TRENDS, ISSUES & POLICIES:

CONTINUING CARE IN THE ATLANTIC REGION

CONTEXT FOR BUILDING CAPACITY

IN RESEARCH

Dept. of Family Studies & Gerontology

Mount Saint Vincent University
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Nova Scotia

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This paper was first prepared for a Continuing Care Workshop, BRIDGING RESEARCHERS & DECISION MAKERS IN THE ATLANTIC REGION, held Oct. 7-8, 2002 in Halifax, Nova Scotia.

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Forward

This paper was initially prepared for a workshop on the Continuing Care sector in Atlantic Canada, held Oct. 7-8, 2002 in Halifax, Nova Scotia. The two-day seminar, *Bridging Researchers & Decision Makers in the Atlantic Region*, brought together 43 stakeholders in Atlantic Canada's continuing care field, and was the first step by Mount Saint Vincent University (MSVU) toward its goal of increasing both the scope and quantity of relevant evidence available for use in policy-making.

The paper, distributed prior to the workshop, served as a launching pad for group discussion and debate among the participants, who hailed from all four Atlantic provinces, and work within the continuum of care in some capacity. They were representatives of the four governments, Veterans Affairs Canada, stakeholder agencies, and university research groups.

The workshop was hosted by Mount Saint Vincent University's Department of Family Studies and Gerontology (FSGN) and the Nova Scotia Centre on Aging (NSCA). It was co-organized by Dr. Janice Keefe, Canada Research Chair in Aging and Caregiving Policy and Associate Professor, FSGN, and Marlene MacLellan, Associate Director, Nova Scotia Centre on Aging, and funded by the Canadian Institutes of Health Research (CIHR) and the Nova Scotia Health Research Foundation (NSHRF), as well as the Nova Scotia Department of Health.

Bridging Researchers & Decision Makers in the Atlantic Region took place before the October 2002 release of the Senate Standing Committee on Social Affairs, Science and Technology (Kirby Commission) final report, and the November 2002 release of the final report of the Commission on the Future of Health Care in Canada (Romanow Commission). The content of the original document was also edited for general distribution.

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The Context

The current need for new knowledge in continuing care stems from several factors, including previously unseen demographic trends in population aging, policy shifts to promote care in the community, concerns about the gray area between formal and informal caregivers, and a desire to maximize the ever-increasing percentage of fiscal resources invested in the continuum of care.

The goal, ultimately, is the provision of a seamless, integrated, client-centred continuum of care. In order to achieve this, programs, services and institutions must be flexible, adaptable and collaborative in design; alternative care strategies must be devised and adopted; and better partnerships must be established with consumers and their families.

For the purpose of this paper, the phrase *continuing care* refers to home, community, and residential care services that provide care to adults with disabilities, and to seniors. In their definition of continuing care, Hollander and Prince (2002, p.2) added:

> The term continuing care refers to care that continues over time and care that continues across service components ... The term community refers to a philosophical preference for care provision in the community and in clients' homes… The term care distinguishes the needs of these populations from curative medical approaches. It means that the primary needs of the individuals in these population groups are generally for care, support and "enablement" rather than cure.

This document focuses on the issues relevant to the policies that frame these services, and limited to those programs and services that are publicly funded.

Trends, Issues and Challenges: A National Perspective[1]

The following is a brief overview of current trends in continuing care, and the issues and challenges facing Canadian jurisdictions:

- Sector Growth

There has been a sharp rise in the past decade in service use in continuing care, and the costs and demands of these services are projected to continue intensifying in the next thirty years. Most Canadian families will depend upon the continuing care sector at some time.

- Increasing Complexity and Diversity

The profile of care users in Atlantic Canada is changing dramatically, and will continue to evolve over the next several decades, placing increasingly complex demands on the care system. A growing number of home care recipients, particularly those with multiple diagnoses, will require post-acute home care, and/or choose to age in place. The preventative and maintenance facets of home care are threatened by funding cutbacks and undermined by the absence of clearly defined outcome measures. Meanwhile, the average age of residents of long-term care facilities is rising, and the instances of frailty and later stage dementia within this group are skyrocketing. There has also been a reduction in the ratio of long term care beds for the cohort over the age of 75 years.

[1]Three principal references were used for this section, each selected because of its currency and comprehensiveness:

- *Continuing the Care: The Issues and Challenges for Long-Term Care, Revised Edition,* (2002) was published by the Canadian Healthcare Association seven years after the first edition. Twenty experts write about topics relevant to the sector, including its users, providers, and facilities; history, structure and governance; and issues related to daily living. The chapters by Anderson, Havens, Keefe, and Pitters were used most frequently.
- *"The Third Way: A Framework for Organizing Health Related Services for Individuals with Ongoing Care Needs and Their Families*" released in February 2002 by Hollander Analytical Services Ltd. It is a final report, preceded by six technical reports, all of which form "a comprehensive analysis of the topic of 'a continuum of care'" (Hollander & Prince, 2002. p.6).
- The Commission on the Future of Health Care in Canada has a website rich in documents – discussion and submission papers, research reports, public opinion reports, fact-finding (national and international) summaries.

The populations of both care providers and care recipients will also become even more ethnically and culturally diverse in the future, giving rise to a unique set of challenges with respect to customs, language preferences, and worker-client discrimination.

In fully assessing the care system, the complexity and diversity within the population of disabled persons must also be recognized. Anderson and colleagues (2001) suggest this diversity mirrors that of the general population (e.g., age, gender, living arrangements, location, attitudes, ethnic background, etc.), and is intensified by the many types of existing disabilities, their severity, and time of onset. The trend toward de-institutionalization has led to an increase in the population of disabled persons living in community, and exacerbated the severity of disability in many cases. Improved medical care and advanced technology have contributed to increased life expectancy for many individuals with either an acquired or a congenital disability, which, while a tribute to our advancements, is also placing unforeseen demands on the system. There is an overall longer-term dependency on services, a greater demand for community-based services, the question of how elderly parents caring for adults with disabilities can remain the primary caregiver, and an emerging need to determine the interactive effect of age-related illnesses on a person with pre-existing disabilities.

- Shifting Funding and Service Responsibilities

From the research of Hollander Analytical Services, a consistent theme from key informants was "issues related to funding" (Hollander and Prince, 2002, p.vi). The impact of inadequate funding has multiple consequences, from engendering inaccessibility to adequate services, to the lack of capital investment to improve existing facilities and build new ones, and to sharply increased demands on family caregivers.

Provinces and territories are now able to independently determine the amount of funding they can request from the federal government for their continuing care programs (Health Canada, 1999). The services are included in the non-insured services identified in the Canada Health Act, and no national policy requirements exist for the provision of such services. Since 1996, the federal government has supported policies relating to continuing care through the Canada Health

and Social Transfer (CHST), while providing block funding to provinces and territories for health care, education and social programs.

Federal transfer payments for health care have gradually been reduced through various initiatives over the years. While there is a consensus that the amount of federal money for health has decreased, different standards make it difficult to calculate the overall loss. Initiatives such as transferring a portion of funding in the form of tax points, increasing existing research funding, the inclusion of continuing care initiatives, and individual income tax credits (such as the Caregiver Tax Credit) mean there are several ways to calculate the federal contribution. The end result, however, is the same- the proportion of the health dollar has decreased for federal governments and increased for provincial governments, placing the burden of increasingly expensive services and increasing numbers of continuing care clients on the provinces and territories.

Much of the extra burden has been assumed by informal caregivers, most often women, who are increasingly being acknowledged as partners with the formal framework that cares for dependent adults, though this status has not yet been formally recognized. There is now acknowledgement and understanding of caregiver stress, a variety of tools to measure it, and strong advocacy for a complement of supports for family/informal caregivers.

The creation of a national framework for home care, which would presumably guarantee federal financial participation, was once considered a priority in federal/provincial negotiations, but plans have become stagnated in recent years, and will remain so until the recommendations of the Romanow Commission are instituted to guide the entire national health system toward a coherent design.

- Jurisdictional Variations

There are variances among the Canadian jurisdictions in such areas as patient eligibility and access to services; treatment, residential and intervention options; wait lists; licensing and quality assurance; information systems and data collection; public/private payment ratios; resources for

innovation and research; for-profit/not-for-profit providers; and policy development. There are also variances within jurisdictions, mainly stemming from rural/urban differences, socio-economic disparities, and the shift towards regionalization.

The transfer of ownership, management, administration and decision-making to regions is intended to allow the provision of comprehensive health care to a geographic region or groups of communities. The provinces are in varying stages of regionalizing home care and long term care, and as yet, there is limited evidence of whether the objectives of regionalization have been realized.

- Human Resources

Caregivers are often characterized as underpaid, overworked, and undervalued. A key component of enhanced continuing care, therefore, is assessing and supporting the caregiver population – be they employed workers, family, friends or volunteers – by determining availability, devising recruitment strategies, retention, and training programs, and establishing a support network.

- Role of technology

The effect of increased technological utilization on caregivers and consumers is emerging as a critical issue as the family home evolves into a miniature hospital. The increased use of technology – in service delivery, communication, and information sharing – necessitates comparative data systems and specialized infrastructures, equipment and training. All require significant financial investment, the absence of which leads to disparities among consumers, and within services and facilities. Improvements in the development of comparative information systems at both the provincial and provider level are needed to adequately track service utilization patterns and analyze program outcomes.

- Public/private financing and public, for-profit, and not-for-profit providers

The public-private mix may refer to the financing of services, or the delivery of services. Multiple delivery systems are evidenced in continuing care services, home care, residential care, and alternative housing arrangements.

There are, for example, more long-term care beds throughout the country in not-for-profit facilities than in for-profit or public facilities (Pitters, 2002, p. 164). The role of private agencies in the delivery of assessed home care needs is further complicated by the ability of clients (and/or their families) to purchase additional services from the same agency as they become necessary. In addition, clients may also access home care services privately without undergoing a provincial assessment of home care needs. More consumers are paying for home care services offered outside the public system, but to what extent is difficult to measure, in terms of both frequency and expenditures (Keefe, 2002, p.133).

- Accountability

In his interim report of February 2002, Commissioner Romanow wrote that one wish Canadians have regarding health care reform is that "their tax dollars for health are being spent in a well-thought out plan that ensures value for money" (Romanow, 2002, p.8). Increased research and best practices, quality assurance and public accountability, information systems, and data analysis in the area of continuing care are essential to this.

What's Different in Atlantic Canada?

Socially and economically, the Atlantic provinces are distinct from the rest of Canada. As evidenced in Table 1, the four provinces have slow population growths with Newfoundland (NL) experiencing the highest out-migration rate. Table 2 shows that New Brunswick (NB), Nova Scotia (NS) and Prince Edward Island (PE) all have a higher proportion of population over age 65 than the national benchmark.

Table 1. Percentage Population Change in Atlantic Canada and Canada 1996-2001.

Province	% Population Change
Cdn	4.0
NL	-7.0
PE	0.5
NS	-0.1
NB	-1.2

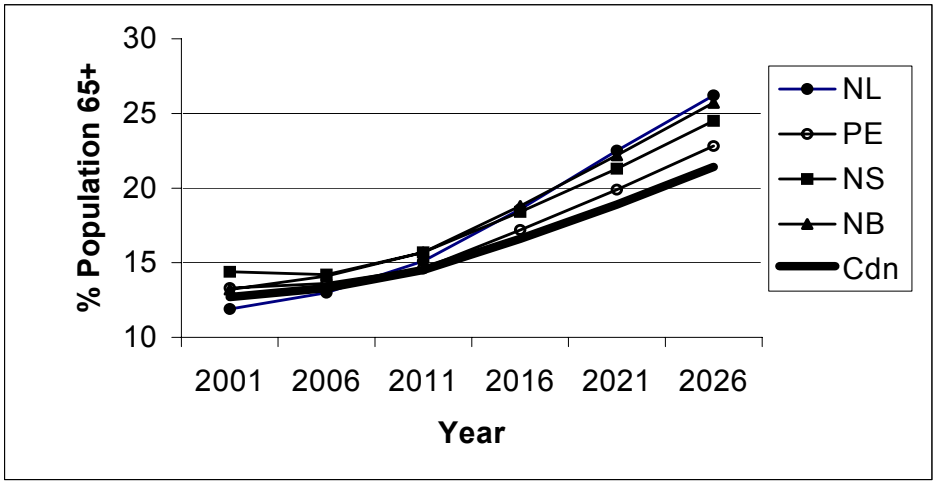
(Statistics Canada, 2002a)

Table 2. Population Size and Percentage of Population 65+ Years in Atlantic Canada and Canada, 2001.

Prov.	Population Size ('000)	% Population 65+
Cdn	31,081.90	12.6%
NL	533.8	11.8%
PE	138.5	13.3%
NS	942.7	13.4%
NB	757.1	13.0%

(Statistics Canada, 2002b)

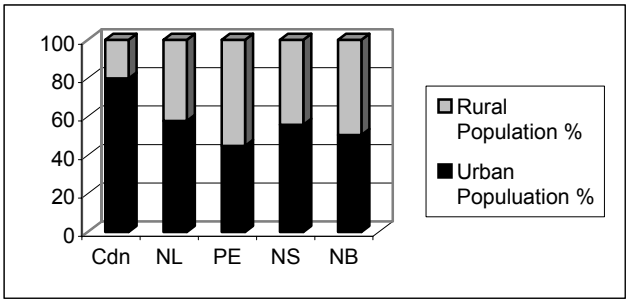
Figure 1. Percentage Population Projections, 65+ years, based on Medium Growth, Atlantic Canada and Canada, 2001-2026.



(adapted from Projected Population by Age Group and Sex, Canada, Provinces and Territories, July 1, 2001-2026. Statistics Canada, 2001)

All four Atlantic provinces have relatively large rural populations – more than double the Canadian average –in part due to the out-migration of young people (Figure 2); Nova Scotia and Quebec have the oldest rural populations in the country.

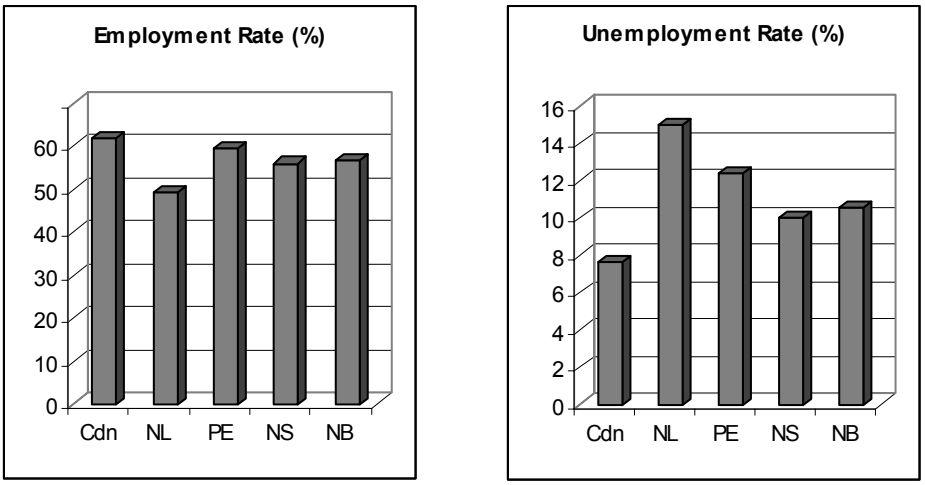
Figure 2. Percentages of Rural-urban Populations in Atlantic Canada and Canada.



(adapted from Population Counts for Canada, Provinces and Territories and Census Divisions by Urban and Rural, 2001 Census. Statistics Canada, 2002c)

Despite more recent positive projections of economic and production growth, the real GDP of the Atlantic region is about 75% of that of the rest of the country. Moreover, unemployment rates are one-third to one-half greater than that of the rest of the country (Figure 3).

Figure 3. Employment Rate (%) (left) and Unemployment Rate (%) (right) for the Atlantic Provinces and Canada, July 2002.



(Statistics Canada, 2002d)

Atlantic Canadians also exhibit higher rates of illness and disability, and score lower on several determinants of health – socio-economic factors, education levels, level of physical exercise, and

lifestyle choices, such as smoking and dietary considerations, in comparison to the national average.

There is also considerable variance within Atlantic Canada. For instance, Prince Edward Island (PEI), Newfoundland and Labrador (NL), and, until recently, New Brunswick (NB), operated amalgamated health and social service departments, while Nova Scotia (NS) maintained two separate departments. NB reverted back to separate departments in 2001. All have regionalized to some extent, but through the introduction of different structures, implemented at different times. PEI, NB and NL have devolved delivery of home care and continuing care to the regions, and Nova Scotia is planning to do so. Single entry access has now been instituted in every Atlantic province, though again with variations of historical context, model, and time of implementation, and the emergence of some terminology in the continuing care field that is province-specific.

What makes continuing care in the Atlantic provinces different from other Canadian jurisdictions is the cost to residents of long term facility-based care. Long-term care in the Atlantic provinces is uninsured: the full cost of facility-based care is borne by all residents that can afford it, with government assistance being determined by a province-specific income/asset test. Residents of long-term facilities in other Canadian jurisdictions are charged a co-payment, which is generally considered to be the cost of room and board, while services generally viewed as the care portion are paid for by the provinces.

In relation to residential long-term care, the differences between the provinces are also evident in varying regulations and standards, assessment procedures, and rates of utilization. The degree of government control over the delivery system is different from one province to another, as is the public/private role in service delivery (i.e. whether the facilities or the service-provision organizations are publicly or privately owned).[2]

[2] Terminology defined by Deber, Lutchmie, Baranek, Sharpe, Duvalko, Zlotnik-Shaul, Coyte, Pink, and Williams.

With regard to home care, differences exist in such areas as definition of terms, organizational models, fee structures and service eligibility, as well as in what types of services provided, by whom, and for how long. Aspects differ in the public/private role in financing, allocation and delivery in home care. As well:

- Eligibility requirements are similar in necessitating a provincial health card (residency); NB requires physician referral for its Extra Mural Program.
- Similarities in the provision of home care services include assessment, nursing, personal care, and home support services in the four provinces. Differences include adult day care only in NB and PEI, respiratory services in NS, NB, and NL, social work and rehabilitation therapy in NB and NL, occupational therapy and a quick response team in NS, self-managed programs in NB and NL, and speech therapy in NB.
- Services are provided using a public provider model in PEI, and a mixture of public and private in NS, NB and NL. Professional workers are typically public employees while home support/personal care workers come from private agencies (though NS contracts with VON to deliver nursing services in urban areas).
- Fees paid by care recipients are determined differently in each province. In PEI and NS, home support payment fees are determined though income assessment. In NS, there are no user fees for the acute care program, or for the Extra Mural Program in NB. In NB's long term care home support program and home support services in NL, fees for services are determined by both income and asset testing.
- Apparent discrepancies exist between the provinces in per capita expenditures, even taking into consideration the lack of consistency in terminology for home care services.

Conclusion

This snapshot of the current continuing care sector in the Atlantic region mirrors much of the entire health care spectrum, not only in Canada but in many other countries around the world. A coherent national strategy to reform the Canadian health care system is anticipated shortly; with respect to the continuum of care, the following quote should serve as a guide for strategic change. Taken from the final report of Hollander Analytical Services' set of reports on the continuum of care, it may be considered a quote of national solidarity (2002, p.x):

> There appears to be a national consensus on the problems … and a proposed solution. Thus, the continuing/community care sector constitutes fertile ground for new initiatives. With the current search for solutions through the Romanow Commission and the Senate's review of health services, it is clear that the public, and senior federal and provincial decision-makers, desire new and constructive ideas. Failure to act may mean that existing problems remain or get worse. Canadians deserve better.

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