INTRODUCTION

# Connecting Health and Social Services for Patients with Complex Care Needs: A Pan-Canadian Comparative Policy Research Program

## Relier services de santé et services sociaux pour les patients ayant des besoins complexes en matière de soins : un programme pancanadien de recherche comparative sur les politiques


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## Abstract

Comprehensive primary healthcare for patients with complex care needs requires connections to other health services, social services and community supports. This descriptive comparative policy research program used publicly available documents and informant interviews to examine progress toward integrated comprehensive care through the lens of services needed by children and youth (0–25 years) and community-dwelling older adults (≥ 65 years) with high functional health needs. This article describes five projects. The following three findings emerged across all the projects: Canada indeed has multiple health systems; numerous integrated service delivery solutions are being trialled and most focus on medical services; and it is an ongoing challenge for ministries of health to engage physicians and physician associations in integration.

## Résumé

Pour offrir des soins de santé primaire globale, aux patients ayant des besoins complexes, il faut établir des liens avec les autres services de santé, les services sociaux ainsi que le soutien communautaire. Ce programme descriptif de recherche comparative sur les politiques a recours aux documents publiquement accessibles et à des entrevues avec des clés informateurs pour examiner les progrès réalisés dans l'atteinte des soins intégrés globaux selon les services dont ont besoin les enfants et les jeunes (de 0 à 25 ans) ainsi que les aînés (≥ 65 ans) qui vivent dans la communauté et ont de forts besoins en matière de santé fonctionnelle. Cet article décrit cinq projets. Les trois constatations suivantes sont ressorties de chacun des projets : le Canada a effectivement plusieurs systèmes de santé; de nombreuses solutions intégrées de prestation de services sont mises à l'essai et la plupart sont axées sur les services médicaux; et il est toujours difficile pour les ministères de la Santé de faire participer les médecins et les associations de médecins aux initiatives d'intégration.

## Introduction

Primary care in the Canadian healthcare system is responsible for first contact and ongoing care to a practice population undifferentiated by age, gender or disease status. Primary care should be organized to be the Patient's Medical Home for person-centred longitudinal care even when patients receive services elsewhere (CFPC 2011). The integrated care framework developed by Valentijn et al. (2013) posits that achieving comprehensive primary care for a defined population requires integration of services beyond the health sector to include social sectors and community-based organizations.

Primary healthcare, as defined aspirationally by the World Health Organization (WHO 1978, 2018), includes health, social and community services that meet the health needs of individuals throughout their life. Since the Canadian health system focuses predominantly on primary care, achieving primary healthcare requires integration of primary care (or the Patient's Medical Home) with other health services, social services and community supports. This special issue of *Healthcare Policy* presents eight linked articles that describe and compare policies and initiatives across Canada, which integrate services across health and social sectors from the perspective of primary care and especially for those with complex care needs.

Comprehensive, integrated primary healthcare is critical for all primary care patients but especially for those with multiple chronic diseases in addition to functional health limitations and social vulnerabilities, such as limited income or social isolation. Patients with complex care needs require smooth coordination and communication among primary care, specialised care, social services and community supports (Jones et al. 2020; Miller et al. 2009). Failure to connect (discontinuity) needed services leads to negative experiences for patients, caregivers and health professionals (Bayliss et al. 2015; Foglino et al. 2016; McCormack et al. 2008), as well as health deterioration, expensive healthcare interventions and costly social consequences (Hwang et al. 2013; Nolte and Pitchforth 2014; Paré et al. 2014).

The importance of integrating health and social services to achieve comprehensive and coordinated care is more often invoked than defined. A 2009 review of healthcare integration reported 175 definitions and concepts in 70 papers (Armitage et al. 2009). For this research program, we defined service integration policies as the governance, funding, strategic, organizational and programmatic directives that aim to facilitate coordination and collaboration among organizations and service providers whose complementary actions work together to achieve desired health outcomes for patients with complex care needs (Villeneuve 2017). Policies are statements of direction that result from decision-making processes. They guide action and are informed by data and evidence (Villeneuve 2017). Macro-level legislative policies, such as the *Canada Health Act* (1985), guide national or provincial authority and governance. Strategic policies such as the 2001 First Ministers Health Accord (Health Canada 2006) guide funding allocations to high-level priorities, such as primary care renewal or the COVID-19 pandemic. Meso-level or programmatic and operational policies pertain to organizations with complementary actions and facilitate connection, communication and

coordinated actions in pursuit of a common objective. An example of a common objective is avoiding institutional care for older adults through facilitated linkages of primary care, day hospitals and home care.

Among the initiatives to promote integrated health-related services in Canada, the pan-Canadian SPOR [Strategy for Patient-Oriented Research] Network in Primary and Integrated Health Care Innovations promoted cross-jurisdictional research and knowledge exchange "to accelerate the pace of integrated care solutions" (CIHR 2016). A priority that emerged across all provinces in 2016 was the need to identify, describe and compare initiatives across Canada to integrate services across health and social sectors for primary care patients with complex care needs.

Our pan-Canadian team (see p. 105) obtained funding from 10 different funders (see "Acknowledgment," p. 108) to conduct a comparative descriptive policy and program analysis with the following objectives:

- to describe and compare the structures and policies in Canadian provinces that govern primary care, community-based social services and community supports required for patients with complex healthcare needs;
- to identify exemplar publicly funded programs that connect primary care to health and social services and to community supports, and to assess facilitators and barriers to successful implementation and integration; and
- to identify recurring policy barriers to and facilitators of data linkage and information sharing across health and social services in key provinces.

This article is an overview of the research program reported in all the articles in this issue. We provide a brief description of the methods of the component projects and key findings that emerged across the different projects. Project-specific results are presented in the relevant papers of this issue.

## Methodology

The research program presented in the articles of this issue consists of key projects, each uniquely focusing on aspects of healthcare integration in Canada since the 2001 First Ministers Health Accord that launched the renewal of primary care in Canada (Health Canada 2007). We focused on the 10 provinces for pragmatic and feasibility reasons reflecting the location of our research team. The majority of the data collection regarding policies and programs occurred during 2018 and into 2019.

The study team involved 46 researchers, clinicians, patient partners and decision makers from all 10 Canadian provinces. The five projects are:

- Consensus on the priority services to be connected for patients with complex care needs.

- Scanning of publicly available documents on macro-level policies that relate to the governance and scope of action of primary care and the priority services.
- Identification of exemplar programs for youth and children and the assessment of the degree of integration.
- Identification of exemplar programs for older adults and the assessment of the degree of integration.
- Comparative health reform analysis of selected exemplar programs.

Project leadership was distributed among principal investigators in Quebec (J. Haggerty, A. Quesnel-Vallée, Y. Couturier,), Manitoba (T. Stewart), New Brunswick/Prince Edward Island (S. Doucet, W. Montelpare), Nova Scotia (R. Urquhart), Alberta (C.M. Scott) and British Columbia (N.D. Oelke).

## *Study population*

The focus of the research presented in the articles of this issue is patients who were managed in primary care clinics, although they had complex care needs that required connection to other medical, social and community-based services to maintain functional health or mitigate its decline. Functional health refers to a person's capacity to carry out activities of daily living that permit the achievement or maintenance of personal autonomy and social integration (Bierman 2001). This outcome is relevant to primary care because it transcends disease categories and encompasses physical, emotional and social dimensions of health. Inspired by the tracer condition methodology (Nutting et al. 1981), we examined the policy and programs through the lens of two patient subgroups: children and youth; and older adults. It is the expectation that policy and programs for these groups will be relevant to other subpopulations that require integration among primary care, social services and community supports.

### CHILDREN AND YOUTH (0–25 YEARS) WITH HIGH FUNCTIONAL HEALTH NEEDS

Children and youth with complex care needs are those with one or more chronic physical, emotional, developmental, neurological or behavioural conditions (Cohen et al. 2012; Goyette et al. 2011), estimated as between 15 and 18% of North American children (Berry et al. 2011; Kaufman et al. 2007). They typically require a high volume of healthcare services, as well as social, educational and community supports, to optimize the development of autonomy and enhance social integration (Cohen et al. 2011, 2012; Kaufman et al. 2007).

### COMMUNITY-DWELLING OLDER ADULTS (≥ 65 YEARS) EXPERIENCING FUNCTIONAL DECLINE

Older adults are living longer and over half have multiple chronic health conditions (CIHI 2011; Doupe et al. 2016). Services across the health, social and community sectors have to be mobilized – sometimes quickly in response to health or social crises – to prevent health decline and maintain community-dwelling autonomy for older adults as long as possible (Hébert 1997; Hoogerduijn et al. 2007).

## Summary of Projects and Results

### *Project #1: Consensus on priority services to be connected*

As a foundation for the research program, the team conducted a rapid consensus process, wherein all co-investigators and collaborators were invited to propose health, social and/or community services that should be linked to ensure integrated comprehensive primary healthcare for one of the two patient groups they best understood. A broad range of services were identified and defined separately for children and youth and for older adults using an electronic nominal group technique (Gallagher et al. 1993). After making an operational definition for each service, the team conducted a modified Delphi study to prioritize the service based on frequency of need and potential health impact of connecting to the service. The top 10 services for each group formed the backbone for the subsequent projects. As reported in the article by Dionne et al. (2023a), most of the top 10 priority services to be linked to primary care are traditional health services, but some are common to both patient groups and together represent a priority for integrating services.

### *Project #2: Scan of provincial governance and scope of primary care and priority services*

Publicly available information from government websites was captured in a data-collection template for each province (Appendix 1, available online at www.longwoods.com/content 27186) that identified the then-current institutional authorities that governed primary care in each province and any relevant macro-level policies affecting primary care since 2001. The team also located the governance entity responsible for each of the top 10 priority services to be connected. The provincial data were transformed into a provincial narrative summary. Summaries were validated by key informants in each province, then analyzed independently by the senior investigators (JH, CS, YC) by the immersion–crystallization method to gather insights and discern patterns (Borkan 1999). The article by Scott et al. (2023) affirms that health service integration has been a persistent policy ambition across provinces. The article by Haggerty et al. (2023) on the prevalent and emerging primary care delivery models and their comprehensiveness reports that federal investments led to an ongoing process of primary care renewal that is more evident in some provinces than others, and that more comprehensive primary care models are the norm in at least five provinces. Policies and structures to integrate social care and community supports with healthcare are still nascent, however.

### *Project #3: Innovative programs for children and youth*

All the co-investigators and collaborators were invited to identify programs in their own provinces that integrated health and social care for children and youth with complex care needs. From these, 16 were selected (at least one per province) as innovative and with potential for scalability. The team developed a tool to assign an integration score to each program to reflect the achievement of 10 principles of care integration (Suter et al. 2009) and

nine implementation facilitators (Damschroder et al. 2009). The team obtained information about the 16 programs from publicly available online documents and key informants. However, a lack of publicly available information precluded the application of the integration measure for a comparative analysis, an issue that is presented in more detail in the article by Stewart et al. (2023b), including the policy implications. The information that was available was used to create program summaries, and 14 of the children and youth co-investigators engaged in a deliberation conversation to identify pan-Canadian trends, as well as strengths and weaknesses that emerged across programs.

The article by Dionne et al. (2023b) reports on the findings, noting several programs that are exemplars of integration across the health and social divide.

### *Project #4: Innovative programs for older adults*

The program identification and data collection was identical to that for children and youth and, again, the paucity of publicly available information posed a challenge to comparative program analyses. As reported in the article by Stewart et al. (2023a), integration pertained predominantly to services in the health system and formal linkage to primary care was rare.

### *Project #5: Comparative health reform analysis of selected innovative programs*

For the comparative health reform analysis, the research team selected and obtained additional information about three programs in three provinces that addressed a similar issue. They identified the factors that influenced how and why each program started (Kingdon 2003), and how institutions, interests, ideas and external factors contributed to the program design (Bates and Andrew 2003; Hall 1997). Finally, the team identified the strengths, weaknesses, opportunities and challenges for implementation and program scale up. The selected children and youth programs focused on integration between primary care and social services but the analysis was not completed and is not included in this special issue. The older adults analysis compared three programs to integrate community-based care for major neurocognitive disorders and has been published elsewhere (Crowell et al. 2020). The findings of the comparative analyses echo the results of the children and youth programs (Dionne et al. 2023b) and the older adults programs (Stewart et al. 2023a). Their policy implications are coherent with other projects in the research program; namely, that building around existing institutional infrastructure and new primary care delivery models facilitates implementation, and that local champions are both critical and a source of fragility.

## Common Findings across Projects

A common frustration and three findings emerged across all of the projects. The common frustration was the difficulty of finding information and how uneven information availability was across provinces. The difficulty of finding information about public policies and structures thwarted our original objectives in assessing the extent to which integration occurred in innovative programs and the lessons for implementation and scale up.

This frustration led to an unanticipated article on the paucity of publicly available information (Stewart et al. 2023b).

Among the three recurring findings, the first affirms the oft-repeated maxim that Canada has multiple health systems but also affirms the importance of federal and national policies in implementing and scaling up better and more equitable healthcare delivery options in all the health systems. A second – and hopeful – finding is the sheer number of integrated service delivery solutions and programs across the country; less hopeful is the limited scale up and cross-provincial learning. A third, if incidental, finding pertains to the policy and implementation challenge of engaging physicians and physician associations in comprehensive integrated care delivery solutions when they are outside the governance purview of the ministry of health.

## Discussion

Here, we briefly discuss some policy implications of each of the three findings that emerged across the projects. We also refer readers to the other articles in the issue that address common challenges in integrating health and social services: multiple health systems, multiple innovations and the challenge of engaging physicians in integration.

### *Multiple healthcare systems and national policies*

The structure and administration of healthcare in Canada rests jointly with federal, provincial and territorial governments. The oft-repeated maxim of 10 different provincial health systems became very evident in the scan of governance structures pertaining to primary care renewal and priority services. As pointed out in the article by Scott et al. (2023), even the nomenclature of hierarchical units in organizational charts for the provincial ministries of health was not comparable among provinces. There were striking similarities, however, in the names – and structures of services had been the object of federal or national policies such as the 2004 Health Accord on home care (Health Canada 2007) and the Mental Health Commission (https://mentalhealthcommission.ca).

Our findings point to the critical influence that policy decision making at a federal level or through cross-provincial accords has on the harmonized allocation of financing and service delivery in provincial and territorial jurisdictions. The integrated care programs for older adults with major neurocognitive disorders were initiated and sustained by the *National Strategy for Alzheimer's Disease and Other Dementias Act* (2017) (Stewart et al. 2023a). Ongoing investment by provinces in strengthening primary care is based on the initial federal investment in the Primary Health Care Transition Fund (Health Canada 2007; Hutchison et al. 2011). Guarantees in the *Canada Health Act* (1985) have created a sense of security among Canadians that they will have access to similar medical service coverage, regardless of jurisdiction. The *Canada Health Act* (1985) only addresses the criteria for transfers pertaining to publicly funded medical services, and it consequently defines comprehensiveness narrowly as "medically-necessary services." The recent experience with the COVID-19

pandemic highlighted to the Canadian public the differences in public health recommendations among provinces, the unequal health consequences between social and racial groups and the fragility of children and youth and of older adults. From our conversations with patient partners (Haggerty and Scott 2023), we think that the Canadian public expects more than just medical services from the health system and wants fewer, not more, differences between provincial health systems. We strongly recommend that it is time to revive federal and cross-provincial conversations to arrive at health accords that expand the definition of comprehensiveness to include health and social service integration, and ensure that Canadians receive the health and social services they require, regardless of jurisdiction.

### *So many integrated service delivery innovations, so little scale up*

Our informal elicitation of exemplary integrated service delivery solutions and programs for both youth and children and older adults across the country revealed a surprisingly large number that started from 2001. This is a testament to the capacity for innovation and the relevance of integration for patients, caregivers, clinicians and policy makers. Programs for children and youth are often grounded in patients' needs and well supported by the community (Dionne et al. 2023b). But the implied sigh of "So much innovation, so little change" (Hutchison et al. 2001), alas, still holds true.

Many of the programs reviewed were pilot or research projects that did not survive end of funding, or they were local programs that were not spread or scaled up because they were so dependent on local champions. Formal program evaluation was rare and, even when available, did not address key dimensions of integration, such as information systems and financial management that are so important to policies for scale up (Stewart et al. 2023b). If our health-related services and system seem anachronistic and calcified, it is not for lack of innovativeness, lack of information or desire for change.

The capacity of provinces to learn from each other to spread and scale up innovations also requires a commitment to making relevant information more available. Inter-jurisdictional differences in regulations on privacy limit information sharing that can inform policy making to support allocation of financial and human resources to assist scale up within a province (Stewart et al. 2023b). It is time for a national dialogue on strategies to facilitate information sharing and to engage the public in understanding the implications of the status quo, much as was done for the Romanow Commission (Romanow 2002). Likewise, evaluation should be an expectation of any new program, especially programs that receive public funding, with the results publicly available in a program repository. The obligatory evaluation of the Primary Health Care Transition Fund may be part of the reason that provinces such as British Columbia, Prince Edward Island and Newfoundland and Labrador were able to trial primary care delivery models, such as the primary care networks, more than a decade after funding ended (Haggerty et al. 2023).

### *Engaging physicians and physician associations in integration policies*

Canadians are justly proud of the policy achievement of universal no-cost coverage of

medically necessary hospital and ambulatory services under the *Medical Care Act* (Government of Canada 1966). However, the negotiated social contract with organized medicine to achieve the Act gave physicians the right to function as private entrepreneurs largely outside the purview of health system governance despite being publicly funded. Clinician integration has been recognized as a challenge even in integrated delivery systems where physicians have an employee–employer relationship (Shortell et al. 2001), so it is not surprising that clinician integration is such a challenge in Canada. An achievement of the many primary care renewal delivery models is that they not only increased comprehensiveness available to patients but also brought autonomous family practices within the governance and policy reach of the ministry of health (Haggerty et al. 2023). The strong network of primary care renewal models in Ontario provided an infrastructure for the spread of integrated programs for older adults with neurocognitive disorders, which was missing for a similar program in Saskatchewan (Crowell et al. 2020). This shows that the benefits extend beyond mere ministry of health influence. The emergence of competing family medicine models designed explicitly to align closely with the model promoted by the College of Family Physicians of Canada (CFPC 2011, 2019) rather than similar ministry of health models in New Brunswick speak to the challenge of fully engaging physicians in ministry of health solutions. The recurring support by physician associations of policies promoting a stronger presence of private healthcare is worrying and could undermine the comprehensiveness, universality, public administration, portability and accessibility guaranteed in the *Canada Health Act* (1985).

## Implications for Policy

National policies such as the *Medical Care Act* (Government of Canada 1966), the *Canada Health Act* (1985) and the Health Accords (2001, 2004) (Health Canada 2006, 2007) and subsequent national initiatives, such as the Primary Health Care Transition Fund (2002–2006) (Health Canada 2007), have created a solid foundation on which to build policies for and collaborate on more comprehensive and integrated care for all Canadians and especially for those with complex care needs. Recent calls from provincial and territorial governments for the federal government to add more money to healthcare and support for more private healthcare have the potential to perpetuate the status quo of a narrow basket of medical care that ignores the social determinants of health and creates healthcare inequity.

Over 150 reports commissioned by governments to study the Canadian health systems have provided recommendations on what we can do better, but few of these recommendations have been implemented (Picard 2022). We do not need more national and provincial strategy reports, nor do we need to inject more money for more administrative restructuring. We need cross-provincial accords (through the Council of the Federation) in collaboration with the federal government, care providers and the public to identify a pathway toward integrated care. We have learned through the COVID-19 pandemic that policy making and changes in service delivery can be nimble when there is a crisis that transcends the interests of any one group.

This research program (with ambitious goals and a modest budget) responded to a felt need in a large group of Canadian health service and policy researchers and decision-making partners to have access to information to support cross-jurisdictional knowledge exchange and learning that would accelerate implementation of integrated care delivery solutions. We vastly underestimated the resources required to obtain even descriptive information. However modest, we hope that our results will be a stepping stone toward the creation of a Canadian repository of the ever-changing structures of our 13 Canadian health systems and also a directory of innovative programs and their evaluation. Meaningful learning and cross-jurisdictional spread of innovation depends on policy makers, researchers and patients having access to such information.

## Conclusion

The articles in this special issue take stock of the integration of priority services for chronic illness in children and youth and older adults with high functional health needs. The findings in these two groups likely pertain to other patient groups, and they suggest that we have not yet achieved integration of medical services, let alone integration of health and social services. Addressing the growing need for chronic illness management in Canada demands better integration of health and social services and the mobilization of community supports. What is needed is a renewed health accord that intentionally complements the *Canada Health Act* (1985) using a social determinants of health lens to integrate health and social services.

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