of care in the home remain narrow and are dominated by a biomedical paradigm that is inconsistent with meeting the needs of the majority of older adults who require long-term supports for chronic conditions and functional impairments. Without the proper supports for older adults and informal caregivers, care closer to home in many ways has become a means to serve the system rather than older adults.

As was described in chapter 6, policies implemented in the 1990s were contrary to the aims of moving care closer to the community. These policies included the discontinuation of services for clients only requiring homemaking services; removal of transportation, housekeeping, and meal preparation from the basket of services; and policies to provide care to only the clients with the greatest needs. In comparison, the 2000s saw some expansions to the continuum of services, including the introduction of the Palliative Care Benefits Program, publicly subsidized assisted living, and the Better at Home program. However, this was also a period when access to home and community services declined and privatization of services increased. For most of the

2000s (2001-2017) the Liberal Party, a party that has strongly embraced neoliberal philosophies, was in power. This significant period of continuity in governance provided an opportunity for major reforms, but instead was primarily a period of stagnation. Despite increasing perceptions of problems with the home and community care system, introduction of prominent new policy actors (the BC Ombudsperson and Seniors Advocate), and development of two home and community care action plans, actions to improve home and community care over 2012-2019 were limited. Since the New Democratic Party (a social democratic party) came to power in 2017 there are signs of a potential re-investment in home and community care and movement away from privatization. However, it should be noted the initial cuts to home support in the 1990s were made under a New Democratic Party government (in power 1991-2001).

It is not just the continuum of available services that makes a continuing care system successful, it is also the mechanisms and structures through which services are delivered. In the Seaton Commission, another guideline proposed was “The Jericho Process: Administrative walls within the Ministry of Health, among all ministries, health care institutions and organizations, and between all of these groups and educational institutions, must be broken down in favour of an integrated health care system.” (Government of BC, 1991, p.7). There have been multiple rounds of funding provided for integrated care initiatives; however, government has failed to translate initiatives into systemic changes. In BC, work has been underway over the past decade to: improve coordination between hospital and community care, establish team-based primary care, ensure the interoperability of information systems, better integrate primary and community care, build relationships and linkages with the community-based seniors’ services sector, and develop coordinated care models for complex patients. In particular, attention has focused on the integration of primary and community care. Many of these initiatives are works in progress and have not yet been fully and systematically embedded across the health care system, though there is the intent to do so which is a departure from the past.

As described in the last chapter, other jurisdictions are facing similar policy issues and challenges as BC. However, as the example from Denmark shows, it is possible to implement substitution policies with minimal downloading onto individuals and their families. The next section describes key areas of action for BC’s home and community care system in order to move towards an integrated continuing care system.

These action areas were identified based on consideration of a) the deficits in home and community care policy that were identified in chapter 8 and b) experiences and promising practices of comparison jurisdictions as described in chapter 14. Finally, the chapter concludes with some thoughts on implementing home and community care reforms within the context of COVID-19.

15.2 Areas for Action in BC

15.2.1 Establishing a Vision for Home and Community Care

As was described in chapter 8, BC lacks an overall vision for home and community care. This can be linked to the way home and community care services are framed by politicians and policy-makers: cost-effective alternatives to institutional care. Purpose is one of the three defining elements of a system (Meadows, 2008); however, the purpose of public institutions and systems are often ill-defined (OECD, 2017a). The purpose of a system shapes not only the policies that are enacted, but also the ways the success of the system is evaluated. Increasingly it seems policy decisions are being made based on whether home and community care services can a) reduce utilization of other health care services and b) reduce costs for the health care system. The value of home and community care should not be judged solely on its substitution abilities; research has shown that receipt of home care has impacts on important measures such as loneliness, life satisfaction, and perceived stress for older adults (Kadowaki, Wister & Chappell, 2014). While evidence suggests home and community care services have the potential to be cost-effective alternatives under the right circumstances, it is important not to lose sight of the true purpose of the home and community care system. Most British Columbians would likely agree that the primary purpose is to care for older adults, not save money for other parts of the health care system. In chapter 7, stakeholders strongly supported the potential substitution role of home and community care services; they also strongly believed in the need to develop a system that supports older adults and informal caregivers and provides true person-centred care. To do this, the lens through which home and community care policy is being developed in BC needs to be adjusted, from home and community care as a means to serve the system through acute and residential care substitution to home and community care as a means to care for older adults and support their health, independence, and quality of life.

A vision needs to be developed for the home and community care system to clearly articulate the purpose of these services and ensure the needs of older adults are at the forefront. Rhetoric on shifting care to the community should shift to allowing older adults to live at home, and this should be situated within broader discussions on aging in place. A range of stakeholders should be involved in developing policy solutions, and as suggested in chapter 7, a vision needs to be developed for how we as a society should care for older adults. Home health services should be a core component of the vision; however, all of the components of the system and their interrelationships must be considered. For example, a recent analysis on long-term care trajectories in BC elucidated that there are a notable proportion of users of home and community care services who enter assisted living or long-term care facilities directly with little or no home care services prior to the entry (Penning, Cloutier, Nuernberger, MacDonald, & Taylor, 2018). There is the need to take a systems approach and review the whole home and community care system when developing strategies and actions. For example:

- Are there adequate health human resources to support policies and programs? Are there changes to staff mix, training, etc. that might facilitate the provision of care?
- What impacts will new programs and policies have on informal caregivers?
- Besides home care, what other supports are required to allow older adults to remain in the home?
- What services' budgets will bear the costs of substitution policies? If home care, will there be adequate increases in budgets to offset the costs and ensure care for long-term care clients is not compromised? If cost-savings are achieved where will this money be reinvested?

15.2.2 Ensuring the Success of Substitution Policies

Systems approaches elucidate that individual services do not operate in isolation. In Ontario, researchers have promoted the concept of the balance of care (e.g., Williams et al. 2009a; 2016; Kuluski et al., 2012), originally based on the work of Challis et al. (1999) from the United Kingdom. Williams et al. (2016) describe this concept as:

While, as observed earlier, conventional projections of the care needs of an aging population often assume that a greater number of older persons will require a proportionately greater number of residential LTC beds, the BoC [Balance of Care] emphasizes that the need for such beds will be determined as well by supply-side factors such as access to appropriate,

cost-effective community-based care and support from informal caregivers. Other things being equal, where needed formal and informal community-based supports are more accessible, the needs tipping point for residential LTC beds will be higher, and older persons will be more likely to age at home or in homelike settings, even those persons with relatively high levels of need. Conversely, where needed community-based supports are less accessible, the needs tipping point will be lower, and older persons will be more likely to require residential LTC, even at lower levels of need. (p.16)

Balance of care implies that for substitution policies to be successful, consideration must be given to the availability of community-based care and supports for informal caregivers. As described in chapter 8, these supports to-date have been inadequate in BC. The concept of balance of care also suggests reconsidering the tendency to view services individually, and instead consider them as a full package of supports. Denmark, as described previously, offers a broad and generous range of community-based services to older adults to allow them to remain at home as long as possible. Furthermore, consideration also must be given to the development of integrated service delivery approaches.

Community-Based Care

Research by Keefe et al. (2014) and the comparative analysis shows BC is quite restrictive in the provision of IADL services compared to other Canadian and international jurisdictions. In particular, housekeeping and meal preparation are gaps. However, even clients who are judged to have “legitimate” home support needs and are high or very high needs usually receive less than 2 hours per day (OSA, 2019a). To-date, in BC policy on the provision of home support has been strongly influenced by economic imperatives, perceptions of whether services are “medical” versus “non-medical” responsibilities, and the utility of these services to other components of the health care system. In order to facilitate successful substitution, BC should: a) increase the availability of home support hours; b) expand the range of available home support services; and c) expand access to Better at Home services.

There are multiple arguments that can be made for shifting home support policies in BC. First and foremost, there is the moral argument that we as a society have a responsibility to care for and ensure the wellbeing of our fellow citizens. Second, while there may be an inclination to restrict home support services to only those that are “medical,” as described above, services do not operate individually and research

suggests lack of IADL supports contributes to long-term care placements (e.g., Laporte et al., 2017; Williams et al., 2009a). Third, providing a broader range of services on the continuum aligns with the concept of person-centred care and recognizes that individuals have different needs and require different supports to be able to stay at home. In the *Setting Priorities* policy document delivering patient-centred care was identified as the first priority for the health care system: “The province will strive to deliver health care as a service built around the individual, not the provider and administration.” (BC MOH, 2014a, p.27). Fourth, the pool of available informal caregivers will decline in the future and someone will need to fill these gaps (MacDonald et al., 2019). In particular it is projected there will be declining availability of adult children (Keefe, 2011), and adult children are more likely to provide IADL supports than personal care (Turcotte, 2013; Williams et al., 2010). Fifth, as described in chapter 7, lack of access to home support has negative consequences for older adults and informal caregivers. Sixth, from a financial perspective paying for home care services out-of-pocket is unaffordable for most Canadians. A recent analysis of home care costs in 26 jurisdictions (including Canada) by the OECD (Oliveira Hashiguchi & Llana-Nozal, 2020) estimated that without publicly subsidized services the costs of receiving as little as 6.5 hours per week of home care is unaffordable for most lower-income people. The analysis concluded the need for adequate social protection for both ADL and IADL supports, and social activities. Seventh, as described in chapter 2 there is evidence suggesting home support services can reduce utilization of other health care services and costs. Eighth, Wister and Speechley (2015) have noted the dynamic nature of future health care needs for older adults, and that there will be cohort-related differences in demands. Given the characteristics of the Baby Boomer cohort it is likely there will be a stronger preference for receiving care in the home, as well as an increased sense of entitlement to needed services.

Regarding expanding the range of available home support services, key policy questions that would be necessary to consider are: 1) Would CHWs become responsible for providing all IADL supports or would some be obtained through other funded programs or contracted service providers?; and 2) Would there be separate models of provision for people with lower level care needs (i.e., a client whose only needs were housekeeping or only transportation)? Based on observation of other jurisdictions there are two different approaches that could be considered: 1) All-Inclusive Home Support:

All clients, even those with only IADL needs, access IADL supports from the formal home support program and receive care from CHWs; and 2) Mixed Economy: IADL supports are provided by CHWs, plus other funded programs/contractors provide IADL supports for lower level clients and/or certain IADL supports for all clients. Table 38 describes the potential strengths and weaknesses of such models. As described in the table these models would have potentially different implications for costs, health human resources, and coordination that would need to be carefully considered. If a mixed economy approach is utilized Better at Home would be well positioned to be scaled up and adopt an expanded role. However, even if an all-inclusive model was developed it would be important to still maintain and expand access to Better at Home to more communities as it provides key services beyond IADLs (e.g., home maintenance, snow shovelling, friendly visiting).

Table 38 Models for Providing IADL Home Supports

	All-Inclusive Home Support Program	Mixed Economy
Strengths	<ul style="list-style-type: none"> -Facilitate smoother coordination of services -Decreases number of providers in home -Allows for smooth transitions between levels of care -Allows for preventive monitoring of lower needs clients 	<ul style="list-style-type: none"> -Allows for more efficient use of CHWs given shortages -Potentially less costly for health care system -Care reflects social model -Potentially less onerous access for lower needs clients or limited users of services
Weaknesses	<ul style="list-style-type: none"> -Potentially inefficient use of CHWs given shortages -Potentially more expensive for health care system -Care may reflect medical approaches -Pathways of access may seem onerous for clients requiring limited services 	<ul style="list-style-type: none"> -Increases number of providers involved in care -Requires clear coordination mechanisms -May be less monitoring of lower level clients -May be regional variations in access depending on geographical distribution of providers

As the experience of Denmark has shown, home care and community services are just one part of the equation, and another is housing. Greater attention should be paid to the linkages between health, continuing care, and housing policy. Housing has been identified as a key social determinant of health (Bryant, 2009) and is also one of the eight areas identified in *WHO Global Age-Friendly Cities: A Guide* (WHO, 2007a). To support older adults, policy should address both the need for the development of specialized housing models for older adults (e.g., assisted living, supportive housing, etc.), as well as broader steps that can be taken to promote aging in place (e.g., age-friendly communities, housing affordability, universal design). Development of supportive

housing policies will require intersectoral efforts and coordination between the MOH and other ministries and government agencies responsible for housing, and health and community care. In chapter 7 stakeholders noted the need for more affordable housing and a broader range of housing alternatives. The OSA (2019b) reports that the number of senior subsidized housing units declined by 8% between 2015-2019 and there is a need to engage with other sectors such as the housing sector when implementing aging in place policies. One of the barriers to home care being cost-effective can be transportation costs (Hébert et al., 2001) and models of housing that encourage clustered care such as seniors' housing buildings or settings where provision of care in congregate settings can occur (e.g., adult day services) should be encouraged.

While at home as long as possible is the ideal, when the needs of older adults become too complex remaining at home or in the community can actually be a maladaptive choice. Government currently is pursuing an expansion of assisted living, and as described in chapters 6-8 there are some potential limitations of such an approach. One of the key caveats about Denmark's success is while most older adults now live in various housing models rather than nursing homes, these housing units and staffing levels for these models have been designed to provide a high level of care. In addition to assisted living, consideration needs to be afforded to whether there are additional alternatives to traditional long-term care facilities that should have a place on the continuum. For example, Regnier (2018) an international expert on assisted living, highlights a range of innovative housing models for older adults such as apartments for life (housing that is designed to allow older adults to age in place in their apartment unit, and as their needs increase higher levels of care are brought to them), continuing care retirement communities (communities that offer the full range of living options for older adults and residents transition into new living arrangements as their needs increase), and small cluster housing (units are clustered into small groups within a building or into multiple smaller buildings).

Supports for Informal Caregivers

One of the most striking divergences revealed in the comparative analysis is the extent informal caregivers have been neglected within home and community care policy in BC. While there has been increased awareness of the needs of informal caregivers since 2018/19, this is an area where further attention is required. It is recommended that

a caregiver policy lens be incorporated into all future home and community care strategies to ensure this neglect does not continue. A caregiver strategy should be developed in partnership with stakeholders. This strategy should develop policies in the four areas identified by Cass et al. (2014) (Caregiver recognition and rights; Services for older adults and caregivers; Work-care reconciliation; and Financial support). Doctors of BC (2016) has published a policy paper on opportunities to support informal caregivers that contains useful policies for consideration in BC. Based on the feedback from key stakeholders in chapter 7 and the experiences from other jurisdictions, some specific policies that might be considered:

- Expand the continuum of services that provide respite to caregivers: Services such as day homes (Denmark) and respite cottages (Australia) are innovative models of providing respite that seem better aligned with the needs of older adults and informal caregivers than current institutional options.
- Continue to invest in adult day services: Adult day services are an often overlooked service yet were highlighted as playing a crucial role to support older adults and informal caregivers. In BC, in 2018/19 there were almost as many people waiting for adult day services (1,503) as long-term care facilities (OSA of BC, 2019b).
- Implement a financial benefit for primary caregivers: Financial help is the most frequently identified form of help needed by informal caregivers in Canada (Statistics Canada, 2018). Furthermore, research suggests that out-of-pocket expenditures on care are associated with increased odds of negative caregiving consequences (Shooshtari, Duncan, Roger, Fast, & Han, 2017). Financial payments to caregivers have proven to be a viable policy option in both Australia and Nova Scotia.

In addition, BC should also reconsider the current organization of caregiver support services. To-date, caregiver supports have evolved in an organic and uncoordinated manner and are provided by a variety of non-profit organizations. There is a need for a better coordinated approach to delivering caregiver supports. BC has already begun moving in this direction, as Family Caregivers of BC is the backbone organization for the caregiver support program demonstration projects (Healthy Aging, 2019a). In addition, in 2020 as a result of COVID-19 the BC MOH provided additional funding to Family Caregivers of BC to expand their telephone line and provincial services (Government of BC, 2020f). BC should consider as a next step formalizing the role of Family Caregivers of BC as the umbrella organization for informal caregiver supports, and establishing either a network model (i.e., like Québec, Nova Scotia or Australia) or coordinating body model (e.g., Ontario). Furthermore, in Australia one of the reasons informal caregivers

has been a significant area of policy development is because the organizations providing support to them were legitimized as HACC program providers. Establishing a dedicated government fund for organizations providing support to informal caregivers would legitimize their role and ensure stability of services in BC.

Integrated Service Delivery Model

The BC MOH has developed plans to implement SCSPs. On paper these models incorporate key components of integrated service delivery models: multidisciplinary teams; introduction of a single coordinated program structure; use of technology to share information; single access point; and links to the PCNs. However, there will also be significant local autonomy to implement the models; therefore, it is unclear what the models will end up being in practice. The experiences with system-wide implementation of the Health Links in Ontario and PRISMA in Québec showed that while local flexibility and creativity is an asset, too much flexibility can lead to drifts away from the intended model. There is a need to evaluate the performance of the prototype SCSPs and develop mechanisms to disseminate successful approaches and components. This is something that BC has historically struggled with, piloting and implementing various programs and models (i.e., the aIPCC initiatives, IHNs) but then failing to systemically disseminate successful ones across the health care system. Based on the feedback from stakeholders in chapter 7 and the experiences from other jurisdictions in chapter 14, some specific considerations for SCSPs are:

- Ensure CHWs are fully incorporated into the care teams.
- Do not perpetuate the dominance of the acute care sector within the SCSP model; ensure home and community care and community-based service providers are incorporated into leadership and decision-making structures.
- Develop mechanisms to coordinate access to community-based services (i.e., informal caregiver supports and IADL supports).
- Ensure that case managers (or equivalents) in the model are adequately resourced. If they are inadequately resourced and juggling clinical and coordination responsibilities it is likely the coordination responsibilities will suffer.
- Adopt new paradigms for delivering care that increase the flexibility and responsiveness of care (see section 15.2.4)

15.2.3 Continuing Care Funding

In BC, underfunding is clearly a root cause of issues within the home and community care system. As described in chapter 14, this was also the case in other jurisdictions, and even if there is a well-designed service delivery system (e.g., Québec) or broad range of community-based services (e.g., Australia) if there is not an adequate level of investment it renders these structures useless. The experience of BC as well as the other cases, reinforces that without adequate funding for home care and other services in the community, substitution policies and efforts to provide care in the home for as long as possible result in downloading onto individuals and their families. The status quo funding arrangements are currently not providing sufficient funding to ensure adequate provision of care in the community and long-term care facilities. The costs of continuing care are expected to continue increasing in the future in Canada (MacDonald et al., 2019). Access to publicly subsidized home and community care services is essential, as without this the OECD has estimated in Canada approximately 30% of people with low level home care needs, 80% with moderate home care needs, 90% with high level home care needs, and 70% with institutional care needs would be living in poverty (it should be noted though that even with publicly subsidized services there is a proportion who are still living in poverty) (Oliveira Hashiguchi & Llana-Nozal, 2020).

Continuing care funding is not just a provincial issue, there is clearly a role that the Federal Government can play in funding reform. Declining federal health care contributions have been decried by provincial governments as impeding their ability to provide health care. While some targeted funding was provided for home care in the most recent bilateral health care agreements, these are not tied to any specific standards and are being used for a broad range of home care related purposes (Canadian Health Coalition & Ontario Health Coalition, 2017). While funding has received little attention on policy agendas (with the exception of Québec), there has been some consideration given to this issue by policy researchers and academics. In 2016 an issue of *Healthcare Papers* focused on long-term care funding, and in the lead paper Adams and Vanin (2016) identified policy options for long-term care funding in Canada: 1) general tax revenues, 2) social insurance, 3) private insurance, and 4) private savings. The time required to implement funding reforms (e.g., in England it took 14 years), public aversion to taxation, and lack of government will were perceived as such significant barriers that options 1 and 2 were dismissed as not feasible. Instead,

Adams and Vanin (2016) advocated for the provision of private tax-sheltered savings. In contrast, the response papers generally supported public financing via options 1 or 2. A few of the considerations that were raised in the response papers were:

- The weakness of private options is they disproportionately favour middle-class and higher-class people and have the potential to leave low-income people without access to care or with inferior care (Torjman, 2016; Grignon, 2016).
- Some funds currently allocated towards health care from the Canada Health Transfer could potentially be diverted from medical care to continuing care (Torjman, 2016; Emery 2016).
- While there is not massive support for increasing taxes in Canadian society, if the alternative is sufficiently unattractive (i.e., cuts to services) and proposed use of taxes is connected to a specific benefit public support can be garnered (Grignon, 2016).
- Consideration needs to be given to what extent the provision of continuing care is a health care issue, and to what extent it is a societal issue. Broader discussions are needed about the extent we are responsible for caring for aging family members (Deber & Laporte, 2016).
- While there are jurisdictional tensions, and provinces implementing their own long-term care funding models is an option, the potential benefits of a national financing scheme cannot be ignored and are worth exploring (Torjman, 2016; Hébert, 2016).

While it is beyond the scope of this dissertation to recommend a specific funding model, it seems clear that for equity reasons publicly financed solutions should be considered. The ambiguous position of continuing care in Canada is contributing to the marginalization, medicalization, and underfunding of continuing care systems. If a federal funding model were introduced this would also provide formal recognition of services such as long-term care homes and home care as necessary services for older adults and ensure that all Canadians are entitled to a general basket of services. Researchers have suggested that this could be achieved by expanding the Canada Health Act or introducing a separate tax-financed or social insurance scheme (e.g., Chappell & Hollander, 2011; Lanoix, 2017; Hébert, 2016). Grignon and Bernier (2012) state “But from an economics perspective, the widespread reluctance among Canadians to accept the tax increases that would be required to pay for a public plan should be overcome, simply because the other options are inefficient and inequitable.” (p.29). Grignon and Bernier (2012) suggest that continuing care should be funded through public insurance and five key questions need to be considered when developing such a

program: 1. Whether the program should be funded through general revenues or earmarked fund?; 2. Whether the program should have an open-ended or fixed budget envelope?; 3. How revenues would be collected and in what form?; 4. Whether the program should provide full or partial coverage?; and 5. Whether the plan should be funded directly or as pay as you go?

15.2.4 New Service Paradigms

The current paradigms of service provision in BC also deserve to be reconsidered as was highlighted in the stakeholder perspectives in chapter 7. Stakeholders wanted care to be person-centred, proactive, and empower older adults. In the comparative analysis it was described how jurisdictions have sought to increase the choice and control older adults have over their care. While “consumer choice” has primarily been used to drive forward neoliberal market reforms, principles related to increasing the flexibility and responsiveness of services have merits. Such principles could be implemented in non-market models, in ways that place minimal burden on older adults and informal caregivers (i.e., in Denmark older adults are allowed to ask for the substitution of tasks when receiving care in the home). The example provided by an informant in the Ontario chapter of personal support workers from the Toronto CCAC asking the clients what they want them to do when they visit and allowing the client to direct the care shows this could work in the Canadian context (see p.175). This type of service paradigm also was promoted by the Seniors Advocate (OSA, 2019a) in her recommendations that care be made more flexible and community support workers empowered to respond to the needs of the client. Such changes in paradigms would help to affect a shift away from the current task-oriented manner of care delivery. One of the key requirements necessary for such paradigm shifts would be allowing CHWs enough time to provide care in a person-centred way.

Second, reablement also aligns with paradigms of proactive and empowering care. Reablement paradigms recognize the dynamic nature of disability and ability, as well as the value of maximizing the functional ability of older adults. If successful, the benefits (improving functional ability and reducing need for ongoing services) are significant. Recent systematic reviews of reablement interventions have found evidence supporting positive effects on health care utilization and improvements in functional abilities (Tessier, Beaulieu, McGinn, & Latulippe, 2016; Sims-Gould, Tong, Wallis-Mayer,

& Ashe, 2017). While it has been noted the evidence is not yet fully conclusive on reablement, Aspinall et al. (2016, p.577) observe:

Although the evidence is still emerging, reablement seems simply ‘the right thing to do’—not trying to support people back to optimal independence would be bad for the individual as well as a poor use of scarce resources.

Experiences with reablement in Denmark and Australia show promise; however, these experiences highlight the need to have realistic expectations for reablement programs and also particularly in a system like BC’s (which has a history of increasing eligibility requirements to ration services) to monitor that reablement is not inappropriately used as a justification to reduce services for those who need them.

A systematic review by Tessier et al. (2016) identified some facilitators that can contribute to the success of reablement interventions: targeting appropriate populations (e.g., people with a recent injury or decline in function); well trained and committed staff; addressing psychological and social needs in addition to physical needs; and being focused on goals established with the care recipients. Sims-Gould et al. (2017) note that more research is required to determine to what extent these approaches are generalizable to other settings and would be beneficial to broad home care populations. Reablement approaches appear to be worth exploring, though should be tested on a small scale first to determine proof of concept and effective models for the BC context. It is important to highlight a contextual difference in terms of cost reduction expectations: within the BC context the range of home support services available is narrower than in Denmark and Australia, therefore the potential economic gains from reducing ongoing public service use may be more limited. Consideration of such factors should be given when setting expectations for programs in the Canadian context.

15.3 Context for Future Reforms

It is important to discuss a key contextual factor that will likely have a significant impact on future policy decisions. In 2020, the first wave of the coronavirus (COVID-19) pandemic began, and at the time of writing this section, the pandemic is still ongoing. The National Institute on Ageing (2020) reported in May 2020 that long-term care home residents have accounted for 82% of COVID-19 deaths in Canada. Long-term care homes in Ontario and Québec have been particularly hard hit, necessitating the

Provincial Governments to request military aid. As described in previous chapters, in the Canadian cases underfunding and staffing levels in long-term care homes were a consistent policy concern. COVID-19 has exposed years of neglect and underfunding in long-term care homes. In particular, reports by Canadian Armed Forces exposing the terrible conditions in Ontario's long-term care homes garnered significant attention (CBC News, 2020). Some pressure is now being exerted on both Federal and Provincial Governments to address the underfunding of long-term care homes (e.g., Harris, 2020; CBC News 2020).

Buse et al. (2005) observe that policy-making is different during a crisis, and there is more likely to be acceptance of radical solutions at such times. With Canada's attention currently on long-term care homes, the COVID-19 pandemic provides a policy window for reforming continuing care funding in Canada. The instinct of government likely will be to inject additional funding into long-term care homes, and this may help to alleviate problems over the short-term. However, focusing solely on long-term care homes would be short-sighted given stated provincial policy objectives of providing care in the home and preferences for care of older adults. A more thoughtful approach would be to initiate a national conversation with Canadians on what type of care we want to provide to our older adult population; a necessary part of this conversation will be discussing how we can adequately finance continuing care as discussed in section 15.2.3. This is particularly imperative given the likelihood of a financial recession occurring. After the global financial crisis in 2009, governments focused on cost containment of health care services and spending slowed (CIHI, 2019a), and given the marginalized position of continuing care services (and specifically home care which has had little visibility during the pandemic) they are at risk of retrenchment. In addition, while it has been noted that shifts in allocations of health care spending need to occur in Canada, COVID-19 will make it difficult for politicians to justify to the public any shifts in funding away from hospitals and long-term care homes in the near future.

In addition to funding reforms, COVID-19 has also exposed additional weaknesses in continuing care systems, and may produce additional policy windows to implement changes in the above described action areas:

- Infection control has been a serious problem in long-term care homes during the pandemic, and new smaller scale models of care (e.g., Greenhouse Models) will likely be of increased interest in the future.

- COVID-19 has exposed the need to address a) appropriate staff training, resources, and levels in long-term care and b) health human resources in the continuing care sector.
- The impact of COVID-19 in long-term care homes will likely strengthen negative perceptions of long-term care homes and reinforce older adults' desire to be cared for in the home or alternative housing models.
- During the pandemic, the need to provide IADL and social supports to isolated and frail older adults has been recognized as a priority through volunteer movements and community initiatives, in order to supplement caregiving, with some funding support from governments. Relying on volunteers will be unsustainable in the long-run. The widespread public support for such measures provides legitimacy to the policy option to fund these services publicly.

15.4 Limitations of Study

This study has critically evaluated information on continuing care systems in BC and other jurisdictions over 2012-2019. Information has been synthesized from a broad range of sources, including policy documents, research and literature, statistical and budget data, and interviews. However, there are some limitations of this research that should be discussed. First, there was a language barrier in regard to obtaining research and information from Québec and Denmark, therefore it is possible that some research or policy issues from these jurisdictions may have been overlooked. Attempts were made to ameliorate these barriers through the use of Google Translate and translation services, triangulation of sources and narratives, and interviews with key informants. Second, due to the lack of evaluation of reforms and general lack of data collected on continuing care services, it at times was difficult to determine the impact of reforms or make comparisons between jurisdictions. Consideration was given to a range of types of evidence when attempting to assess reforms, policies, and systems in jurisdictions. Third, health care systems are complex systems and the studies of cases were meant to be comparative cases and not in-depth case studies, therefore it is possible that some unique contextual factors were overlooked, though efforts were made to develop an understanding of key contextual areas. Fourth, due to the dynamic nature of health care reforms and time required to observe impacts, not all of the reforms were fully implemented by the end of the study or in place long enough to determine what the impacts were. Further follow-up and critical analysis of these reforms, and Australia in particular, is recommended.

15.5 Future Research Directions

As noted above, due to the dynamic and progressive nature of health care reforms and policy-making, further research should be conducted to follow-up on some of the reforms in the jurisdictions of interest. In particular, areas of interest include:

- Denmark: Impact of allowing municipalities to sell supplemental services; whether retrenchment is occurring in Denmark's elder care system.
- Australia: Effectiveness of reablement approaches; development of integrated carer support services; progress and impact of scaling up home care packages.
- BC: Impact of expanding the number of prescribed services in assisted living; development of the SCSPs.
- Ontario: Impact of restructuring by the Progressive Conservative government.
- Québec: Progress in developing a caregiver policy; continued implementation and impact of RSIPA.
- Nova Scotia: Whether a new Continuing Care Strategy is developed.

Additional proposed research areas to explore include: the merits of potential funding models for continuing care; barriers and facilitators for implementing funding reforms; Canadian models for reablement and person-centred care; and best practices for supporting informal caregivers.

15.6 Conclusion

Integrated continuing care models rely on the logic of substitution policies. As has been described in this study, there are certain foundational requirements (i.e., supportive vision, adequate funding, supports for informal caregivers, comprehensive continuum of services) that need to be met for substitution policies to be effective and in the best interest of older adults. Currently BC, as well as other jurisdictions, are failing to develop the coherent package of policies necessary to ensure the success of substitution policies. When substitution policies are directed primarily by cost containment motivations, and inadequately supported by other policies, there is the risk that they will result in significant and unsustainable downloading of responsibilities onto older adults and informal caregivers. However, the example from Denmark shows it is possible for a significant shift in care from institutions to the home and community to

occur with limited downloading onto individuals and their families. This chapter has outlined some of the potential reforms necessary to transform the continuing care system in BC.

The amount of policy attention continuing care has received in BC (as well as in the other Canadian cases) has not been commensurate with the scale and magnitude of the policy issues. Wister and Speechley (2015) lay bare the potential outcomes of continuing on with the status quo for the health care system: mounting health care costs; sectors and professionals competing with each other for scarce health care resources; greater privatization and a move towards a two-tiered health care system; and increasing inequities in health between haves and have nots. One of the key challenges for reforms identified for BC (as well as the other Canadian cases) is the ambiguous position of continuing care within the Canadian welfare state that has contributed to the marginalization, medicalization, and underfunding of continuing care systems. A key conclusion from this study is that a funding model for continuing care needs to be developed at the national level, which has become particularly apparent during the COVID-19 pandemic.

References

- Abbott, S., Shaw, S., & Elston, J. (2004). Comparative analysis of health policy implementation. *Policy Studies*, 25(4), 259-266.
- Adams, O., & Vanin, S. (2016). Funding long-term care in Canada: Issues and options. *HealthcarePapers*, 15(4), 7-19.
- Advisory Panel on Healthcare Innovation. (2015). *Unleashing innovation: Excellent healthcare for Canada: Report of the advisory panel on healthcare innovation*. Ottawa, ON: Health Canada.
- Aged Care Financing Authority. (2019). *Seventh report on the funding and financing of the aged care sector*. Retrieved May 28, 2020 from <https://www.health.gov.au/sites/default/files/documents/2019/11/seventh-report-on-the-funding-and-financing-of-the-aged-care-industry-july-2019.pdf>
- Aged Care Sector Committee. (2015). *Aged Care Sector Statement of Principles*. Retrieved May 28, 2020 from <https://www.health.gov.au/resources/publications/aged-care-sector-statement-of-principles>
- Aged Care Sector Committee. (2016). *Aged care roadmap*. Retrieved June 12, 2020 from https://www.health.gov.au/sites/default/files/aged-care-roadmap_0.pdf
- Anaf, S., Drummond, C., & Sheppard, L. (2007). Combining case study research and systems theory as a heuristic model. *Qualitative Health Research*, 17(10), 1309-1315.
- Andersen, P., & Jensen, J. (2010). Healthcare reform in Denmark. *Scandinavian Journal of Public Health*, 38(3), 246-252.
- Araki, Y. (2004). Assisted living settings in British Columbia: policy goals and gaps. [Master's Thesis, Simon Fraser University].
- Armitage, G., Suter, E., Oelke, N., & Adair, C. (2009). Health systems integration: state of the evidence. *International Journal of Integrated Care*, 9e82.
- Armstrong, P., Armstrong, H., & Coburn, D. (Eds.). (2001). *Unhealthy times: Political economy perspectives on health and care in Canada*. Don Mills, ON: Oxford University Press.
- Aronson, J. (2002). Elderly people's accounts of home care rationing: missing voices in long-term care policy debates. *Ageing and Society*, 22(4), 399-418.

- Aspinal, F., Glasby, J., Rostgaard, T., Tuntland, H., & Westendorp, R. G. J. (2016). New horizons: Reablement - supporting older people towards independence. *Age and Ageing, 45*(5), 572–576. <https://doi.org/10.1093/ageing/afw094>
- Auditor General of British Columbia. (2017). *Health funding explained 2*. Retrieved January 6, 2018 from <https://www.bcauditor.com/pubs/2017/health-funding-explained-2>
- Auditor General of Québec. (2013). *Value-for-money audit – Report of the Auditor General of Québec to the National Assembly for 2013-2014, Spring 2013*. Retrieved May 28, 2020 from <https://www.vgq.qc.ca/en/publications?lang=en&typeRapport=RA&annee=2013>
- Australian Association of Gerontology. (2019). *AAG Fact Sheet 2: Australian approaches to reablement in the home support and care program*. Australian Association of Gerontology.
- Australian Bureau of Statistics. (2019). 2016 Census Quickstats. In *Australian Bureau of Statistics*. Retrieved June 4, 2020 from https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/036#:~:text=In%20the%202016%20Census%2C%20there,up%202.8%25%20of%20the%20population.&text=The%20median%20age%20of%20people%20in%20Australia%20was%2038%20years.
- Australian Department of Health [DOH]. (2016). *Increasing choice in home care – stage 1: Discussion paper feedback*. Canberra: Australian DOH.
- Australian DOH. (2017a). *Legislated review of aged care 2017*. Retrieved May 28, 2020 from <https://www.health.gov.au/resources/publications/legislated-review-of-aged-care-2017-report>
- Australian DOH. (2017b). *Future reform – an integrated care at home program to support older Australians*. Retrieved May 28, 2020 from <https://consultations.health.gov.au/aged-care-policy-and-regulation/discussion-paper-future-care-at-home-reform/>
- Australian DOH. (2018a). *Streamlined consumer assessment for aged care*. Retrieved May 28, 2020 from <https://consultations.health.gov.au/in-home-aged-care-division/streamlined-consumer-assessments-for-aged-care-ser/>
- Australian DOH. (2018b). *A matter of care: Australia's aged care workforce strategy, Aged care workforce strategy taskforce*. Canberra: Australian DOH.
- Australian DOH. (2018c). *Wellness and reablement report outcomes 2018*. Retrieved May 28, 2020 from <https://www.health.gov.au/resources/publications/outcomes-of-the-commonwealth-home-support-programme-chsp-wellness-and-reablement-report-2018>

- Australian DOH. (2019). *2018-2019: Report on the operation of the Aged Care Act, 1997*. Canberra: Australian DOH.
- Australian DOH. (2020). *Home care packages program: Data report 2nd quarter 2019-20*. Retrieved May 29, 2020 from https://gen-agedcaredata.gov.au/www_ahwgen/media/Home_care_report/HCP-Data-Report-2019%e2%80%9320-2nd-Qtr.pdf
- Australian Department of Social Services [DSS]. (2015). *Aged care changes – the journey so far*. Australian DSS.
- Australian DSS. (2016a). Carer Payment. In *Department of Social Services*. Retrieved April 16, 2020 from <https://www.dss.gov.au/disability-and-carers/benefits-payments/carer-payment>
- Australian DSS. (2016b). *Increasing choice in home care – Stage 1 discussion paper*. Canberra: Australian DSS.
- Australian DSS. (2016c). *Delivering an integrated carer support service: A draft model for the delivery of carer support services*. Canberra: Australian DSS.
- Australian DSS. (2017). *Public consultation on the draft service delivery model: Summary report*. Canberra: Australian DSS.
- Australian DSS. (2019). *Implementation Timeline*. Retrieved May 28, 2020 from <https://www.dss.gov.au/disability-and-carers-carers-integrated-carer-support-service/implementation-timeline>
- Australia Institute of Health and Welfare [AIHW]. (2015). *Australia's welfare 2015*. Canberra: AIHW.
- AIHW. (2018). *Australia's health 2018*. Canberra: AIHW.
- AIHW. (2019). *Admissions into Aged Care*. In *GEN Aged Care Data*. Retrieved June 15, 2020 from <https://www.gen-agedcaredata.gov.au/Topics/Admissions-into-aged-care>
- AIHW. (2020). *GEN fact sheet 2018–19: Government spending on aged care*. Canberra: AIHW.
- AMR. (2016). *My Aged Care stage two wave 1 research: Summary of findings*. Retrieved May 28, 2020 from <https://www.health.gov.au/sites/default/files/documents/2019/12/my-aged-care-stage-two-wave-1-research-summary-of-findings.pdf>

- AMR. (2017). *My Aged Care evaluation: Stage two wave 2 research: Summary of findings*. Retrieved May 28, 2020 from <https://www.health.gov.au/resources/publications/my-aged-care-stage-two-wave-2-research-summary-of-findings>
- AMR. (2018). *Home care package research*. Retrieved May 28, 2020 from <https://www.health.gov.au/resources/publications/home-care-packages-program-research-report>
- Avoidable Hospital Advisory Panel. (2011). *Enhancing the Continuum of Care*. Retrieved January 29, 2020 from http://www.health.gov.on.ca/en/common/ministry/publications/reports/baker_2011/baker_2011.pdf
- Baird, P. (2006). *Aging well in British Columbia: Report of the Premier's Council on aging and seniors' issues*. BC Ministry of Healthy Living and Sport.
- Banks, P. (2004). *Policy Framework for Integrated Care for Older People*. London: King's Fund/EHMA.
- Baranek, P. (2011). *Integration of Care: Perspectives of Home and Community Providers Care Coordinators*. The Change Foundation.
- Baranek, P., Deber R., & Williams, P. (2004). *Almost home: Reforming home and community care in Ontario*. University of Toronto Press.
- Barczyk, D., & Kredler, M. (2019). Long-term care across Europe and the United States: The role of informal and formal care. *Fiscal Studies*, 40(3), 329-373.
- Beed, J. (2017). *Expanding caregiver support in Ontario*. Retrieved May 28, 2020 from <https://www.ontario.ca/document/report-expanding-caregiver-support-ontario>
- Béland, F., Bergman, H., Lebel, P., Dallaire, L., Fletcher, J., Tousignant, P., & Contandriopoulos, A. (2006). Integrated services for frail elders (SIPA): A trial of a model for Canada*. *Canadian Journal on Aging*, 25(1), 25-42.
- Béland, F., & Hollander, M. (2011). Integrated models of care delivery for the frail elderly: International perspectives. *Gaceta Sanitaria*, 25, 138-146.
- Bell, E. (2010). *Research for health policy*. New York: Oxford University Press.
- Benoit, M., & Perron, L. Aging "at home" in an era of austerity: Home care services under pressure. *Journal of the Center for Research and Expertise in Social Gerontology*, 8(1), 20-23.

- Bertelsen, T. M., & Rostgaard, T. (2013) Marketisation in eldercare in Denmark: Free choice and the quest for quality and efficiency. In G. Meagher & M. Szebehely (Eds.), *Marketisation in Nordic eldercare, A research report on legislation, oversight, extent and consequences* (pp. 127–161). Normacare, Stockholm University
- Best, A., Clark, P., Leischow, S., & Trochim, W. (2007). *Greater than the sum: Systems thinking in tobacco control*. Retrieved August 21, 2017 from https://cancercontrol.cancer.gov/brp/tcrb/monographs/18/m18_complete.pdf
- Bigonnesse, C., & Chaudhury, H. (2019). The landscape of “aging in place” in gerontology literature: emergence, theoretical perspectives, and influencing factors. *Journal of Housing for the Elderly*, 1-19.
- Billings, J., & Leichsenring, K. (2014). Methodological development of the interactive INTERLINKS Framework for Long-term Care. *International Journal of Integrated Care*, 14, E021.
- Binney, E.A., Estes, C.L., & Ingman, S.R. (1990). Medicalization, public policy and the elderly: Social services in jeopardy? *Social Science & Medicine*, 30(7), 761-771.
- Bjornsdottir, K. (2013). Assisting the frail elderly to live a good life through home care practice. In C. Ceci, M. Purkis, and K. Björnisdóttir (Eds.), *Perspectives on care at home for older people* (pp.121-135). New York, NY: Routledge.
- Blank, R., & Burau, V. (2010). *Comparative health policy*. New York, NY: Palgrave MacMillan.
- Brackley, M. E., & Penning, M. J. (2009). Home-care utilization within the year of death: trends, predictors and changes in access equity during a period of health policy reform in British Columbia, Canada. *Health & Social Care in The Community*, 17(3), 283-294.
- Breton, M., Wankah, P., Guillette, M., Couturier, Y., Belzile, L., Gagnon, D., & Denis, J. L. (2019). Multiple perspectives analysis of the implementation of an integrated care model for older adults in Québec. *International Journal of Integrated Care*, 19(4), 6.
- British Columbia Care Providers Association [BCCPA]. (2015). *Strengthening seniors care delivery in BC*. Retrieved May 28, 2020 from <https://bccare.ca/wp-content/uploads/BCCPA-White-Paper-QulC-FINAL-2015.pdf>
- BCCPA. (2017). *Strengthening seniors care: A made-in-BC roadmap*. Retrieved May 28, 2020 from https://bccare.ca/wp-content/uploads/2017/01/BCCPA_Roadmap_Full_Jan2017.pdf
- BCCPA. (2018). *Situation critical: A made-in-BC plan to address the seniors care labour shortage*. Retrieved May 28, 2020 from <https://bccare.ca/wp-content/uploads/2018/10/Situation-Critical-July-2018-updated.pdf>

- BCCPA. (2019a). *Bedlam in BC's continuing care sector: Projecting future long term care bed needs*. Retrieved May 28, 2020 from https://bccare.ca/wp-content/uploads/2019/05/Bedlam_in_BC_Continuing_Care_Sector.pdf
- BCCPA. (2019b, March 13). *No benefit to seniors in government "expropriation" of home support staff* [Press Release]. Retrieved from <https://bccare.ca/2019/03/no-benefit-to-seniors-in-government-expropriation-of-home-support-staff/>
- British Columbia Government and Service Employees Union. (2019, March 14). *BCGEU celebrates announcement to bring home support workers under government employment* [Press Release]. Retrieved from https://www.bcgeu.ca/bcgeu_celebrates_announcement_to_bring_home_support_workers_under_government_employment
- British Columbia Liberals. (2001). *A new era for British Columbia*. BC Liberals.
- British Columbia Medical Association. (2008). *Bridging the islands: Re-building B.C.'s home & community care system*. Retrieved May 28, 2020 from https://www.B.C.ma.org/files/HCC_paper.pdf
- British Columbia Ministry of Health [BC MOH]. (2005). *Health authority redesign accomplishments: A four-year picture*. BC MOH.
- BC MOH. (2007). *Primary health care charter: A collaborative approach*. Retrieved March 14, 2020 from https://www.health.gov.bc.ca/library/publications/year/2007/phc_charter.pdf
- BC MOH. (2011). *Ministry of Health revised 2011/12-2013/14 service plan*. Retrieved March 14, 2020 from <http://www.bcbudget.gov.bc.ca/2011/sp/pdf/ministry/hlth.pdf>
- BC MOH. (2012a). *Ministry of Health 2012/13-2014/15 service plan*. Retrieved March 14, 2020 from <http://www.bcbudget.gov.bc.ca/2012/sp/pdf/ministry/hlth.pdf>
- BC MOH. (2012b). *The provincial dementia action plan for British Columbia*. Retrieved March 14, 2020 from <https://www.health.gov.bc.ca/library/publications/year/2012/dementia-action-plan.pdf>
- BC MOH. (2013a). *Revised 2013/14-2015/16 service plan*. Retrieved March 14, 2020 from http://www.B.C.budget.gov.B.C..ca/2013_june_update/sp/pdf/ministry/hlth.pdf
- BC MOH. (2013b). *The provincial end-of-life care action plan for British Columbia*. Retrieved March 14, 2020 from <https://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf>

- BC MOH. (2014a). *Setting priorities for the B.C. health system*. Retrieved May 14, 2020 from <http://www.health.gov.B.C..ca/library/publications/year/2014/Setting-priorities-B.C.-Health-Feb14.pdf>
- BC MOH. (2014b). *B.C. health system strategy implementation: A collaborative and focused approach*. Retrieved March 14, 2020 from http://www.cchl-ccls.ca/document/1088/BC_Health_System_Strategy_Implementation.pdf
- BC MOH. (2015a). *Primary and community care in B.C.: A strategic policy framework*. Retrieved May 14, 2020 from <http://www.health.gov.B.C..ca/library/publications/year/2015/primary-and-community-care-policy-paper.pdf>
- BC MOH. (2015b). *Enabling effective, quality population and patient-centred care: A provincial strategy for health information management and technology*. Retrieved May 14, 2020 from <http://www.health.gov.bc.ca/library/publications/year/2015/IMIT-policy-paper.pdf>
- BC MOH. (2015c). *Rural health services in BC: A policy framework to provide a system of quality care*. Retrieved May 14, 2020 <https://www.health.gov.bc.ca/library/publications/year/2015/rural-health-policy-paper.pdf>
- BC MOH. (2015d). *Enabling effective, quality population and patient-centred care: A provincial strategy for health human resources*. Retrieved May 14, 2020 <https://www.health.gov.bc.ca/library/publications/year/2015/health-human-resources-policy-paper.pdf>
- BC MOH. (2015e). *Future directions for surgical services in British Columbia*. Retrieved June 15, 2020 from <https://www.health.gov.bc.ca/library/publications/year/2015/surgical-services-policy-paper.pdf>
- BC MOH. (2015f). *Taking the next steps: Repositioning health care for older adults*. Retrieved June 15, 2020 from <https://www2.gov.bc.ca/assets/gov/government/ministries-organizations/ministries/health/next-steps.pdf>
- BC MOH. (2017a). *An action plan to strengthen home and community care for seniors*. Retrieved October 10, 2017 from <http://www.health.gov.bc.ca/library/publications/year/2017/home-and-community-care-action-plan.pdf>
- BC MOH. (2017b). *Residential care staffing review*. Retrieved June 19, 2020 from <https://www.health.gov.bc.ca/library/publications/year/2017/residential-care-staffing-review.pdf>
- BC MOH. (2018). *Ministry of Health 2018/19-2020/21 service plan*. Retrieved June 15, 2020 from <https://www.bcbudget.gov.bc.ca/2018/sp/pdf/ministry/hlth.pdf>

- BC MOH. (2019a). *Home and community care policy manual: Overview*. Retrieved May 14, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards/home-and-community-care-policy-manual>
- BC MOH. (2019b). *Ministry of Health 2019/20-2021/22 service plan*. Retrieved June 15, 2020 from <https://www.bcbudget.gov.bc.ca/2019/sp/pdf/ministry/hlth.pdf>
- BC Ministry of Health Services. (2010). *Ministry of Health Services 2010/11-2012/13 service plan*. Retrieved June 2, 2020 from <http://bcbudget.gov.bc.ca/2010/sp/pdf/ministry/hserv.pdf>
- BC Ministry of Health Planning. (2002). *The picture of health*. Retrieved May 14, 2020 from https://www.health.gov.bc.ca/library/publications/year/2002/picture_of_health.pdf
- BC MOH and Ministry Responsible for Seniors. (1999). *Home and community care model standards for continuing care and extended care services*. Retrieved June 18, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards>
- BC MOH, Ministry Responsible for Seniors and Ministry of Social Development and Economic Security. (1999). *Supportive housing in supportive communities*. Retrieved May 14, 2020 from <https://www.health.gov.bc.ca/library/publications/year/1999/housing.pdf>
- BC Office of the Ombudsperson. (2009). *The best of care: Getting it right for seniors in British Columbia (part 1)*. Public report no. 46 to the Legislative Assembly of British Columbia.
- BC Office of the Ombudsperson. (2012a). *The best of care: Getting it right for seniors in British Columbia (part 2). Report volume 1*. Public report no. 47 to the Legislative Assembly of British Columbia.
- BC Office of the Ombudsperson. (2012b). *The best of care: Getting it right for seniors in British Columbia (Part 2). Report volume 2*. Public report no. 47 to the Legislative Assembly of British Columbia.
- BC Office of the Ombudsperson. (2015a). *Update on status of recommendations. The best of care: Getting it right for seniors in British Columbia (part 1)*. Retrieved June 15, 2020 from <https://bcombudsperson.ca/assets/media/Best-of-Care-Part-1-2015-update.pdf>
- BC Office of the Ombudsperson. (2015b). *Update on Status of Recommendations. The Best of Care: Getting it Right for Seniors in British Columbia (Part 2)*.
- BC Office of the Ombudsperson. (2019). *Systemic investigation update: The best of care: Getting it right for seniors in British Columbia (part 2)*. Victoria, BC: BC Office of the Ombudsperson.

- BC Patient & Safety Quality Council. (2012). *Hospital care for seniors: 48/6 approach*. Retrieved June 18, 2020 from https://bcpsqc.ca/wp-content/uploads/2018/05/Key-Messages-for-48_6-24Sept2012-1.pdf
- Bødker, M., Langstrup, H., & Christensen, U. (2019). What constitutes 'good care' and 'good carers'? The normative implications of introducing reablement in Danish home care. *Health & Social Care in the Community*, 27(5), E871-E878.
- Boiling, P. (2010). Effects of policy, reimbursement, and regulation on home health care. In S. Olson, *The role of human factors in home health care: Workshop summary* (pp.275-301). Washington, DC: The National Academies Press.
- Boscart, V. M., Sidani, S., Poss, J., Davey, M., d'Avernas, J., Brown, P., Heckman, G., Ploeg, J., & Costa, A. P. (2018). The associations between staffing hours and quality of care indicators in long-term care. *BMC Health Services Research*, 18(1), 750.
- Bourgon, J. (2017). *NS live case series 2017: Elder care in Fredericia, Denmark*. Retrieved March 12, 2020 from http://www.pgionline.com/wp-content/uploads/2017/08/Eldercare-2017.Ebook_.pdf
- Bowen, G. (2009). Documentary analysis as a qualitative research method. *Qualitative Research Journal*, 9(2), 27-40.
- Bronfenbrenner, U. (1994). Ecological models of human development. In T. Husen and T. N. Postlethwaite (Eds.), *International Encyclopedia of Education* 2nd ed. (Vol. 3, pp.3-44). Oxford, UK: Elsevier.
- Bryant, T. (2009). Housing and Health: More than Bricks and Mortar. In D. Raphael (Ed.), *Social Determinants of Health* 2nd Ed. (pp.235-249). Toronto, ON: Canadian Scholars' Press Inc.
- Bulamu, N., Kaambwa, B., Gill, L., Cameron, I., Mckechnie, S., Fiebig, J., Grady, R., & Ratcliffe, J. (2017). Impact of consumer-directed care on quality of life in the community aged care sector. *Geriatrics & Gerontology International*, 17(10), 1399-1405.
- Bureau, V. , & Dahl, H.M. (2013). Trajectories of change in Danish long-term care policies - reproduction by adaptation through top-down and bottom-up reforms . In C. Ranci and E. Pavolini (Eds.), *Reforms in long-term care policies in Europe. Investigating institutional change and social impacts* (pp. 79-96). New York: Springer Science + Business Media.
- Bureau, V. D., Theobald, H., & Blank, R. H. (2007). *Governing home care: a cross-national comparison*. Edward Elgar.
- Bureau, V., Zechner, M., Dahl, H., & Ranci, C. (2017). The political construction of elder care markets: Comparing Denmark, Finland and Italy. *Social Policy and Administration*, 51(7), 1023-1041.

- Buse, K., Mays, N., & Walt, G. (2005). *Making health policy*. New York, NY: Open University Press.
- Busetto, L., Luijckx, K., & Vrijhoef, H. J. M. (2016). Development of the COMIC Model for the comprehensive evaluation of integrated care interventions. *International Journal of Care Coordination*, 19(1-2), 47-58.
- Byrne, T., & Woods, S. (2007). *Developing a system of non-medical home support for British Columbians: A background paper*. Government of BC.
- Calciolari, S., Gonzalez-Ortiz, L., Goodwin, N., & Stein, V. (2016). *The Project INTEGRATE Framework*. Retrieved June 15, 2020 from <http://www.projectintegrate.eu.com/integrated-care/resource/the-project-integrate-framework>
- Calciolari, S., & Ilinca, S. (2011). Comparing (and learning from) integrated care initiatives: an analytical framework. *Journal of Integrated Care*, 19(6), 4-13.
- Cameron, I. D., Crotty, M., Gray, L., Kurrle, S. E., Peel, N. M., Monaghan, N., & Parker, S. G. (2010). Whither transition care. *Australasian Journal on Ageing*, 29(4), 147-149.
- Campbell, L., & Wagner, L. (2009). *Prevention and rehabilitation in the long-term care system: National report Denmark*. Odense: Interlinks.
- Campbell, L., & Wagner, L. (2010). *Governance and financing of LTC: National report Denmark*. Odense: Interlinks.
- Canadian Health Coalition & Ontario Health Coalition. (2017). *Health accord break down: Costs & consequences of the failed 2016/17 negotiations*. Retrieved June 2, 2020 from <http://www.healthcoalition.ca/wp-content/uploads/2017/10/Health-Accord-Report.pdf>
- Canadian Home Care Association. (2013). *Portraits of home care in Canada*. Canadian Home Care Association
- Canadian Hospice Palliative Care Association. (2015). *The way forward national framework: A roadmap for an integrated palliative approach to care*. Canadian Hospice Palliative Care Association
- Canadian Institute for Health Information [CIHI]. (2009). *Analysis in brief: Alternate level of care in Canada*. Ottawa, ON: CIHI.
- CIHI. (2010). *Supporting informal caregivers—the heart of home care*. Ottawa, ON: CIHI.
- CIHI. (2011a). *Health care in Canada, 2011: A focus on seniors and aging*. Ottawa, ON: CIHI.

- CIHI. (2011b). *Seniors and the Health Care System: What Is the Impact of Multiple Chronic Conditions?* Ottawa, ON: CIHI.
- CIHI. (2011c). *Health care cost drivers: The facts*. Ottawa, ON: CIHI.
- CIHI. (2012). *Seniors and alternate level of care: Building on our knowledge*. Ottawa, ON: CIHI.
- CIHI. (2017). *Seniors in transition: Exploring pathways across the care continuum*. Ottawa, ON: CIHI.
- CIHI. (2019a). *National health expenditure trends, 1975 to 2019*. Ottawa, ON: CIHI.
- CIHI. (2019b). *Provincial and territorial health spending*. Retrieved June 15, 2020 from <https://www.cihi.ca/en/national-health-expenditure-trends-1975-to-2019>
- CIHI. (2020). *How Canada compares: Results from the Commonwealth Fund's 2019 international health policy survey of primary care physicians*. Ottawa, ON: CIHI.
- Canadian Medical Association (CMA). (2013). *Health and health care for an aging population*. Retrieved May 28, 2020 from https://www.cma.ca/sites/default/files/2018-11/CMA_Policy_Health_and_Health_Care_for_an_Aging-Population_PD14-03-e_0.pdf
- CMA. (2015). *A policy framework to guide a national seniors strategy for Canada*. Retrieved March 14, 2020 from https://cma.ca/sites/default/files/pdf/News/policy-framework-to-guide-seniors_en.pdf
- CMA. (2016). *The state of seniors health care in Canada*. Retrieved March 14, 2020 from <https://www.cma.ca/sites/default/files/2018-11/the-state-of-seniors-health-care-in-canada-september-2016.pdf>
- CMA. (2019, September 30). *Marguerite Blais: the woman looking out for Québec's caregivers* [Press Release]. Retrieved May 28, 2020 from <https://www.demandaplan.ca/post/marguerite-blais-the-woman-looking-out-for-Quebecs-caregivers>
- Caregivers Nova Scotia. (2014). *Strategic plan: 2015-2020*. Retrieved March 14, 2020 from <https://caregiversns.org/who-we-are/strategic-plan/>
- Carstairs, S., & Keon, W. J. (2009). *Special senate committee on aging: Final report. Canada's aging population: Seizing the opportunity*. Retrieved December 31, 2015 from <http://www.parl.gc.ca/Content/SEN/Committee/402/agei/rep/AgingFinalReport-e.pdf>

- Cass, B., J. Fast, & Yeandle, S. (2014). The challenge of caring, now and in the future: Learning from across the world. Discussion Paper for Westminster Seminar. Leeds, UK: University of Leeds.
- CBC News. (2019, November 26). Québec government announces \$2.6B investment to revamp seniors' homes. CBC News. Retrieved <https://www.cbc.ca/news/canada/montreal/chsld-renovations-1.5373587>
- CBC News. (2020, May 26). Ford faces blowback after military report reveals 'horrific' conditions at Ontario long-term care homes. *CBC News*. Retrieved from <https://www.cbc.ca/news/canada/toronto/covid-19-coronavirus-ontario-update-may-26-1.5584665>
- Ceci, C. (2012). 'To work out what works best.' What is good in home care? In C. Ceci, M. Purkis, and K. Björnsdóttir (Eds.), *Perspectives on care at home for older people* (pp.81-100). New York, NY: Routledge.
- Ceci, C., & Purkis, M. E. (2009). Bridging gaps in risk discourse: home care case management and client choices. *Sociology of Health & Illness*, 31(2), 201-214.
- Ceci, C., & Purkis, M. E. (2011). Means without ends: Justifying supportive home care for frail older people in Canada, 1990–2010. *Sociology of Health & Illness*, 33(7), 1066-1080.
- Challis, D., Hughes, J., McNiven, F., Stewart, K., & Darton, R. (1999). *Estimating the balance of care*. Canterbury, UK: Personal Social Services Research Unit.
- Chappell, N., & Hollander, M. (2011). An evidence-based policy prescription for an aging population. *HealthcarePapers*, 11(1), 8-18.
- Chappell, N., & Hollander, M. (2013). *Aging in Canada*. Don Mills, ON: Oxford University Press.
- Chaudhury, H., Cooke, H., Cowie, H., & Razaghi, L. (2018). The influence of the physical environment on residents with dementia in long-term care settings: A review of the empirical literature. *The Gerontologist*, 58(5), E325-E337.
- Cheng, S. (2018). Study of the local health integration network: Impact of Ontario's regionalization policy. *Journal of Integrated Care*, 26(4), 277-285.
- Chomik Consulting & Research Ltd. (2012). *Evaluation of the community action for seniors independence (CASI) pilot project*. Chomik Consulting & Research Ltd.
- Chomik Consulting & Research Ltd. (2014). *Better at home program evaluation: Summary of evaluation findings and recommendations*. Chomik Consulting & Research Ltd.

- Cohen, M. (2012). *Caring for B.C.'s aging population: Improving health care for all*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Cohen, M., & Franko, J. (2015). *Living up to the promise: Addressing the high costs of underfunding and fragmentation in B.C.'s home support system*. BC Health Coalition.
- Cohen, M., McLaren, A., Sharman, Z., Murray, S., Hughes, M., & Ostry, A. (2006). *From support to isolation: The high cost of BC's declining home support services*. Vancouver, BC: Canadian Centre of Policy Alternatives.
- Cohen, M., Murphy, J.M., Nutland, K., & Ostry, A. (2005). *Continuing care renewal or retreat? BC residential and home health care restructuring 2001-2004*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Cohen, M., Tate, J., & Baumbusch, J. (2009). *An uncertain future for seniors: BC's restructuring of home and community health care, 2001-2008*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Commissaire À La Santé Et Au Bien-Être. (2016). *Entendre la voix citoyenne pour améliorer l'offre de soins et services – Un état des lieux*. Retrieved June 15, 2020 from https://www.csbe.gouv.qc.ca/fileadmin/www/2016/PanierServices_Rapport/CSBE_Panier_Services_Voix_Citoyenne.pdf
- Commissaire À La Santé Et Au Bien-Être. (2017). *Info-performance: Les personnes de 75 ans et plus en attente d'une place d'hébergement en CHSLD*. Retrieved June 15, 2020 from https://www.csbe.gouv.qc.ca/fileadmin/www/2017/InfoPerformance/CSBE_Info_Performance_no16.pdf
- Commonwealth of Australia. (2009). *A healthier future for all Australians – Final report of the National Health and Hospitals Reform Commission – June 2009*. Commonwealth of Australia.
- Commonwealth of Australia. (2011). *National carer strategy*. Retrieved June 15, 2020 from <https://www.carerstats.org/wp-content/uploads/2017/06/2011-National-Carer-Strategy.pdf>
- Commonwealth of Australia. (2012a). *Living Longer. Living Better*. Commonwealth of Australia.
- Commonwealth of Australia. (2012b). *Australian Government response to the Productivity Commission's caring for older Australians report*. Retrieved June 15, 2020 from <https://www.health.gov.au/resources/publications/caring-for-older-australians>
- Connelly, E., Allen, C., Hatfield, K., Palma-Oliveira, J., Woods, D., & Linkov, I. (2017). Features of resilience. *Environmental Systems and Decisions*, 37(1), 46-50.

- Cordon, C. (2013). System theories: An overview of various system theories and its application in healthcare. *American Journal of Systems Science*, 2(1), 13-22.
- Council of Australian Governments. (2011). *National health reform agreement*. Retrieved June 15, 2020 from http://www.federalfinancialrelations.gov.au/content/npa/health/_archive/national-agreement.pdf
- CUPE. (2008). *Home care competitive bidding in crisis*. Retrieved June 15, 2020 from <https://cupe.on.ca/wp-content/uploads/webarc/archivedat818.pdf>
- Curry, P. (2014). *Broken homes: Nurses speak out on the state of long-term care in Nova Scotia and chart a course for a sustainable future*. Dartmouth, NS: Nova Scotia Nurses Union.
- Curry, N., & Ham, C. (2010). *Clinical and service integration: The route to improved outcomes*. London: King's Fund.
- Daatland, S.O., Høyland, K., & Otnes, B. (2015). Scandinavian contrasts and Norwegian variations in special housing for older people. *Journal of Housing for the Elderly*, 29(1-2), 180-196.
- Dahl, H., Eskelinen, L., & Hansen, E. (2015). Coexisting principles and logics of elder care: Help to self-help and consumer-oriented service? *International Journal of Social Welfare*, 24(3), 287-295.
- Danish Ministry of Health (MOH). (2016). *Denmark's national follow-up to the UNECE regional implementation strategy (RIS) of the Madrid plan of action on ageing (MIPAA) from 2012-2016*. Retrieved June 15, 2020 from https://www.unece.org/fileadmin/DAM/pau/age/country_rpts/2017/DNK_-_National_Report.pdf
- Danish MOH. (2017a). *Healthcare in Denmark - An overview*. Retrieved June 15, 2020 from <https://www.sum.dk/Aktuelt/Publikationer/Healthcare-in-Denmark-dec-2016.aspx>
- Danish MOH. (2017b). *A Safe and dignified life with dementia national action plan on dementia 2025*. Retrieved June 15, 2020 from https://www.sum.dk/English/~/_media/Filer%20-%20dokumenter/Dementia-english/A-safe-and-dignified-life-with-dementia-jan2017.pdf
- Danish MOH. (2018a). *A coherent and trustworthy health network for all: Digital health strategy 2018–2022*. Retrieved June 15, 2020 from <https://sum.dk/Aktuelt/Publikationer/A-Coherent-and-Trustworthy-Health-Network-for-All.aspx>
- Danish MOH. (2018b). *National goals of the Danish healthcare system*. Retrieved June 15, 2020 from <https://sum.dk/Aktuelt/Publikationer/National-Goals-of-the-danish-healthcare-system-nov-2018.aspx>

- Danish MOH. (2018c). Værdighed i ældreplejen en hjertesag. Retrieved June 15, 2020 from <https://sum.dk/Aktuelt/Publikationer/Vaerdighed-i-aeldreplejen-en-hjertesag-marts-2018.aspx>
- Danish MOH. (2019). *Endelig status for værdighedsmilliarden og midtvejsstatus for anvendelsen af midlerne til en bedre bemanning i ældreplejen*. Retrieved June 15, 2020 from <https://sum.dk/Aeldre/Vaerdier-og-kvalitet-i-aeldreplejen/Vaerdighedspolitik.aspx>
- Danish Ministry of Social Affairs and Integration. (2011). *Social policy in Denmark*. Retrieved June 4, 2011 from <http://www.oim.dk/media/14947/social-policy-in-denmark.pdf>
- Dansereau, L., Hande, M.J., & Kelly, C. (2019). Establishing a crown agency amid multiple service providers: Self-directed personal support services Ontario (SDPSSO). *Health Reform Observer*, 7(1).
- Davidson, A. (2008). Sweet nothings? The BC conversation on health. *Healthcare Policy*, 3(4), 33-40.
- Day, J., Thorington Taylor, A. C., Hunter, S., Summons, P., van Der Riet, P., Harris, M., Maguire, J., Dilworth, S., Jeong, S., Bellchambers, H., Haydon, G., & Higgins, I. (2018). Experiences of older people following the introduction of consumer-directed care to home care packages: A qualitative descriptive study. *Australasian Journal on Ageing*, 37(4), 275–282.
- Deber, R., & Laporte, A. (2016). Funding long-term care in Canada: Who is responsible for what? *Healthcare Papers*, 15(4), 36-40.
- Deloitte. (2015). *The economic value of informal care in Australia in 2015*. Retrieved June 2, 2020 from <https://www2.deloitte.com/content/dam/Deloitte/au/Documents/Economics/deloitte-au-economic-value-informal-care-Australia-2015-140815.pdf>
- Demers, L. (2013). Mergers and integrated care: The Québec experience. *International Journal of Integrated Care*, 13, e002.
- Derfel, A. (2018, September 17). Québec election: Health care is no. 1 voter issue. *The Montreal Gazette*. Retrieved from <https://montrealgazette.com/news/local-news/Québec-election-health-care-is-no-1-voter-issue/>
- Derfel, A. (2019, September 23). Class action against Québec nursing homes can proceed: Judge. *The Montreal Gazette*. Retrieved from <https://montrealgazette.com/news/local-news/500-million-class-action-against-Québec-nursing-homes-can-proceed-judge/>

- Divisions of Family Practice. (2020). *Seniors prototype initiative*. Retrieved June 19, 2020 from https://www.divisionsbc.ca/sites/default/files/CMSMedia_Retrieved/P08b_DBC_Seniors_Event.pdf
- Doctors of BC. (2016). *Circle of care: Supporting family caregivers in BC*. Vancouver, BC: Doctors of BC.
- Doctors of BC. (2020). *Primary care networks*. In General Practice Services Committee. Retrieved June 19, 2020 from <http://www.gpsc.bc.ca/what-we-do/system-change/primary-care-networks>
- Duckett, S. (2017). Health policies for an ageing Australia. In K. O'Loughlin, C. Browning, and H. Kendig, *Ageing in Australia* (pp.209-224). New York, NY: Springer.
- Duffy, R., Royer, G., & Beresford, C. (2014). *Who's picking up the tab? Federal and provincial downloading onto local governments*. Centre for Civic Governance, Columbia Institute.
- Duncan, S., & Reutter, L. (2006). A critical policy analysis of an emerging agenda for home care in one Canadian province. *Health & Social Care in the Community*, 14(3), 242-253.
- Dyck, I., & England, K. (2012). Homes for Care: Reconfiguring Care Relations and Practices. In C. Ceci, M. Purkis, and K. Björnsdóttir (Eds.), *Perspectives on care at home for older people* (pp.62-77). New York, NY: Routledge.
- Dye, T. (2017). *Understanding public policy* (15th ed.). Boston: Pearson.
- Eckert, J. K., Morgan, L. A., & Swamy, N. (2004). Preferences for receipt of care among community-dwelling adults. *Journal of Aging & Social Policy*, 16(2), 49-65.
- eHealth Ontario. (2018). CHRIS. In *eHealth Ontario*. Retrieved January 28, 2020 from <https://www.ehealthontario.on.ca/en/asset-inventory/chris>
- Eklund, K., & Wilhelmson, K. (2009). Outcomes of coordinated and integrated interventions targeting frail elderly people: A systematic review of randomised controlled trials. *Health & Social Care in the Community*, 17(5), 447-458.
- Emery, J. (2016). A fifth option for funding long-term care in Canada - Shift the resources from medical treatment and universal pension entitlements. *HealthcarePapers*, 15(4), 41-44.
- Esping-Andersen, G. (1996). *Welfare states in transition: National adaptations in global economies*. London: SAGE.

- Estes, C. (2001). Political economy of aging: A theoretical framework. In C. Estes (Ed.), *Social policy and aging: A critical perspective*, pp.1-22. Thousand Oaks: SAGE Publications Inc.
- European Commission. (2019). *Joint report on health care and long-term care systems & fiscal sustainability: Country documents update 2019*. Retrieved June 19, 2020 from https://ec.europa.eu/info/publications/joint-report-health-care-and-long-term-care-systems-and-fiscal-sustainability-country-documents-2019-update_en
- Evans, R. (2003). *Political wolves and economic sheep: The sustainability of public health insurance in Canada*. University of British Columbia. Centre for Health Services Policy Research.
- Evans, R. (2008). Reform, re-form, and reaction in the Canadian health care system*. *Health Law Journal*, 265-286.
- Expert Advisory Panel on Long Term Care. (2018). *Minister's Expert Advisory Panel on Long Term Care*. Retrieved June 19, 2020 from <https://novascotia.ca/dhw/publications/Minister-Expert-Advisory-Panel-on-Long-Term-Care.pdf>
- Expert Group on Home and Community Care. (2015). *Bringing care home*. Retrieved January 28, 2020 from http://health.gov.on.ca/en/public/programs/lhin/docs/hcc_report.pdf
- Fancey, P., & Keefe, J. (2014). *Home to nursing home: Understanding factors that impact the path seniors take: Final report*. Nova Scotia Centre on Aging, Mount Saint Vincent University.
- Fast, J. (2015). *Caregiving for older adults with disabilities: Present costs, future challenges*. Montreal: Institute for Research on Public Policy.
- Fast, J., D. Lero, R. DeMarco, H. Ferreira, & Eales, J. (2014). *Combining care work and paid work: Is it sustainable?* Edmonton, AB: University of Alberta, Research on Aging, Policies and Practice.
- Fersch, B. (2015). Expectations towards home care re-ablement in Danish municipalities. *The International Journal of Sociology and Social Policy*, 35(3/4), 126-140.
- Fierlbeck, K. (2018). *Nova Scotia: A healthy system profile*. Toronto, ON: University of Toronto Press.
- Fierlbeck, K. (2019). Amalgamating provincial health authorities: Assessing the experience of Nova Scotia. *Health Reform Observer*, 7(3).
- Fischer, F. (2003). *Reframing public policy: Discursive politics and deliberative practices*. Retrieved June 15, 2020 from <https://ebookcentral-proquest-com.proxy.lib.sfu.ca>

- Financial Accountability Office of Ontario. (2018). *Ontario health sector: Updated assessment of Ontario health spending*. Toronto, ON: Queen's Printer for Ontario.
- Financial Accountability Office of Ontario. (2019a). *Ontario health sector: 2019 updated assessment of Ontario health spending*. Toronto, ON: Queen's Printer for Ontario.
- Financial Accountability Office of Ontario. (2019b). *Expenditure estimates 2019-20: Ministry of Health and Long-Term Care*. Toronto, ON: Queen's Printer for Ontario.
- FIQ. (2017). *The black book of care safety*. FIQ.
- Fischer, F. (2019). *Politics, values, and public policy: The problem of methodology*. Routledge.
- Forester, J. (1993). *Critical theory, public policy, and planning practice: Toward a critical pragmatism*. State University of New York Press.
- Fraser, K. (2003). Are home care programs cost-effective? A systematic review of the literature. *Care Management Journals*, 4(4), 198-201.
- Friedman, B. & Allen, K. (2014). Systems theory. In J. Brandell (Ed.), *Essentials of clinical social work* (pp. 3-20). London: SAGE Publications Ltd.
- Gaumer, B., & Fleury, M. (2008). CLSCs in Québec: Thirty years of community action. *Social Work in Public Health*, 23(4), 89-106.
- Gee, E. (2002). Misconceptions and misapprehensions about population ageing. *International Journal of Epidemiology*, 31(4), 750-753.
- Gee, E., & Gutman, G. (Eds.). (2000). *The overselling of population aging: Apocalyptic demography, intergenerational challenges and social policy*. Don Mills, ON: Oxford University Press.
- Gill, L., Bradley, S. L., Cameron, I. D., & Ratcliffe, J. (2018). How do clients in Australia experience consumer directed care? *BMC Geriatrics*, 18(1), 148.
- Gill, L., McCaffrey, N., Cameron, I. D., Ratcliffe, J., Kaambwa, B., Corlis, M., Fiebig, J., & Gresham, M. (2017). Consumer directed care in Australia: Early perceptions and experiences of staff, clients and carers. *Health & Social Care in the Community*, 25(2), 478–491.
- Gilmour (2018a). *Formal home care use in Canada*. Retrieved June 15, 2020 from https://www150.statcan.gc.ca/n1/en/pub/82-003-x/2018009/article/00001-eng.pdf?st=_nEkYYuh

- Gilmour. (2018b). *Unmet home care needs in Canada*. Retrieved June 15, 2020 from <https://www150.statcan.gc.ca/n1/en/pub/82-003-x/2018011/article/00002-eng.pdf?st=57wSh2HH>
- Golant, S. M. (2014). *Aging in the right place*. Health Professions Press.
- Gorman, M. (2018, Sept.5). Panel appointed to improve long-term care in N.S. after woman's death. *CBC News*. Retrieved from <https://www.cbc.ca/news/canada/nova-scotia/health-care-long-term-seniors-bed-sores-randy-delorey-1.4811048>
- Greve, B. (2017). Long-term care in Denmark, with an eye to the other Nordic welfare states. In B. Greve (Ed.), *Long-term care for the elderly in Europe: Development and prospects* (pp. 168-185). Routledge.
- Greve, B. (2020a). Denmark: A universal welfare system with restricted austerity. In S. Blum, J. Kuhlmann, and K. Schubert (Eds.), *Routledge handbook of European welfare systems* (pp. 129-144). Routledge International Handbooks
- Greve, B. (2020b). *Austerity, retrenchment and the welfare state: Truth or fiction?* Edward Elgar Publishing.
- Gouvernement du Québec. (2003). *Chez soi: Le premier choix* [Translated from French to English]. Retrieved from <https://publications.msss.gouv.qc.ca/msss/document-001351/>
- Gouvernement du Québec. (2012). *Aging and living together - At home, in your community, in Québec* [English Courtesy Version]. Retrieved June 19, 2020 from <http://collections.banq.qc.ca/ark:/52327/bs2250125>
- Gouvernement du Québec. (2013). *Autonomy for all: White paper on the creation of autonomy insurance*. Gouvernement du Québec.
- Gouvernement du Québec. (2017). *Budget 2017-2018 health funding – For a fair share of federal health funding*. Gouvernement du Québec.
- Gouvernement du Québec. (2018a). *Programs and services for seniors 2019 edition*. Gouvernement du Québec.
- Gouvernement du Québec. (2018b). *Un Québec pour tous les âges*. Retrieved June 19, 2020 from <https://publications.msss.gouv.qc.ca/msss/fichiers/ainee/F-5234-MSSS-18.pdf>
- Gouvernement du Québec. (2020a). Service program: Support for the independence of the elderly. In *Gouvernement du Québec*. Retrieved June 19, 2020 from <http://www4.gouv.qc.ca/FR/Portail/Citoyens/programme-service/Pages/Info.aspx?sqctype=sujet&sqcid=2515>

- Gouvernement du Québec. (2020b). Accommodation in a public facility. In *Régie de l'assurance maladie du Québec*. Retrieved June 19, 2020 from <https://www.ramq.gouv.qc.ca/en/citizens/aid-programs/Pages/accomodation-public-facility.aspx>
- Gouvernement du Québec. (2020c). Accommodation in an intermediate resource. In *Régie de l'assurance maladie du Québec*. Retrieved June 19, 2020 from <https://www.ramq.gouv.qc.ca/en/citizens/aid-programs/Pages/accomodation-in-intermediate-resource.aspx>
- Gouvernement du Québec. (2020d). Québec Health Record. In *Gouvernement du Québec*. Retrieved June 19, 2020 from <https://www.Québec.ca/sante/vos-informations-de-sante/dossier-sante-Québec/>
- Government of BC. (1991). *Closer to home: Summary of the report on the British Columbia Royal Commission on Health Care and Costs. Volume I*. Royal Commission on Health Care and Costs.
- Government of BC. (2007a). *Seniors in British Columbia: A healthy living framework*. Victoria, BC. Government of BC.
- Government of BC. (2007b). *Summary of input on the conversation on health*. Government of BC.
- Government of BC. (2012). *Improving care for B.C. seniors: An action plan*. Retrieved June 2, 2020 from <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/about-seniorsbc/seniors-action-plan>
- Government of BC. (2018a). *Governments of Canada and British Columbia sign agreement to improve health-care services* [Press Release]. Retrieved from <https://news.gov.bc.ca/releases/2018HLTH0085-001829>
- Government of BC. (2018b). *B.C. government's primary health-care strategy focuses on faster, team-based care* [Press release]. Retrieved from <https://news.gov.bc.ca/releases/2018PREM0034-001010>
- Government of BC. (2018c). *Family-and-friend caregivers to receive much-needed relief with expanded supports* [Press Release]. Retrieved from <https://news.gov.bc.ca/releases/2018HLTH0063-001227>
- Government of BC. (2018d). *B.C. seniors to get the hours of care they need as funding and staffing increased* [Press Release]. Retrieved from <https://news.gov.bc.ca/releases/2018PREM0072-001861>
- Government of BC. (2019). *More choices, stronger protection for people in assisted living* [Press release]. Retrieved from <https://news.gov.bc.ca/releases/2019HLTH0097-001627>

- Government of BC. (2020a). Home and Community Care Policy Manual. In *Government of BC*. Retrieved June 19, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/accountability/policy-and-standards/home-and-community-care-policy-manual>
- Government of BC. (2020b). Care Options and Costs. In *Government of BC*. Retrieved June 19, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost>
- Government of BC. (2020c). Are you Eligible? In *Government of BC*. Retrieved June 19, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/are-you-eligible>
- Government of BC. (2020d). Who Pays for Care? In *Government of BC*. Retrieved June 19, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/who-pays-for-care>
- Government of BC. (2020e). How to arrange for care. In *Government of BC*. Retrieved June 19, 2020 from <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/how-to-arrange-for-care>
- Government of BC. (2020f, April 26). *More support for family caregivers during COVID-19* [Press Release]. Retrieved from <https://news.gov.bc.ca/releases/2020HLTH0141-000763>
- Government of Nova Scotia. (2007, March 1). *More help for Nova Scotians who need palliative care* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20070301003>
- Government of Nova Scotia. (2008). *Shaping the future of continuing care in Nova Scotia*. Province of Nova Scotia.
- Government of Nova Scotia. (2009, August 11). *Allowance to aid caregivers* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20090811002>
- Government of Nova Scotia. (2010). *Better care soon: The plan to improve emergency care*. Retrieved June 19, 2020 from <https://novascotia.ca/dhw/publications/Better-Care-Sooner-plan.pdf>
- Government of Nova Scotia. (2011, March 16). *New program helps provide better health care for seniors* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20110316002>
- Government of Nova Scotia. (2012a, October 10). *Province supports caregivers* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20121010005>

- Government of Nova Scotia. (2012b, November 19). *New programs will help Nova Scotian seniors receive care at home* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20121119002>
- Government of Nova Scotia. (2014). *Integrated palliative care strategy*. Province of Nova Scotia.
- Government of Nova Scotia. (2015a). *Continuing care a path to 2017: Review, refocus, renewal*. Province of Nova Scotia
- Government of Nova Scotia. (2015b). *Towards understanding: A dementia strategy for Nova Scotia*. Province of Nova Scotia.
- Government of Nova Scotia. (2015c). *Continuing care 2006 strategy evaluation: Executive summary*. Government of Nova Scotia.
- Government of Nova Scotia. (2015d, March 30). *Paramedics to provide in-home support for palliative care patients* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20150330001>
- Government of Nova Scotia. (2016, July 21). *Home care waitlists eliminated in many communities* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20160721003>
- Government of Nova Scotia. (2018a). Caregiver Benefit. In *Department of Health and Wellness*. Retrieved June 19, 2020 from <https://novascotia.ca/dhw/ccs/caregiver-benefit.asp>
- Government of Nova Scotia. (2018b, March 13). *Province expands caregiver benefit program* [Press release]. Retrieved from <https://novascotia.ca/news/release/?id=20180313003>
- Government of Nova Scotia. (2019). *Expert Advisory Panel on Long Term Care: Update – September 2019*. Retrieved June 19, 2020 from <https://novascotia.ca/dhw/publications/Expert-Advisory-Panel-on-Long-Term-Care-Update-September-2019.pdf>
- Government of Nova Scotia. (2020). Long-term care. In *Healthcare wait times*. Retrieved June 19, 2020 from <https://waittimes.novascotia.ca/procedures/long-term-care>
- Government of Ontario. (2012, December 6). About Health Links [Press Release]. Retrieved from <https://news.ontario.ca/en/backgrounder/22834/about-health-links>
- Government of Ontario. (2014). *Ontario's action plan for health care – Year two progress report*. Retrieved June 19, 2020 from http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/progress_healthy_change_2yr.pdf

- Government of Ontario. (2017). *Aging with confidence: Ontario's Action Plan for Seniors*. Queen's Printer for Ontario.
- Government of Ontario. (2018). *A guide to programs and services for seniors in Ontario*. Queen's Printer for Ontario.
- Government of Ontario. (n.d.). *Guide to the Advanced Health Links Model*. Retrieved June 19, 2020 from <http://www.health.gov.on.ca/en/pro/programs/transformation/docs/Guide-to-the-Advanced-Health-Links-Model.pdf>
- Government of Ontario. (2019a, February 26). *Building a connected public health care system for the patient* [Press Release]. Retrieved from <https://news.ontario.ca/mohltc/en/2019/02/building-a-connected-public-health-care-system-for-the-patient.html>
- Government of Ontario. (2019b, November 13). *Ontario taking next steps to integrate health care system* [Press Release]. Retrieved from <https://news.ontario.ca/mohltc/en/2019/11/ontario-taking-next-steps-to-integrate-health-care-system.html>
- Government of Ontario. (2019c). Home and community care. In *Government of Ontario*. Retrieved January 27, 2020 from <https://www.ontario.ca/page/homecare-seniors>
- Government of Ontario. (2019d). Long-term care overview. In *Government of Ontario*. Retrieved January 27, 2020 from <https://www.ontario.ca/page/about-long-term-care>
- Government of Ontario. (2019e). Supportive housing options. In *Government of Ontario*. Retrieved from <https://www.ontario.ca/page/long-term-care-options>
- Grignon, M. (2016). Funding for long-term care: Why public insurance makes sense. *HealthcarePapers*, 15(4), 21-24.
- Grignon, M., & Bernier, N. F. (2012). *Financing long-term care in Canada*. Montreal: Institute for Research on Public Policy.
- Habermas J. (1973) *Knowledge and human interests*. Boston, MA: Beacon.
- Hanlon, N., Rosenberg, M., & Clasby, R. (2007). Offloading social care responsibilities: Recent experiences of local voluntary organisations in a remote urban centre in British Columbia, Canada. *Health & Social Care in the Community*, 15(4), 343-351.
- Hansen, E. (2009). Integrated care for vulnerable older people in Denmark. *HealthcarePapers*, 10(1), 29-33.

- Harkin, D. J., O'Connor, C., Birch, M. R., & Poulos, C. J. (2020). Perspectives of Australian family carers of people with dementia on the 'cottage' model of respite: Compared to traditional models of residential respite provided in aged care facilities. *Health & Social Care in the Community*, 28(3), 850-861.
- Harris, K. (2020, May 10). Pressure mounts on federal government to help fix, build long-term care homes as pandemic takes deadly toll. *CBC News*. Retrieved June 19, 2020 from <https://www.cbc.ca/news/politics/long-term-care-infrastructure-1.5559331>
- Health Association Nova Scotia. (2014). *Rising to the challenge: Responding to increasing demands in home care*. Retrieved June 19, 2020 from http://caregiversns.org/images/uploads/Responding_to_the_Challenge_Report_-_FINAL_July_7_2014.pdf
- Health Canada. (2017, March 10). *Canada reaches health funding agreement with Ontario* [Press Release]. Retrieved from https://www.canada.ca/en/health-canada/news/2017/03/canada_reaches_healthfundingagreementwithontario.html
- Health Canada. (2018, August 10). *Governments of Canada and Nova Scotia sign agreement to improve health care services* [Press Release]. Retrieved from <https://www.canada.ca/en/health-canada/news/2018/08/governments-of-canada-and-nova-scotia-sign-agreement-to-improve-health-care-services.html>
- Health Canada. (2019). Canada's health care system. In *Health Canada*. Retrieved June 19, 2020 from <http://www.hc-sc.gc.ca/hcs-sss/pubs/system-regime/2011-hcs-sss/index-eng.php>
- Health Council of Canada. (2012). *Seniors in need, caregivers in distress: What are the home care priorities for seniors in Canada?* Toronto, ON: Health Council of Canada.
- Healthcare Denmark. (2019). *Assisted living: A dignified elderly care in Denmark*. Retrieved June 19, 2020 from <https://www.healthcaredenmark.dk/media/plvbj4yz/elderly-care-v10919.pdf>
- Healthy Aging. (2019a). *Healthy aging by United Way: 2018/19 annual report*. Retrieved June 18, 2020 from <https://www.uwlm.ca/wp-content/uploads/2019/08/2018-19-Healthy-Aging-by-United-Way-Annual-Report.pdf>
- Healthy Aging. (2019b). *Call for proposals: Integrated community-based programs for older adults with higher needs, 2019-2022*. Retrieved June 18, 2020 from <https://healthyagingcore.ca/sites/default/files/2019-05/Integrated%20Community-Based%20Programs%20for%20Older%20Adults%20Call%20for%20Proposals%20FINAL.pdf>

- Healthy Aging. (2019c). *Request for proposals: Evaluation of healthy aging by United Way: Integrated community-based programs for older adults with higher needs program*. Retrieved June 18, 2020 from <https://www.uwlm.ca/wp-content/uploads/2019/08/2019-HN-Evaluation-RFP-August-22.19.pdf>
- Health Quality Ontario. (2015). *The reality of caring*. Retrieved January 29, 2020 from <https://www.hqontario.ca/Portals/0/documents/system-performance/reality-caring-report-en.pdf>
- Health Quality Ontario. (2019). *Measuring up 2019*. Retrieved May 24, 2020 from <https://www.hqontario.ca/System-Performance/Yearly-Reports/Measuring-Up-2019>
- Hébert, R. (2009). Home care: From adequate funding to integration of services. *HealthcarePapers*, 10(1), 58-64.
- Hébert, R. (2016a). Still-born autonomy insurance plan in Québec: An example of a public long-term care insurance system in Canada. *HealthcarePapers*, 15(4), 45-50.
- Hébert, R. (2016b). L'intégration des services aux personnes âgées: Une transformation encore inachevée. *Le Point en Santé et Services Sociaux*, 12(3).
- Hébert, R. (2017a). Canada: Application of a coordinated-type integration model for vulnerable older people in Québec: The PRISMA project. In V. Amelung, V. Stein, N. Goodwin, R. Balicer, E. Nolte, and E. Suter (Eds.), *Handbook of Integrated Care* (pp.490-510). Springer, Cham
- Hébert, G. (2017b). L'armée manquante au Québec: Les services à domicile. Retrieved June 19, 2020 from https://iris-recherche.qc.ca/publications/services-domicile?category_id=11
- Hébert, R. & The PRISMA Group. (2005). PRISMA: A new model of integrated service delivery for the frail older people in Canada. In R. Hébert, A. Tourigny and M. Gagnon (Eds.), *Integration of services for disabled people: Research leading to action. Volume I* (p.7-22). Canada: EDISM.
- Hébert, R., Bravo, G., Desrosiers, J., Dubuc, N., Buteau, M., Trottier, L., St-Hilaire, C., Roy, C. (2001). Resources and costs associated with disabilities of elderly people living at home and in institutions. *Canadian Journal on Aging*, 20(1), 1-21.
- Hébert, R., Raïche, M., Dubois, M., Gueye, N. R., Dubuc, N., & Tousignant, M. (2010). Impact of PRISMA, a coordination-type integrated service delivery system for frail older people in Québec (Canada): A quasi-experimental study. *Journals of Gerontology Series B: Psychological Sciences & Social Sciences*, 65B(1), 107-118.

- Hendry, L. (2018, August 30). 'We live with a cloud over our heads': Québecers say home care services fall short. *CBC News*. Retrieved June 19, 2020 from <https://www.cbc.ca/news/canada/montreal/home-care-services-Québec-1.4803676>.
- Hermus, G., Stonebridge, C., & Edenhoffer, K. (2015). *Future care for Canadian seniors: A status quo forecast*. Ottawa, ON: The Conference Board of Canada
- Hjelmar, U., & Rostgaard, T. (2020). Supplemental home care and topping-up: A shift from service universalism towards a new and privatised public service model? *International Journal of Social Welfare*, 29(2), 118-128.
- Hollander Analytical Services Ltd. (2006). *Home Care Program Review*. Hollander Analytical Services.
- Hollander, M., & Chappell, N. (2002). *Final report of the national evaluation of the cost-effectiveness of home care*. Victoria, BC: National Evaluation of the Cost-Effectiveness of Home Care.
- Hollander, M. J., & Chappell, N. L. (2007). A comparative analysis of costs to government for home care and long-term residential care services, standardized for client care needs. *Canadian Journal on Aging*, 26(S1), 149-161.
- Hollander, M. J., Cherry, L., MacAdam, M., Pallan, P., & Ritter, R. (2007). *Continuing care service delivery systems: Case studies of current models*. Hollander Analytical Services.
- Hollander, M., Liu, G., & Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 43-49.
- Hollander, M., & Prince, M. (2008). Organizing healthcare delivery systems for persons with ongoing care needs and their families: A best practices framework. *Healthcare Quarterly*, 11(1), 42-52.
- Hollander, M., & Tessaro, A. (2001). *Evaluation of the maintenance and preventative function of home care*. Retrieved February 26, 2013, from <http://www.homecareontario.ca/public/docs/publications/preventive-home-care-report.pdf>
- Hooyman, N., Browne, C., Ray, R., & Richardson, V. (2002). Feminist gerontology and the life course: Policy, research and teaching issues. *Gerontology & Geriatrics Education*, 22(4), 3-26.
- Horkheimer, M. (1972). *Critical theory: Selected essays* [Translated by Matthew J. O'Connell and others]. Herder and Herder.

- Howe, A. (2002). Recent developments in aged care policy in Australia. *Journal of Aging & Social Policy*, 13(2-3), 101-116.
- Howlett, M., & Giest, S. (2015). Policy cycle. In J. Wright (Ed.), *International encyclopedia of the social & behavioral sciences* (pp. 288-292). Amsterdam: Elsevier
- Høy, B., Wagner, L., & Hall, E. (2007). The elderly patient's dignity. The core value of health. *International Journal of Qualitative Studies on Health and Well-being*, 2(3), 160-168.
- Hughes, M. (2011). The Productivity Commission Inquiry into aged care: A critical review. *Australian Social Work*, 64(4), 526–536.
- Hulko, W., Mirza, N., & Seeley, L. (2020). Older adults' views on the repositioning of primary and community care. *Canadian Journal on Aging*, 1-13.
- Institute for Health System Transformation and Sustainability. (2018). *A roadmap for home health: Accelerating best practices in BC*. Retrieved June 18, 2020 from <http://ihsts.ca/wp-content/uploads/2018/08/IHSTS-A-Roadmap-for-Home-Health-Workshop-Proceedings-Report.pdf>
- Ivanova, I. (2009). *Towards an enhanced and more accessible home support system for BC's seniors*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Jacobs, J. C., Lilly, M. B., Ng, C., & Coyte, P. C. (2013). The fiscal impact of informal caregiving to home care recipients in Canada: How the intensity of care influences costs and benefits to government. *Social Science & Medicine*, 8(1), 102-109.
- Jetté, C. & Vaillancourt, Y. (2011). Social economy and home care services in Québec: Co-production or co-construction? *VOLUNTAS: International Journal of Voluntary and Nonprofit Organizations*, 22(1), pp.48-69.
- Jiwani, I., & Fleury, M. (2011). Divergent modes of integration: The Canadian way. *International Journal of Integrated Care*, 11(Spec 10th Anniversary Ed), e018.
- Johnson, C.S., Bacsu, J., McIntosh, T., Jeffery, B., & Novik, N. (2017). *Home care in Canada: An environmental scan*. Regina, SK: Saskatchewan Population Health and Evaluation Research Unit, University of Regina and University of Saskatchewan.
- Johnson, M. (1995). Interdependency and the generational compact. *Ageing and Society*, 15(2), 243-265.
- Johri, M., Béland, F., & Bergman, H. (2003). International experiments in integrated care for the elderly: A synthesis of the evidence. *International Journal of Geriatric Psychiatry*, 18(3), 222-235.

- Jorgensen, M., Siette, J., Georgiou, A., Warland, A., & Westbrook, J. (2018). Modeling the association between home care service use and entry into residential aged care: A cohort study using routinely collected data. *Journal of the American Medical Directors Association, 19*(2), 117.
- Kadowaki, L., & Cohen, M. (2017). *Raising the profile of the community-based seniors' services sector in B.C.: A review of the literature*. Vancouver, BC: Raising the Profile Project.
- Kadowaki, L., Wister, A., & Chappell, N. (2015). Home care needs and their influence on life satisfaction, perceived life stress, and loneliness. *Canadian Journal on Aging, 34*(1), 75-89.
- Kail, B. L., Quadagno, J., & Reid-Keene, J. (2009). The Political Economy Perspective of Aging. In V. L. Bengston, D. Gans, N. M. Putney and M. Silverstein (Eds.), *Handbook of Theories of Aging* (2nd ed.) (pp.555-571). New York, NY: Springer Publishing Company.
- Keefe, J. (2011). *Supporting caregivers and caregiving in an aging Canada*. Montreal, QC: Institute for Research on Public Policy.
- Keefe, J., Dill, D., Ogilvie, R., & Fancey, P. (2017). Examining a "household" model of residential long-term care in Nova Scotia. *Health Reform Observer, 5*(1).
- Keefe, J., Kelloway, K., McInnis, A., Earl, M., Stadnyk, R., & Nickerson Rak, C. (2015). *Care and construction: Assessing differences in nursing home models of care on resident quality of life. Final report*. Halifax, Nova Scotia: Nova Scotia Centre on Aging, Mount Saint Vincent University
- Keefe, J., Ogilvie, R., Stevens, S., MacPherson, D., & Stoddart, N. (2014). *Provincial/regional variation in availability, cost of delivery and wait times for accessing home care services to address avoidable admissions to long term care, alternate level of care bed days and hospitalization*.
- Kelly, R., Puurveen, G., & Gill, R. (2016). The effect of adult day services on delay to institutional placement. *Journal of Applied Gerontology, 35*(8), 814-835.
- Kernick, D. (2004). *Complexity and healthcare organization: A view from the street*. Oxford; San Francisco: Radcliffe Medical Press.
- Khadka, J., Lang, C., Ratcliffe, J., Corlis, M., Wesselingh, S., Whitehead, C., & Inacio, M. (2019). Trends in the utilisation of aged care services in Australia, 2008-2016. *BMC Geriatrics, 19*(1), 213.
- Kingdon, J. W. (1984). *Agendas, alternatives, and public policies*. HarperCollins.

- Kirby M. (2003). *The health of Canadians: The federal role. Final report. Volume six: Recommendations for reform*. Retrieved February 26, 2013 from <https://sencanada.ca/content/sen/committee/372/soci/rep/repoct02vol6-e.htm>
- Kirst, M., Im, J., Burns, T., Baker, G. R., Goldhar, J., O'Campo, P., Wojtak, A., & Wodchis, W. P. (2017). What works in implementation of integrated care programs for older adults with complex needs? A realist review. *International Journal for Quality in Health Care*, 29(5), 612-624.
- Kodner, D. (2004). Following the logic of long-term care: Toward an independent, but integrated sector. *International Journal of Integrated Care*, 4(1).
- Kodner, D., & Spreeuwenberg, C. (2002). Integrated care: Meaning, logic, applications, and implications - A discussion paper. *International Journal of Integrated Care*, 2e12.
- KPMG. (2012). *Evaluation of the consumer-directed care initiative: Final report*. KPMG.
- KPMG. (2015). *Formative evaluation of the home care packages programme - Detailed findings report*. KPMG.
- Kuluski, K., Williams, A. P., Berta, W., & Laporte, A. (2012). Home care or long-term care? Setting the balance of care in urban and rural Northwestern Ontario, Canada. *Health & Social Care in the Community*, 20(4), 438-448.
- Kvist, J. (2014). *Update 2014. Pensions, health and long-term care: Denmark*. European Commission.
- Kvist, J. (2018). *ESPN thematic report on challenges in long-term care*. European Union.
- La Commission de la Santé et des Services Sociaux. (2016). *Les conditions de vie des adultes hébergés en centre d'hébergement et de soins de longue durée*. Retrieved May 29, 2020 from <http://www.assnat.qc.ca/fr/travaux-parlementaires/commissions/csss/mandats/Mandat-32725/index.html>
- Lamarche, P., Hébert, R., & Béland, F. (2014, November 20). Opinion: Bill 10 health-care administrative 'reform' seems likely to backfire. *Montreal Gazette*. Retrieved June 19, 2020 from <https://montrealgazette.com/news/Québec/opinion-bill-10-health-care-administrative-reform-seems-likely-to-backfire/>
- Lanoix, M. (2017). No longer home alone? Home care and the Canada Health Act. *Health Care Analysis: Journal of Health Philosophy and Policy*, 25(2), 168-189.
- Laporte, A., Rohit Dass, A., Kuluski, K., Peckham, A., Berta, W., Lum, J., & Williams, A. P. (2017). Factors Associated with Residential Long-Term Care Wait-List Placement in North West Ontario. *Canadian Journal on Aging*, 36(3), 286-305.

- L'Appui. (2015). *Comité consultatif de l'Appui national sur la valorisation du rôle des proches aidants d'aînés*. Retrieved June 19, 2020 from <https://www.lappui.org/Publications-et-references/Rapport-de-valorisation>
- L'Appui. (2020). About us. In *L'Appui*. Retrieved May 16, 2020 from <https://www.lappui.org/en/L-Appui-national/About-us>
- Laszlo, A., & Krippner, S. (1998). Systems theories: Their origins, foundations, and development. In J. S. Jordan (Ed.) *Systems theories and a priori aspects of perception* (pp. 47-74). Amsterdam: Elsevier Science.
- Lavergne, M. R. (2015). *Regional variation in Alternate Level of Care (ALC) service use in British Columbia hospitals: An opportunity for intervention?* Institute for Health System Transformation & Sustainability.
- Lavoie, J-P, Guberman, N., & Marier, P. (2014). *La responsabilité des soins aux aînés au Québec*. Montreal, QC: Institute for Research on Public Policy.
- Lawless, M. T., Marshall, A., Mittinty, M., & Harvey, G. (2020). What does integrated care mean from an older person's perspective? A scoping review. *BMJ Open*, 10(1), e035157.
- Le Protecteur du Citoyen. (2012). *Is home support always the option of choice? Investigation report on the accessibility of long-term home support services*. Protecteur du citoyen.
- Le Protecteur du Citoyen. (2014a). *Brief by the Québec Ombudsman presented to the Committee on Health and Social Services*. Protecteur du citoyen.
- Le Protecteur du Citoyen. (2014b). *Québec Ombudsman's Brief presented to the Commission de la Santé et des Services Sociaux*. Protecteur du citoyen.
- Le Protecteur du Citoyen. (2017). *2016-2017 annual report*. Protecteur du citoyen.
- Le Protecteur du Citoyen. (2018). *2017-2018 annual report*. Protecteur du citoyen.
- Le Protecteur du Citoyen. (2019). *2018-2019 annual report*. Protecteur du citoyen.
- Leatt, P., Pink, G., & Guerriere, M. (2000). Towards a Canadian model of integrated healthcare. *HealthcarePapers*, 1(2), 13-35.
- Lee, Y., & Penning, M. (2019). The determinants of informal, formal, and mixed in-home care in the Canadian context. *Journal of Aging and Health*, 31(9), 1692–1714.
- Leichsenring, K. (2004). Developing integrated health and social care services for older persons in Europe. *International Journal of Integrated Care*, 41-18.

- Leichsenring, K., Billings, J., & Nies, H. (2013). *Long-term care in Europe: Improving policy and practice*. Palgrave Macmillan.
- Leutz, W. (1999). Five laws for integrating medical and social services: Lessons from the United States and the United Kingdom. *The Milbank Quarterly*, 77(1), 77.
- Levels of Care Expert Panel. (2017). *Thriving at home: A levels of care framework to improve the quality and consistency of home and community care for Ontarians*. Retrieved May 28, 2020 from http://health.gov.on.ca/en/public/programs/lhin/docs/loc_report_2017.pdf
- Lewin, G., De San Miguel, K., Knuiman, M., Alan, J., Boldy, D., Hendrie, D., & Vandermeulen, S. (2013). A randomised controlled trial of the Home Independence Program, an Australian restorative home-care programme for older adults. *Health & Social Care in the Community*, 21(1), 69-78.
- Lewin, G., Alfonso, H., & Alan, J. (2013). Evidence for the long term cost effectiveness of home care reablement programs. *Clinical Interventions in Aging*, 8, 1273-1281.
- Liljas, A., Brattström, F., Burström, B., Schön, P., & Agerholm, J. (2019). Impact of integrated care on patient-related outcomes among older people - A systematic review. *International Journal of Integrated Care*, 19(3), 6.
- Livadiotakis, G. (2001). *The impact of continuing care reforms to home support service on former senior clients: A regional assessment* [Unpublished master's thesis]. Simon Fraser University, Vancouver, Canada.
- Lloyd, J., & Wait, S. (2006). *Integrated care: A guide for policymakers*. London: Alliance for Health and the Future.
- Lodge, M. (2007). Comparative public policy. In F. Fischer and G. J. Miller (Eds.), *Handbook of public policy analysis: Theory, politics, and methods* (pp. 273-288). Boca Raton: CRC Press.
- Longhurst, A. (2017). *Privatization & declining access to BC seniors' care: An urgent call for policy change*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Longhurst, A. (2020). *Assisted living in British Columbia: Trends in access, affordability and ownership*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Long-Term Care Expert Innovation Panel. (2012). Why not now? A bold, five-year strategy for innovating Ontario's system of care for older adults. Retrieved June 12, 2020 from https://www.oltca.com/oltca/Documents/Reports/WhyNotNowFULL_March2012.pdf
- Long-Term Care Homes Act [2007, c.8]. Retrieved from Ontario Laws website <https://www.ontario.ca/laws/statute/07108>

- Looman, W. M., Huijsman, R., & Fabbriotti, I. N. (2019). The (cost-)effectiveness of preventive, integrated care for community-dwelling frail older people: A systematic review. *Health & Social Care in the Community*, 27(1), 1-30.
- Lopez Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: A systematic review. *International Journal of Integrated Care*, 12(5).
- Low, L., Chilko, N., Gresham, M., Barter, S., & Brodaty, H. (2012). An update on the pilot trial of consumer-directed care for older persons in Australia. *Australasian Journal on Ageing*, 31(1), 47-51.
- Lum, J., Williams, P., Sladek, J., & Ying, A. (2010). *Balancing care for supportive housing: Final report*. Retrieved June 19, 2020 from <https://www.ryerson.ca/content/dam/crncc/knowledge/relatedreports/balancecare/Balancing%20Care%20for%20Supportive%20Housing%20Final%20Report.pdf>
- Lynch, M., & Estes, C. (2001). The underdevelopment of community-based services in the U.S. long-term care system: A structural analysis. In C. Estes (Ed.), *Social policy and aging: A critical perspective* (pp.201-216). Thousand Oaks: SAGE Publications Inc.
- MacAdam, M. (2008). *Frameworks of integrated care for the elderly: A systematic review*. Retrieved October 26, 2013 from http://www.cprn.org/documents/49813_EN.pdf
- MacAdam, M. (2011). Progress toward integrating care for seniors in Canada: "We have to skate toward where the puck is going to be, not to where it has been." *International Journal of Integrated Care*, 11 Spec Ede016.
- MacAdam, M. (2015). PRISMA: Program of Research to Integrate the Services for the Maintenance of Autonomy. A system-level integration model in Québec. *International Journal of Integrated Care*, 15(6).
- MacDonald, M. (2015). Regulating individual charges for long-term residential care in Canada. *Studies in Political Economy*, 95.
- MacDonald, B.J., Wolfson, M., & Hirdes, J. (2019). *The future cost of long-term care in Canada*. National Institute on Ageing, Ryerson University.
- Madsen, S. B., Beedholm, K., Bro, F., Ledderer, L. K., Vestergaard, L. O., & Burau, V. (2019). Implementing integrated community-based primary healthcare: applying the iCoach-approach to case selection to Denmark. *International Journal of Integrated Care*, 19(4), 3.
- Martin-Matthews, A., Sims-Gould, J., & Tong, C. (2012). Canada's complex and fractionalized home care context: Perspectives of workers, elderly clients, family carers, and home care managers. *Canadian Review of Social Policy*, 68/69(2013), 55-74.

- Martinsen, B., Norlyk, A., & Lomborg, K. (2015). Experiences of intermediate care among older people: A phenomenological study. *British Journal of Community Nursing, 20*(2), 74-79.
- Maxwell, C. J., Amuah, J. E., Hogan, D. B., Cepoiu-Martin, M., Gruneir, A., Patten, S. B., Soo, A., Le Clair, K., Wilson, K., Hagen, B., & Strain, L. A. (2015). Elevated hospitalization risk of assisted living residents with dementia in Alberta, Canada. *Journal of the American Medical Directors Association, 16*(7), 568-577.
- Maxwell, C. J., Soo, A., Hogan, D. B., Wodchis, W. P., Gilbert, E., Amuah, J., Eliasziw, M., Hagen, B., & Strain, L. A. (2013). Predictors of nursing home placement from assisted living settings in Canada. *Canadian Journal on Aging, 32*(4), 333-348.
- McCallum, J. & Rees, K. (2017). *Consumer directed care in Australia: Early stage analysis and future directions*. Brisbane: National Seniors.
- McGrail, K., & Ahuja, M. (2017). What is bending the cost curve? An exploration of possible drivers and unintended consequences. *Healthcare Policy, 13*(2), 20-30.
- McGrail, K., Ahuja, M., Huang, X., Law, M., Wong, S., Harrison, M., McGregor, M., Berg, S., Bryan, S., & Mitton, C. (2019). *An evaluation of the accelerated integrated primary and community care initiatives*. Vancouver, BC: UBC Centre for Health Services and Policy Research.
- McGrail, K., Broemeling, A., McGregor, M., Salomons, K., Ronald, L., & McKendry, R. (2008). *Home health services in British Columbia*. Vancouver, BC: UBC Centre for Health Services and Policy Research.
- McGrail, K., Lilly, M., McGregor, M., & Broemeling, A. (2013). Health care services use in assisted living: A time series analysis. *Canadian Journal on Aging, 32*(2), 173-83.
- McGregor, M. J., McGrail, K. M., Abu-Laban, R. B., Ronald, L. A., Baumbusch, J., Andrusiek, D., & Cox, M. B. (2014). Emergency department visit rates and patterns in Canada's Vancouver Coastal Health region. *Canadian Journal on Aging, 33*(2), 154-162.
- McLeroy, K. R., Bibeau, D., Steckler, A., & Glanz, K. (1988). An ecological perspective on health promotion programs. *Health Education Quarterly, 15*(4), 351-377.
- Meadows, D. (2008). *Thinking in systems: A primer*. Retrieved October 2, 2017 from <http://wtf.tw/ref/meadows.pdf>
- Milligan, C. (2009). *There's no place like home: Place and care in an ageing society*. Burlington, MA: Ashgate.
- Ministère de la Santé et des Services Sociaux [MSSS]. (2009). Focus on the Québec health and social services system. Gouvernement du Québec.

- MSSS. (2010). *Plan stratégique 2010-2015*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-000295/>
- MSSS. (2011). *Approche adaptée à la personne âgée en milieu hospitalier - Cadre de référence*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-000697/>
- MSSS. (2015). *Orientations ministérielles en gestion de cas*. Retrieved June 15, 2020 from http://cio.partenaires-de-soins.ca/wp-content/uploads/2016/11/BAO_CSS3900_M1L3_Orientations_ministerielles_gestion_de_cas_et_fiches_2015.pdf
- MSSS. (2017a). *The health and social services system in Québec: In brief*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/en/document-000153/>
- MSSS. (2017b). *Plan stratégique 2015-2020*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-001550/>
- MSSS. (2019a). *Rapport annuel de gestion 2018-2019*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-002394/?&date=DESC&type=rapport&critere=type>
- MSSS. (2019b). *Plan stratégique: 2019-2023*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-002438/>
- MSSS. (2020a). *Plan d'action pour l'attraction et la fidélisation des préposés aux bénéficiaires et des auxiliaires aux services de santé et sociaux*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-002450/>
- MSSS. (2020b). *Données de la liste d'attente pour une place en centre d'hébergement de soins longue durée (CHSLD). Période 9 - 2019-2020*. Retrieved June 15, 2020 from <https://publications.msss.gouv.qc.ca/msss/document-001637/?&date=DESC&type=statistiques-et-donnees&critere=type>
- Ministeriet for Sundhed og Forebyggelse. (2013). *Mere borger, mindre patient – Et stærkt fælles sundhedsvæsen*. Retrieved May 28, 2020 from <https://sum.dk/Aktuelt/Publikationer/Mere-borger-mindre-patient-maj-2013.aspx>
- Minkler, M. (1996). Critical perspectives on ageing: New challenges for gerontology. *Ageing and Society*, 16(4), 467-487.
- Misfeldt, R., Suter, E., Mallinson, S., Boakye, O., Wong, S., & Nasmith, L. (2017). Exploring context and the factors shaping team-based primary healthcare policies in three Canadian provinces: A comparative analysis. *Healthcare Policy*, 13(1), 74-93.

- Moberg, L. (2017). Marketisation of Nordic Eldercare – Is the model still universal? *Journal of Social Policy*, 46(3), 603-621.
- Mondor, L., Song, K., Wodchis W.P. (2016). *Assessing value in Ontario Health Links. Part 5: health system performance trends in Health Links populations: 2012-2014*. Toronto, ON: Health System Performance Research Network.
- Mondor, L., Walker, K., Bai, Y., & Wodchis, W. (2017). Use of hospital-related health care among Health Links enrollees in the Central Ontario health region: A propensity-matched difference-in-differences study. *CMAJ Open*, 5(4), E753-E759.
- Morin, D., Tourigny, A., Robichaud, L., Pelletier, D., Bonin, L., Vézina, A., Mathieu, L., & Buteau, M. (2008). Evaluation of an information system within an integrated services network for frail seniors: Its use and user perception of usefulness and impact. In R. Hébert, A. Tourigny and M. Raïche (Eds.), *Integration of services for disabled people: Research leading to action. Volume II* (pp.289-304). Canada: EDISM.
- Motiwala, S., Flood, C., Coyte, P., & Laporte, A. (2005). The First Ministers' Accord on health renewal and the future of home care in Canada. *Healthcare Quarterly*, 8(1).
- Murphy, J. (2006). *Residential care quality: A review of the literature on nurse and personal care staffing and quality of care*. Victoria, BC: Nursing Directorate, British Columbia Ministry of Health.
- Muscedere, J., Barrie, C., Chan, K., Cooper, B., Critchley, K., Kim, P., Lorbergs, A., Mackenzie, I., Martineau, C., Noseworthy, T., O'Neil, M., Resin, J., Sinha, S., & Williams, R. (2019). Frailty and aging: How the Danish experience might inform Canada. *Healthcare Quarterly*, 22(1), 14–21.
- Mustel Group. (2020). *2020 generational real estate trends: Aging in place*. Retrieved June 19, 2020 from <https://sothebysrealty.ca/insightblog/2020/03/04/2020-generational-real-estate-trends-report-aging-in-place/>
- National Aged Care Alliance [NACA]. (2009). *Leading the way: Our vision for support and care of older Australians*. Retrieved June 15, 2020 from https://naca.asn.au/wp-content/uploads/2018/11/NACA_Vision.pdf
- NACA. (2012). *Blueprint for aged care reform*. Retrieved June 15, 2020 from <https://naca.asn.au/wp-content/uploads/2018/11/NACA-Blueprint-I-for-Aged-Care-Reform-February-2012.pdf>
- NACA. (2015). *Enhancing the quality of life of older people through better support and care*. Retrieved June 15, 2020 from https://naca.asn.au/wp-content/uploads/2018/11/NACA_Blueprint_2015_Final-1.pdf

- National Institute on Ageing. (2019). *Enabling the future provision of long-term care in Canada*. Toronto, ON: National Institute on Ageing.
- National Institute on Ageing. (2020). NIA Long-Term Care COVID-19 Tracker. In *NIA Long-Term Care COVID-19 Tracker*. Retrieved May 18, 2020 from <https://ltc-covid19-tracker.ca/>
- NOUS. (2019). *Wellness and reablement: A summary of consultations across the home care sector*. Retrieved June 15, 2020
<https://www.health.gov.au/sites/default/files/documents/2019/12/wellness-and-reablement-summary-of-consultations-across-the-home-care-sector.pdf>
- Nova Scotia Department of Health. (2006). *Continuing care strategy for Nova Scotia: Shaping the future of continuing care*. Government of Nova Scotia.
- Nova Scotia Department of Health and Wellness. (2015). *Living well: Continuing care services*. Retrieved June 15, 2020
<https://novascotia.ca/dhw/ccs/documents/Living-Wel-%20Continuing-Care-Services.pdf>
- Nova Scotia Department of Health and Wellness. (2018). *Home care policy manual*. Retrieved June 15, 2020
https://novascotia.ca/dhw/ccs/policies/HomeCare_Policy_Manual.pdf
- Nova Scotia Department of Health and Wellness. (2019). *Long term care program requirements: Nursing homes & residential care facilities*. Retrieved June 15, 2020 <https://novascotia.ca/dhw/ccs/policies/Long-Term-Care-Facility-Program-Requirements.pdf>
- Nova Scotia Department of Seniors. (2017). *Shift: Nova Scotia's action plan for an aging population*. Halifax, NS: Province of Nova Scotia.
- Nova Scotia Health Authority [NSHA]. (2016a). *Geriatric restorative care*. Retrieved June 15, 2020
<http://www.nshealth.ca/sites/nshealth.ca/files/patientinformation/0287.pdf>
- NSHA. (2016b). *Nova Scotia health authority: 2015-2016 annual report*. Retrieved June 15, 2020 <http://www.nshealth.ca/AnnualReport2016/index.html>
- NSHA. (2019). *Nova Scotia health authority: 2018-19 annual report*. Retrieved June 15, 2020 <http://www.nshealth.ca/AnnualReport2018-19/>
- Office of the Auditor General of British Columbia. (2008). *Home and community care services: Meeting needs and preparing for the future*. Victoria, BC: Office of the Auditor General of British Columbia.

- Office of the Auditor General of Nova Scotia. (2017). *Health and wellness and Nova Scotia health authority: Managing home care support contracts*. Retrieved June 15, 2020 from https://oag-ns.ca/sites/default/files/publications/Ch3Nov2017_2.pdf
- Office of the Auditor General of Ontario. (2015a). *2015 annual report*. Queen's Printer for Ontario.
- Office of the Auditor General of Ontario. (2015b). *Community care access centres – Financial operations and service delivery*. Queen's Printer for Ontario.
- Office of the Seniors Advocate [OSA]. (2014a). *The journey begins: Together we can do better*. Retrieved June 15, 2020 from <https://www.seniorsadvocatebc.ca/osa-reports/the-journey-begins-together-we-can-do-better/>
- OSA. (2015a). *Caregivers in distress: More respite needed*. Retrieved November 10, 2015 from <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2015/09/Caregivers-in-Distress-Report.pdf>
- OSA. (2015b). *B.C. seniors survey: Bridging the gaps*. Retrieved July 21, 2015 from <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2014/10/Seniors-Advocate-Survey-Results-Summary.pdf>
- OSA. (2015c). *Placement, drugs and therapy... We can do better*. Retrieved July 21, 2015 from <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2014/10/SA-Placement-Drugs-Therapy-Report.pdf>
- OSA. (2015d). *Seniors' housing in B.C.: Affordable, appropriate, available*. Retrieved September 4, 2015 from <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2015/05/Seniors-Housing-in-B.C.-Affordable-Appropriate-Available.pdf>
- OSA. (2015e). *Monitoring seniors services 2015*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2016/01/SA-MonitoringSeniorsServices-2015.pdf>
- OSA. (2016a). *Listening to your voice: Home support survey analysis and results*. Retrieved October 12, 2016, from <https://www.seniorsadvocatebc.ca/wp-content/uploads/sites/4/2016/09/SA-HomeSupportSurveyReport-Sept2016-Final.pdf>
- OSA. (2016b). *Making progress: Placement, drugs and therapy update*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/osa-reports/report-making-progress-placement-drugs-and-therapy-update/>
- OSA. (2016c). *Monitoring seniors services 2016*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2016/12/OSA-MonitoringReport2016.pdf>

- OSA. (2017a). *Caregivers in distress: A growing problem*. Retrieved November 10, 2015 from <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2017/08/Caregivers-in-Distress-A-Growing-Problem-Final.pdf>
- OSA. (2017b). *Every voice counts: Office of the Seniors Advocate residential care survey provincial results*. Retrieved November 10, 2017 from <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2017/09/Provincial-Results-Final-HQ.pdf>
- OSA. (2017c). *Monitoring seniors services 2017*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2017/12/MonitoringReport2017.pdf>
- OSA. (2018a). *Seniors transportation: Affordable, appropriate, and available*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/osa-reports/seniors-transportation-affordable-accessible-and-appropriate/>
- OSA. (2018b). *Monitoring seniors services 2018*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2019/01/MonitoringReport2018.pdf>
- OSA. (2019a). *Home support review*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/osa-reports/report-home-support-review/>
- OSA. (2019b). *Monitoring seniors services 2019*. Retrieved June 19, 2020 from <https://www.seniorsadvocatebc.ca/monitoring-seniors-services/>
- Office of the Veterans Ombudsman. (2014). *A review of assisted living options for veterans*. Retrieved April 28, 2018 from <http://www.ombudsman-veterans.gc.ca/eng/reports/reports-reviews/assisted-living-review>
- Ogilvie, K., & Eggleton, A. (2012). *Time for transformative change: A review of the 2004 health accord*. Retrieved May 25, 2020 from <http://www.parl.gc.ca/content/sen/committee/411/soci/rep/rep07mar12-e.pdf>
- O'Hara, M. (2014). *Analyzing provincial supports for family/friend caregivers: A comparison of the Manitoba primary caregiver tax credit and the Nova Scotia caregiver benefit* (Unpublished master's thesis). Mount Saint Vincent University, Nova Scotia, Canada.
- Ontario Association of Community Care Access Centres. (2014). *Making way for change: Transforming home and community care for Ontarians*. Retrieved June 15, 2020 from <https://hssontario.ca/Policy/White%20Paper/OACCAC-Whitepaper-FINAL.pdf>

- Ontario Association of Non-Profit Homes and Services for Seniors. (2016). *Improving seniors' services in Ontario: OANHSS position paper on capacity planning and development*. Retrieved June 12, 2020 from <https://www.pshsa.ca/research/improving-seniors-services-in-ontario-oanhss-position-paper-on-capacity-planning-and-development>
- Ontario Caregiver Organization. (2019). *The Ontario Caregiver Organization 2018-19 annual report*. Retrieved January 28, 2020 from https://ontariocaregiver.ca/wp-content/uploads/2019/12/OCO-2018-19-Annual-Report_EN.pdf
- Ontario Health Coalition. (2011). *Still waiting: An assessment of Ontario's home care system after two decades of restructuring*. Retrieved January 28, 2020 from <http://www.ontariohealthcoalition.ca/wp-content/uploads/Full-Report-April-4-2011.pdf>
- Ontario Health Coalition. (2015). *The care we need*. Retrieved May 31, 2020 from <http://www.ontariohealthcoalition.ca/wp-content/uploads/home-care-the-care-we-need-report-final.pdf>
- Ontario Health Coalition. (2019). *Caring in crisis: Ontario's long-term care PSW shortage*. Retrieved January 28, 2020 from <https://www.ontariohealthcoalition.ca/wp-content/uploads/final-PSW-report.pdf>
- Ontario Health Coalition. (2020). The Ford Government's planned changes to home & community care. Retrieved May 28, 2020 <https://www.ontariohealthcoalition.ca/wp-content/uploads/briefing-note-new-home-care-act-and-regulations.pdf>
- Ontario Ministry of Health and Long-term Care [MOHLTC]. (2012). Ontario's action plan for health care. Retrieved January 28, 2020 from http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_healthychange.pdf
- Ontario MOHLTC. (2014). A vision for home and community care in Ontario. Retrieved from http://www.health.gov.on.ca/en/public/programs/lhin/ccac_vision.pdf
- Ontario MOHLTC. (2015a). Patients first: Action plan for health care. Retrieved January 28, 2020 from http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf
- Ontario MOHLTC. (2015b). Patients first: A roadmap to strengthen home and community care. Retrieved January 28, 2020 from <http://www.health.gov.on.ca/en/public/programs/lhin/roadmap.pdf>
- Ontario MOHLTC. (2015c). *Patients first: A proposal to strengthen patient-centred health care in Ontario*. Retrieved January 28, 2018 from http://www.health.gov.on.ca/en/news/bulletin/2015/docs/discussion_paper_2015_1217.pdf

- Ontario MOHLTC. (2017, June 23). Update: Health system integration [Press release]. Retrieved from http://health.gov.on.ca/en/news/bulletin/2017/hb_20170127_21.aspx
- Ontario MOHLTC. (2018). Home and Community Care. In *Ontario Ministry of Health and Long-Term Care*. Retrieved June 19, 2020 from <http://www.health.gov.on.ca/en/public/programs/lhin/>
- Ontario Non-Profit Housing Association. (2016). *Aging in place in social housing*. Retrieved June 4, 2020 from <https://www.onpha.on.ca/Content/PolicyAndResearch/focusONs/Aging%20in%20place%20in%20social%20housing.aspx>
- Ontario Seniors Secretariat. (2013). *Ontario's action plan for seniors*. Queen's Printer Ontario.
- Organisation for Economic Co-Operation and Development [OECD]. (2011). *Canada: Long-term care*. OECD.
- OECD. (2013). *OECD reviews of health care quality: Denmark 2013: raising standards*. OECD.
- OECD. (2017a). *Systems approaches to public sector challenges: Working with change*. Paris: OECD Publishing.
- OECD. (2017b). *State of health in the EU: Denmark country health profile 2017*. Paris: OECD Publishing.
- OECD. (2019a). *State of health in the EU: Denmark country health profile 2019*. Paris: OECD Publishing.
- OECD. (2019b). Informal carers. In *OECD iLibrary*. Retrieved June 15, 2020 from <https://www.oecd-ilibrary.org/sites/a80d9f62-en/index.html?itemId=/content/component/a80d9f62-en>
- Oliveira Hashiguchi, T., & Llana-Nozal, A. (2020). *The effectiveness of social protection for long-term care in old age: Is social protection reducing the risk of poverty associated with care needs?* OECD Health Working Papers, No. 117. Paris: OECD Publishing.
- Ostry, A. S. (2006). *Change and continuity in Canada's health care system*. CHA Press.
- Ottmann, G., Allen, J., & Feldman, P. (2013). A systematic narrative review of consumer-directed care for older people: Implications for model development. *Health & Social Care in the Community*, 21(6):563-581.

- Peckham A., Kreindler S., Church J., Chatwood S., & Marchildon, G. (2018a). *Primary care reforms in Ontario, Manitoba, Alberta, and the Northwest Territories*. Retrieved January 28, 2020 from https://ihpme.utoronto.ca/wp-content/uploads/2018/09/NAO-Rapid-Review-2-_EN.pdf
- Peckham, A., Morton-Chang, F., Williams, A. P., & Miller, F. A. (2018c). Rebalancing health systems toward community-based care: The role of subsectoral politics. *Health policy*, 122(11), 1260-1265.
- Peckham, A., Rudoler, D., Li, J. M., & D'Souza, S. (2018b). Community-based reform efforts: The case of the aging at home strategy. *Healthcare policy*, 14(1), 30-43.
- Penning, M.J., Brackley, M. E., & Allan, D. E. (2006). Home care and health reform: Changes in home care utilization in one Canadian province, 1990-2000. *Gerontologist*, 46(6), 744-758.
- Penning, M.J., Cloutier, D.S., Nuernberger, K., MacDonald, S., & Taylor, D. (2018). Long-term care trajectories in Canadian context: Patterns and predictors of publicly-funded care. *The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 73(6), 1077-1087.
- Penning, M.J. & Votova, K. (2009). Aging, health and health care: From hospital and residential care to home and community care. In B. S. Bolaria and H. D. Dickinson (Eds.), *Health, illness, and health care in Canada*, (pp. 349-366). Toronto, ON: Nelson Education.
- Perry, K-M. (2020). *The place of assisted living in BC's seniors care system: Assessing the promise, reality and challenge*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- Petersen, A., Graff, L., Rostgaard, T., Kjellberg, J., & Kjellberg, P. K. (2017). *Rehabilitering på ældreområdet - Hvad fortæller danske undersøgelser os om kommunernes arbejde med rehabilitering i hjemmeplejen?* KORA.
- Petersen, O. H., & Hjelm, U. (2013). Marketization of welfare services in Scandinavia: A review of Swedish and Danish experiences. *Scandinavian Journal of Public Administration*, 17(4), 3-20.
- Phillipson, L., Johnson, K., Cridland, E., Hall, D., Neville, C., Fielding, E., & Hasan, H. (2019). Knowledge, help-seeking and efficacy to find respite services: An exploratory study in help-seeking carers of people with dementia in the context of aged care reforms. *BMC Geriatrics*, 19(1), 2.
- Phillipson, L., Low, L., & Dreyfus, S. (2019). Consumer-directed care for older Australians: Are resources identified on the Web adequate to support decisions about home-based care packages? *Australian Journal of Social Issues*, 54(2), 135-156.

- Pineault, E. (2015). Austerity: A matter of choice. In *Behind the Numbers*. Retrieved June 19, 2020 from <http://behindthenumbers.ca/2015/07/13/austerity-a-matter-of-choice/>
- Pinto, A.D., Manson, H., Pauly, B., Thanos, J., Parks, A., & Cox, A. (2012). Equity in public health standards: A qualitative document analysis of policies from two Canadian provinces. *International Journal for Equity in Health*, 11(1), 28.
- Poirier, L-R, Descôteaux, S., Levesque, J-F, & Tourigny, A. (2013). *Expedited knowledge synthesis on factors affecting implementation of integrated services networks for the elderly*. Retrieved June 19, 2020 from <https://www.inspq.qc.ca/en/publications/1664>
- Pollack, N. (2000). *Cutting home support: from "closer to home" to "all alone"*. Vancouver, BC: Canadian Centre for Policy Alternatives.
- PopData BC. (2018). Is caring for BC's seniors 'Better at Home'? In *PopData BC*. Retrieved June 15, 2020 from https://www.popdata.bc.ca/news/project_approval_17-113
- Potter, J. (2008). Discourse analysis. In L. M. Given (Ed.), *The SAGE encyclopedia of qualitative research methods* (pp. 218-220). Thousand Oaks, CA: SAGE Publications Ltd.
- Powell, J. (2004). An introduction to systems theory: From hard to soft systems thinking in the management of complex organizations. In D. Kernick (Ed.), *Complexity and healthcare organization: A view from the street* (pp.43-58). Oxford; San Francisco: Radcliffe Medical Press.
- Productivity Commission. (2011a). *Caring for older Australians: Volume 1*. Canberra: Commonwealth of Australia.
- Productivity Commission. (2011b). *Caring for older Australians: Volume 2*. Canberra: Commonwealth of Australia.
- Quesnel-Vallée, A., & Carter, R. (2018). Improving accessibility to services and increasing efficiency through merger and centralization in Québec. *Health Reform Observer*, 6(1).
- Rabig, J., Thomas, W., Kane, R. A., Cutler, L. J., & McAlilly, S. (2006). Radical redesign of nursing homes: Applying the green house concept in Tupelo, Mississippi. *Gerontologist*, 46(4), 533–539.
- Raïche, M., Hébert, R., Blanchette, D., Durand, S., Dubois, M-F, Gueye, N. R., & the PRISMA Estrie Group. (2008). RISPA overall performance: Impacts on the use of health services, their costs and efficiency under the PRISMA-Estrie study. In R. Hébert, A. Tourigny and M. Raïche (Eds.), *Integration of services for disabled people: Research leading to action Volume II* (p.265-288). Canada: EDISM.

- Raising the Profile Project. (2017). Therapeutic activation program for seniors. Retrieved June 18, 2020 from http://www.seniorsraisingtheprofile.ca/wp-content/uploads/2017/06/Program_Profile_TAPS.pdf
- Reed, J., Cook, G., Childs, S., & McCormack, B. (2005). A literature review to explore integrated care for older people. *International Journal of Integrated Care*, 5, 1-10.
- Regnier, V. (2018). *Housing design for an increasingly older population: redefining assisted living for the mentally and physically frail*. John Wiley & Sons, Inc.
- Regroupement des Aidants Naturels du Québec. (2018). *Empower and support caregivers, these essential allies for a fair province of Québec*. Retrieved June 19, 2020 from <https://ranq.qc.ca/wp-content/uploads/2018/08/RANQ-National-strategy-Eng-1.pdf>
- Rehnsfeldt, A., Lindwall, L., Lohne, V., Lillestø, B., Slettebø, Å., Heggstad, A. K., Aasgaard, T., Råholm, M. B., Caspari, S., Høy, B., Sæteren, B., & Nåden, D. (2014). The meaning of dignity in nursing home care as seen by relatives. *Nursing Ethics*, 21(5), 507-517.
- Romanow, R. J. (2002). *Building on values: The future of health care in Canada*. Retrieved June 19, 2020 from <http://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf>
- Rostgaard, T. (2012). Quality reforms in Danish home care - Balancing between standardisation and individualisation. *Health & Social Care in the Community*, 20(3), 247-254.
- Rostgaard, T. (2016). Socially investing in older people – Reablement as a social care policy response? *Research on Finnish Society*, 9, 19-32.
- Rostgaard, T. (2018). Revisiting the public care model: The Danish case of free choice in home care. In K. Christensen, and D. Pilling (Eds.), *The routledge handbook of social care work around the world*. Routledge.
- Rostgaard, T. & Szebehely, M. (2012). Changing policies, changing patterns of care: Danish and Swedish home care at the crossroads. *European Journal of Ageing*, 9(2), 101-109.
- Royal Academy of Engineering. (2017). *Engineering better care: A systems approach to health and care design and continuous improvement*. Retrieved January 12, 2017 from <https://www.raeng.org.uk/publications/reports/engineering-better-care>
- Royal Commission into Aged Care Quality and Safety. (2019a). *Interim report: Neglect*. Commonwealth of Australia.

- Royal Commission into Aged Care Quality and Safety. (2019b). *Aged care program redesign: Services for the future*. Retrieved June 19, 2020 from <https://agedcare.royalcommission.gov.au/publications/Documents/consultation-paper-1.pdf>
- Rudkjøbing, A., Olejaz, M., Okkels Birk, H., Juul Nielsen, A., Hernández-Quevedo, C., & Krasnik, A. (2012). Integrated care: A Danish perspective. *British Medical Journal (Overseas & Retired Doctors Edition)*, 345(7867), 21-24.
- Rudkjøbing, A., Strandberg-Larsen, M., Vrangbaek, K., Andersen, J., & Krasnik, A. (2014). Health care agreements as a tool for coordinating health and social services. *International Journal of Integrated Care*, 14, E036.
- SafeCare BC. (2016, November 22). *SafeCare BC HR survey identifies shortage of workers* [Press Release]. Retrieved from <https://www.safecarebc.ca/2016/11/22/safecare-bc-hr-survey-identifies-shortage-workers/>
- SafeCare BC. (2017). (2017, May 16). *New strategy is needed to address shortage of continuing care workers* [Press Release]. Retrieved from <https://www.safecarebc.ca/2017/05/16/media-release-new-strategy-needed-address-shortage-continuing-care-workers/>
- Schulz, E. (2010). *The long-term care system for the elderly in Denmark*. Retrieved October 31, 2015 from [http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI%20 _ANCIEN_%20RRNo.73DenmarkREV2.pdf](http://www.ancien-longtermcare.eu/sites/default/files/ENEPRI%20_ANCIEN_%20RRNo.73DenmarkREV2.pdf)
- Schulz, E. (2014). *Impact of ageing on long-term care workforce in Denmark*. Retrieved June 19, 2020 from [http://www.neujobs.eu/sites/default/files/publication/2014/02/NEUJOBS%20Work ing%20Paper-D12.2-Denmark-2.pdf](http://www.neujobs.eu/sites/default/files/publication/2014/02/NEUJOBS%20Working%20Paper-D12.2-Denmark-2.pdf)
- Self-Directed Care Ontario. (2018). Annual report for Self-Directed Care Ontario: 2017-2018. Retrieved January 29, 2020 from http://www.health.gov.on.ca/en/common/ministry/publications/reports/sdco/SDCO_AR.pdf
- Senate Community Affairs Committee Secretariat. (2013). Community Affairs Legislation Committee: Aged care (Living longer living better) Bill 2013 [Provisions] and related bills. Canberra: Senate Printing Unit, Parliament House.
- Shapiro, E. (2002). *Sharing the learning: Health transition fund. Synthesis series: Home care*. Health Canada.
- Shaw, R. (2019, March 14). B.C. moving private home support services back into health authorities. *Vancouver Sun*. Retrieved June 15, 2020 from <https://vancouversun.com/news/politics/b-c-moving-private-home-support-services-back-into-health-authorities>

- Sheppard, S. (2019). Integrating primary care, home care, and community health services in Ontario. *Health Reform Observer*, 7(1).
- Shooshtari, S., Duncan, K.A., Roger, K., Fast, J., & Han, J. (2017). Care-related out-of-pocket spending and caregiving consequences: Results from a Canadian population-based study. *Journal of Family and Economic Issues*, 38, 405-420.
- Sims-Gould, J., Tong, C., Wallis-Mayer, L., & Ashe, M. (2017). Reablement, reactivation, rehabilitation and restorative interventions with older adults in receipt of home care: A systematic review. *Journal of the American Medical Directors Association*, 18(8), 653-663.
- Sinha, S. (2012). *Living longer, living well*. Retrieved June 19, 2020 from http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/
- Sivananthan, S. N., Doupe, M., & McGregor, M. J. (2015). Exploring the ecology of Canada's publicly funded residential long-term care bed supply. *Canadian Journal on Aging*, 34(1), 60-74.
- Slade, S., Shrichand, A., & DiMillo, S. (2019). *Health care for an aging population: A study of how physicians care for seniors in Canada*. Ottawa, ON: The Royal College of Physicians and Surgeons of Canada.
- Smith, P.M., Cawley, C., Williams, A., & Mustard, C. (2020). Male/female differences in the impact of caring for elderly relatives on labor market attachment and hours of work: 1997-2015. *The Journals of Gerontology: Series B*, 75(3), 694-704.
- Somme, D. Hébert, R., Bravo, G., & Blanchard, F. (2005). Individualized service plan (isp) concept and utilization: A review of experiments on integrated services for the elderly in Québec and elsewhere. In R. Hébert, A. Tourigny and M. Gagnon, *Integrated service delivery to ensure persons' functional autonomy. Volume I* (pp.273-290). Acton Vale, QC: Edisem.
- Squires, J., Hoben, M., Linklater, S., Carleton, H., Graham, N., & Estabrooks, C. (2015). Job satisfaction among care aides in residential long-term care: A systematic review of contributing factors, both individual and organizational. *Nursing Research and Practice*, 2015, 24.
- Stanfors, M., Jacobs, J. C., & Neilson, J. (2019). Caregiving time costs and trade-offs: Gender differences in Sweden, the UK, and Canada. *SSM - Population Health*, 9.
- Statistics Canada. (2016). *Research highlights on health and aging*. Retrieved June 19, 2020 from <https://www150.statcan.gc.ca/n1/pub/11-631-x/11-631-x2016001-eng.htm>
- Statistics Canada. (2017). *Age and sex, and type of dwelling data: Key results from the 2016 Census*. Retrieved June 19, 2020 from <https://www150.statcan.gc.ca/n1/daily-quotidien/170503/dq170503a-eng.htm>

- Statistics Canada. (2018). The daily: Caregivers in Canada, 2018. In *Statistics Canada*. Retrieved June 19, 2020 from <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm>
- Statistics Canada. (2019a). *Population projections for Canada (2018 to 2068), provinces and territories (2018 to 2043)*. Retrieved June 19, 2020 from <https://www150.statcan.gc.ca/n1/pub/91-520-x/91-520-x2019001-eng.htm>
- Statistics Canada. (2019b). *Age and sex highlight tables, 2016 census*. Retrieved May 30, 2020 from <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/hltfst/as/Table.cfm?Lang=E&T=11>
- Statistics Denmark. (2020). RESI01: Clients in nursing dwellings and dwellings for the elderly by region, type of measure and time. Retrieved May 30, 2020 from <https://www.statbank.dk/RESI01>
- Stewart, M. J., Georgiou, A., & Westbrook, J. I. (2013). Successfully integrating aged care services: A review of the evidence and tools emerging from a long-term care program. *International Journal of Integrated Care*, 13, 1-14.
- Stuart, M., & Weinrich, M. (2001). Home- and community-based long-term care: Lessons from Denmark. *Gerontologist*, 41(4), 474-480.
- Suter, E., Oelke, N.D., Adair, C.E., & Armitage, G.D. (2009). Ten Key Principles for Successful Health Systems Integration. *Healthcare Quarterly*, 13(SP1), 16–23.
- Team Play Consulting Inc. and Shift Collaborative. (2018). *Better at Home: Provincial Evaluation 2017/18*. Better at Home.
- Temple, J. B., & Dow, B. (2018). The unmet support needs of carers of older Australians: Prevalence and mental health. *International Psychogeriatrics*, 30(12), 1849-1860.
- Tessier, A., Beaulieu, M., Mcginn, C., & Latulippe, R. (2016). Effectiveness of reablement: A systematic review. *Healthcare Policy*, 11(4), 49-59.
- The Change Foundation. (2012). Loud and clear: Seniors and caregivers speak out about navigating Ontario's healthcare system. Retrieved June 12, 2020 from <https://changefoundation.ca/loud-and-clear-seniors-caregivers/>
- The Change Foundation. (2015). *Out of the shadows and into the circle: Partnering with family caregivers to shift Ontario's health care system*. Retrieved January 29, 2020 from <https://www.changefoundation.ca/family-caregivers-overview/>
- The Change Foundation. (2020). Spotlight on Ontario's caregivers report 2019. In *The Change Foundation*. Retrieved January 29, 2020 from <https://www.changefoundation.ca/spotlight-on-caregivers-report/>

- Theou, O., Park, G. H., Garm, A., Song, X., Clarke, B., & Rockwood, K. (2017). Reversing frailty levels in primary care using the CARES model. *Canadian Geriatrics Journal*, 20(3), 105–111.
- Threapleton, D. E., Chung, R. Y., Wong, S., Wong, E., Chau, P., Woo, J., Chung, V., & Yeoh, E. K. (2017). Integrated care for older populations and its implementation facilitators and barriers: A rapid scoping review. *International Journal for Quality in Health Care*, 29(3), 327–334.
- TNS. (2016). *Provider and consumer research regarding recent and future changes in home care*. TNS.
- Torjman, S. (2016). Long-term commitment for long-term care. *HealthcarePapers*, 15(4): 31-35.
- Tousignant, M., Dubuc, N., Hébert, R., & Coulombe, C. (2005). Public funding of home care services for frail older adults: Are the Needs Being Met? In R. Hébert, A. Tourigny and M. Gagnon, *Integrated service delivery to ensure persons' functional autonomy* (pp.225-240). Acton Vale, QC: Edisem.
- Townsend, P. (1981). The structured dependency of the elderly: A creation of social policy in the twentieth century. *Ageing and Society*, 1(1), 5–28.
- Turcotte, M. (2013). *Family caregiving: What are the consequences?* Cat. no. 75-006-X. Ottawa, ON: Statistics Canada.
- United Way of the Lower Mainland. (2016). *Family & friend caregivers information and resource handbook*. Retrieved June 19, 2020 from <https://www.uwlm.ca/wp-content/uploads/2017/05/Caregivers-Guide-2016-web.pdf>
- van der Boom, H. (2009). *Home nursing in Europe: Patterns of professionalisation and institutionalisation of home care and family care to elderly people in Denmark, France, the Netherlands, and Germany*. Amsterdam: Aksant.
- van Olmen, J., Criel, B., Bhojani, U., Marchal, B., Belle, S., Chenge, M. F., Hoérée, T., Pirard, M., Van Damme, W., & Kegels, G. (2012b). The Health System Dynamics Framework: The introduction of an analytical model for health system analysis and its application to two case-studies. *Health, Culture and Society*, 2(1), 1-21.
- van Olmen, J., Marchal, B., Van Damme, W., Kegels, G., & Hill, P. S. (2012a). Health systems frameworks in their political context: Framing divergent agendas. *BMC Public Health*, 12(1), 774-786.
- Vedel, I., Monette, M., Beland, F., Monette, J., & Bergman, H. (2011). Ten years of integrated care: Backwards and forwards. The case of the province of Québec, Canada. *International Journal of Integrated Care*, 11 Spec Ede004.

- Veil, A., & Hébert, R. (2008). Perceived self-efficacy of case managers. In R. Hébert, A. Tourigny and M. Raïche (Eds.), *Integration of services for disabled people: Research leading to action. Volume II* (p. 125-148). Canada: EDISM.
- Visvanathan, R., Amare, A., Wesselingh, T., Hearn, S., McKechnie, R., Mussared, J., & Inacio, M. (2019). Prolonged wait time prior to entry to home care packages increases the risk of mortality and transition to permanent residential aged care services: Findings from the registry of older South Australians (ROSA). *The Journal of Nutrition, Health & Aging*, 23(3), 271–280.
- Vogel, D. (2000). *Unfulfilled promise: How health care reforms of the 1990s are failing community and continuing care in B.C.* Vancouver, BC: Canadian Centre for Policy Alternatives.
- Voyer, L., & Hébert, R. (2008). Family physicians' perception of the integrated services network and case managers. In R. Hébert, A. Tourigny and M. Raïche (Eds.), *Integration of services for disabled people: Research leading to action. Volume II* (pp.167-178). Canada: EDISM.
- Wagner, L. (2001). Integrated health care for older people in Denmark - Evaluation of the Skaevinge project "ten years on." *Journal of Oita Nursing and Health Sciences*, 2(2), 32-39.
- Walker, A. (1981). Towards a political economy of old age. *Ageing and Society*, 1(1), 73-94.
- Walker, D. (2011). *Caring for our aging population and addressing alternate level of care.* Toronto, ON: Ontario Ministry of Health and Long-Term Care.
- Walker, K., Hall, R. & Wodchis, W. (2019). *Evaluation of six integrated funding model pilot projects – a difference-in-differences analysis.* Toronto, ON: Health System Performance Research Network
- Walt, G., & Gilson, L. (1994). Reforming the health sector in developing countries: The central role of policy analysis. *Health Policy and Planning*, 9(4), 353-70.
- Wankah, P., Couturier, Y., Belzile, L., Gagnon, D., & Breton, M. (2018b). Providers' perspectives on the implementation of mandated local health networks for older people in Québec. *International Journal of Integrated Care*, 18(2), 2.
- Wankah, P., Guillette, M., Dumas, S., Couturier, Y., Gagnon, D., Belzile, L., Mosbah, Y., Breton, M. (2018a). Reorganising health and social care in Québec: A journey towards integrating care through mergers. *London Journal of Primary Care*, 10(3), 48-53.
- Warner, G., Poss, J., & McDougall, B. (2015). Using the RAI-HC to assess the effect of a financial subsidy on caregiver distress and home-care client long-term care admissions [Unpublished manuscript]. Dalhousie University.

- Williams, P., Challis, D., Deber, R., Watkins, J., Kuluski, K., Lum, J., & Daub, S. (2009a). Balancing institutional and community-based care: Why some older persons can age successfully at home while others require residential long-term care. *Healthcare Quarterly*, 12(2), 95-105.
- Williams, A. P., Lum, J., Deber, R., Montgomery, R., Kuluski, K., Peckham, A., Watkins, J., Williams, A., Ying, A., & Zhu, L. (2009b). Aging at home: Integrating community-based care for older persons. *HealthcarePapers*, 10(1), 8–21.
- Williams, A. P., Lum, J., Morton-Chang, F., Kuluski, K., Peckham, A., Warrick, N., & Ying, A. (2016). *Integrating long-term care into a community-based continuum: Shifting from “beds” to “places.”* Montreal, QC: Institute for Research on Public Policy.
- Williams, A. P., Peckham, A., & Kuluski, K., Montgomery, R., Morton, F., & Watkins, J. (2010). *Formal and informal care for older persons: Assessing the balance in Ontario*. Canadian Research Network for Care in the Community. <https://deslibris.ca/ID/225710>
- Williams, P., Deber, R., Baranek, P. & Gildiner, A. (2001). From medicare to home care: Globalization, state retrenchment, and the profitization of Canada’s health-care system. In P. Armstrong, H. Armstrong, and D. Coburn (Eds.), *Unhealthy times: Political economy perspectives on health and care in Canada* (pp.7-30). Don Mills, ON: Oxford University Press.
- Winkel, A., Langberg, H., & Wæhrens, E. (2015). Reablement in a community setting. *Disability and Rehabilitation*, 37(5), 1347-352.
- Wister, A. V. (2011). Population pressures, system-level inertia and healthy aging policy revisited. *HealthcarePapers*, 11(1), 41-45.
- Wister, A. & Speechley, M. (2015). Inherent tensions between population aging and health care systems: What might a modern health care system look like in twenty years? *Journal of Population Ageing*, 8(4), 227-243.
- Wodchis, W. P., Dixon, A., Anderson, G. M., & Goodwin, N. (2015). Integrating care for older people with complex needs: Key insights and lessons from a seven-country cross-case analysis. *International Journal of Integrated Care*, 15, e021.
- Wojtak, A., & Purbhoo, D. (2015). Perspectives on advancing bundled payment in Ontario's home care system and beyond. *Healthcare Quarterly*, 18(1), 18-25.
- World Health Organization [WHO]. (2007a). *WHO global age-friendly cities: A guide*. France: WHO.
- WHO. (2007b). *Everybody's business: Strengthening health systems to improve health outcomes: WHO's framework for action*. Retrieved January 12, 2018 from http://www.who.int/healthsystems/strategy/everybodys_business.pdf

WHO. (2009). *Systems thinking for health systems strengthening*. Retrieved June 19, 2020 from http://whqlibdoc.who.int/publications/2009/9789241563895_eng.pdf

WHO Regional Office for Europe. (2016). *Integrated care models: An overview*. Copenhagen: WHO Regional Office for Europe.

WHO Regional Office for Europe. (2019). *Denmark: Country case study on the integrated delivery of long-term care*. Copenhagen: WHO Regional Office for Europe.

Appendix A

INTERLINKS Framework for Long-Term Care

INTERLINKS Framework for Long-Term Care
<p>1. Identity of Long-Term Care</p> <p>1.1 Values</p> <ul style="list-style-type: none">• How key principles that characterise LTC are expressed; what values dominate for which stakeholder perspectives? (e.g., economic and quality perspectives, citizenship)• Whether there are sets of values that are shaping political, organisational and individual choices in LTC (e.g., through surveys of older peoples' specific needs for care and support)• How informal care and/or family ethics are addressed in legislative frameworks• How issues of dignity, quality of life and empowerment are described in policy papers• How values relating to prevention and rehabilitation are considered• How values embrace the diversity of users and carers (according to gender, culture and social inequalities) and support the specific needs of hard-to-reach groups <p>1.2 Mission Statements</p> <ul style="list-style-type: none">• Organisations that explicitly address problems at the interfaces between, for example, formal/informal and health and social care, prevention and rehabilitation or the use of migrant care workers• A description of how the problems are addressed and what particular factors distinguish an organisation as a 'LTC organisation', rather than a health or social care organisation <p>1.3 Organisational Definitions</p> <ul style="list-style-type: none">• How LTC is defined within or between organisations• How health care providers define their purpose in relation to LTC (cure vs. care; needs vs. supply; expectations vs. preferences)• How clients are defined and positioned
<p>2. Policy and Governance</p> <p>2.1 Policy</p> <ul style="list-style-type: none">• Policy barriers and opportunities in terms of linking social and health care (e.g., rhetoric as opposed to more achievable opportunities and results, workforce planning)• Policies addressing continuity and mechanisms to overcome barriers at the interfaces between social and health care• Policies addressing continuity and mechanisms to overcome barriers at the interfaces between formal and informal care, in particular to set the balance between caring informally and working• Policies addressing continuity and mechanisms to overcome barriers at the interfaces between prevention/rehabilitation and cure/care• Policies addressing continuity and mechanisms to overcome barriers at the interfaces between care at home and residential care• Implementation strategies

- Policies addressing issues of diversity and equal access, i.e. considering differences according to gender, culture and/or social inequalities

2.2 Legal Framework

- Legislation which explicitly addresses LTC with respect to informal carers
- Legislation which explicitly addresses LTC with respect to interfaces between health and social care
- Legislation which explicitly addresses LTC with respect to workforce planning
- Legislation which explicitly addresses LTC with respect to authorisation, accreditation, quality systems
- Legislation which explicitly addresses LTC with respect to co-ordination or integration of facilities or services

2.3 Governance Mechanisms

- Institution building to support and emphasize LTC as a specific area of concern (e.g., quality assurance agencies, insurance system, awareness campaigns)
- Incentives linked to contractual and financial mechanisms
- Incentives to provide LTC by addressing multi-level governance
- A description of steering mechanisms concerning access and eligibility criteria

2.4 Visibility of Key Topics

- Programmes and initiatives to promote prevention and rehabilitation
- Programmes and initiatives to promote informal care
- Programmes and initiatives to promote quality development
- Programmes and initiatives to promote user empowerment

3. Pathways and Processes

3.1 Accessing Services

- Case finding through routine screening services (e.g., preventative home visits)
- Transfer of information to users and carers and about users and carers between services or agencies
- The older person's and carers' interests and involvement which should consider rights, information, choice, and entitlements
- How services deal with diversity and equality of access, considering culture, gender and class to counter discrimination
- Performance management/indicators that relate to service access
- Ethical guidelines

3.2 Assessing Needs

- Multidisciplinary assessment (protocols, tools and instruments)
- Assessment tools and instruments (older peoples' and/or informal carers' needs), protocols
- Follow up of needs assessment (transfer of information)
- Older peoples' and/or informal carers' rights: information, shared decision making, consent, privacy regulations, complaints, second opinion
- Dealing with diversity (cultural, socio-economic inequalities)

3.3 Discharge, terminating professional contacts

- How professional and/or informal follow-up is properly communicated, available and well prepared
- How older people's and carers' rights are ensured (user-friendly information, shared decision making, consent to care, privacy regulations, complaints, second opinion)
- How information (files, care plan) and responsibilities are transferred (logistics issues)
- How information to and dialogue with older people and their informal network are facilitated, and how capacities are enabled and strengthened
- How funding of next stage care and service delivery is ensured
- How outcomes are assessed

3.4 Interdisciplinary Work

- Fostering a culture of collaboration (requirements, training, team building)
- Inter-professional exchange/development/agreement about views on care and pathways
- Transfer of information (joint care plans, registers/files)
- Accountability, responsibilities, dealing with hierarchies and professional-cultural clashes
- New ways of involving older people and/or informal carers

4. Management and Leadership

4.1 Management and leadership competence and skills

- Foster leadership and management using appropriate training
- Establish management and leadership competences in organisations through mentorship, secondment and shadowing
- Establish leadership competencies regarding the management of networks

4.2 Quality assurance at workforce levels

- Training of professionals in interdisciplinary/interprofessional working
- Enabling interprofessional knowledge transfer
- Fostering diversity-sensitive knowledge and attitudes of staff, promote and make use of multi-ethnic teams
- Shaping job profiles, fostering and mutual understanding of comprehensive pathways
- Establishing competence regarding preventive and rehabilitative LTC
- Establishing competence and providing capacity for supporting and negotiating with older people and/or informal carers at their level

4.3 Contractual or pre-contractual bases of pathway links

- Using contracts or agreements to enable and sustain processes between services and/or organisations
- Contracts or agreements that link between services professionally and managerially
- Contracts or agreements that specify funding across services

4.4 Administrative support at interfaces

- How organisations foster enabling administrative patterns as well as processes between services or organisations, making administrative systems compatible, reducing administrative burden

4.5 Ensuring relationships with stakeholders

- Enable participation of older people and carers' representatives in shaping pathways and appropriate linkages Ensure conditions for older people's and carers' shared decision-making
- Mobilise volunteers' organisations, and ensure their participation
- Consider socio-economic, socio-cultural and gender differences of older people and carers

4.6 Quality management

- Approaches for promoting and facilitating the quality of mechanisms in relation to linkage, networking, coordination or integration of agencies and organisations
- Approaches to ensure diversity-suitable structures and processes
- Approaches to ensure high quality structures and processes involving informal carers
- Approaches to shape preventive and rehabilitative structures and processes
- Approaches focusing on quality of structures, processes and results of LTC providers
- Approaches to measure and consider user satisfaction

5. Organisational Structures

5.1 Nursing and residential care homes

- Multi-disciplinary teams
- Structures that facilitate individual and multi-professional care planning
- Integrated access points (eg concerning referral, financial issues, payment regulation, one-stop-shops)
- Programmes integrating prevention/rehabilitation/reintegration
- Facilities that help preserving and maintaining informal family relationships
- Structures that facilitate free choice and access to additional external services including medical (own GP), social (own hairdresser, friendships) or voluntary services
- Diversity-friendliness: recognition of the specific care needs of hard-to-reach groups

5.2 Care within a hospital setting

- Multi-professional teams for assessment, care and treatment
- Flexible out-patient/out-reach services/ geriatric ambulatory teams
- Integrated prevention, rehabilitation/remobilisation/reintegration programmes
- Access points (referral, one-stop-shops)
- Day clinic services
- Structures that facilitate communication and planning with existing formal care resources and informal carers
- Structures that facilitate integrated discharge and follow-up planning
- Diversity-friendliness: recognition of the specific care needs of hard-to-reach groups

5.3 Transitory care facilities

- Structures that facilitate communication and planning with formal care resources and informal carers
- Access points (referral, one-stop-shops)
- Structures that facilitate re-assessment and follow-up planning
- Structures that facilitate individual and multi-professional care planning
- Integrated prevention/rehabilitation/remobilisation/reintegration programmes

- Diversity-friendliness: recognition of the specific care needs of hard-to-reach groups

5.4 Assisted living arrangements

- Structures that facilitate individual and multi-professional planning of care and living arrangements e.g., care communities, small units, service housing, sheltered housing (i.e., without care facilities)
- Access points (referral, one-stop-shops)
- Structures that facilitate preserving and maintaining informal family relationships
- Structures that facilitate free choice and access to additional external services including medical (e.g., own GP), social (e.g., own hairdresser, friendships) or voluntary services
- Structures that facilitate coordination with formal care resources (e.g., prevention and/or rehabilitation)

5.5 Formal care in the home and the community

- Access points (referral, counselling, one-stop-shops)
- Flexible and adaptable services to suit individual needs and individual lifestyle
- Multi-professional teams (e.g., preventive/rehabilitative measures)
- Structures that facilitate coordination and cooperation with other formal and/or informal care
- Structures that facilitate communication, planning and care delivery with informal carers
- Practitioners in independent practice as gate keepers and/or personal case and care managers
- Diversity-friendliness: recognition of the specific care needs of hard-to-reach groups

5.6 Specialised case or care management centres

- Access points (referral, counselling, one-stop-shops)
- Structures that facilitate multi-professional and inter-agency care planning and coordination
- Structures that are responsible for care planning and coordination between different kinds of services (as independent provider)
- Diversity-friendliness: recognition of the specific care needs of hard-to-reach groups

6. Means and Resources

6.1 (Shared) funding

- Types of funding (insurance-based vs. tax-based)
- Financial incentives between different levels of funding (national vs. regional or local; health vs. social; formal vs. informal levels; the role of insurance companies/agencies)
- Commissioning and contracting with individual or pooled budgets

6.2 Enabling, allocating and funding human resources

- Recruiting models (including ethical international recruitment)
- Levels of payment of staff in LTC
- (New) job profiles in LTC
- Innovative education or career patterns

6.3 Supporting informal carers as a resource for LTC

- Financial support schemes for informal carers and their funding
- Funding of services, training and other in-kind support directed at informal carers
- Funding of initiatives to reconcile work and caring

6.4 Financial indicators

- Expenditures for LTC as a percentage of GDP
- Percentage of population with LTC needs in residential care as opposed to home care
- Percentage of population with LTC needs using community care services
- Number of staff working in LTC (as a percentage of total workforce)
- Percentage of funding by stakeholders (public, private out-of-pocket, other)

6.5 Outcome indicators

- Initiatives that strive to develop and implement outcome indicators
- Costs of different services in relation to number of users
- Methods and indicators used to measure quality of service

6.6 Role of information technology

- IT solutions in ambient assisted living and smart housing
- IT solutions in LTC management
- IT applications at the interfaces between health and social care professionals
- IT applications at the interfaces between health and social care administrations
- IT applications at the interfaces between formal and informal care

Appendix B

Sample Interview Questions

Sample Initial Interview Questions

1. The following services are offered to seniors through home and community care (community nursing, community rehabilitation, adult day services, home support, choice in supports for independent living, caregiver respite, assisted living, group homes, family care homes, palliative care, and short- and long-term residential care).
6. Do you believe that in BC seniors currently have adequate access to these home and community care services?
 - b. Are there any services currently not being offered to seniors which you think should be provided?
7. The importance of non-medical home support services (eg., housekeeping, meal preparation, etc.) often is overlooked by health care systems. How important do you think these services are for seniors? Do you believe there currently is adequate access to these types of services?
8. Do you believe that the home and community care system in BC is easy for seniors to navigate?
 - a. Can you think of any ways the home and community care system could be made easier for seniors to navigate?
9. Do you believe home and community care services are adequately integrated with other sectors of the health and social care system (ie., hospital care, primary care, social care, voluntary sector)?
10. Do you believe adequate support is provided to caregivers in BC?
11. What do you believe is working well in our home and community care system?
12. Can you think of any best practices in home and community care from BC or other regions which you would like to see implemented or more widely disseminated?
13. What do you believe are the areas in our home and community care system that need the most improvement?
8. Do you think BC should develop a provincial strategy for continuing care services?
14. How do you think the home and community care system could be improved? What is your vision for home and community care in BC?

15. Is there anything else you would like to say about home and community care services for seniors in BC?

Sample Follow-up Interview Questions

1. Have you observed any changes (e.g., changes in accessibility, delivery, coordination, integration with other services, services available, ease of navigation, etc.) to the home and community care system in the past 3-4 years in BC? If yes, please describe these changes.

a) Do you believe these changes have had a positive or negative impact on the home and community care system?

b) Overall, do you feel the home and community care system is currently able to meet the needs of older adults and their caregivers in BC?

2. Past interviews highlighted gaps in services for older adults requiring “non-medical” home supports and preventative community services which are often provided by the community sector. Do you believe any improvements have been made in this area?

3. What do you believe are the most important challenges to the home and community care system in BC?

4. The integration of primary and community care services has been a key priority of the BC Ministry of Health.

a) What impacts do you believe efforts to integrate primary and community care services have had on a) care for older adults and b) the home and community care system?

b) Can you think of any examples of specific initiatives to integrate primary and community care services that you believe have improved care for older adults?

5. Are there any initiatives or innovations that you believe are having a positive impact on home and community care in BC?

6. How would you describe the current vision of the Ministry of Health and health authorities for home and community care for older adults?

Appendix C

Document Analysis Questions

First Round of Document Analysis

- What values are expressed in the document?
- What are the key policy issues discussed in the document? How are these policy issues framed?
- What rationale is provided for the proposed vision/policy/strategy in the document?
- What policy instruments or actions are proposed in the document?
- How are the tensions and links between health–social care and formal–informal care addressed in the document?
- How are older adults and caregivers referenced in the document?

Second Round of Document Analysis

- Is the important role of caregivers acknowledged in the document? If yes, are there concrete actions proposed to support caregivers?
- How are policy objectives on providing care in the home framed?
- Are the key rationales for action in the document driven by potential benefits for the older adults or the health care system?
- To what extent are home and community care services posed as a solution for other ills in the health care system?

Appendix D

Summary of Key BC Policy Documents: 1990-2010

Report	Key Findings and Recommendations
<p>Closer to Home: Summary of the Report of the British Columbia Royal Commission on Health Care and Costs. (Government of British Columbia, 1991)</p>	<ul style="list-style-type: none"> • The Commission proposed the following guidelines for the health care system: Providing care closer to home; Putting the public first; Outcomes (need to improve health outcomes and evaluate outcomes); Community involvement; Reforms within current levels of funding; the Jericho Process (integrated health care system); Necessary education (requirements for education and credentials are appropriate); Use of volunteers (but should not replace paid staff); and Openness of information. • In the report, in addition to providing care closer to home it was also emphasized that care for seniors should maximize autonomy and provide a continuum of care options. • The report recognized the needs (and challenges) of shifting resources from acute care to the community.
<p>Supportive housing in supportive communities (BC MOH, Ministry Responsible for Seniors, Ministry of Social Development and Economic Security, 1999)</p>	<ul style="list-style-type: none"> • This report does not recommend a specific model of supportive housing for BC and recognizes there are a range of models that may be appropriate for different communities. • The committee made five recommendations for supportive housing in BC: 1. Support local governments to address supportive housing initiatives in their communities; 2. Coordinate health and housing policies/practices to define the role of supportive housing; 3. Make supportive housing more affordable for low and middle-income seniors; 4. Develop consumer protection measures for supportive housing residents; and 5. Address the housing/support needs of seniors in emergency situations.
<p>The Picture of Health: How We are Modernizing British Columbia's Health Care System (BC Ministry of Health Planning, 2002)</p>	<ul style="list-style-type: none"> • This policy paper discussed the changes needed to modernize the BC health care system and provide better care to British Columbians, as well as control costs. • The consolidation and redesign of acute care services was a key strategy discussed in the paper. Other changes discussed include offering a broad range of choices for home and community care through the home and community care strategy, improving primary health care, expanding prevention and health promotion services, and addressing health human resource issues.
<p>Ageing well in British Columbia: Report of the Premier's Council on Aging and Seniors' Issues (Baird, 2006)</p>	<ul style="list-style-type: none"> • This report made recommendations in eight key areas: participation in society, transforming work, reshaping neighbourhoods, staying healthy, ensuring sufficient incomes, supporting independence, providing medical services, and implementation. • The recommendations relevant to home and community care included: providing a broader range of home support services, transferring non-medical home support services to a different ministry, pressuring federal government for additional funding for care in the home, enhancing respite and financial support for caregivers, ensuring there are sufficient long-term care beds, and primary care renewal.

<p>Developing a System of Non-Medical Home Support for British Columbians: A Background Paper (Byrne & Woods, 2007)</p>	<ul style="list-style-type: none"> • This background paper discussed various international and national examples of non-medical home support systems for older adults • The common principles for these systems that were identified included: citizen-centric, providing an integrated continuum of services, support independence and aging in place, choice and flexibility, prevention-focused, high quality services, evidence-based, engage stakeholders, equity, and support social inclusion.
<p>Seniors in British Columbia: A Healthy Living Framework (Government of BC, 2007a)</p>	<ul style="list-style-type: none"> • The Seniors Healthy Living Framework consisted of four cornerstones: Create age-friendly communities, Mobilize and support volunteerism, Promote healthy living, and Support older workers. • To implement the framework the Seniors' Healthy Living Secretariat was established within the Ministry of Healthy Living and Sport and one of its tasks was to explore innovative models of delivering non-medical home supports
<p>Summary of Input on the Conversation on Health (Government of BC, 2007b)</p>	<ul style="list-style-type: none"> • A summary of input was created reporting on the broad range of topics discussed in the consultations. • Input related to seniors included: concerns about costs of care, lack of continuity and coordination of care, the unfairness of being viewed as a burden on the health care system, and issues with quality of care. • Input related to home care and support included: lack of access to services, cuts and gaps in service delivery, lack of funding, the need for adequate caregiver supports and shortages of home care workers/poor working conditions. • Input related to long-term care and assisted living included: lack of access to beds and services, gaps in services, quality care issues, improving funding models, and staffing levels.
<p>Primary Health Care Charter: A Collaborative Approach (Government of BC, 2007c)</p>	<ul style="list-style-type: none"> • The charter proposed the development of integrated health network teams. • The charter identified 7 priority areas for primary care: 1. Improved access to primary health care; 2. Increased access to primary maternity care; 3. Increased chronic disease prevention; 4. Enhanced management of chronic diseases; 5. Improved coordination and management of co-morbidities; 6. Improved care for the frail elderly; and 7. Enhanced end-of-life care.