ORIGINAL ARTICLE

Policy programs and service delivery models for older adults and their caregivers: Comparing three provinces and two states

Allie Peckham MSW, PhD[1,2] | Marianne Saragosa PhDc[1,2] | Madeline King MSc[2,3] | Monika Roerig MA, BSc[2,3] | James Shaw PhD[3,4] | Stephen Bornstein PhD[5,6] | Kimberlyn McGrail PhD[7] | Madeline Morris DNPc[8] | Yuchi Young PhD[9] | Maksim V. Papenkov BA[10] | Greg Marchildon JD, PhD[2,3]

[1]Edson College of Nursing and Health Innovation, Arizona State University, Phoenix, Arizona, USA

[2]North American Observatory on Health Systems and Policies, Toronto, Ontario, Canada

[3]Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Ontario, Canada

[4]Department of Physical Therapy, Temerty Faculty of Medicine, University of Toronto, Toronto, Ontario, Canada

[5]Department of Political Science Memorial University, St. John's, Newfoundland and Labrador, Canada

[6]Community Health and Humanities, Faculty of Medicine, Memorial University, St. John's, Newfoundland and Labrador, Canada

[7]Centre for Health Services and Policy Research, School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada

[8]College of Nursing and Health Sciences, University of Vermont, Burlington, Vermont, USA

[9]School of Public Health, Department of Health Policy, Management & Behavior, State University of New York at Albany, Albany, New York, USA

[10]School of Arts and Sciences, Department of Economics, State University of New York at Albany, Albany, New York, USA

Correspondence
Allie Peckham, Edson College of Nursing and Health Innovation, Arizona State University, 550 N 3rd Street Phoenix Arizona 85004, USA.
Email: allie.peckham@asu.edu

Funding information
This work was supported by the Canadian Institute for Health Research (CIHR) #150705 and the Alzheimer Society of Canada #17D.

Abstract

Despite an increase in prevalence of complex chronic conditions and dementia, long-term care services are being continuously pushed out of institutional settings and into the home and community. The majority of people living with dementia in Canada and the United States (U.S.) live at home with support provided by family, friends or other unpaid caregivers. Ten dementia care policy programs and service delivery models across five different North American jurisdictions in Canada and the U.S. are compared deductively using a comparative policy framework originally developed by Richard Rose. One aim of this research was to understand *how* different jurisdictions have worked to reduce the fragmentation of dementia care. Another aim is to assess, relying on the theory of smart policy layering, the extent to which these policy efforts 'patch' health system structures or add to system redundancies. We find that these programs were introduced in a manner that did not fully consider how to patch current programs and services and thus risk creating further system redundancies. The implementation of these policy programs may have led to policy layers, and potentially to tension among different policies and unintended consequences. One approach to reducing these negative impacts is to implement evaluative efforts that assess 'goodness of fit'. The degree to which these programs have embedded these

efforts into an existing policy infrastructure successfully is low, with the possible exception of one program in NY.

1 | INTRODUCTION

Dementia is the most common form of neurodegenerative disorder and involves symptoms that reduce ability to function and perform everyday activities. The physical, psychological, social and economic impact affect those living with the disease, their unpaid caregivers and society (World Health Organisation, 2019). One in 10 people in the United States (U.S.) age 65 and older have Alzheimer's-related dementia (Alzheimer's Association, 2018; 2019). In 2019, the estimated total global economic cost of dementia was U.S. $1.3 trillion, and the costs are expected to surpass U.S. $2.8 trillion by 2030 (Alzheimer's Association, 2019; World Health Organization, 2021).

Canadian-based literature predicts a 7% drop in Canadians with dementia living in residential long-term care between 2008 and 2038 (Alzheimer Society of Canada, 2010). This trend is in part due to a shift in focus to care provided in community and home care settings (Alzheimer Society of Canada, 2010). Similarly, in the U.S., Medicaid programs are moving long-term care services from institutional care to home and community-based services. More Americans with dementia are living and dying at home: people with dementia who died in nursing homes decreased from 68% to 51% between 1999 and 2016 (2020 Alzheimer's Disease Facts and Figures, 2020), while deaths at home increased from 14% to 27% during the same period (Lepore, 2017).

This shift in care settings is, in part the result of policy efforts to contain health system spending while meeting the popular demand for aging in place (Marek et al., 2012). These otherwise laudable policy efforts rely on the ever-increasing time of unpaid caregivers to support older adults with dementia in community settings (Kasper et al., 2015). Unpaid caregivers of persons living with dementia spend more hours per week than caregivers of individuals without dementia—26h compared to 17, respectively (Canadian Institute for Health Innovation, 2018a,b). The estimated annual value of this care in Canada has been reported at CAD$230.1 billion, in addition to caregivers' reported out-of-pocket expenses amounting to CAD$1.4 billion (Canadian Institute for Health Innovation, 2018b; Lepore, 2017). The U.S. reports similar statistics with an estimated 18.4 billion hours of care, valued at over USD$232 billion, provided by unpaid caregivers in 2017 (Alzheimer's Association, 2018). In the U.S., family, friends and other unpaid caregivers provide 83% of the care for older adults (Alzheimer's Association, 2018). Lower levels of perceived life satisfaction and higher rates of depression and anxiety have been found in such caregivers when compared to those caring for non-impaired people (Berger et al., 2005).

What is known about the topic

- Dementia has significant social and economic impacts for individuals and communities.
- Efforts to meet the needs of individuals living with dementia and their caregivers have increased in prevalence.
- The degree to which these support efforts are meeting the needs of people remains unknown.

What this paper adds

- This research offers an understanding of how five different jurisdictions have worked to support the needs of individuals living with dementia and their caregivers.
- Relying on the concept of policy layering, this research offers an assessment of the degree to which these programs are sustainable.

In recent years, some subnational governments in both countries have funded and otherwise encouraged the coordination of community-based services to support these populations (Mark, 2016). The availability of home and community-based services, including respite care, assistance with personal care and educational opportunities on disease trajectories can support and sustain patient-caregiver dyads in the community (Forbes et al., 2008). Even when community health and support services are available, research demonstrates that these services are underutilised and lack meaningful integration or coordination (Brodaty et al., 2005; Ploeg et al., 2009; Robinson et al., 2005).

While much attention has been given to care coordination for older adults living with complex needs to address fragmented and inefficient healthcare systems, the degree to which these efforts have been effective remains unknown (Hughes et al., 2017). Institutional barriers involving reimbursement structures, limited team-based approaches and limited use of electronic medical records, as well as sub-sectoral politics seem to provide additional challenges. (Hughes et al., 2017; Peckham, Morton-Chang, et al., 2018; Sanna & Reuben, 2013; Weiner et al., 2017).

We conducted a comparative analysis of policy programs in five North American jurisdictions, (British Columbia [BC], Ontario [ON], Newfoundland and Labrador [NL], New York State [NY] and the state of Vermont [VT]). Our approach is to assess the design of these policy programs rather than their outcomes in order to understand the extent to which each is seeking to offer a coordinated experience for caregivers

and those living with dementia. Given that these policy programs are all aiming to improve integration and care coordination we rely on the concept of *smart policy layering* to provide an assessment of *if and how* these approaches to care may offer a foundation for longer-term structural change. Care coordination efforts have been on the political agenda for decades, with some efforts demonstrating more lasting impacts. The policy programs assessed were mostly time-limited tests of new models of care delivery with the intent of improving system integration and co-ordination. This research relies on the concepts of incrementalism and smart policy layering to assess if these approaches have the potential to reduce institutional barriers and achieve a more coordinated health and social service delivery model by patching the current gaps in the system rather than layering onto the current policy mix (Rudoler et al., 2019).

2 | METHODS

This research was conducted as part of a larger mixed methods study funded by the Canadian Institutes of Health Research and the Alzheimer Society of Canada. In developing the proposed study, these five jurisdictions were selected as they all have similar regulatory and institutional constraints, and all have seen a political drive to improve care coordination for individuals living with dementia and their caregivers. The first phase of this larger project was to conduct a jurisdictional review of these policy programs. These reviews were used to inform this analysis and the development of qualitative interviews for the second phase of the project. An adapted comparative public policy framework by Rose (2005) was used to synthesise the policy programs. Rose's framework involves seven elements: laws and regulations, organisational set-up, personnel, money, program outputs/objectives, program recipients and goals. Three additional elements were added to capture relevant information; policy initiatives, guidelines and strategic frameworks; information management and evaluation and leadership and priority setting. These additional elements were included to offer a richer understanding of the broader political context within which these policy programs are embedded. Please refer to Table 1 for a description of each of these elements.

2.1 | Document retrieval

Local experts completed the jurisdictional reviews. The reviews involved scanning public documents derived from academic and grey literature (e.g. program, government and para-government websites, media releases). A detailed summary of the search strategy for each jurisdiction has been published elsewhere (Ho & Peckham, 2017; Mackey & Bornstein, 2019; Morris & Baker, in press; Shaw, in press; Young & Papenkov, in press).

2.2 | Analysis

Analysis was done in two phases. Phase one involved an examination of the reviews (Ho & Peckham, 2017; Mackey & Bornstein, 2019;

Morris & Baker, in press; Shaw, in press; Young & Papenkov, in press). Phase two consisted of a deductive analysis of the findings from the jurisdictional reviews to categorise information based on the framework in Table 1. We developed data extraction forms to organise information about each policy program, including an inventory of documents and key details according to concepts in the Rose framework (see Table 3). The deductive analysis focused mainly on the results of the jurisdictional reviews. However, when information was unclear (MK, MS, AP) we went back to original documents to conduct a more thorough extraction. Researchers (MK, MS, AP) systematically identified, interpreted and synthesised the data within the extraction table. This process allowed us to describe and compare key features of the programs as well as to identify aspects of delivery and implementation to assess the extent to which these policy programs engage in the three elements of smart policy layering and determine potential long-lasting impact. We synthesised the key features of the policy programs and then assessed if they were implemented to (1) acknowledge and partner with the existing policy mix and programs, (2) with on-going evaluative approaches to flexibly adapt to maximise 'goodness of fit' and (3) if they were patching current system gaps (i.e. cross sectoral communication) that impact successful care coordination. The analytical process was enhanced through regular team meetings to address divergent interpretations.

3 | RESULTS

3.1 | Summary of policies and programs in five jurisdictions in North America

We identified policies and programs that were introduced between 2015 and 2017 and aimed to support unpaid caregivers and people living with dementia and other complex needs. Of the included programs, First Link was initiated first in ON in 2008 and later implemented across Canada, including NL in 2012 and BC in 2019. The ON government also initiated Health Links and Behavioural Support Ontario (BSO) in 2012. NL implemented the Protective Community Residence (PCR) program in 2009 and the Paid Family Caregiving Option in 2014. In 2013, the BC government started the Home First program, a province-wide publicly funded program (Government of British Columbia, n.d.).

In the U.S., the state of NY implemented the Delivery System Reform Incentive Payment (DSRIP) program in 2014, focusing on ambulatory intensive care units (DSRIP-AICUs) and, in 2015, the Alzheimer's Disease Community Assistance Program (AlzCAP). Finally, the state of VT expanded its managed care delivery system in 2017 and included Adult Day Services (ADS) as a reimbursable service. Under the National Family Caregiver Support Program (NFCSP) of 2000, VT offers caregiver support through the Dementia Respite Grant (DRG) Program. A description of the policy programs is presented in Table 2.

All findings are organised using the framework elements discussed above and summarised by jurisdiction in Table 3.

TABLE 1 Comparative policy framework applied to dementia-complex care with additional elements

	Element	Description
Analytic Framework Elements	Laws and regulations	The laws and regulations that inform the design and delivery of the policy program. Differentiating between provincial/state and/or federal laws and regulations
	Organisational set-up	The specific organisations that are involved in the delivery of services and their linkage with each other in delivering (or not delivering) on the objectives of the policy. Differentiating partnerships with provincial governments, other long-term care organisations, community organisations and NPOs, and/or hospitals
	Personnel	The type and distribution of human resources involved in delivering the services. Differentiating between funded personnel and leveraging existing personnel for both administrative personnel and healthcare professionals. Highlighting whether program includes case manager, physician, nurses, personal support workers, and/or other support staff
	Money	The amount and distribution of funding devoted to the functioning of the services. Differentiating between initial allocation and multi-year funding and highlighting whether the program is funded by the provincial/state government
	Program outputs/objectives	The specific activities and outcomes that will represent the performance of the program functions. Differentiating between an objective to increase timely access to care, create effective care plans, reduce readmission to hospital, reduce transfers to long-term care, increase awareness of supports, reduce financial burden for caregivers, and/or improve overall coordination of care
	Program recipients	The eligibility criteria that specify the types of individuals to be recipients of the services. Differentiating between programs aiming to serve people with multiple chronic conditions, people living with dementia, family and caregivers, healthcare professionals, and/or people who require financial support
	Goal(s)	The ultimate outcome(s) the program is intended to achieve overall. Differentiating between programs aiming to improve integrated health outcomes, support caregivers, increase disease knowledge, reduce costs of complex patients, reduce transfers to emergency, and/or delay admission to long-term care
Additional elements	Policy initiatives, guidelines and strategic frameworks	The political strategies and policies in place to support the development and implementation of the program. Differentiating between programs being supported by Provincial Action Plans, Mental Health Strategies, Dementia/Alzheimer's Strategies, and/or long-term care and Community Support Strategies
	Information management and evaluation	The ways in which health information systems are incorporated into service delivery. Differentiating between programs that have formal evaluations and/or accountable reporting in place and highlighting whether programs report to the government and/or an internal head office
	Leadership and priority setting	The champions of the program and the priorities of the program leaders at the policy level. Differentiating between champions at a Department of Health/Ministry of Health & long-term care level and individual provincial/state champions who advocate for the program

Source: Adapted from Rose, 2005

3.2 | Laws and regulations

State and provincial governments are responsible for social policy regulatory frameworks which, in turn, provide the legal architecture for most government interventions in dementia care. State legislation is mentioned in the NY and VT programs. The Paid Family Caregiving Option of the NL Provincial Support Program is linked to the *Regional Health Authority Act* and to the Provincial Home Support Program's Operational Standards. Because of the funding mechanisms of the U.S. health insurance programs, these programs are subject to federal laws, regulations and policies including the *Older Americans Act*, the *Social Security Act*, Medicare and Medicaid. Along with 38 other U.S. states, NY and VT

participate in the Medicaid 1115 Waiver Demonstration Program under the authority of section 1115(a) of the *Social Security Act* (Centers for Medicare & Medicaid Services [CMS], 2018). This inspired the DSRIP-AICUs and AlzCAP in NY, as well as the NY Medicaid Redesign Team who initiated the DSRIP program. VT's *Choices for Care Medicaid Waiver* lays out reimbursement for home and community-based services including ADS. The waiver allows for NY and VT to administer Medicaid funding that is otherwise not allowed under standard Medicaid laws (CMS, 2018).

National and subnational regulations are referenced in ON, NL, NY and VT. ADS are utilised for healthcare maintenance of adults in the U.S. since 1960 (O'Keefe & Siebenaler, 2006). The waiver demonstration allowed eligible Vermonters to utilise ADS to meet

TABLE 2 Selected policy programs in five north American jurisdictions

Jurisdiction	Policy program	Description
ON	Health Links	• Aims to reduce hospital admissions by enhancing the management of complex needs in community-based settings through inter-professional primary care (MOHLTC, 2012) • Provides coordinated care plans for patients living with complex needs (MOHLTC, 2015b) • Flexibly structured collaborations between organisations that receive funding from the Ministry of Health and Long-Term Care (Fairclough, 2016) and managed by independent healthcare organisations (Fairclough, 2016)
	Behavioural Support Ontario (BSO)	• Aims to safely manage residents with aggressive behaviours and the safety of others (Behavioural Supports Ontario, 2010) • Provides training and respite services for caregivers working with people living with dementia who have challenging behaviours (Alzheimer Society of Ontario, 2015) • Leverages and enhances existing programs in multiple sectors including mental health, primary care, hospital care, long-term care and specialty care (Gutmanis et al., 2017)
	First Link	• Aims to connect people living with dementia and their caregivers to appropriate services at diagnosis (Carrie A Mcainey et al., 2009) • Services include connecting people to the local Alzheimer Society, linking patients to other health and social service providers in their community, helping them find resources to manage challenges such as loss of driver's licence (Alzheimer Society of Canada, n.d.) • Collaboration between Alzheimer Society, primary care providers and other health professionals (Carrie A Mcainey, Harvey, & Schulz, 2009)
BC	First Link	• Aims to promote a better understanding and awareness of dementia knowledge, rapid support to patients and family caregivers and prevent a reactive, crisis-based approach to dementia care (C. A. McAiney et al., 2012) • Provides information and education to people living with dementia (Alzheimer Society of Canada, n.d.) • Physicians send referral to the Alzheimer Society (Alzheimer Society of Canada, n.d.)
	Home First/ Home is Best	• Aims to strengthen partnerships between home and community care services, acute care and primary care to improve a senior's journey with the healthcare system. (Canadian Home Care Association, 2012) • Supports seniors to go home safely after a hospital stay (Erie St. Clair LHIN, 2014) • Collaborations between health and social services, families and patients (Canadian Home Care Association, 2012)
NL	First Link	• Aims to connect people with Alzheimer's disease or other dementias and their families or caregivers with support services early and throughout the course of the disease (Alzheimer Society of Newfoundland and Labrador, 2020)) • Uses outreach to build referring partnerships with health professionals and community service providers to make it possible for providers to proactively refer people and families to the Alzheimer Society ((Alzheimer Society of Newfoundland and Labrador, 2020) • Offered through the Alzheimer Society of NL (Alzheimer Society of Newfoundland and Labrador, 2017)
	Paid Family and Caregiving Option (Home Support)	• Aims to provide individuals with the support services they need to live and develop fully and independently within the community in keeping with their assessed needs (Newfoundland and Labrador, 2005) • Provides subsidy for a seniors or adults with disabilities to pay a family member who meets the program's eligibility criteria to provide home support such as personal care and behavioural supports (Government of Newfoundland and Labrador, 2014) • Part of NL Provincial Home Support Program (Government of Newfoundland and Labrador, n.d.-b)
	Protective Community Residence (PCR)	• Aims to provide residence designed to meet the environmental, functional and psychosocial needs of individuals with mild to moderate dementia (O'Brien, 2014) • Small residences that seek to provide a safe, home-like environment for individuals with mild to moderate dementia (Government of Newfoundland and Labrador, n.d.-a) • Community Residences operated and monitored by the individual Regional Health Authorities (Government of Newfoundland and Labrador, n.d.-a)

TABLE 2 (Continued)

Jurisdiction	Policy program	Description
NY	Delivery System Reform Incentive Payment (DSRIP) focusing on ambulatory intensive care units (DSRIP-AICUs)	• Aims to create ambulatory intensive care units that have multi-provider team-based visits to patients with complex morbidities (New York State, 2015) • Community-based non-physician care for stable patients in need of chronic disease monitoring (New York State, 2015) • Domain 2B of the DSRIP projects which work to implement the Medicaid Redesign Team Waiver Amendment (New York State, 2015)
	Alzheimer's Disease Community Assistance Program (AlzCAP)	• Aims to provide services to dementia caregivers and disseminate dementia information on state-wide level to community leaders • Provides services to caregivers including care consultation services, support groups, caregiver education and a 24-h hotline (University at Albany, 2017) • Contracted to and implemented by the NY State Alzheimer's Association NY State Coalition (New York State Department of Health, 2017)
VT	Adult Day Services (ADS)	• Aims to meet the needs of adults with impairments through individual care plans • Provides structured, comprehensive, non-residential programs to provide a variety of health, social and related support services • Provides day-time care in a safe environment for adults with cognitive and/or physical disabilities • Collaboration between the Vermont Agency of Human Services, and the Department of Disabilities, Aging and Independent Living (State of Vermont, 2009)
	Dementia Respite Grant (DRG)	• Aims to help delay or prevent nursing home placement by offering support and relief to caregivers who care for their loved ones (ACL Administration for Community Living, 2019) • Family caregivers apply for respite funds which can be used to pay for services that provide respite from their caregiving responsibilities • The NFCSP provides grants to states for family caregiver supportive services via the *Older Americans Act*

Notes. NFCSP (National Family Caregiver Support Program); AAAs (Area Agencies on Aging).

state goals. In other jurisdictions, legislative measures appear to have influenced the development of policy programs. For example, in ON, the *Excellent Care for All Act* and the *Patients First Act* encouraged patient-centred philosophies based on strengthening care coordination and integration, which facilitated policy programs like Health Links (MOHLTC, 2015). Similarly, the programs assessed in BC (First Link and Home First) were preceded by the Ministry of Health's 2007 *Primary Care Charter* that detailed rising healthcare costs from the growing prevalence of older adults with chronic conditions (British Columbia Ministry of Health, 2007). The U.S. *Older Americans Act* added the NFCSP in 2000 that may have generated more family caregiver programs or increased support of existing programs (NFCSP 2021).

Interestingly, not all programs had laws and regulations explicitly connected to their implementation. However, in some cases, legislation (i.e. the *Older Americans Act*) may have spearheaded the programs. Despite being unable to explicitly connect laws and regulations to the development of these policy programs, regulations, leadership and laws all seem to have had an impact and influence.

3.3 | Policy initiatives, guidelines and strategic frameworks

Long-term care and community support strategies influenced several policy programs (ON BSO and Health Links; BC; NL; VT), followed by

Dementia or Alzheimer's related strategies (ON BSO and First Link; BC First Link; NL First Link and PCR; NY AlzCAP; VT) (Government of Newfoundland and Labrador, 2001; Morton-Chang, 2015). The three ON policy programs are also guided by Provincial Health Action plans. In VT, the *State Plan on Aging* (2019–2022) and *State Plan on Dementia* aim to identify home- and community-based services to support older adults. ADS was specifically identified as a potential 'stepping stone' for those who may require routine care, as placement in a nursing home is either undesirable or premature (Gaugler et al., 2003).

Examples from ON, NL and VT where overarching frameworks supported the development of certain policy programs. Notably, NL's strategic plan, *Close to Home: A Strategy for Long-Term Care and Community Support Services* (2012) followed by the government's policy intentions published in *The Way Forward* (2016), set the course for the Provincial Home Support Program. There were numerous political action plans or strategies that focused broadly on people's health (ON; VT ADS; NY DSRIP-AICU), and mental health (ON BSO; NL Paid Family Caregiving Option; VT).

In BC, VT and NY, pre-existing policies set the context for program development and implementation. BC's Ministry of Health's 2007 *Primary Care Charter* underlay future policy changes with its warning of rising healthcare costs associated with a growing aging population (British Columbia Ministry of Health, 2007). The BC government later adopted the U.S.-based Institute for Healthcare Improvement's 'Triple Aim' performance measures to improve

TABLE 3 Comparison of policy programs by framework element

Framework element		ON Health Links	ON BSO	ON First Link	BC First Link	BC First Link	BC Home First	NL First Link	NL Paid Family Caregiving Option	NL PCR	NY DSRIP-AICUs	NY AlzCAP	VT ADS	VT DRG
Laws and regulations	Provincial/State laws/reg.	✓	✓	*	*	*	*	✓	✓	✓	*	*	✓	✓
	Federal laws/reg.	✓	*	*	*	*	*	✓		✓	✓	*	✓	✓
Policy initiatives, guidelines and strategic frameworks	Provincial/State Health Action Plan	✓	✓	✓							*		✓	✓
	Mental health strategy		✓						✓		*		✓	✓
	Dementia/Alzheimer's strategy		✓	✓	✓	✓		✓		✓	*	✓	✓	✓
	LTC & community support strategy		✓	✓	✓	✓	✓	✓	✓	✓	*		✓	✓
Organization setup	Partnership with provincial/ state government	✓	✓						✓	✓	✓	✓	✓	✓
	Partnership with LTC organization										✓	✓		
	Partnership with community organization/NPO/PPS	✓	✓	✓	✓	✓		✓			✓	✓	✓	✓
	Partnership with hospital	✓	✓							✓	✓		✓	✓
Personnel	Admin/support personnel: program-funded	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	
	Admin/support personnel: Existing			✓	✓	✓	✓	✓	✓					
	Healthcare professional personnel: program-funded		✓		✓	✓	✓			✓	✓	✓	✓	
	Healthcare professional personnel: Existing	✓		✓	✓	✓	✓	✓	✓	✓	✓			
	Case manager/coordinator			✓	✓	✓	✓	✓	✓	✓	✓			✓
	Physician				✓					✓	✓			
	Nurse(s)	✓	✓	✓	✓					✓	✓	✓	✓	
	PSW(s)	✓								✓	✓			
	Support staff	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Money	Pilot Funding	✓	✓		✓	✓	*	✓	✓	✓	✓	✓	✓	✓
	Multi-year funding	✓	✓	✓	✓	✓	*	✓	✓	✓	✓	✓		✓
	Funded by provincial/state government	✓	✓	✓	✓	✓	*	✓	✓	✓	✓			✓

TABLE 3 (Continued)

Framework element		ON			BC		NL		PCR	NY		VT	
		Health Links	BSO	First Link	First Link	Home First	First Link	Paid Family Caregiving Option	PCR	DSRIP-AICUs	AlzCAP	ADS	DRG
Program objectives/ outputs	Timely access to care	✓										✓	
	Effective care plans	✓	✓									✓	
	Reduction in readmission to hospital/ED visits	✓	✓		✓							✓	✓
	Reduce transfers to LTC					✓	✓					✓	✓
	Increase awareness of supports			✓			✓						
	Reduce financial burden for caregivers							✓			✓	✓	✓
	Improve coordination of care	✓			✓	✓	✓	✓	✓	✓	✓		✓
Program recipients	People with multiple chronic conditions	✓							✓	✓		✓	✓
	People living with dementia		✓		✓	✓	✓	✓	✓			✓	✓
	Family & caregivers		✓		✓	✓	✓	✓			✓	✓	✓
	Healthcare professionals				✓	✓	✓						
	Need for financial support	✓					✓	✓					✓
Goal; vision	Improve integrated care/ health outcomes	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Caregiver support/reduce burden of care		✓		✓		✓	✓	✓	✓	✓	✓	✓
	Increase disease knowledge			✓			✓				✓	✓	
	Reduce costs of complex patients	✓				✓							
	Reduce/avoid ED use				✓					✓			
	Reduce/delay admission to LTC				✓								✓
Information management and evaluation	Formal evaluation/external reports	✓	✓	*	✓	*	✓	✓	✓	✓	✓	✓	
	Accountable reporting		✓	*		*				✓			✓
	Reporting to provincial gov.			*		*	✓			✓			✓
	Reporting to internal head office	✓	✓	*		*				✓			
Leadership and priority setting	Dept. Of Health/ Ministry of Health and LTC	✓	✓	*	*	*	*	*	*	✓	✓	✓	*
	Provincial/state leaders			*	*	*	*	*	*	✓	✓	✓	*

Legend ✓ represents the inclusion of the program element.

*Represents information that was not found.

Abbreviations: ED, Emergency Department; Reg., Regulation; LTC, long-term care.

population health, enhance the care experience for patients and providers and reduce the cost of care (Park et al., 2014).

Further, several federal initiatives have had both direct and indirect impact on the DSRIP projects (NY), and ADS and the DRG (VT). The *Older Americans Act* was amended in 2000 to include the NFCSP (Title IIIE) to offer states grants to support their caregiver workforce. This allowed funding to assist families in caring for older, dependent adults living at home for as long as possible (Barber, 2013). An overhaul of the U.S. healthcare system in 2010 introduced the *Patient Protection and Affordable Care Act* (PPACA) with the primary goal to increase health insurance coverage while decreasing the insurance cost (Rice, Rosenau, Unruh & Barnes; 2021). Following the PPACA in 2010, the state government of NY reformed the healthcare delivery system through the Medicaid Reform Team (MRT) 1115 Waiver Demonstration. The MRT offered state-level opportunities to adapt health system delivery structures, including the DSRIP program (DiNapoli, 2015). Similarly, in VT, the Choices for Care Medicaid Waiver demonstration ensures that participants can receive integrated services in their communities (State Of Vermont Agency of Human Services Department of Disabilities, Aging And Independent Living Division Of Disability And Aging Services, 2009).

While no programs had explicit laws and regulations, they did have broad strategies that were closely tied to their development and implementation. We discuss this in more detail below: while no explicit connection could be identified, the goals and objectives of the programs resembled the purposes of provincial and state/ strategies.

3.4 | Leadership and priority settings

Information about leadership and priority setting was reported only for Health Links and BSO in ON, DSRIP in NY and ADS in VT. Some of the policy programs had involvement of governmental stakeholders in the initiation of the reform efforts. For example, three important stakeholders were responsible for NY's healthcare system reform: Centers for Medicare and Medicaid Services (CMS), the NY Governor (Cuomo) and the Commissioner of Health (Dr. Zucker) within the NY Department of Health. Similarly in VT, goals were set by the governor, DAIL and the State Unit on Aging, which are developed out of state needs assessments.

In contrast, leadership oversight and priority setting for ON's Health Links have largely been informed by the MOHLTC which implemented an 'Advanced Health Links Model' in 2015/16 that comprised four policy and operational areas. At the program-level the BSO has developed, alongside the MOHLTC, a three-pillar framework of care: (1) system coordination and management; (2) knowledgeable care team and capacity building and (3) integrated service delivery: intersectoral and interdisciplinary.

One interesting finding is the limited clarity around leadership and priority setting for these policy programs. There is clear alignment with respect to goals of department/ministries of health, national and state/provincial priorities and the objectives and goals of these policy programs. However, identifying clear channels of leadership for these policy programs was difficult, with the exceptions of BSO and Health Links in ON and DSRIP in NY.

3.5 | Money

The majority of the programs receive funding from the provincial/ state government and allocate the funding to local healthcare organisations (sometimes affiliated with government authority) to operate the program. Programs in several jurisdictions were initially funded as a 'demonstration project' to test new models of care delivery as in the case of First Link (ON, BC), Home First (BC) and the Paid Family Caregiving Option (NL), DSRIP (NY) and ADS (VT) (Adult Services Division, 2020; Alzheimer Society of British Columbia, 2019; Government of Newfoundland and Labrador, 2014; McAiney et al., 2010). Notably, First Link lacks a central listing of programs due to unstable funding (Frank et al., 2011). Rather than dedicated base funding, injections of money were more common over a specified time frame. CAD$8.15 million was distributed over 3 years to enhance the ON First Link program (Alzheimer Society of Ontario, 2017).

Other programs like the BSO (ON), Health Links (ON), PCR (NL), the AICU (NY) and the DRG (VT) receive ongoing or base funding through provincial/state-level agencies. However, funding is downloaded to and managed by independent or local organisations. The BSO program in ON received CAD$44 million in base funding and top-up funding committed by the provincial government of $10 million in 2016 (Government of Ontario, 2016). Similarly, while NL's Paid Family Caregiving Option started as a pilot, it was later adopted as a permanent service of the Provincial Home Support Program. Block funding is then provided by the NL government to the regional health authorities to manage the program. Through the *Older Americans Act* and the NFCSP, the federal government awarded VT the state minimum for caregiver support based on its small population size which was $889,377 in 2020. This funding does not directly fund the grants administered to family caregivers but staffs coordinators who manage the DRG program (Administration for Community Living, 2019). VT State General Funds, equating to $250k USD per year, is awarded to grantees via the DRG ($1 k per grant). Overall programs were mainly funded through provincial or state governments and the organisation of the programs remained at this level for some (BSO, Health Links, Home First).

The majority of the programs have received funding from the provincial/state governments and the funding was allocated to local organisations to operate the programs on the ground. Many programs were initially funded as 'demonstration' or 'pilot' projects in efforts to test new models. These models were intending to bridge the gaps between health and social care sectors and improve coordination of care.

3.6 | Organisational setup

All policy programs attempt to bridge care gaps through inter-organisational and intersectoral collaborations. Developing partnerships with community organisations and/or non-profit organisations are their most common organisational structure (ON; BC; NL First Link; NY; VT). In NY under DSRIP, these partnerships were labelled Performing Provider Systems (PPSs). These PPSs have one designated lead, and partnerships and collaborations exist among hospitals, health homes, skilled nursing facilities and community-based organisations (among others).

Similar to AlzCAP (NY), First Link is administered by provincial Alzheimer Societies and funded and delivered by local chapters. Most of the remaining policy programs appear to be led at the provincial/state-level, with Ministries of Health and/or regional authorities responsible for implementation and funding (ON Health Links; NL PCR and Paid Family Caregiving Option). The DRG in VT is administered by Area Agencies on Aging (AAAs).

In ON until 2019, the Ministry of Health and Long-Term Care (MOHLTC), the Local Health Integration Networks (LHINs) and Health Quality Ontario (HQO) performed distinct roles to deliver Health Links together. The MOHLTC guided the strategy; the LHINs were responsible for funding and were accountable for individual Health Links and HQO supported data collection, performance measurement and development of best practices. Since 2019, the LHINs have merged from 14 to 5 interim regions and an entity called 'Ontario Health' that is now responsible for healthcare delivery across the province (Government of Ontario, 2020; Ontario Health, n.d.). Similarly, NL's PCR and Paid Family Caregiver Option program are managed by the Department of Health and Community Services while regional health authorities are responsible for monitoring and operations.

Most programs had the objective of improving coordination across healthcare sectors. Some involved community and hospitals (ON Health Links; NY DSRIP and VT ADS and DRG) and some partnered with institutional-based long-term care (NY DSRIP and AlzCAP). Beyond this, with the exception of community organisations (mostly those with the funding to implement), the degree to which additional efforts to engage with organisations or sectors beyond the community remains limited. Given program objectives, this is a deficiency in program design.

3.7 | Personnel

All the policy programs include interdisciplinary teams, but the types and distribution of human resources varied. In some cases, new administrative and support roles were created and programs hired new personnel (ON Health Links, BSO; NY AlzCAP; VT ADS); whereas others used existing human resource structures (ON First Link; BC; NL First Link; VT DRG). In the case of NL's First Link and the Paid Family Caregiving Option of the Provincial Home Support Program, they relied on both existing and new personnel. In VT, the regional

AAAs receive grant funding, and existing staff manage applications and determine awardees.

Programs require a variety of newly funded healthcare professionals (ON BSO; NL PCR; NY AlzCAP; VT ADS) as well as healthcare professionals external to the program itself (relying on outside organisations like primary care) (ON Health Links; NL Paid Family Caregiving Option, PCR; NY DSRIP-AICUs). Existing organisations in ON, such as Family Health Teams and hospitals, took the lead role of a Health Link. In NY, DSRIP-AICU's consist of emergency departments, nurse care managers, social workers, psychiatric nurse practitioners and community healthcare workers to coordinate care (New York Presbyterian, 2019). The DSRIP-AICU program requires either staffing by, or patients having access to, an existing network of providers outlined above (New York Presbyterian, 2019). The VT Department of Disabilities, Aging and Independent Living (DAIL) and the designated State Unit on Aging mandates a minimum staffing ratio for ADS, which will vary depending on clientele assistance level (Vermont Agency of Human Services Department of Disabilities, 2018). In certain programs, staffing was either 'mobile' or stationed in places of residence, like long-term care homes (ON BSO). A case manager/coordinator was consistent for the First Link programs, Home First (BC); PCR (NL) and VT (ADS and DRG). NL's PCR rely on a case coordinator staffed by a licensed practical nurse, registered nurse, or an advanced practice nurse.

All the policy programs help facilitate interdisciplinary care teams, yet the types and distribution of providers varied. Interestingly, the majority included a case manager/coordinator in some capacity and support staff that presented in a variety of ways.

3.8 | Goals

The goals for most of these policy programs were broad in nature with only four programs (BC Home First; NY DSRIP; VT) guided by a philosophy of care or a logic model. The overarching goal of DSRIP (NY) and Home First (BC) is to achieve the 'Triple Aim': improve quality, improve health outcomes and reduce healthcare costs (Sanna & Reuben, 2013). VT's state plan on aging's goal is to have Vermonters age in the community, often by delaying or avoiding long-term care placement (Vermont Agency of Human Services Department of Disabilities, 2018).

The broader goals for the other programs are to improve integrated care and patient outcomes (ON Health Links and First Link; BC Home First; NL PCR; NY DSRIP-AICUs; VT), to improve caregiver support and reduce burden of care (ON BSO; BC First Link; NL; NY AlzCAP; VT) and to increase disease knowledge and connect people to appropriate services (ON First Link; NL First Link; NY AlzCAP). Cost-containment and cost-shifting have been the main goals of Home First in BC. Long-term goals for the program look at patients' care experience, safety, well-being and health outcomes. Five program objectives guide the PCR program in NL which include 1) providing a safe and home-like environment for residences, 2)

developing individualised plans of care, 3) including family and other individuals where possible, 4) having skilled staff in caring for cognitive impaired people and 5) having specific recreation, social and leisure programs available.

3.9 | Program objectives/outputs

The most common program objective is to improve care coordination (ON First Link; BC; NL First Link, PCR; NY). Program objectives reflect provincial and state priorities, for example reducing readmission to hospital (ON Health Links and BSO; BC Home First) and transfers to long-term care (BC; VT). Across jurisdictions, the First Link program maintains a similar objective to connect people living with dementia and their caregivers to appropriate services at the point of diagnosis. VT's state plans intend to offer a person-centred approach and the DRG offers flexible and individualised caregiver respite, whereby the individual caregiver can define what respite means for themselves and use the funds to achieve this.

While the connections were not explicit, program objectives, goals and target populations all resemble provincial/state priorities (i.e. supporting high-cost users, increasing coordination of care). Most programs were intending to improve coordination and collaboration, or system integration. Yet, as we discussed above, coordination and collaboration across sectors remains inconsistent.

3.10 | Program recipients

Target populations included: 1) older adults with more than one chronic condition and multiple providers (i.e. Health Links, Home First, DSRIP-AICU, Paid Family Caregiving Option); 2) individuals with dementia and their family caregivers (i.e. First Link, AlzCAP, DRG, ADS) and 3) older patients with complex and responsive behaviours associated with cognitive impairment (i.e. BSO, PCR, ADS). The VT state plan used ADS to strengthen caregiver support and respite (Vermont Agency of Human Services Department of Disabilities, 2018). Additionally, some of the programs have specific eligibility criteria (Health Links, Paid Family Caregiving Option, PCR, DRG). Those that aim to coordinate care around high-cost users, like Health Links and DSRIP-AICU, require a level of chronicity among recipients. While there are specific eligibility criteria to bill Medicaid for ADS, anyone can utilise ADS. For those not qualified for Medicaid, a sliding scale fee is applied (Disability and Community Services, 2013).

How individuals access these programs vary? NL uses a centralised application process. Details regarding at which point and how recipients access BC's Home First program remains less clear and is seemingly done at bedside. The exception in this case is First Link, which allows both self and professional referrals across all jurisdictions.

Similar to the objectives and goals of the programs, the targets were similar to the populations identified in strategies of each jurisdiction. Programs were targeting 'high-cost users', individuals with multimorbidities and eight programs were also targeting unpaid caregivers.

3.11 | Information management and evaluation

Some of these programs lack an integrated evaluative system and electronic health record approach that collects systematic information to allow for sharing of information across organisations. User-level data are not linked to providers and services. Instead, they rely on qualitative evidence, outcome indicators and third-party program evaluations. For example, the First Link (ON, BC, NL), Home First (BC) and PCR (NL) relied on qualitative evaluative data through surveys and interviews (Craven, Byrne, Sims-Gould, & Martin-Matthews, 2012; Carrie A. McAiney, Hillier, & Stolee, 2010; Wallack, Harris, Ploughman, & Butler, 2018). In contrast, DSRIP is a highly structured program. The health outcomes of DSRIP patients are directly tied to the providers' payments (value-based payment). Information management and outcome evaluation metrics are predetermined prior to contractual agreements signed by the NY Department of Health DSRIP and each PPS. Most programs rely on formal evaluations (ON Health Links and BSO; BC First Link; NL; NY), with very few collecting their own common metrics across provincial/state levels (ON BSO; NY DSRIP-AICUs; VT DRG).

Other programs rely on indicators for tracking program outcomes. Ontario's BSO and Health Links policy programs have outcome indicators to monitor operational program indicators (i.e. total number of referrals received). Health Links, with support from HQO, report on outcomes using the Quality Improvement Reporting and Analysis Platform. Results-based indicators, including 30-day readmission rates, emergency department visits and referral time to home care are used to evaluate performance. Data are shared between the LHINs to promote transparency and inter-organisational learning.

Some jurisdictions rely on external third-party evaluations that could potentially be used to refine and improve policy initiatives. For example, the government of NL contracted a third-party consultant, Deloitte, to evaluate the Paid Family Caregiving program in July 2016 with a follow-up 2018 report that focused on how to improve the self-managed care option within the Home Support Program. These reports identified potential improvements, informed future program changes and presented ways to ensure that the program could be sustained (Deloitte, 2016, 2018; Gallant et al., 2018). A few programs are expected to report outcomes to the provincial (ON and BC First Link) or federal and state governments (NY), while ON's Health Links and BSO report to an internal head office.

The majority of programs mentioned 'formal evaluations' yet few relied on accountable reporting. Given the finding of unclear leadership and accountable oversight, this is not surprising. Even those programs that included reporting did so inconsistently. The degree to which these programs were flexible and adapted to reported findings, remains unknown.

4 | DISCUSSION

While not all jurisdictions had laws and regulations that were explicitly associated with the implementation of the policy programs, all five had broader political strategies or more general legislation (i.e. *the Older Americans Act*; Dementia Strategy) that either inspired or shaped some of the contours of the programs. Interestingly, programs' objectives, goals and target populations resembled the purposes and targets of provincial/state priorities and strategies (i.e. supporting high-cost users, providing timely access to care, improving integration, increasing coordination of care). Literature has highlighted the importance of coordination and timely access to services in the community in order to meet the needs of older adults and caregivers (Kuluski et al., 2017; Peckham, Morton-Chang, et al., 2018; Peckham, Rudoler, et al., 2018; Williams et al., 2009). As identified in the literature, all included jurisdictions have long-standing institutional and legislative barriers that can make innovative change difficult (Camillo, 2016; Lazar et al., 2013; Rudoler et al., 2019; Starfield, 1994). These barriers can prevent systems from being flexible and adaptive to the ever-changing needs of populations (Deber, 2004). Interestingly, the use of DSRIP 'Waivers' in NY supports efforts that veer from the 'norm' and offer innovation targeting improved system flow for vulnerable populations (Camillo et al., 2019; Helgerson, n.d.). DSRIP waivers are used to promote program implementation or to remove/bypass barriers created by existing programs. Waivers could open the door to initiate new programs/projects or identify areas in need of innovation.

These policy programs are mostly time limited. The question is, then, do they offer the potential, if they are continued, for long-term changes to meet the needs of older populations and their caregivers (Bauer & Sousa-Poza, 2015; Kuluski et al., 2018; Peckham, 2016; Peckham et al., 2014). All policy programs were aligned, in some respect, to overarching policy objectives, initiatives and strategies. These policy objectives (i.e. coordinated care, integration, community-based supports) have been on political agendas for decades with some attempts demonstrating more lasting impacts (Hutchison et al., 2001; Marchildon & Hutchison, 2016; Peckham, Morton-Chang, et al., 2018). Incrementalism is considered an effective approach to reform when institutional barriers exist, as it often involves lower barriers to implementation (Hutchison et al., 2001; Rudoler et al., 2019). There is argument that small wins can lead to big change (Hutchison et al., 2011; Lindblom, 1959) and may be particularly helpful when there is uncertainty in process and outcomes (Feindt & Flynn, 2009; Lindblom, 1959; Rayner & Howlett, 2009; Rudoler et al., 2019; Thelen, 2009). This is apparent when attempting to implement new approaches to care delivery—there is uncertainty in process, outcomes and stakeholder response.

Despite incrementalism being a relied upon approach to provide a foundation for longer-term structural changes, incremental change efforts can lead to poor policy layering. It has become increasingly important to consider the current mix of policy layers when developing new approaches. Identifying and considering the current mix of policy layers is critical to reduce tension between current

policy mixes and avoid unintended consequences (Kay, 2007; van der Heijden, 2011). A recent assessment of policy layering literature identified three elements of *smart policy layering*: 1) new policies should acknowledge the existing policy mix, 2) new layers should be evaluated and revised to maximise 'goodness of fit' with current policy mixes and 3) policies should patch current gaps in policies to avoid redundancies in policy efforts (Rudoler et al., 2019). This theory suggests that policies that incorporate these features are generally less contested by interest groups, reduce complexities with current policy mixes and structures, and are more likely to facilitate broader system change.

The policy efforts included in this research attempt to improve integration, coordination and health system flow. In order for these programs to achieve a foundation for longer-term structural change they would had to have been implemented in a manner that considers the elements of smart policy layering. None of these programs were fundamental system overhauls, most were time-limited as a result of system uncertainty, and all were layered onto a community sector that was already navigating several complex policy layers and subsectoral politics (Deber, 2004; Peckham, Morton-Chang, et al., 2018). None of these programs were introduced in a manner that directly reflected *smart policy layering*, did not ostensibly consider how to patch new and existing elements of the policy-mix and, as such, risk leading to more (rather than less) healthcare system redundancies. One approach to minimise redundancies is to combine evaluative efforts from the onset to assess 'goodness of fit' in an ongoing manner. The degree to which these policy programs have embedded these efforts successfully (or at all) is low, with the possible exception of DSRIP (NY). DSRIP was, at the time, a new federal-state joint program to reform the NYS Medicaid program in a way that allows for flexibility in smart policy layering.

4.1 | Limitations

This study contributes to an understanding of policy programs aiming to support the needs of individuals living with dementia or other complex needs and their caregivers. We note that findings may not be generalisable across the two countries due to different national policies. For example, the results of NY may not be generalisable to broader populations as they focus on Medicaid beneficiaries, a health system that stands in marked contrast to Canada's system of universal coverage for hospital, diagnostic and medical care services. It is possible that some system-level differences (e.g. funding models) may limit direct comparisons across jurisdictions and policy programs. Nevertheless, our analysis revealed many similarities across programs. This study used publicly available documents and local partners, for which we rely on the accuracy, transparency and availability of information. Additionally, given the limited and varied efforts around evaluation and data and information management, we were unable to compare the actual outcomes of the programs within this research and these

should be considered for future research. However, given that the data were collected and reviewed by experts who understood the local context this concern is limited.

5 | CONCLUSION

Our analysis of 12 programs in five North American jurisdictions offers a comparison of service delivery models using a well-established comparative framework. While clear differences across programs were noted, it was apparent that these programs were responding to provincial/state priorities that targeted care coordination. The notion of *incrementalism* has been described as an effective approach to health system reform. Unfortunately, incremental change can also lead to incompatible policy layering and redundant healthcare systems. The challenges arise if policy programs are implemented without acknowledging pre-existing layers, developing attempts to 'patch' current redundancies; and engaging in on-going evaluative efforts to assess 'goodness of fit'. All jurisdictions face similar challenges with bridging health and social care sectors. These challenges exist despite having different (yet similar) institutional boundaries, historical legacies and competing agendas. There remains an incongruence within the community subsector and between the community and other subsectors (i.e. hospital, LTC, primary care). In order for decision makers to effectively implement policy programs to improve care coordination across sectors, we need to first consider the current policy mix and contemplate adaptive and flexible policy programs that improve redundancies by patching existing inconsistencies. While these programs were intended to improve health system flow and access for vulnerable populations, the degree to which they achieved these goals and represent sustained system change remains elusive.

AUTHOR CONTRIBUTION

Peckham, Marchildon, Bornstein, McGrail, Young and Shaw were involved with the conceptualisation of the larger funded project. Peckham, Morris, Roerig and Papenkov were involved in the data collection and analysis for corresponding jurisdictional reviews. Peckham, Saragosa, King and Rorig collectively engaged in collating data and analysis from the jurisdictional reviews. All authors contributed to refining analysis and writing various aspects of the manuscript. All authors reviewed and revised the manuscript and provided approval to submit.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The datasets generated and analyzed during the current study are not publicly available but can be made available from the corresponding author, AP, on reasonable request.

ORCID

Allie Peckham https://orcid.org/0000-0001-6199-6903
Monika Roerig https://orcid.org/0000-0002-9117-0368
Greg Marchildon https://orcid.org/0000-0003-4898-2392

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