

MAY 2021

Working Together to Bring Home Care Home! A Continuing Care Position Paper

Closing the Gaps in Nova Scotia Home Care

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Introduction

To ensure that Home Care works for all Nova Scotians, we need innovation, vision, investment and political will. With strong and responsive Home Care, people can leave acute care earlier and remain in their homes and communities longer. The existing strategy, programs and policies are out-of-date, fragmented and under-funded. Home Care must be there for all who need it, now and into the future!

C.A.R.P. Nova Scotia believes that *competencies*, *communications* and *continuity* are at the core of effective Home Care. This Position Paper puts forward *our vision for a renewed provincial approach* that is well-funded and implemented effectively by the Department of Health and Wellness (DHW), Nova Scotia Health (NSH) and service delivery agencies. We understand that each are already working on improvements, so we offer our analysis and recommendations to further assist this process.

C.A.R.P. – A New Vision of Aging is Canada's largest member-based advocacy association for older Canadians. Our mission is to achieve equitable access to health care, financial security, and freedom from ageism for older Canadians. With more than 320,000 members across the country, C.A.R.P. is a non-partisan association committed to working with all political parties. C.A.R.P. members engage in polls and petitions, lobby their elected representatives, connect with local chapters, and share stories, opinions and insights on urgent issues.

C.A.R.P.'s National Campaign recommends major reforms to both Long-Term Institutional Care and Home and Community Care, including eventually moving these services under the umbrella of a new Canada Long-Term Institutional Care Act. The COVID-19 pandemic has galvanized C.A.R.P.

members across the country to address deeprooted, systemic problems in seniors' health care and other supports for quality ageing. Recent national research concludes that COVID-19 has shifted the perspective of many older Canadians – surveys show that 95% of Canadians over the age of 65 report that they plan to live at home for as long as possible.

C.A.R.P. Nova Scotia, founded in 2008, is one of 27 chapters across Canada. We represent 10,000 members across the province. Our volunteer Executive Board includes health professionals, environmentalists, researchers, legal and finance experts, businesspeople, and community activists. C.A.R.P.'s newsletters and other communications inform our members. We also organize on-line and in-person educational events.

A top priority for C.A.R.P. Nova Scotia in 2021/22 is to transform our province's Home Care, building on C.A.R.P.'s National Advocacy Campaign. Now is the time for the provincial government to address the rising demand for Home Care. Now is the time to act. Now is the time to close the gap between rhetoric and reality. Now is the time to establish a foundation for a better Home Care future. Now is the time to Bring Home Care Home!

Priority Actions

C.A.R.P. Nova Scotia's *Five Priority Actions* for Home Care are aligned with our national campaign and adapted for our context. In Nova Scotia, Home Care is part of Continuing Care (which includes Long-Term Care), but here we focus only on Home Care here. We propose the following Five Priority Actions to be implemented starting immediately:

Focus on Person-Centred and Family-Centred Home Care Approaches

Review and update Home Care standards, policies, guidance and regulatory materials to place responsiveness, dignity, knowledge and choice at the heart of Home Care planning, assessment and delivery, based on personand family-centred care.

2. Increase Recruitment, Retention and Quality for Home Care Human Resources

Increase Home Care worker recruitment based on a specific strategy with demographic and labour force projections and provide an improved compensation package for workers with generous educational support, sick leave, on-the-job supportive supervision, guaranteed hours, paid travel time, wage parity and safety protection, that will collectively enhance worker recognition, respect and motivation.

3. Improve Home Care Communication

Develop stronger communications channels across Home Care, to ensure that Home Care clients and their families receive timely, accurate and useful information. This should include skill-building in positive interpersonal communications at all levels of Home Care, from front-line service delivery to care team coordination, as well as stronger client and family participation in review and renewal of quality standards for communications in the Home Care manual.

4. Improve Public Transparency and Accountability for Home Care

An up-to-date multi-year and fully funded Home Care Sector Plan is urgently needed, along with more robust public accountability mechanisms such as regular wait-list updates with regional breakdowns, and impartial, accountable and transparent client feedback and complaint process. C.A.R.P. recommends a province-wide advisory council of residents and family members be formed to advise and recommend improved policies and procedures for home and community care in Nova Scotia.

Expand and Untax Home Care Direct Financial Support

Increase funding for Home Care, both to expand the number of Home Care service provider agencies and to increase the Caregiver Benefit and the Supportive Care Program. Direct caregiver benefits should not be federally taxed, and they require innovations to reduce bureaucracy and improve access. There should be a refundable tax credit for all family-funded home and community care.



Focus on Person-Centred and Family-Centred Home Care Approaches

C.A.R.P. Nova Scotia members and supporters hear regularly from people who receive funded Home Care services. They describe many *gaps* between what Home Care says it is delivering through its service provider agencies, and what families and clients are actually experiencing on the ground. We would like to see these gaps addressed.

A key tenet of Nova Scotia Home Care is that service must be person- and family-centred. This means that services are designed flexibly and responsively around the complex needs of both the individual being provided the service (client) and their families, and that everything possible is done to maintain capability, choice, flexibility, respect and dignity. 'Persons' are not just 'clients' or 'patients' - they are real people with real needs. In practice, Home Care clients and their families tell C.A.R.P. Nova Scotia that their realities are not always adequately taken into account during assessments and care planning. The roles of family members who coordinate Home Care services are often ignored, and there is a need for more respite care. C.A.R.P. supporters tell us that there are many instances where institutional procedures take precedence over client and family preferences.

Home Care in Nova Scotia follows detailed guidelines and standards under the 'Home First' approach by the Department of Health and Wellness (DHW) and Nova Scotia Health (NSH). Services are delivered via contracted Home Care provider agencies (both for-profit and not-for-profit). While standardization for quality assurance is important, these institutional guidance materials and standards require an urgent review (with beneficiary participation) to resolve problems experienced from the client and family perspective.

For example, scheduling and continuity of staffing do not always meet client and family expectations. Care workers often arrive late, are unavailable when clients and families really need them, and/ or they change too often to build relationships and respond to client needs. The monthly cap on hours for Home Care services means that some clients cannot receive enough care. We know that additional hours are sometimes available, but only if certain criteria are met. Quality of life for Home Care clients and their families depend on flexible, timely services that meet their needs. This includes having the 'right' provider at the 'right' time.

Person-centred care is a core principle of the 'Home First' approach as well as in the Nova Scotia Dementia Strategy and it is recommended by researchers and advocates. C.A.R.P. Nova Scotia recommends that person- and family-centred care be consistently supported in Home Care from top to bottom, via more flexibility for clients as well as specialized training for workers and continuous values reinforcement.



Priority Action #1:

Review and update Home Care standards, policies, guidance and regulatory materials to place responsiveness, dignity, knowledge and choice at the heart of Home Care planning, assessment and delivery, based on person- and family-centred care.

Increase Recruitment, Retention and Quality for Home Care Human Resources

We are facing a 'demographic crunch' in Nova Scotia – rising numbers of those who need Home Care, and a decline in numbers of those who can fill Home Care jobs. Lack of available staffing influences the length of Home Care wait lists and the frequency and quality of services. More Continuing Care Assistants (CCAs) and Home Care Aides (HCAs) are urgently required in Nova Scotia, and they deserve better pay, working conditions and other supports.

C.A.R.P. strongly endorses past recommendations for improving labour market quality supply for Home Care in Nova Scotia. A comprehensive 2014 report from the Health Association of Nova Scotia outlined human resource challenges in Home Care and proposed evidence-based changes to increase staffing and assure quality. We applaud the government's efforts so far to increase Home Care human resources (such as subsidies offered under the Recognizing Prior Learning initiative), but we also recommend rapidly scaling up the numbers of trained staff.

Full training for CCAs is expensive (around \$7500 tuition and program costs). Financial and other incentives for those entering training are needed, including generous bursaries, partially forgivable loans, reimbursement for childcare costs during training, and other cost-sharing arrangements. Similar supports should be offered for the new HCA role.

Once on the job, C.A.R.P. N.S. would like to see Home Care workers provided with a living wage, adequate full-time hours, recognition, sick leave, health benefits, vacation pay, and the education and supportive supervision needed to do their jobs with minimum stress. This should include more funding to enable agencies to offer workers guaranteed minimum hours per week (to increase job stability), fair payment for travel time, and reasonable scheduling changes. The province must ensure that wages and working conditions in Home Care are monitored and adjusted continuously to match those of workers in acute care and Long-Term Care. Home Care workers should be provided with government-financed in-service training to continuously enhance their competencies, whether it be skills in dementia care or how to communicate and build relationships with clients.

C.A.R.P. understands that the province has access to resources from the federal government to 'top up' Home Care expenditures in Nova Scotia. We want to see these additional resources invested in the most strategic areas such as keeping Home Care staff well-paid, motivated and engaged in their jobs for years to come.



Priority Action #2:

Increase Home Care worker recruitment based on a specific strategy with demographic and labour force projections and provide an improved compensation package for workers with generous educational support, sick leave, on-the-job supportive supervision, guaranteed hours, paid travel time, wage parity and safety protection, that will collectively increase worker recognition, respect and motivation.

3 Improve Home Care Communication

Communications on multiple levels and channels is essential to the planning and delivery of high quality, person-centred Home Care. We are aware that Home Care has many established communications processes. However, feedback from C.A.R.P. Nova Scotia members and supporters is that stronger communications and information-sharing is needed between Home Care policy makers and the general public, as well as among health professionals, case managers, service agencies, Home Care workers, and Home Care clients and their families.

Gaps in what Home Care clients and their families know about how Home Care services work can give rise to misunderstandings and confusion. DHW and NSH provide basic information on their websites, but individuals and families under stress do not always clearly understand them. While we agree that Home Care applicants and their families need to stay well-informed, C.A.R.P. Nova Scotia wants to see more done proactively to educate, dialogue with, and orient Home Care clients and their families about their options.

C.A.R.P. Nova Scotia's members and supporters are concerned that poor communication among

the care team involved in a Home Care client's support makes it very difficult to provide proper care. In peoples' homes, at the point of service delivery, there are instances of poor communications between Health Care workers and families that need urgent attention.

The current 2011 Home Care policy manual needs updating to provide better information on how to streamline and enhance communications among the care team and between those delivering services and Home Care clients and families, based on active beneficiary participation. The manual contains no quality standards for Nova Scotia Home Care regarding client communications and participation in discussions around key care decisions. There are no specific guidelines for ensuring quality and respect in inter-cultural and inter-racial communications. C.A.R.P. Nova Scotia knows that some Home Care clients do not provide honest feedback for fear of being stigmatized or penalized by the NSH and service providers. There is an urgent need to diagnose and correct these systemic communications challenges.



Priority Action #3:

Develop stronger communications channels across Home Care, to ensure that Home Care clients and their families receive timely, accurate and useful information. This should include skill-building in positive interpersonal communications at all levels of Home Care, from front-line service delivery to care team coordination, as well as stronger client and family participation in review and renewal of quality standards for communications in the Home Care manual.

4 Increase Public Transparency and Accountability for Home Care

Nova Scotia health statistics indicate that between January 2020 to January 2021, there was a 35% increase in the wait times for Home Care, likely due to backlogs created by the pandemic but also increased interest in Home Care as an alternative to entering a Long-Term Care facility. But Home Care spaces have evidently decreased in the past several years. In 2011, there were approximately 23,000 clients receiving Home Care in the province, compared to 17,000 in 2021. At the same time, Home Care provincial expenditures rose from \$136.1 million per year in 2008, to \$260 million annually in 2020, possibly due to addition of more direct caregiving benefits (see Priority Action #5).

There is currently no up-to-date provincial reporting system for the Home Care sector available to the public, from which to assess and monitor Home Care funding patterns, efficiency, delivery mechanisms, and results. C.A.R.P. members and supporters have many unanswered questions and concerns about wait lists, scope of coverage, assessments, complaints, funding and planning in Home Care. There is no public and regularly updated wait-time data with detailed information about the location and number of those waiting for Home Care services.

Recent provincial auditor reports have identified the need to strengthen Home Care client complaint and feedback mechanisms, which DHW has worked to improve. C.A.R.P Nova Scotia knows that NSH has recently conducted client satisfaction surveys, which we think is a good first step, but client-based feedback loops regarding the quality, responsiveness and value of Home Care should be routine. Some Home Care clients and families are reluctant to offer complaints as they are afraid of being stigmatized. C.A.R.P. Nova Scotia is concerned that there are limited formal opportunities for Home Care clients and their families to provide feedback on wait times, the quality of Home Care assessments and care plans, and how well Home Care meshes with what clients and their families expect.

Building on recommendations in recent provincial audits, C.A.R.P. Nova Scotia believes that there is a need for a third-party oversight mechanism (perhaps administered by the Nova Scotia Ombudsman's Office) that can help mediate concerns or complaints received from clients and families about individual workers, service providers and provincial Home Care policies.



Priority Action #4:

An up-to-date multi-year and fully funded Home Care Sector Plan is urgently needed, along with more robust public accountability mechanisms such as regular wait-list updates with regional breakdowns, and impartial, accountable and transparent client feedback and complaint processes. C.A.R.P. recommends a province-wide advisory council of residents and family members be formed to advise and recommend improved policies and procedures for home and community care in Nova Scotia.

5 Expand and Untax Home Care Financial Support

C.A.R.P. Nova Scotia advocates for continued provision of quality government-funded services through contracted Home Care agencies. With rising Home Care demands due to demographic and social factors, there will be a need for rapid expansion of service providers and on-going quality improvement – for example, through recruiting additional qualified Home Care agencies to take on more clients and reduce the growing Home Care wait list. With these changes sufficient funding will be required to enable service providers to cover the true costs of providing quality Home Care with high quality staffing (as noted under Priority Action #2).

At the same time, the Home Care budget must increase to put more funds into direct support for Home Care clients and their families. Caregivers Nova Scotia and other organizations highlight the essential role of unpaid, unacknowledged family and friend caregivers who help keep people at home rather than in Long-Term Care. Approximately 7% of the provincial Home Care budget is allocated for direct caregiving benefit programs. According to DHW, investment in direct caregiving programs has already increased due to the pandemic. The demand for these options will undoubtedly continue to increase over time.

Two provincial programs that Nova Scotia Home Care clients and family caregivers can access within Continuing Care are the Caregiver Benefit and the Supportive Care Program. The Caregiver Benefit offers a modest \$400 monthly payment to qualifying family caregivers. The Supportive Care Program offers a higher monthly allocation for a range of self-managed Home Care needs on a reimbursable basis. Both programs are income- or needs-based and require assessments. C.A.R.P. Nova Scotia's members and supporters are pleased that these programs exist and are slowly being expanded, but they are concerned about the barriers presented by restrictive income ceilings, unfair taxation implications, coordination challenges, and bureaucratic complexity in the application and reimbursement process.

C.A.R.P. National advocates for all direct funded Home Care programs to be exempt from federal taxation and that all family-funded costs of home and community care should be eligible for a refundable tax credit. In the meantime, the province could offer tax credits to those receiving direct caregiver benefits. More funding is needed for the Nova Scotia Supportive Care Program, so that clients and their families have greater scope to choose what support they need. These programs must be more widely available, through simplification of application and administrative processes and expansion of qualifying criteria.



Priority Action #5:

Increase funding for Home Care, both to expand the number of Home Care service provider agencies and to increase the Caregiver Benefit and the Supportive Care Program. Direct caregiver benefits should not be federally taxed, and they require innovations to reduce bureaucracy and improve access. There should be a refundable tax credit for all family-funded home and community care.

Conclusion

In Nova Scotia, C.A.R.P. envisions a much brighter future for Home Care as the 'preferred option' for seniors and for all those needing specialized support who want to live in their homes and communities. The ability of Home Care to meet growing needs will be dependent on the political will and vision of citizens, elected officials, policy makers, home care service providers and health system administrators.

C.A.R.P. National is advocating that Home and Community Care options be expanded quickly across the country. National advocacy work by C.A.R.P. is expected to gain momentum as we plan and lobby with leaders at all levels for the post-pandemic recovery. Let's get on board and all be leaders in this national movement!

The time is now to innovate and plan for better Home Care in Nova Scotia and therefore we applaud recent information shared by DHW that a renewal is coming soon. Our hope is for an improved 'Continuum of Care' in Nova Scotia, that is well-funded, safe, responsive to client and family needs, publicly accountable, and implemented with compassion and quality. We urge all provincial politicians and policy makers, as well as the general public and C.A.R.P.

members, to work together for stronger Home Care. We are optimistic that C.A.R.P. Nova Scotia's Priority Actions are a step in the right direction. Please contact C.A.R.P. Nova Scotia for more information on these Priority Actions or to request support if you wish to advocate for better Home Care. In brief, here's how you can be involved:

- 1. Write letters and speak with politicians about the need for better Home Care
- 2. Contact the media about your concerns
- 3. Join and follow C.A.R.P. Nova Scotia to add your voice to our work.

We will continue to update this Position Paper over time, to adapt to changing circumstances. We look forward to your comments.

Working Together to Bring Home Care Home!



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