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Jurisdictional Review

Overview of Policy Programs for Dementia and Co-Existing Complex Needs for Residents and their Caregivers: Newfoundland and Labrador

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The views expressed by the authors are not intended to represent the views of the North American Observatory on Health Systems and Policies.

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About

The North American Observatory on Health Systems and Policies (NAO) is a collaborative partnership of interested researchers, research organizations, governments, and health organizations promoting evidence-informed health system policy decision making.

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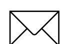 naobservatory@utoronto.ca

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List of Abbreviations

CFHI	Canadian Foundation for Healthcare Improvement
CHRSP	Centre for Applied Health Research's Contextualized Research Synthesis Program
HCS	Department of Health and Community Service
NL	Newfoundland and Labrador
RAI	residential assessment instrument
RCT	randomized controlled trial
RHA	Regional Health Authority

Introduction and Background

This report summarized the findings of a jurisdictional review focused on three policy programs in the province of Newfoundland and Labrador (NL) that seek to provide community and home-based support for people living with dementia and other complex, co-morbid conditions as well as to their unpaid caregivers. The results of the review are intended to inform future interviews with program stakeholders including senior program administrators at the policy level, junior program administrators, additional personnel responsible for implementing the program, and if possible, program recipients. The results of this review will be assessed for accuracy and comprehensiveness through these key informant interviews.

The jurisdictional review was undertaken to develop: 1) a high-level assessment of publicly available information on the programs, including program websites, government websites, media releases, para-governmental websites, and peer reviewed literature; 2) a more detailed examination of the literature to identify program elements and environmental contexts; and 3) recommendations on possible candidates for key informant interviews. We relied on publicly available information about them using program and government websites, media materials, peer-reviewed articles, and grey literature.

This work is part of a broader comparative study of policy programs for people living with dementia and co-existing complex health needs in five North American jurisdictions: British Columbia, Ontario, NL, Vermont, and New York State. The purpose of the broader study is to examine and assess the key features of policy programs in these five jurisdictions that address the health and social needs of people living with dementia and coexisting complex conditions and their unpaid caregivers.

Methods

We concentrated on web-based searches for relevant materials on the websites of the Government of NL, the four regional health authorities (RHAs), and key non-profit organizations in the province. We also undertook a general search of published and grey literature using the Google search engine. For these searches, we used the terms "dementia", "dementia programs", "community support", "Alzheimer Society", "home care", and "community care" combined with "Newfoundland and Labrador", "Eastern Health", "Central Health", "Western Health", and "Labrador Grenfell Health" using AND as appropriate. Once our initial searches had produced a list of potential programs of interest, we consulted key informants in NL's health system to help us select a few on which to focus, weeding out programs that were not broadly active, had not yet been fully implemented, or had ceased operation. The programs we chose to cover are**:**

- First Link®
- The Paid Family Caregiving Option of the NL Provincial Home Support Program
- The Protective Community Residence Program

Once these three programs were selected, the program names were added to our search strings and we repeated the search. The websites of the provincial government's two health-related ministries (the Department of Health and Community Services and the Department of Children, Seniors and Social Development) were particularly helpful for identifying key legislation, regulations, policy frameworks, and internal evaluations. We also used the search bar option "News Releases Only" on NL's government website to find specific news releases that contained information about our chosen programs.

In addition, we searched for primary research studies or evaluations completed in NL that pertained to dementia care in the province. We also searched Memorial University of NL's website as well as the electronic archives of presentations made at the Research Exchange Groups of the Newfoundland and Labrador Centre for Applied Heath Research, with which we are affiliated, using the terms "dementia" and "research" to see what local research has been conducted.

The primary output of the broader study is to identify and synthesize the features of policy programs across jurisdictions based on the elements of a program model outlined by Rose (2005). These policy program elements are:

- **Laws and regulations**: The criteria for determining how services are to be delivered and the conditions for being a recipient of services;
- **Organizational setup**: The specific organizations 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;
- **Personnel**: The type and distribution of human resources involved in delivering the services;
- **Money**: The amount and distribution of funding devoted to the functioning of the services;
- **Program outputs**: The specific activities and outcomes that will represent the performance of the program functions;
- **Program recipients**: The eligibility criteria that specify the types of individuals to be recipients of the services; and,
- **Goal(s)**: The ultimate outcome(s) the program is intended to achieve overall.

We also included the following additional features of policy programs that are not included in Rose's (2005) methodology:

- **Policy frameworks and guidelines**: the key policy initiatives, guidelines, or strategic frameworks that provided the context for the development, support, or enhancement of the program; and
- **Local research and evaluation:** local research or program evaluations that are directly or indirectly linked to the program.

Although several of the other project teams included a discussion of information management and evaluation (Ho & Peckham, 2017), we were not able to find any publicly available materials on these points for our province.

Summary of Findings by Program

First Link®

First Link® is a program for patients with Alzheimer's and other dementias and their caregivers. It has been offered through the Alzheimer Society of Newfoundland since 2012 (Alzheimer Society of Newfoundland and Labrador, n.d.).

Laws and Regulations

This program is administered by the Alzheimer Society of NL, a charitable organization. Accordingly, it is subject to federal and provincial legislation and regulations pertaining to charitable organizations, primarily the *Canadian Income Tax Act* through the Charities Directorate of the Canada Revenue Agency (Agency & Agency, 2015). In NL, it is also subject to the *Trustee Act, RSNL 1990, c T-10* (Trustee Act, 1990).

Policy Frameworks and Guidelines

First Link has some connections to policy frameworks in the province through the government's support of the Alzheimer Society of NL. The Alzheimer Society is listed as one of a number of community partners with which the Department of Health and Community Services works to support people living with chronic diseases in the province (D. of H. and C. S. Government of Newfoundland and Labrador, n.d.-b).

In 2001–02, the Department of Health and Community Services and the Alzheimer Society of NL collaborated to develop a *Provincial Strategy for Alzheimer Disease and Other Dementias*. In particular, two goals of this strategy support the provision of programs like First Link. One of these prioritized access to current information on Alzheimer's disease and other dementias, and another prioritized support for individuals with Alzheimer's disease and other dementias, and their families/caregivers (D. of H. and C. S. Government of Newfoundland and Labrador, 2002).

In 2004 the provincial government released its *Provincial Strategy for Alzheimer Disease and Other Dementias: A Plan of Action!*. This document outlined how the goals outlined in the 2002 strategy would be achieved (D. of H. and C. S. Government of Newfoundland and Labrador, 2004). Although these policy documents were created well before the implementation of the First Link program, they helped set the context for its development.

The government included enhanced seniors' care in its 2016 strategic plan *The Way Forward.* Action 2.10 of the plan, "Improve Community Support Services," pledges to improve support for seniors and persons with disabilities (Government of Newfoundland and Labrador, 2016). Since then, the government has updated this document several times by adding information about what it says has been achieved on each of the document's goals. Phase 3, entitled *the Way Forward: Building for our Future* was released in the spring of 2018. The section on "achieving better outcomes," includes Action 3.11.2 focused on enhanced support for persons living with dementia. Steps listed included:

- starting work towards implementing a *Dementia Care Action Plan*;
- training 811 HealthLine staff and other system staff to provide advice on appropriate services for dementia care and system navigation;
- increasing access to specialized adult day programs;
- integrating *Home First* initiatives and its philosophy of care into community-based care for people living with dementia; and

- developing a federally funded *Home Dementia Project* (Government of Newfoundland and Labrador, n.d.-a).

Organization

The main organization involved in the delivery of services in the First Link program in NL is the Alzheimer Society of NL. The program was first offered in the province in 2012 (Alzheimer Society of Newfoundland and Labrador, n.d.). It is administered by the Society and funded by the Department of Health and Community Services.

First Link 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. Physicians, health care professionals, and community organizations working with individuals and families affected by dementia can all refer interested persons to the program. When First Link staff receive a referral, they contact the person or family directly (Alzheimer Society of Newfoundland and Labrador, n.d., 2017). Potential participants can also self-refer by contacting the Alzheimer Society and inquiring about the program or by emailing a First Link coordinator. This information is available through a First Link hyperlink on the Alzheimer Society of NL's website (Alzheimer Society of Newfoundland and Labrador, 2017).

Personnel

First Link brings together the staff of the Alzheimer Society, primary care physicians, and other health professionals to coordinate with local health services and resources that best suits each person's situation. The program is designed to connect participants to a range of services and programs needed by a person or their family. The most likely first point of contact would be either a health care provider or a community organizer that is referring a person to the First Link program or First Link staff within the Alzheimer Society (Alzheimer Society of Newfoundland and Labrador, 2017).

Goals

The goal of First Link is to connect people with Alzheimer's disease or other dementias and their families or caregivers to early support services and throughout the course of the disease. It also provides information and access to other educational and/or health and community services that will support their care (Alzheimer Society of Newfoundland and Labrador, 2017).

Financial Arrangements

There does not appear to be any publicly available information about how the First Link program is currently funded. The section of the webpage of the Department of Health and Community Services on chronic disease lists the Alzheimer Society as one of a number of community partners through which they work to support people living with chronic disease (Department of Health and Community Services, 2018).

A 2015 news release from the Department of Health and Community Services announced the provision of $40,000 to the Alzheimer Society of NL for the First Link program through the *Chronic Disease Policy Framework*, but it is unclear if this was an annual allocation or a one-time contribution only (H. and C. S. Government of Newfoundland and Labrador, 2015).

Program Outputs

The focus of this program is to inform, support, and connect people living with Alzheimer's disease and other forms of dementia to services that can help them. The program focuses on outreach, referring partnerships, proactive contacts, connections to services, and "intentional follow-up"(Alzheimer Society of Newfoundland and Labrador, n.d.).

A 2015 document available on the First Link webpage explains that referred individuals or family members will receive:

- a phone call from the First Link coordinator within the time frame indicated on the referral form;
- an information package specific to their needs including information about a 15-week "learning series";
- contact information for community and health care services that may be helpful; and
- follow-up contact at a minimum of 6, 12, and 18 months (Alzheimer Society of Newfoundland and Labrador, 2015).

Also available on the Alzheimer Society's website is information about a Caregiver Support Group for caregivers, family, or friends. Caregiver Support Groups are listed for Mount Pearl, Bay St. George, Grand Falls-Windsor, New Wes Valley, and Corner Brook (Alzheimer Society of Newfoundland and Labrador, 2018).

Program Recipients

The main eligibility criterion for the First Link program is to be a person affected by Alzheimer's disease or other dementia, or someone that provides support as a caregiver, family, or friend. According to materials published in 2015 by the provincial Alzheimer Society, once a referral is received (either through a self-referral or through a health professional or community organization) a First Link coordinator will call the referred person. The referring professional then receives notification from First Link that contact with the individual or family has been established (Alzheimer Society of Newfoundland and Labrador, 2015).

Local Research and Evaluation

Our local research identified a 2016 Memorial University master's thesis by Elizabeth Wallack, who examined an online application of the First Link learning series for rural NL residents in May–August, 2013 (E. Wallack, 2016). While the learning series is typically offered in person, Wallack filmed in-person sessions and provided videos of them with commentary using Skype and YouTube. She described the experiences of the informal service providers who participated in the online series and noted the barriers and facilitators reported by caregivers while using the First Link learning series online. Key themes identified were access, connection, and privacy. Participants in the online cohort described the series as facilitating social and personal connections; allowing for privacy and flexibility in terms of sending or receiving information; and being easy to use, familiar, and not requiring any travel. On the other hand, some reported fear and/or discomfort about their privacy, and identified time, caregiving duties, and technology failures as barriers to accessing the online resources (E. Wallack, 2016).

In a later study, Dr. Roger Butler and his colleagues (including Wallack) explored the use of First Link to deliver remote telegerontology interventions for adults with dementia living in rural NL communities. The First Link education session was made available to participants as a component of their study. In this case, it was offered over 10 weeks and could be remotely accessed through Skype. Links to internet-based

resources were also provided. The protocol for this study was published in 2018 and the results were expected to be published in 2019 (E. M. Wallack et al., 2018). According to email correspondence with Dr. Butler, preliminary results garnered a lot of positive attention in the province, including support at the policy level. Dr. Butler and his colleagues intend to set up a Provincial Dementia Program (R. Butler & S. Bornstein, personal communication, February 14, 2019). More detail about this program are described below in the section "Recent Developments."

The Paid Family Caregiving Option of the Provincial Home Support Program

The Paid Family Caregiving Option is part of the NL Provincial Home Support Program. Home support services are provided in three programs: self-managed care, agency-managed care, or paid family caregiving (Government of Newfoundland and Labrador, n.d.-b). The Paid Family Caregiving option was introduced in 2014 and provides a subsidy to a senior or adult with disabilities to pay a family member who meets the program's eligibility criteria to provide personal care and behavioural supports (Government of Newfoundland and Labrador, 2014).

Two reports commissioned by the Department of Health and Community Services are particularly useful in providing insight into the details of the Provincial Home Care Program and the Patient and Caregiving option. Deloitte completed a review of the Provincial Home Support Program in July 2016 (Deloitte Inc., 2016) and the NL Centre for Health Information completed an evaluation of the Paid Family Caregiving Option in September of the same year (Newfoundland and Labrador Centre for Health Information, 2016). We have cited these two documents at various points below.

Laws and Regulations

Information on the Provincial Home Support Program refer to the *Regional Health Authority Act* (Regional Health Authorities Act, 2006) and to the *Provincial Home Support Program's Operational Standards* (D. of H. and C. S. Government of Newfoundland and Labrador, 2005). As part of the Home Support Program, the Paid Family Caregiving Option is subject to the same regulations as the program as a whole.

The Provincial Home Support Program has specific policy and program goals that are mandated by the Department of Health and Community Services. According to the review completed by Deloitte in 2016 for the Department of Health and Community Services:

> *The HCS* [Department of Health and Community Services] *is responsible for developing the Provincial Operational Standards and financial assessment manuals on which the Regional Health Authorities (RHAs) and subsequently the home support agencies have their roles and responsibilities defined in administering the Program. At the same time, the RHAs derive their authority to deliver the Program through the Regional Health Authority Act though HCS (through the Minister) can direct the RHAs on implementation. While HCS and the RHAs have their defined roles, the nature of the Program issues requiring HCS interpretation and direction results in ongoing dialogue about approvals of a small segment of client applications. At the same time, HCS is concerned about consistency of approvals across the regions.* (Deloitte Inc., 2016)

The Deloitte review reported that few changes had been made to the Operational Standards Manual for the Provincial Home Support Program since its introduction in 2005 (Deloitte Inc., 2016). The manual outlines the operational standards, required forms, and program requirements such as eligibility, service delivery, monitoring of services, and approval of home support agencies. It also specifies that the

Department of Health and Community Services is required to review the provincial operation standards for the Home Support Program every three years (D. of H. and C. S. Government of Newfoundland and Labrador, 2005).

The Deloitte review also points out that there is some confusion about who has the final authority over the implementation of the program. The review states that:

> *While it is not appropriate for HCS to become involved in RHA operational matters within the Program, there are client inquiries made with HCS that require follow-up and investigation.* (Deloitte Inc., 2016)

Policy Frameworks and Guidelines

The Provincial Home Support Program is an integral part of the province's strategy for long-term care that was presented in the 2012 document, *Close to Home: A Strategy for Long-Term Care and Community Support Services* (Deloitte Inc., 2018; D. of H. and C. S. Government of Newfoundland and Labrador, 2012). The brochure for the Paid Family Caregiving Option also notes that it is an important part of the *Close to Home* strategy (Government of Newfoundland and Labrador, 2014).

The Provincial Home Support Program has received continued policy support over the years. The overall program and some of its components, including the Paid Family Caregiving Option, are mentioned in a number of other policy documents. For example, the 2015 *Status Report of the Provincial Healthy Aging Policy Framework* used the results of the 2014 Paid Family Caregiving pilot as an example of the government's efforts to offer a new and improved option for caregivers in the province (D. of S. Government of Newfoundland and Labrador Wellness and Social Development, 2015).

Similarly, NL's policy roadmap, *The Way Forward*, released initially in 2016 and followed up annually thereafter, includes, under "better services" intended action to improve community support services (Government of Newfoundland and Labrador, 2016, 2017) by making updates to the Home Support Program. The 2018 update, posted on the government website, includes a list of changes, including the development of a new brochure and client handbook to promote the Home Support Program. Similarly, the Strategic Plan of the Department of Health and Community Services for 2017-2020 identifies community supports and capacity building as one of its five priority areas and lists the Provincial Home Support Program as a key focus of the first of these areas (D. of H. and C. S. Government of Newfoundland and Labrador, 2017b).

Organization

The 2016 Deloitte review of the overall Home Support Program, including the Paid Family Caregiver option, is the best public source of information on the program's governance. The program falls under the Department of Health and Community Services, which sets the standards for the program, monitors compliance, and provides funding through its annual budget. Individual RHAs are responsible for the program's day-to-day management (Deloitte Inc., 2016).

Introduced in March 2014, the Paid Family Caregiving Option is the most recent of the three options offered within the Provincial Home Support program (H. and C. S. Government of Newfoundland and Labrador, 2018; Newfoundland and Labrador Centre for Health Information, 2016). Before its launch, the department took steps to train personnel in the RHAs using a train-the-trainer model in which regional trainers worked with family members and frontline staff (Newfoundland and Labrador Centre for Health Information, 2016).

Personnel

Certain family members are eligible to be paid to care for a loved one as a part of the Family Caregiving option. These can include parents, children, siblings, grandparents, grandchildren, and relatives residing in the same home, but exclude spouses and common law partners (H. and C. S. Government of Newfoundland and Labrador, 2018).

The program also involves supervisors who conduct quarterly in-person visits to assess and monitor care the outcomes that were set out in the client assessment completed at their intake to the program. Additional personnel include providers of respite for caregivers and administrative support for payroll tasks.

Financial Arrangements

Detailed information about the overall funding model for the Provincial Home Support Program can be found in Deloitte's 2016 review. The HCS establishes the annual budget, which is then allocated as block funding to each RHA:

> *The four RHAs receive block funding and they have the flexibility in approvals of subsidies. Clients are required to contribute to cost of care based on sliding-scale determined through an income assessment. Some block funding arrangements are in place under the Paid Family Caregiver Option.* (Deloitte Inc., 2016)

Subsidies for the Paid Family Caregiving Option are provided as direct individualized funding. This is described as a self-directed payment option that is intended to give a client greater flexibility and reduce administrative burden (H. and C. S. Government of Newfoundland and Labrador, 2018; Newfoundland and Labrador Centre for Health Information, 2016). Further details on the *Direct Individualized Funding Framework* can be found in Appendix F of the *Centre for Health Information Evaluation Report on the Paid Family Caregiving Option* (Newfoundland and Labrador Centre for Health Information, 2016).

A 2015 Status Report for *the Provincial Healthy Aging Policy Framework* reported that the NL government committed $8.2 million starting in March 2014 for the pilot program that would be the first stage in the option's implementation (D. of S. Government of Newfoundland and Labrador Wellness and Social Development, 2015).

Program Outputs

Each approved recipient of the Paid Family Caregiver option receives a subsidy towards services for:

- personal care/behavioral supports;
- homemaking/meal preparation; and
- respite for a caregiver who lives with an individual requiring 24-hour-a-day care.

Personal care/behavioral supports for seniors are funded for a maximum of four hours a day. For an adult with a disability, personal care/behavioral supports are funded for five hours a day. The particular personal care/behavioral supports for each client are determined during their assessment for program eligibility.

The number of hours of funding that a client can be given for homemaking/meal preparation and respite for caregivers depends on whether or not the caregiver lives with the individual. When the caregiver does not live with the client funding is available for:

- up to two hours per week of homemaking (when required); and

- up to one hour per day for meal preparation.

When the caregiver lives with the client, funding for homemaking is available for two hours per week (when this is required to care for the client). When a client requires 24-hour-a-day care or supervision, funding for respite care is provided "up to the balance within the financial ceiling" (H. and C. S. Government of Newfoundland and Labrador, 2018).

An evaluation of the Paid Family Caregiving Option conducted by the Newfoundland and Labrador Centre for Health Information published in 2016 gives a sense of the initial average number of support hours used over the 18-month pilot period that started in 2014 when the option was first offered:

> *The average number of weekly home support hours among seniors was 23 hours per week with homemaking hours averaging nine hours per week. There was no reported behavioural support hours for this subsidy category. Adults with a disability received an average of 26 hours per week of home support hours with homemaking hours averaging two hours per week and behavioural supports averaging 13.5 hours per week. There were 11 clients with respite (nine seniors and two adults with disability). Weekly respite hours ranged from 10 to 25 hours with an average of 14.3 hours weekly.* (Newfoundland and Labrador Centre for Health Information, 2016)

Program Recipients

Eligibility criteria for individuals interested in the Paid Family Caregiving Option are listed on the Department of Health and Community Services' website. Individuals must meet the following eligibility criteria:

- be a new or current client of one of the Adult Home Support Programs;
- have a long-term need for a home support subsidy;
- meet the eligibility requirements for publicly funded home support services as outlined in the Provincial Home Support Program Operational Standards (2005);
- be eligible for service under the Adults with Disability Home Support Program or the Seniors Home Support Program;
- meet the conditions outlined in the clinical and financial assessment for service, including an enhanced focus on the role of informal support;
- have a clinical assessment that indicates a need for personal care/behavioural support and that care can be appropriately provided by a family member; and
- agree to the required financial contribution, if any, as indicated in the financial assessment (H. and C. S. Government of Newfoundland and Labrador, 2018).

As noted in the "Personnel" section above, in order to be paid under the Paid Family Caregiving Option, the caregiver must be a parent, child, sibling, grandparent, grandchild, or relative residing in the same home. Spouses and common law partners cannot be paid providers (H. and C. S. Government of Newfoundland and Labrador, 2018).

Goals

The overall goals of the Home Support Program are summarized in Deloitte's 2016 review of the program conducted on behalf of the Department of Health and Community Services. The goals listed are:

- that individuals who meet the program's admission criteria should have the support services they need to live and develop fully and independently within the community in keeping with their assessed needs;
- that individuals should have choice in how they live; and
- that the program be equitable for all eligible population groups across the province (Newfoundland and Labrador Centre for Health Information, 2016).

A 2016 evaluation of the Paid Family Caregiving Option, completed by the Newfoundland and Labrador Centre for Health information, specifies the following objectives:

- to increase client choice and flexibility in how clients manage their support services;
- to maintain existing informal caregiving relationships;
- to maintain accountability for care and public funds; and
- to mitigate risks of abuse, collusion, and/or coercion (Newfoundland and Labrador Centre for Health Information, 2016).

Local Research and Evaluation

As just referred to, one program review and one evaluation were conducted for the Department of Health and Community Services related to the Paid Family Caregiving Option. In the former, the department commissioned Deloitte to review the Provincial Home Support Program, which was published in July 2016. The review was to take a critical look at how the program was operating in order to identify potential improvements, inform future program changes, and consider ways to ensure the program's sustainability. Dementia is specifically mentioned twice in the review. In one instance, Deloitte found inconsistency in the clinical assessment process used in different RHAs with regard to whether staff routinely request that family or other informal caregivers be present. This was identified as important for certain clients like those with dementia or cognitive impairment who may have trouble communicating with staff. Further, in a section regarding opportunities to improve assessment tools, the review found there was "under emphasis on the importance of the functional implication of cognitive deficits." This included differentiating clients at different stages of dementia, frailty, or cognitive impairment. In total, the Deloitte review found 25 opportunities for program improvement and offered an implementation strategy and a roadmap for enacting the suggested changes (Deloitte Inc., 2016). We should note that a 2018 follow-up report by Deloitte also focuses on how to improve the self-managed care option within the Home Support Program (Deloitte Inc., 2018).

A second, narrower report conducted by the Newfoundland and Labrador Center for Health Information on behalf of the Department of Health and Community Services was completed in September 2016. This report evaluated the Paid Family Caregiving Option pilot, launched in 2014. Several key considerations for improvement were suggested in the areas of clinical assessment, the funding model, program monitoring and review, and program sustainability and alignment. This evaluation most often referred to seniors and adults with disability but there were also examples that referred to clients with Alzheimer's and those with cognitive deficits (Newfoundland and Labrador Centre for Health Information, 2016).

Many of the recommendations of these two reports have been addressed since 2016. We comment on this in the last section of this review ("Recent Initiatives").

Protective Community Residences

Protective Community Residences are small, specially designed residences that seek to provide a safe, home-like environment for individuals with mild to moderate dementia (D. of H. and C. S. Government of Newfoundland and Labrador, 2018b) . These residences are arranged to meet the environmental, functional, and psychosocial needs of these individuals while avoiding some of the drawbacks and constraints of standard institutional facilities (O'Brien et al., 2014). According to local researchers Kelli O'Brien et al. (2014), these residences are intended to be "similar to supportive housing or assisted living offered in other jurisdictions in Canada" (O'Brien et al., 2015).

The key design features of these units include:

- size and scale that is home-like with a maximum of 10 residents per bungalow;
- natural light and outdoor views;
- warm and reassuring inside décor and furniture;
- private bedrooms with cable and phone lines;
- shared kitchen, dining, living, and bathroom areas;
- access to a garden and walking path; and
- use of reminder cues and other strategies to minimize disorientation while limiting restrictions on movement (O'Brien, 2008; O'Brien & Fequet, n.d.).

Laws and Regulations

The province's *Protective Community Residence Operational Standards* document, published in 2009, makes no reference to any specific legislation or regulations other than the regulations and procedures of the RHA in which the residence is located.

Policy Frameworks and Guidelines

As far back as 2002, the *Provincial Strategy for Alzheimer Disease and Other Dementias* recognized the need to support affected individuals and their families and caregivers (D. of H. and C. S. Government of Newfoundland and Labrador, 2002). The Action Plan that followed in 2004 suggested that one way to support families and their caregivers was to strengthen provincial efforts to create and design alternative residential options (D. of H. and C. S. Government of Newfoundland and Labrador, 2004).

The research conducted by O'Brien and her colleagues gives some context to the provision of Protective Community Residences in the province. They cite a 2005 unpublished review prepared by the Clinical Epidemiology Unit of Memorial University for the Department of Health and Community Services on long-term care bed analysis and facility planning services in the city of Corner Brook[1]. The review found that:

> *15% of residents in institutional care had mild to moderate dementia as the only indicator for admission. It was suggested that these residents would be more appropriate for an alternative living arrangement where their care needs could be met, namely the supervised care plus option.*

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[1] The unpublished report is cited as Rarfrey, P. & McDonald, J. (2005). LTC Bed Analysis and Facility Planning Services.

> *Supervised care plus refers to a setting specifically designed to meet the environmental, physical and psychosocial needs of the individual with mild to moderate dementia.* (O'Brien et al., 2014)

According to O'Brien et al. (2014), the construction and opening of Protective Community Residences in the province over the 2008-2017 period was a response to this 2005 review and a commitment by the provincial government to update and improve options for long-term care residences across the province (O'Brien et al., 2014).

Close to home – A Strategy for Long-Term Care and Community Support Services released in 2012 set out a formal plan to further revitalize the long-term care and community support services system. Goals for this plan included providing residential options to allow people to remain in their communities and providing increased support for caregivers (D. of H. and C. S. Government of Newfoundland and Labrador, 2012).

In 2015, the *Provincial Healthy Aging Policy Framework Status Update* cited Protective Community Residences as one of a number of "advancements to support seniors and other adults who require high levels of support and care" (D. of S. Government of Newfoundland and Labrador Wellness and Social Development, 2015).

Organization

The Department of Health and Community Services provides funding for Protective Community Residences. They are operated and monitored by the individual RHAs. Protective Community Residences are currently available in three of four of the province's regions:

- In Western Health, four Protective Community Residences in Corner Brook with 10 beds each have been in operation since 2008 (Hutchings et al., 2011, 2011; O'Brien et al., 2013);
- In Eastern Health, one 12-bed Protective Community Residence in Bonavista has been in operation since 2014 (D. of H. and C. S. Government of Newfoundland and Labrador, 2014a) and another in Clarenville with 12 beds has been in operation since 2016 (Curley, 2016); and
- In Central Health there is one 12-bed Protective Community Residence in Lewisporte that has been in operation since 2012–13 (D. of H. and C. S. Government of Newfoundland and Labrador, 2013).

Personnel

The *Operational Standards* document outlines the roles for personnel tasked with running the province's Protective Community Residences. The document defines the roles of principal personnel, including the Care and Support Team, Clinical Care Coordinator, a Resident Care Companion, a Recreational Specialist, and a Social Worker. Other disciplines may be required by referral to provide therapeutic, rehabilitative, and restorative services such as occupational therapy or physical therapy (D. of H. and C. S. Government of Newfoundland and Labrador, 2009b).

The available web materials related to the Protective Community Residences indicate that these roles appear to be fulfilled in different ways in different locations. Western Health's webpage on Protective Community Residences in Corner Brook states that 24-hour supervision and support is provided for residents by licensed practical nurses and personal care attendants. From Monday to Friday, there is also a nurse practitioner available on site as well as a social worker and a recreational therapist. Other services

are available by referral, such as occupational therapy, dietician, physiotherapy, and specialists (Western Health, n.d.-a).

Central Health's website for the Protective Community Residence in Lewisporte describes employing a full-time nurse practitioner and resident support workers (Central Health, n.d.). Eastern Health has posted informational videos on their website about Protective Community Residences in Clarenville and Bonavista but does not provide detailed information about staffing within the residences (Eastern Health, 2016b).

Financial Arrangements

Funding for the construction and operation of Protective Community Residences is provided by the Department of Health and Community Services. A study by Hutchings et al. (2011) provides insight into the initial funding for the first Protective Community Residences built in Corner Brook. According to this paper, the Western Regional Health Authority received dedicated funding for the redevelopment of long-term care (LTC) services from the NL's government in 2004. One of the components of this redevelopment included the construction of four Protective Community Residences (Hutchings et al., 2011).

Significant investment in infrastructure for long-term care facilities across the province was prominent in the provincial budget for 2008. $32.6 million was set out to complete work related to the four Protective Community Residences as well as to continue construction of a new long-term care home in Corner Brook. In the same budget, $2.6 million was set aside for site infrastructure and the design of a new health centre in Lewisporte (D. of H. and C. S. Government of Newfoundland and Labrador, 2008).

Over the years, news releases by the Department of Health and Community Services have reported on the funding and progress of other Protective Community Residences as they were built and opened. A 2009 news release cited an investment of $68.5 million for the Protective Care Residences and the LTC facility in Corner Brook (D. of H. and C. S. Government of Newfoundland and Labrador, 2009a). In 2014, another release reported a $2.6 million investment for a residence in Bonavista (D. of H. and C. S. Government of Newfoundland and Labrador, 2014a). In June the same year, an investment of approximately $2.5 million was announced for the facility in Clarenville (D. of H. and C. S. Government of Newfoundland and Labrador, 2014b).

Program Outputs

Overall, there is a strong focus on maintaining residents' quality of life through the provision of safe, home-like environments that have 24-hour supervision. Standards for services and care in a Protective Care Residence are outlined in considerable detail in the 74-page *Operational Standards* document. Standards, outcomes, and performance measures are set out for governance, human resources, care services, care access and delivery, individual empowerment, individual support services, the environment, and personal safety and security (D. of H. and C. S. Government of Newfoundland and Labrador, 2009b).

Key features of Protective Community Residences, as outlined in the Operational Standards document, include:

- a psychosocial model of care emphasizing choice and promoting the use of functional abilities through purposeful activities and social interactions;
- staff, standards, legislation, and staffing requirements to help create "a holistic individual centred approach to care";
- safe and secure home-like accommodations for 8–12 individuals;

- private bedrooms;
- shared spaces;
- access to a secure outside area; and
- a smoke-free environment (D. of H. and C. S. Government of Newfoundland and Labrador, 2009b).

Program Recipients

The assessment process used to determine if an individual can be admitted to a Protective Community Residence is described in varying detail depending on the source.

According to the website of the Department of Health and Community Services, two types of assessment are used to determine admittance. Individuals must be assessed by RHA staff to determine their suitability for the Protective Community Residence model of care. Individuals must also undergo a financial assessment to determine the amount of subsidy that will be made available to them (D. of H. and C. S. Government of Newfoundland and Labrador, 2018b).

Details of the assessment process and admission criteria are outlined in the Community Residence Operational Standards document. A process called a Single Entry Assessment and Placement is said to be used to determine an individual's approval for admission to the residence. An assessment tool called the Continuing Care Adult Assessment Tool is mentioned. An individual is assessed on cognitive, behavioral, functional and medical criteria in order to ensure that the type of care provided is appropriate for each individual (D. of H. an Smoke-free environment

A brochure from Western Health explains that a "residential assessment instrument" (RAI) Home Care Placement tool is used to determine an individual's admissibility (Western Health, n.d.-b). The Eastern Health website on the admission process explains that "the office of placement services coordinates all admissions to personal care homes, protective community residences and nursing homes in the Eastern Region through a single-entry system" (Eastern Health, 2016a).

Goals

The overarching goal of the Protective Community Residence Program identified in the Provincial Protective Community Residence *Operational Standards* document (2009) is "to provide specialized care and accommodations for individuals with mild to moderate dementia." Additional objectives of the program are:

1. to provide a safe and home-like environment for individuals that enables them to function to the fullest potential;
2. to develop individualized plans of care and support that are tailored to meet the needs of each resident;
3. to include the family, substitute decision-maker, and/or significant other and the individual whenever possible in developing a plan of care and support;
4. to have staff skilled in caring for the cognitively impaired; and
5. to have specific recreational, social, and leisure programs geared to each resident's cognitive functioning ability (D. of H. and C. S. Government of Newfoundland and Labrador, 2009b).

Local Research and Evaluation

We found three studies from province's western region that examined the relocation of individuals with mild-to-moderate dementia from institutional-based care or private home care to a Protective Community Residence. A fourth study from the Newfoundland and Labrador Center for Applied Health Research also discusses the use of Protective Community Residences in the province.

Hutchings et al. (2011) examined the experiences of the families of residents with mild to moderate dementia that were relocated to Protective Community Residences in Corner Brook in 2008. Family members reported that the relocation of their loved one into this kind of care was a positive experience. Family members also reported that the move had resulted in improvements in residents' physical, cognitive, and behavioral functioning (Hutchings et al., 2011). They highlighted a number of areas that they considered important elements of successful relocation, including:

- family involvement;
- ongoing communication with the families about the relocation;
- the care approach of the staff and their engagement with residents; and
- the fact that the move was optional (Hutchings et al., 2011).

In 2014, a related quantitative study (O'Brien et al., 2014) investigated functional changes in residents after they relocated from private homes or institutional-based care to Protective Care Residences. The study found that:

> *relocation to an appropriate enhanced assisted living environment for individuals with mild to moderate dementia will not result in negative impacts on function, cognition, or behaviour within 8 weeks post relocation. There is evidence to suggest that participation and involvement in normal daily activities may have a positive impact on overall function of individuals with mild to moderate dementia. The findings support that an appropriate program for individuals with mild to moderate dementia can be delivered by a skill mix which includes unregulated workers with clinical supervision and support.* (O'Brien et al., 2014)

The authors of this study also point out that most of the study population had only mild cognitive impairment. They recommend undertaking a comparison of outcomes between those with mild and those with moderate cognitive impairments, and further research to examine what levels of dementia are best supported by this type of care residence (O'Brien et al., 2014).

A subsequent study by O'Brien et al. (2015) examined family involvement in Protective Community Residences (O'Brien et al., 2015). The authors gathered the perspectives of the families of seven residents who had moved into two of the Protective Community Residences in the western region. These families wanted to see increased family involvement—family support groups, care planning meetings that include family members, and opportunities for families to suggest improvements in the quality of care.

At the request of the HCS and the four RHAs, the Newfoundland and Labrador Centre for Applied Health Research's Contextualized Research Synthesis Program (CHRSP), published a study in 2015 that examined how to better support the independence of persons with dementia in NL. In this report, the authors found that Protective Community Residences provided "a more affordable range of residential care options for persons who have been diagnosed with dementia but who do not require level three care or higher" (Chappell et al., 2015).

Recent Initiatives

The NL government and its two health-related ministries have recently intensified their focus on the aging of the province's population and on the challenge of dementia in particular. Of special interest are three initiatives all of which involve partnerships with national agencies or funders—the adoption of "Home First" as an overarching strategy for public policy; the expansion of a pilot project in tele-gerontology into a new provincial home dementia program; and the implementation of a program to reduce inappropriate use of antipsychotic drugs in institutionalized seniors.

Other related research projects in NL that are not directly linked to the programs are listed in Appendix B.

A New Overarching Policy Approach: Home First

A relatively new development is the adoption of a broad strategy called "Home First" that is intended to govern the way the province goes about developing and implementing wide range of specific policy initiatives affecting people with dementia and related complex needs as well as other groups of citizens.

In 2017, the provincial government released the *Newfoundland and Labrador Action Plan on Home and Community Care and Mental Health and Addictions Services*. This plan, also known as *The Home First Initiative*, is not a specific policy or set of policies but rather a broad approach intended to govern the design, implementation, and evaluation of existing and new programs, including the three programs analysed in this report. It involves the intention to shift away from acute care, institution-based care, including for people with dementia, to an emphasis on providing what is described as integrated, person-centred care at home and in the community (D. of H. and C. S. Government of Newfoundland and Labrador, 2018c).

Responding to Deloitte's 2016 review (Deloitte Inc., 2016) of its home support program and taking advantage of 10 years of new funding specified in a December 2016 agreement with the federal government, the province has committed to improving home and community care through the Home First approach. While the new approach covers policies for a wide range of population groups and conditions, dementia care will play an important role. As noted in the *Action Plan*:

> *[O]ver the 10-year period (2017-18 to 2026-27), the Government of Canada will support home and community care and mental health and addictions initiatives in Newfoundland and Labrador through combined funding of an estimated $160.7 million ($87.7 million for home care and $73 million for mental health initiatives). This Action Plan outlines how federal funding will be invested for the first five years of this 10-year period.* (D. of H. and C. S. Government of Newfoundland and Labrador, 2017a)

In 2018, a further bilateral agreement was announced that included substantial funding for priority areas of Home First, including a Home First Integrated Network, Palliative Care/End-of-Life Improvement, and Support for Individuals with Dementia (E. C. Government of Newfoundland and Labrador & Department of Health and Community Services, 2018). Specific goals outlined for individuals with dementia and their caregivers in the Action Plan are:

- to provide better respite services for caregivers;
- to implement professional development for providers and caregivers; and
- to expand remote monitoring technology through a Provincial Dementia Care Program (D. of H. and C. S. Government of Newfoundland and Labrador, 2017a).

Provincial Home Dementia Program

Local research conducted in the province has gained support from the provincial and federal governments for the development of a Provincial Dementia Program. In 2013, Drs Roger Butler, Michelle Ploughman, and Gerard Farrell, and Ann Hollett of Memorial University were awarded $40,000 from the Newfoundland and Labrador Healthy Aging Research Program (NL-HARP) for their project entitled *Telegerontology: A Novel Approach to Optimize Health and Safety among people with Dementia in Newfoundland and Labrador*. This funding helped complete a pilot study in rural Newfoundland and Labrador that aimed to show that the provision of remotely delivered expertise via Skype can decrease caregiver stress and hospital visits for individuals living with dementia (Butler, 2015). The team moved from this small pilot project to a full-fledged randomized controlled trial (RCT) (E. M. Wallack et al., 2018) whose results were published at the time of writing this review, but that have been sufficiently impressive to convince the provincial government to use some of the new federal funding just described to develop a home dementia program to be rolled out over the next three years with co-funding by the province and the Government of Canada (Government of Canada, 2018). Health Accord Funding has allotted $2.1 million for this program over the period of 2018–2022 (D. of H. and C. S. Government of Newfoundland and Labrador, 2017a).

The first step will be to implement internet-based home support for dementia patients in Eastern Health, the province's largest RHA. Once the program is up and running in Eastern Health it will be expanded to the rest of the province. Initial plans have the program targeting 400–500 clients in its first year and then 800–1,000 in the second (D. of H. and C. S. Government of Newfoundland and Labrador, 2017a). The provincial office will be situated at the Leonard A. Miller Centre in St. John's and will coordinate services across the province (R. Butler & S. Bornstein, personal communication, February 14, 2019).

At the time of writing, two nurse practitioners were being hired for the eastern region. By year three, when the program is fully up and running, the intention is to have a total of six specially trained nurse practitioners across the province (Butler, 2017; R. Butler & S. Bornstein, personal communication, February 14, 2019). The program will have staff to run the central coordination office and a program team, including a geriatrician, a geriatric psychiatrist, an internist, a neurologist, and allied health professionals to take part in e-consults/virtual clinics (involving a geriatrician, geriatric psychiatrist, internist, and neurologist) (Butler, 2017). There are also plans to hire a part-time occupational therapist that will be scaled up to a full-time position as the program is rolled out to the central region in year two, and then to the rest of the province in year three (R. Butler & S. Bornstein, personal communication, February 14, 2019).

Clients of the program will be individuals with moderate-to-severe dementia recruited through their family physicians, local specialists, and the provincial Alzheimer Society. They will receive a comprehensive home assessment, including a full medical assessment, a medication review, a chronic disease management assessment, and a fall risk assessment. Personnel working for the Dementia Program will collaborate with local family physicians and care teams to enhance the patients' care at home. The care team will follow up with patients regularly, at least once per month, using technology such as the phone or telecommunication such as Skype or Facetime. Video conferencing software available through certification with the Newfoundland and Labrador Centre for Health Information is being considered as a potential confidential communication platform for this service. As well, a phone line will be set up to connect the team with caregivers and family physicians if problems arise (R. Butler & S. Bornstein, personal communication, February 14, 2019).

Dementia Care Improvement Initiative

Another recent initiative announced on June 4, 2018, involves an 18-month collaboration between the Canadian Foundation for Healthcare Improvement (CFHI) and the Government of NL to reduce the inappropriate use of antipsychotics in LTC institutions, including in all Protective Care Residences. Results from the pan-Canadian Appropriate Use of Antipsychotics collaborative have already shown positive effects. In NL, a provincial advisory committee with representatives from each RHA, the HSC. The provincial government agreed to provide $319,000 over three years to support the implementation and sustainability of this initiative with additional support from CFHI (D. of H. and C. S. Government of Newfoundland and Labrador, 2018a).

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Appendix A. Program Comparison

Table A1. Comparison of First Link, the Paid Family Caregiving Option, and Protective Community Residences

Feature	Program		
	First Link	Paid Family Caregiving Option, NL Home Support Program	Protective Community Residences
Laws and Regulations	*Canadian Income Tax Act*, Canada Revenue Agency *Trustee Act*, RSNL 1990, C T-10 (4)	*Regional Health Authority Act, 2006* *Operational Standards Manual* for the Provincial Home Support Program 2005	*Protective Community Residence Operational Standards*, 2009
Policy Frameworks and Guidelines	NL Provincial Strategy for Alzheimer Disease and Other Dementias, 2002 and 2004 *The Way Forward*, Government of NL, 2016 and 2018	*Close to Home: A Strategy for Long-Term Care and Community Support Services*, 2012 NL Government, *The Way Forward, 2016*	*Provincial Strategy for Alzheimer Disease and Other Dementias, 2002* *Close to home – A Strategy for Long-Term Care and Community Support Services*, 2012
Organization	Delivered by Alzheimer Society of NL Funded by the NL Department of Health and Community Services	Program is managed by Department of Health and Community Services, Regional Services Branch, Long-Term Care and Community Support Services Division	Operated by three of the province's four RHAs.
Personnel	First Link Coordinators on staff of Alzheimer Society of NL Primary care physicians and other health professionals	Family members of dementia patient Regional trainers for pilot phase Assessors employed by each RHA Providers of respite care for family caregivers Administrative support for bookkeeping and reporting	Each home requires: • a Case Coordinator • one or more a Resident Care Companions (one for every 7 residents during daytime and one for 12 residents at night • a recreation specialist • a social worker
Goals	To connect people with dementia and their families/caregivers with health professionals and support services To help arrange early and ongoing support	Increased client choice and flexibility Maintaining existing informal caregiving relationships Equitable support services for all eligible persons	To provide a safe home-like environment to enable residents to function to fullest potential To include family members in decision making To provide access to skilled and trained staff To provide programming geared to each resident's cognitive functioning ability
Financial Arrangements	Initial allocation of $40,000 from provincial government in 2015 Continuing financial arrangements need to be clarified in interviews	Pilot program in 2014 received $8.2 million from Department of HCS Ongoing funding by Department through block funding to the RHAs	Funding is provided by the RHA as part of its annual budget Amount of subsidy provided to each accepted resident is determined through a financial assessment
Program Outputs	Communication with referring health professionals	Subsidies for personal care/behavioural support for a	Small units each for 8–12 residents Safe and secure home-like smoke-free accommodations with private

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	Telephone outreach to potential clients Tailored information packages for each client Contact information and guidance Regularly scheduled follow-up	family caregiver for each approved client; Amount of subsidy varies, based on individual assessment Respite for family caregivers providing 24/7 care	bedrooms, shared spaces and access to a secure outside space A resident-centred, holistic model of care
Program Recipients	Any person with Alzheimer Disease or other dementia and their family members and caregivers Referral by primary care provider or self-referral	The client must be a new or current client of the Adult Home Support Program who has a long-term need for home support Eligibility determined by a clinical and a financial assessment Caregiver must be a close relative but not a spouse or common-law partner of the client	Individuals with mild to moderate cognitive impairment Eligibility is based on an assessment of suitability using the Single Entry Assessment and Placement Tool or the RAI Home Care Placement Tool
Local Research and Evaluation	Elizabeth Wallack, Master's thesis, MUN (2016) Dr. Roger Butler et al. (2015) pilot project including online delivery of First Link education materials	Report by Deloitte (2016) reviewing the Paid Family Caregiver policy as part of a broader review of the Provincial Home Support Program Follow-up report by Deloitte (2018) Evaluation of the 2014 pilot for the Option, NL Center for Health Information (2016)	O'Brien et al. (2014) "Impact of relocation from home or institution to assisted living on adults with mild to moderate dementia" Hutchins et al. (2011) "From institution to 'home'…" Chappell et al., (2015) Supporting the Independence of Persons with Dementia, NLCAHR

Appendix B. Other Research

Below is a list of related research projects in NL that are not necessarily directly linked to any of the programs we examined in our analysis but that bear on the care and health of individuals living with dementia (Table B1).

Table B1. List of other research projects

Project and Description	Link
2018 Evidence Update: Managing Agitation and Aggression in Long-Term Care Residents with Dementia Completed through the Newfoundland and Labrador Centre for Applied Health Research's Contextualized Health Research Synthesis Program (Navarro & Bornstein, n.d.).	https://www.nlcahr.mun.ca/CHRSP/2018_Update_AMD_Report.pdf
For the people by the people": Engaging seniors with mild dementia to improve awareness of and access to support services in newfoundland and Labrador Funded through Quick Start Fund for Public Engagement. Project started in March 2017 and projected to end March 21, 2019.	https://mun.yaffle.ca/projects/3312
CHRSP Evidence in Context Report: Agitation and Aggression in Long-Term Care Residents with Dementia in Newfoundland and Labrador, 2014 Completed through the Newfoundland and Labrador Centre for Applied Health Research's Contextualized Health Research Synthesis Program (Chappell et al., 2014).	https://www.nlcahr.mun.ca/CHRSP/CHRSP_Dementia_LTC_2014.pdf
Health Promotion through the Arts: Exploring New Methodologies in Research; Creative-Arts Workshops for Caregivers of Partners with Dementia, 2013 Funded by the Medical research Fund	https://www.yaffle.ca/projects/2173
Does a Dementia Unit Reduce Polypharmacy in a Veterans' Pavilion? 2010 Project Grant Funded by NLHARP, NLCAHR (Newfoundland and Labrador Centre for Applied Health Research, 2016)	https://www.nlcahr.mun.ca/Research_Exchange/Aging8_R_Butler.pdf
Determining the Needs of Community Dwelling Older Adults with Age-Associated Memory Loss and Mild Cognitive Impairment in Newfoundland (Newfoundland and Labrador Centre for Applied Health Research, 2016) Project started in January 2007 and ended December 31, 2009. Coauthors: Aimee Surprenant, Anne-Marie Tracey, Dr. Marshall Godwin	https://mun.yaffle.ca/projects/1334

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