

Building Capacity in Continuing Care

Bridging Researchers & Decision Makers in the Atlantic Region

Workshop Report

**Continuing Care Workshop
October 7-8, 2002**

December, 2002

**Dept. of Family
Studies &
Gerontology**



**Centre
on
Aging**
Nova Scotia

March 2003

A note to our participants:

This report is written for those who attended BRIDGING RESEARCHERS & DECISION MAKERS IN THE ATLANTIC REGION: BUILDING CAPACITY IN CONTINUING CARE. It is a review of the proceedings of October 7-8, 2002 and our deliberations since then.

We have structured it to be a user-friendly document. The main text is in summary form; the details are in the appendixes. For instance, our “Background Paper” is replicated in Appendix A, our large group presentations and the small group discussions are detailed in Appendixes B through E, the evaluation form is in Appendix F, and the list of workshop participants is provided in the final appendix. The work that we have done since our meeting is outlined in the last section of the main text, titled “Future Directions”. Our hope is that you will get an overview of the process in the main text, and the details in the appendixes.

The workshop was a critical first step for the Mount’s program of fostering applied research in continuing care in the Atlantic region. We appreciate the support of our workshop funders, Canadian Institutes of Health Research (CIHR) and the Nova Scotia Health Research Foundation (NSHRF), the in-kind assistance from the Nova Scotia Department of Health, the generosity and skill of our facilitator Susan Weagle, and the help of our small group leaders. And to each of you, a sincere and hearty thank you. This was very much a *workshop*, and your contributions were generous. We agree with the evaluations that this was a worthwhile endeavor.

We will build on what was produced in our time together. You will hear from us with respect to our continuing agenda, as outlined in “Future Directions”. We invite you to continue this dialogue and hope that you will collaborate with us as we move forward on the identified research activities.

Regards,

Janice Keefe, Ph.D.
Canada Research Chair in Aging & Caregiving Policy
and Associate Professor

Marlene MacLellan, MAHE
Associate Director
Centre on Aging

For further information, please contact:

Janice Keefe, Ph.D.
Canada Research Chair in Aging & Caregiving Policy
and Associate Professor
Mount Saint Vincent University
Halifax, Nova Scotia, Canada. B3M 2J6
Tel: 902-457-6466
Fax: 902-457-6134
E-mail: janice.keefe@msvu.ca

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Workshop Overview

BRIDGING RESEARCHERS & DECISION MAKERS IN THE ATLANTIC REGION: BUILDING CAPACITY IN CONTINUING CARE was held October 7-8, 2002 at the Ramada Plaza Hotel, Dartmouth, Nova Scotia.

The workshop was a joint effort by the Department of Family Studies and Gerontology (FSGN) and the Nova Scotia Centre on Aging (NSCA), both at Mount Saint Vincent University (MSVU). It was funded by the Canadian Institutes of Health Research (CIHR) and the Nova Scotia Health Research Foundation (NSHRF). In-kind support was provided by the Nova Scotia Department of Health (DoH).

The workshop was part of Mount Saint Vincent University's efforts to establish a collaborative network within Atlantic Canada to support applied research in continuing care. The specific focus of the workshop was to increase research in policy-making, and the task of participants was to identify topics that would make a relevant contribution to regional policy development. The goals of the workshop were to:

- Identify common strengths and gaps in policy directions
- Determine the similarities and differences in policies across the Atlantic region and areas for collaborative work
- Establish priorities for applied research in policy issues relevant to continuing care
- Develop a potential collaboration on a specific issue within the scope of MSVU research expertise.

In small groups, participants collaborated to first identify issues of concern and gaps in knowledge in the field of continuing care, and then to develop research questions and projects to address them.

Forty-three people from across Atlantic Canada attended, of which 7 assisted in organization (see Appendix G). There were 17 representatives from Nova Scotia, 8 from Prince Edward Island, 6 from New Brunswick and 5 from Newfoundland. Of this, 15 were provincial government representatives, 13 were researchers, 7 represented community-based agencies and 1 was from Veterans Affairs Canada.

Workshop coordinators, 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 led the organizing team. Susan Weagle, Senior Policy Analyst, DoH, Nova Scotia, was the facilitator. Glenda Hawkins was assisted by Marlie Manning and Ethel Langille Ingram in organizing. Small group discussions were facilitated by Pat Conrad, Donna Dill, Glenda Hawkins, Ethel Langille Ingram, Marlie Manning and Shannon McEvenue.

Setting the Stage

In July 2002, invitations to participate in the workshop were extended to key stakeholders in continuing care. Efforts were taken to establish equal representation among the four provinces, and from each of them, balanced representation from government departments, researchers, associations and service providers.

Registrants were invited to review a background paper that served as both an orientation to issues for discussion, and an outline of similarities and differences among Atlantic provinces. The paper described trends, issues and challenges in the continuing care sector from a national perspective:

- Sector growth
- Increasing complexity and diversity of care in home care and long term care facilities
- Shifting of funding and services
- Variations among and within jurisdictions
- Human resources
- Role of technology; public/private and for-profit/not-for-profit mixes in financing services or delivering services; and public accountability, quality assurance, best practices and research.

Unique social and economic features of Atlantic Canada were also identified - a slow population growth, high proportion of the population over the age of 65, and high proportion of a rural population. The feature common to all Atlantic provinces, and which distinguishes it from the rest of the country, is the cost to residents of long term care facilities. Variations among many aspects of long term care and home care were as well identified. (The background paper is in Appendix A).

Prior to the workshop, key government officials, researchers, and representatives of the invited organizations/agencies were asked to respond to a survey, a set of questions “from the perspective of your organization” that identified issues of priority in home care and facility-based care, as well as identifying research projects in process. The response rate was 84% and the results identified the overall issues and research:

- In continuing care: issues related to human resources (recruitment and retention, wages, working conditions), standards, and acuity of clients
- In facility-based care: cost of facility-based care to residents (including the process of determination), supportive/alternative housing, need for capital investment
- In home care: family caregivers, cost of program, access to service in rural areas.

The survey results determined the starting point of the workshop proceedings. Both the survey and a detailed analysis of the results are in Appendix D.

Workshop Highlights

This section outlines the workshop proceedings in brief, and with greater emphasis on the end of the process than its beginning. As well, it describes prospective “next steps” proposed by the organizers. A detailed chronology of the proceedings is contained in Appendix E, a collection of the recordings from small group discussions.

The proceedings began with introductions and an orientation, followed by a description of the nine issues and knowledge gaps identified in the results of the survey, as documented in Appendix D. Participants were invited to expand the list in small group format, and then each group identified five issues considered of highest priority for applied research. This ended the first half-day of the workshop.

The issues and gaps were clustered by the organizing team into four broad research themes, a set of “considerations” relevant to all themes, and a few issues and gaps that could not be placed into a category. The four themes were:

- Models / Organizations of Service Delivery
 - Integration vs. fragmentation
 - Evaluation of best practices
 - Underlying philosophies
- Human Resources
 - Recruitment and retention
 - Training and education
 - Scope of practice and core competencies
 - Entry to practice
- Cost Effectiveness of Home Care
 - Comparisons of cost with facility-based care, and with family/informal care
 - Estimates of future cost effectiveness, at what ethical risk
- Alternatives along the Continuum
 - Cost benefit of alternative options (home care, assisted living, etc.)

Participants were encouraged to select themes that were of particular interest to them. Again in small groups, the themes were discussed according to five questions (identifying knowledge gaps and the causes of such, barriers and enablers to filling the gaps, and prospective project collaborators), and through several lenses (diversity, gender, jurisdictional, socio-economic and rural / urban specifics). The process was repeated, so each participant discussed two themes, and each theme was discussed twice.

The results of the small group discussions were considered by the organizing team and collated according to six topics. The six topics were:

- Organizations of Service Delivery
 - What are the characteristics of quality continuing care for seniors in Atlantic Canada?
- Models of Service Delivery
 - Evaluation of user pay models in Atlantic Canada, including an assessment of how these funding models impact decisions to accept continuing care.
- Evaluation of Service Models
 - Self-managed care (funding) versus service provision in the Atlantic region context.
 - What is the sensitivity within these models to specific consumer groups (culture, poverty, etc.)?
- Human Resources
 - Issues include recruitment & retention, training & education, entry to practice, core competencies and scope of practice.
- Cost effectiveness of Interventions along the Continuum of Care
 - A longitudinal study of consumers to understand how clients move through the continuum of care - including transition points of prevention, maintenance, and acute services; home care, facility care, and acute care; and cost effectiveness, including human cost.
- Alternatives along the Continuum of Care
 - Estimating the need for facility-based services and alternative supports in Atlantic Canada, including comparisons of supports such as assisted living, enriched housing and ambulatory care.

The topic “Evaluation of Service Models” was not selected by participants.

Continuing small group discussion addressed three questions (key research question, projects that may be developed, and pre-tests/exploratory studies that might enhance further proposals). From this, several research questions emerged. How each emerged and evolved is a process unique to the topic. Each of the topic areas has been summarized in the following pages with emphasis on the later stages of discussions. We have added proposed “next steps” in each of the topic areas.

The Topic:
Organizations of Service Delivery

What are the characteristics of quality continuing care for seniors in Atlantic Canada?

Research Areas, first identified (on Tuesday morning). Of them, the first two were developed in the afternoon session, and are detailed in the following two pages.

- What are the characteristics of an ideal model of quality continuing care?
- Models of Service Delivery
- What is the best way to serve adults with disabilities?
- Application of best practice, at the policy/ system and delivery/ practice levels.
- Deinstitutionalization – does it work for people with physical disabilities and those who are mentally challenged? What should it be to meet consumer needs?
- Are current service models sensitive to location, culture and poverty levels of specific consumers?

The Research Question:

Identify a project that would describe the characteristics of quality continuing care for seniors in rural Atlantic Canada?

The Projects:

- Review of literature and best practices of continuing care in rural areas.
- Define continuing care using Atlantic and rural lenses. Design survey of available services. Create asset map, compare best practices.
- Develop framework guided by principles of primary care, capacity building, community development and social marketing.
- Employ qualitative research tools (key informant interviews, focus groups, etc.).
- Define the indicators of quality: Client satisfaction? Wait lists? Response time standards? Service access? Service barriers? Ease of use? Public participation? Appropriate technology? Inter-sectoral collaboration? Prevention and health promotion? Cost efficiency and effectiveness? Utilization of services.

Proposed Next Steps:

- Define policies of continuing care in each province. Analyze how policies are implemented in selected regions of the provinces.
- Invite interested workshop participants to collectively consider development of a research proposal.
- Create a synthesis of Atlantic Canada's best practices in continuing care.
- Identify research topics/questions. Establish time lines, action plan and budget for a research proposal to be conducted by interested others.

The Topic:
Models of Service Delivery

Evaluation of user pay models in Atlantic Canada, including an assessment of how these funding models impact on decisions to accept continuing care.

The Research Questions:

- What are the impediments to Atlantic Canada using public programs?
- Comparison of self-managed model versus service provision model.
- What are the underlying value systems of the public and decision makers?

Hypothesis:

Increased rates to residents and increased intrusiveness in financial assessments prevents timely access to services, creates inappropriate care arrangements and crisis intervention, delays service until crisis, and increases levels of risk, use of unregulated private services, acute care, and physician care.

The Projects:

- Evaluation of funding policies.
- Evaluation of the user pay model.
- Impact of how funding policies effect decisions to accept continuing care?

Proposed Next Steps:

- Develop portraits of home care, long term care, and other programs in the four Atlantic provinces. Expand on other analyses, for instance Hollander et al.
- Invite people who want to participate in a working group to identify key priority models that should be researched (i.e. long term care vs. home care, user population groups and interested provinces)
- Work towards developing a more specific research proposal in the same area.

The Topic: Human Resources

Issues under this heading included recruitment & retention, training & education, entry to practice, core competencies, and scope of practice.

Research questions emerged under this topic, but did not develop beyond their identification. Several factors were determined to hamper progress, including the breadth and complexity of the subject, and multiple perspectives of stakeholders.

Research Areas first Identified (Tuesday morning):

- Estimating continuing education – topics, methodology, time, technology.
- Core curriculum – what are the basics for all positions of caregiving?
- Continuing care teams – what are the ingredients to good ones? How can they be transplanted to others? The impact on disciplines of collaborative models.
- Providers - how to improve recruitment & maintenance, public image.
- Safe, effective, and efficient practice – who does best for what function?
- Wages & benefits – public vs. private.
- Aging workforce.
- Family caregivers – needs as a team member, what training, what support?
- Assessment tools vs. life satisfaction ratings.

The Research Questions:

- “De-skilling” and “de-professionalization” – what are the impacts on client outcomes?
- Credentialing – Does it work, across the disciplines?
- Issues of quality vs. issues of quantity – How to define, how to measure, how to research?
- Continuing care teams - What is the “magnet team”? Its professional composition? Its dynamics? What are the barriers / enablers to effective teams? How to maintain the team wellbeing? Multi-disciplinary vs. inter-disciplinary?
- Patient navigator - What is the effectiveness?
- Continuing care workers – How to increase profile, valuing of & respect for them?

Proposed Next Steps:

- Identify individuals interested in developing specific research projects related to human resources in the continuing care sector in Atlantic Canada.
- Consult with Health Human Resource Sector Council to determine willingness to facilitate a project.

The Topic:
Cost Effectiveness of Interventions along the Continuum of Care

A longitudinal study of consumers to understand how clients move through the continuum of care - including transition points of prevention, maintenance, and acute services; home care, facility care, and acute care; and cost effectiveness, including human cost.

Research Areas first Identified (Tuesday morning):

- What does cost effectiveness mean?
 - At what point is home care no longer cost effective?
 - What are the human costs of formal and informal caregiver systems?
 - What is the cost of post-acute home care to families, volunteers, formal support staff?
 - Cost benefit analysis of preventative, maintenance, substitution, post-acute functions; of other interventions.
- How does the client move through the continuum of care?

The Research Questions:

- How cost effective are informal caregivers to the overall care plan?
- How can we demonstrate that services are cost effective and are making a difference?
- Is it the right level of care provider?
- How does the preventative component help to maintain and sustain caregivers and the independence of care receivers?

The Projects:

- Using MDS data,
 - Determine the costs saved to formal home care programs by the provision of care by family caregivers.
 - Assess the long term cost benefits of providing formal home care services in situations where there is family caregiving.
- Longitudinal study using home care data to develop profiles of home care users according to fluctuations in their levels of dependence.

Proposed Next Steps:**Project One:**

- Determine if data can be extracted and assess its comparability among the Atlantic Provinces to answer the research question.
- Identify prospective government partners, in this research topic and interrelated topics.
- Conduct literature review of research examining cost effectiveness of informal caregivers in the formal home care system.
- Establish working group composed of government decision makers, university researchers and relevant constituency groups to develop a funding proposal to be considered (for CIHR, CHSRF, NSHRF).

Project Two:

- Determine the components of a longitudinal study.
- Identify who would be interested.

The Topic:
Alternatives along the Continuum of Care

Estimating the need for facility-based services and alternative supports in Atlantic Canada, including comparisons of supports such as assisted living, enriched housing, and ambulatory care.

Research Areas first Identified (Tuesday morning):

- What exists, and what is needed to maintain seniors in the community?
- Models of home care in rural / urban areas: should it be expanded?
- Facility residents: who are more appropriate for alternative housing interventions?
- Compare interventions of assisted living, enriched housing, small residential care facilities, licensed facilities and small option homes.
- Identify smart housing options for aging in place through an Atlantic Canada lens.
- Identify peripheral policy that impacts on our ability to offer alternatives along the continuum of care (e.g. health & wellness promotion, and Good Samaritan legislation around volunteerism)
- Overlapping with cost effectiveness:
 - Post-acute clients in home care: cost effectiveness, from a holistic framework (i.e. emotional, financial, and other costs to client, family caregivers, home support workers).
 - Cost benefit analysis of each function of home care. Are costs being downloaded to family caregivers? Are dollars being taken from prevention & maintenance functions?
 - Cost effectiveness: Is there benefit of doing “secondary” prevention?

The Research Question:

What kind of services do we require in Atlantic Canada to meet the needs of persons requiring continuing care?

The Projects:

- Develop a standardized language for continuing care.
- Create a database of current services, programs and residential settings.
- Compare those current services, programs and residential settings in the Atlantic region with other jurisdictions.
- Develop profiles of past, current and future users of continuing care services.
- Determine gaps in services, programming and residences.
- Consider innovative pilot projects where gaps exist.

Proposed Next Steps:**Project One:**

- Identify interested participants to examine other areas of research in regards to the above.

Project Two:

- Assisted Living Project:

Foundation Work:

The NSCA has begun a process of development of a synthesis paper on the status of assisted living options along the continuum of care in the Atlantic provinces for the purpose of providing background information to the development of a comprehensive proposal. It is essentially the lead-up to the development of research questions, research teams and a research design focused on supportive housing. Over the next couple of months, a researcher at the NSCA will gather information about the status of assisted living in the Atlantic provinces, including relevant current and planned policy directions and issues in order to begin the process of identifying the pertinent research questions. As well, NSCA will be developing a network of people interested in being a member of a research project team for the development of a comprehensive proposal on the policy implications for assisted living in the Atlantic region.

Objectives of the Foundation Work

- To identify pertinent (key) literature relevant to assisted living.
- To determine the range of assisted living options available in the public and private sectors in the four Atlantic Provinces, including the method of financing.
- To identify continuing care policies relevant to assisted living.
- To identify the gaps in information needed to inform decisions about assisted living options.
- To identify a network of interested participants for research project relevant to assisted living.

Method

The steps involved in the process will include:

- *Literature search:* Canadian literature about assisted living and particularly, the organization and financing of these services, will be compiled. The search will include discussions with others who have undertaken literature searches and reviews.
- *Provincial document collection and review:* Relevant policy documents as well as service brochures will be gathered.
- *Key informant interviews:* Key policy-makers in each province will be contacted for a telephone interview. As well, private providers of assisted living options as well as some users of services will be contacted.
- *Consultation and feedback on document:* The synthesis will be reviewed by key contacts in each province to determine its relevancy and accuracy.

Workshop Evaluation

The following are highlights of the results of the evaluation. In summary, they indicate that the workshop was very well received, and all participants were eager to work together to enhance the program of research in the Atlantic region.

The response rate was 83%, and respondents well represented government, researchers and community organizations. More than 80% indicated their expectations were met “to a great extent”. The Background Paper was considered very helpful by most, and almost all indicated that the workshop process was conducive to achieving its goals. The opportunity to network and partner with others was appreciated.

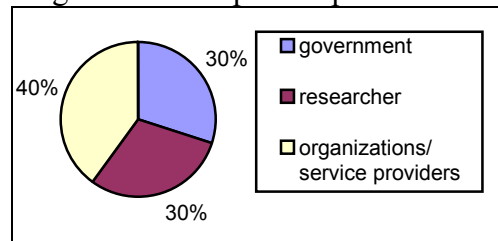
One result of the evaluation is worthy of note. While two-thirds of those from government and community agencies indicated they were “able to identify where your particular skills and interests were best suited”, only one-third of the researchers agreed. We think this discrepancy may be important, and deserves some attention. If we are to foster the creation and sharing of applied knowledge among organizations, policy-makers and researchers, and if we are to attract researchers from multiple disciplines, a greater understanding of the researchers expertise and its applicability to issues affecting organizations and policy-makers needs to be made. Exchanges such as this venue begin to breakdown barriers to truly collaborative research.

The following provides greater detail of the evaluation results. Please refer to Appendix F for the Evaluation Form.

▪ Evaluation response rate and constituency representation

The response rate was 83%. There were 36 workshop participants, excluding 7 organizers, and 30 completed evaluations forms were received. Of them, 9 were from government, 9 from universities, and 12 from other organizations/ service providers.

Figure 1. Participant Representation.

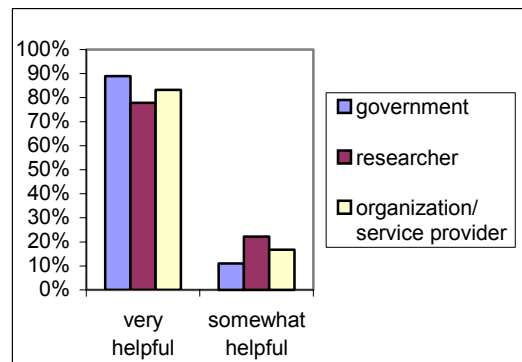


▪ Background material

The Background Paper (presented in Appendix A) was the main focus of this material; 80% of respondents considered it helpful, and 20% considered it somewhat helpful. A few comments complimented the Atlantic region summary, its extensiveness and success in creating a

common understanding. Another comment suggested that a workshop presentation dedicated to the gaps in research would have focused the workshop.

Figure 2. Usefulness of the background paper.



▪ Process set-up conducive to achieving goals

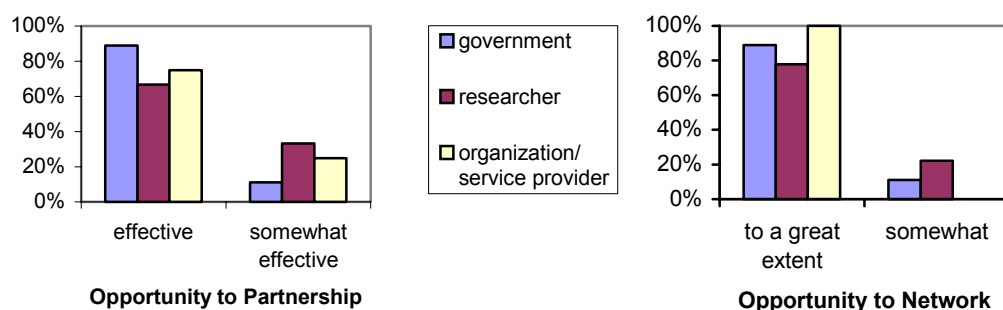
Of the respondents, 90% considered the workshop process to be effective. All who represented organizations and agencies gave this score, as did 90% of government representatives and 80% of the researchers. Eighty percent reported their personal expectations for workshop were met to a great extent. Of the researchers, 70% indicated their expectations were met, 30% indicated they were “somewhat” met.

▪ Networking and partnerships

Ninety percent of the response forms indicated that network opportunities existed to a great extent. Again, all representatives of the agencies and organizations were scored in this way, 89% of government delegates, and 78% of researchers. Seventy-five percent of the representatives of agencies and organizations, 89% of government delegates, and 68% of the researchers considered that partnership opportunities were provided effectively.

There were enthusiastic comments provided in the open-ended response. The timing was excellent, new players in all sectors got to know one another, and the workshop was a forum to learn what was happening in the region. One person indicated feeling forced into interest areas.

Figure 3. Opportunity to partnership (left) and network (right).

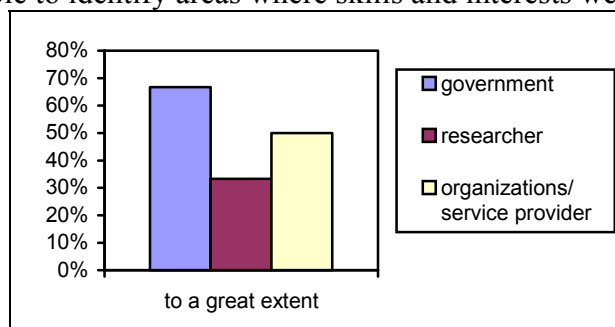


▪ **Areas where skill could be put to use**

Of those who represented organizations and agencies, 50% considered that there were areas where their skills and interests were best suited “to a great extent”, as did 68% of government representatives. However, only 33% of the researchers gave such a score. This discrepancy is important. It may reflect the limited number of researchers dedicated to research within the home and continuing care sector in Atlantic Canada. Researchers may need encouragement to recognize how their area of expertise fits within home and continuing care. The divide between research, policy and practice needs bridging. Applied research within this sector is critical and expertise from many disciplines have much to contribute to our understanding of the issues in continuing care.

Two comments signaled a continuing need to strengthen exchanges among researchers, policy-makers and service providers. One researcher wrote “*Only researcher in my topic area. [I was] at cross purposes to many people who wanted to talk about their program*”. A provider wrote “*There are still some barriers in terms of providers and government policy-makers*”.

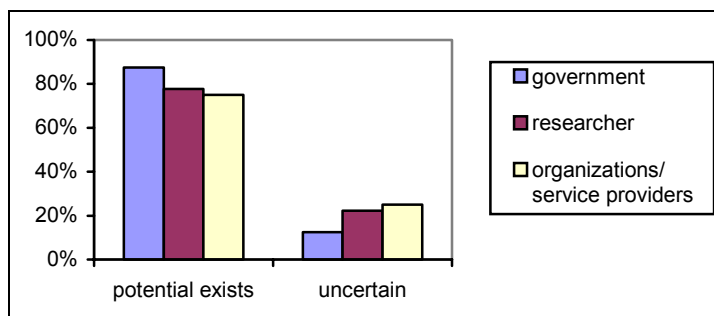
Figure 4. Able to identify areas where skills and interests were best suited.



▪ **Potential for research in continuing care**

Participants were also asked to assess the potential for continuing care research to emerge as a result of this workshop. Eighty percent of the respondents indicated that the potential exists. Of the seven who commented to the question, most identified the need to partner with the Mount. One participant wrote “*with MSVU as unifying element & networking among the provinces that occurred within workshop – HOPE*”.

Figure 5. The potential for research in continuing care to emerge as a result of the workshop.



▪ Overall Comments

Respondents were asked a series of open-ended questions on potential areas of improvement, positive and negative aspects of the workshop, and overall comments. One third of the respondents identified areas of improvement – most often, the need for more time (hard to focus on key issues within the time frame). One agency representative felt alienated between this group and the policy-makers. When asked whether something different could have facilitated the outcomes a number of interesting comments emerged. Some wrote very concrete suggestions such as “*give everyone 5 dots on day one rather than trying to achieve consensus on issues*” or “*have a representation of care receivers*”. (There were organizations representing care receivers, but it was felt that the individuals themselves should participate.) Others were more general. Insufficient time was a consistent theme although there was no consensus on when to increase the time. One comment indicates the need to integrate material - “*more time to digest the issues and do reflection*”.

The two most effective aspects of the workshop were the opportunity to network with others interested in research in the Atlantic region, and the facilitation and organization of the workshop to achieve the end results. Networking and meeting others were viewed as positive by all types of participants, but particularly by representatives of agencies and organizations. Additional comments revealed the participants’ gratitude at being invited to the workshop, the timeliness of the workshop and the issues and their eagerness to continue their participation / involvement on the proposed research:

“Would like to see provinces connect this way on an annual basis... Would love to see more opportunities like this. Perhaps some mini group to follow-up the questions derived” and “We need to continue what we have started - we have some exciting possibilities- let’s keep going”.

Future Directions

We began our workshop with four goals:

- Identify common strengths and gaps in policy directions
- Determine the similarities and differences in policies across the Atlantic region and areas for collaborative work
- Establish priorities for applied research in policy issues relevant to continuing care
- Develop a potential collaboration on a specific issue within the scope of MSVU research expertise.

There was general agreement that the first three goals were met during the proceedings. To achieve the fourth goal, workshop coordinators have agreed to initiate the following action:

1. Fund a pilot project by the NSCA to gather information on assisted living programs and facilities in Atlantic Canada. A project has been initiated and may serve as the formative phase of a larger research project.
2. To act as lead in research activities in two topics, Alternatives along the Continuum of Care, and Cost Effectiveness of Interventions along the Continuum of Care. The intent is to apply to CIHR for funding for one project in Fall 2003 and the other in Fall 2004.
3. To initiate the process of documenting the topics of research interest of the participants, distribute a list, and invite individuals to facilitate the first meetings.
4. Workshop coordinators will investigate funding opportunities with CIHR, CHSRF, NSHRF and partners, for an Atlantic Canada Continuing Care workshop / conference. The workshop will be a venue to discuss the research initiatives and also to showcase such things as best practices, innovative projects, and collaborative activities. It is our hope to further link policy-makers with researchers, providers and other stakeholders that we began with this process.

As well, MSVU researchers, including student researchers, are available to consider other collaborative projects that may germinate as a result of the workshop.

Our expectation is that each action will provide continuing opportunities for discussion among those in the sector.

Appendices

- Appendix A: Background Paper
- Appendix B: Workshop Agenda
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Appendix A: Background Paper

Building Capacity in Continuing Care

Background Paper

**Bridging Researchers & Decision Makers in the
Atlantic Region**

October, 2002

Contributors:

Marlie Manning, MA (in progress)
Janice Keefe, PhD
Glenda Hawkins, MA (in progress)
Marlene MacLellan, MAHE

Dept. of Family
Studies &
Gerontology



Centre
on
Aging
Nova Scotia

Building Capacity in Continuing Care¹

Bridging Researchers & Decision Makers in the Atlantic Region

October 7-8, 2002

Background Paper

This Continuing Care Workshop is a first step by Mount Saint Vincent University (MSVU) towards achieving the objective of fostering research in continuing care in the Atlantic region with the intent of increasing the use of relevant evidence in policy-making.

This paper serves as an orientation to issues for discussion at the workshop, by providing the context and scope of the proceedings, current trends and terminology commonly used in the sector. As well it will outline similarities and differences among Atlantic provinces. We invite you to review it prior to our gathering, and use it as reference during the workshop.

The Context

What

For the purpose of the workshop, the phrase *continuing care* refers to home, community and residential care services which provide care to adults with disabilities and seniors. Our focus will be on the issues relevant to continuing care policy that frames these services.

The parameters of the workshop are determined by the objective of designing applied research that is customized to match the prioritized knowledge gaps in continuing care in Atlantic Canada with the expertise of our researchers. Discussions and activities will be directed towards this achievement. Topics will be related to policy formation rather than service provision in continuing care, and applied research rather than theoretical. We will focus on adults who are disabled and seniors with functional limitations who require assistance to live in the community. Attention will be restricted to issues affecting their care, and to continuing care programs administered by the Atlantic jurisdictions and the two federal jurisdictions, Indian and Northern Affairs Canada and Veterans Affairs Canada. We will also limit our discussion to those programs and services that are publicly funded.

¹ This background paper has been published under a separate cover and is titled Trends, Issues & Policies: Continuing Care in the Atlantic Region. MSVU, 2002.

Why

The need for new knowledge in continuing care is driven by demographic trends of population aging, policy shifts to promote care in the community, concerns about formal and informal caregivers, and an ever-increasing percentage of fiscal resources invested in the continuum of care. The direction is towards a client-centred, integrated and seamless continuum of care. Such requires that programs, services and institutions be flexible, adaptable and collaborative in design, alternative care strategies be created, and better partnerships be fostered with consumers and their families.

The timeliness of this workshop is demonstrated by positioning it between the recent release of 2001 Census data (which indicated the high proportion of seniors in this region), and the anticipated final reports from the Commission on the Future of Health Care in Canada (the Romanow Commission) and the Senate Standing Committee on Social Affairs, Science and Technology (the Kirby Commission).

Who

Mount Saint Vincent University has a history of both education and research in gerontology. The Gerontology program began in 1979, and merged with studies in human ecology in 1998 to become the Department of Family Studies and Gerontology (FSGN). Currently, the Gerontology option awards Bachelor and Master degrees, and a Certificate. The graduate program now has a student body of 21, many of whom will contribute to research in issues of aging and caregiving.

Under the leadership of Marlene MacLellan, MAHE, Associate Director, the Nova Scotia Centre on Aging (NSCA) is an excellent example of MSVU's efforts to foster innovative partnerships as the Centre works with government and the private sector on research, community education and outreach. Established in 1992, with a mandate of applied research, education and community outreach in age-related matters, the Centre also houses a resource library on aging and caregiving that is available to the community. The Department of FSGN and NSCA have developed research expertise in the areas of home and continuing care, caregiving, standardized assessment tools, facility-based care operations, and policy analysis of funding and delivery of health care services.

In July of this year, Janice Keefe, Ph.D., Associate Professor in FSGN, was awarded the Canada Research Chair in Aging and Caregiving Policy. As well, Dr. Keefe recently received infrastructure funding from the Canadian Foundation for Innovation (CFI) to develop the Maritime Data Centre for Aging Research and Policy Analysis. Keefe and MacLellan are part of a research team at the Mount who have received funding from the Canadian Institutes for Health Research (CIHR) to, among other goals, build upon existing capacity in the area of home and continuing care. CIHR funding, together with additional support from the Nova Scotia Health Research Foundation, have enabled MSVU to gather the regions key policy-makers and researchers in continuing care to this workshop.

Trends, Issues and Challenges²

A National Perspective

The following is a brief overview of current continuing care trends, issues and challenges in Canadian jurisdictions. It is not exhaustive, and presented with an invitation for workshop participants to respond with further ideas.

▪ Sector Growth

There has been an explosive increase in growth rates of service use in continuing care in the last decade, and costs and demands of these services are projected to intensify over the next twenty to thirty years. Most Canadian families will depend upon the continuing care sector at some time.

▪ Increasing Complexity and Diversity

The increasing complexity and diversity of care is the result of changing profiles in persons requiring care. There are greater numbers of home care recipients, and of them, an amplification in proportion of people who have multiple diagnoses, require post-acute home care, and/or choose to age in place. Preventative and maintenance functions of home care are threatened by funding cutbacks and a lack of clearly defined outcome measures. There is a rise in the average age of long term care facility residents, and of them, an increase in frailty and later stage dementia. There is a reduction in the ratio of long term care beds for the cohort that is over the age of 75 years.

As well, the continuing care sector will become increasingly ethnically/culturally diverse, both in the population of the care recipients or residents and of those who care for them. This trend presents unique challenges with respect to custom, language preferences and worker-client discrimination.

The complexity and diversity in the population of disabled persons also needs to be recognized. Anderson and colleagues (2001) suggest the diversity reflects the general

²Three 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.

population (e.g., age, gender, living arrangements, location, attitudes, ethnic background and so on) and is intensified by the many types of disabilities including severity and time of onset – e.g. born with a disability or acquired over one's lifetime. Advanced technology, improved medical care, and social policies such as deinstitutionalization have contributed to an increase in life expectancy for many individuals who have either an acquired or congenital disability. This trend, while a tribute to our advancements, creates challenges for the system. These challenges include longer term dependency on services, a need to enhance community-based services, the ability of elderly parents who are caring for adults with disabilities to remain as the primary caregiver, and an emerging need to understand the interactive effect of age-related illnesses on the person with pre-existing disabilities.

- Shifting Funding and Service Responsibilities

From Hollander's research, 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 creating inaccessibility to adequate services to the need for capital investment in improving existing facilities and designing new ones, and to increased demands on family caregivers.

Continuing care services are part of the non-insured services identified under the Canada Health Act, however there are no national policy requirements in continuing care. Provinces are free to fund as much or as little service as they want. In 1996, the federal government changed the funding strategy for health care. With the development of the Canada Health and Social Transfer (CHST), block funding is now provided to provinces and territories for health care, education and social programs. Thus, provinces are now able to independently determine the amount of funding offered to their provincial or territorial continuing care programs (Health Canada, 1999). Today, the CHST is the vehicle through which the federal government supports policies related to continuing care.

Federal transfers for health care have gradually been reduced through various initiatives over the years. While there is agreement that federal money for health has decreased, different configurations - such as some of the money being paid in the form of tax points, an increase in research funding, including continuing care initiatives, and initiatives directed to individuals through income tax credits (such as the Caregiver Tax Credit) rather than to provincial programs - makes it possible to calculate the federal contribution in different ways. The end result, however, is that the proportion of the health dollar has decreased for federal governments and increased for provincial governments, making it a challenge for some of the provincial governments to pay for increasingly expensive services and the increasing numbers of continuing care clients.

Costs of and provision for services of continuing care have shifted to informal caregivers, most often women. Informal caregivers are increasingly acknowledged as partners with the formal system in the care of dependent adults, although this status has not yet been formally recognized. There is now increased knowledge of caregiver stress, a variety of

tools for measurement of it and strong advocacy for a complement of supports to family/informal caregivers.

A national framework for home care, which presumably would ensure federal financial participation, was once considered a priority for federal/provincial negotiations. These considerations have been stagnant for some time, and will remain so until the recommendations of the Commission on the Future of Health Care in Canada guide the entire national health system towards a coherent design.

- Jurisdictional Variations

There are variances among the Canadian jurisdictions - in such factors as service eligibility and access; treatment, residential and intervention options; waitlists; licensing and quality assurance; information systems and data collection; public/private payment splits; resources for innovation and research; for-profit/not-for-profit providers; and policy development. There are variances within jurisdictions as well, the result in most instances, of rural/urban differences, socio-economic differences, and the shift towards regionalization.

The transfer of ownership, management, administration and decision-making to regions is intended to provide 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 there is limited evidence of whether the objectives of regionalization have been realized.

- Human Resources

Caregivers are often described as underpaid, overworked, and undervalued. The critical issues concerning those who provide continuing care services - whether they are employed workers, or family, friends or volunteers – include availability, recruitment, retention, training, and support.

- Role of Technology

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

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

The public-private mix may refer to the financing of the services or the delivery of the services. For example, continuing care services are provided by public, private for-profit and private not-for-profit organizations. There are more long term care beds in for-profit facilities throughout the country (Pitters, 2002, p.164). Multiple delivery systems are also evidenced in home care, residential care, and alternative housing arrangements. 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 buy additional services from the same agency. Moreover, clients may access home care services privately without going through the provincial assessment of home care needs. More consumers are paying for home care services that are outside the public system, but the extent in terms of both frequency and expenditures are difficult to measure (Keefe, 2002, p.133). The ability to assess the merits of the public, for-profit and not-for-profit models is dependent upon agreed upon standards, data, evidence and research.

- Accountability

Commissioner Romanow, in his interim report of February 2002, described the wishes of Canadians regarding health care reform, including 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?

The Social and Economic Context

As evidenced in Table 1, the four provinces have slow population growths with Newfoundland (NL) experiencing the highest out-migration rate. Table 2 illustrates how New Brunswick (NB), Nova Scotia (NS) and Prince Edward Island (PE) have a higher proportion of population over aged 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)

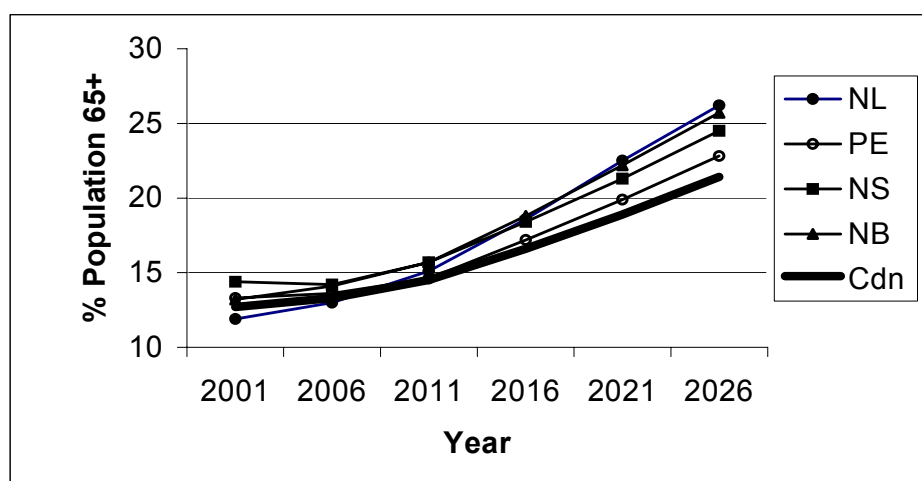
Table 2. Population Size and Percentage of Population 65+ Years in Atlantic Canada and Canada, 2001.

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 represents the projected populations in Atlantic Canada and Canada for the next twenty-five years.

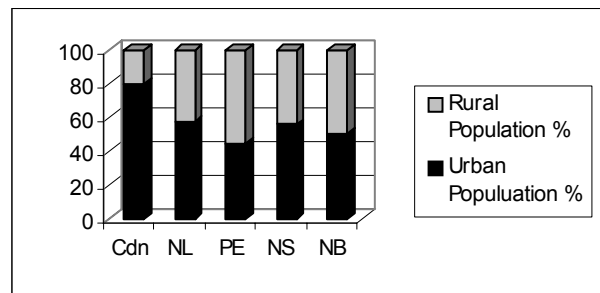
Figure 1. Percentage Population Projections, 65+ years, based on Medium Growth, Atlantic Canada and Canada, 2001-2026.



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

All Atlantic provinces have high percentages of rural population - more than twice that of the Canadian average, in part as a result of out-migration of young people (Figure 2); Nova Scotia and Quebec have the oldest rural populations in the country.

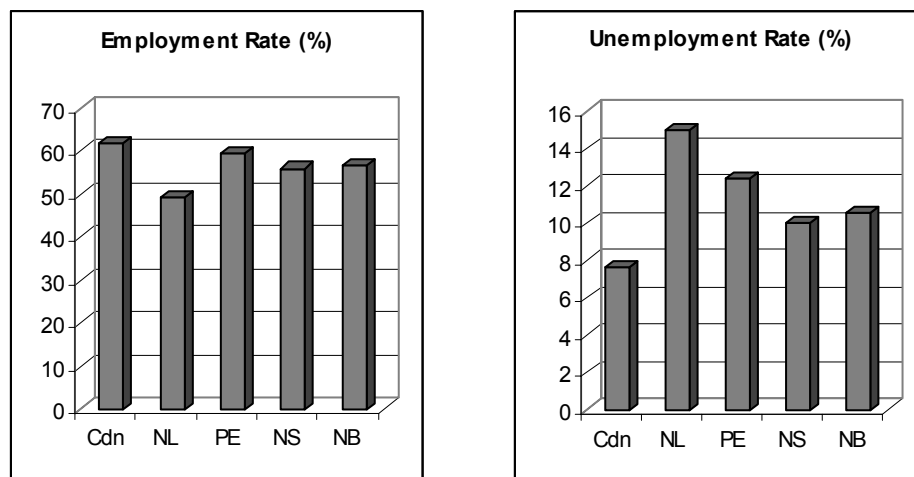
Figure 2. Percentages of Rural-urban Populations in Atlantic Canada and Canada.



(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 have higher burdens of illness and disabilities, and lower scores on several determinants of health – socio-economic factors, education levels, level of physical exercise, and lifestyle matters such as smoking and dietary considerations compared to the national average.

Similarities and Differences in Continuing Care

There is variance among the Atlantic provinces according to several descriptors. For instance, until recently, Prince Edward Island (PEI), New Brunswick (NB) and Newfoundland and Labrador (NL) had amalgamated health and social service departments; while Nova Scotia (NS) has separate departments. However in 2001, NB returned to separate departments. All provinces have regionalized, but with different structures, implemented at different times. PEI, NB and NL have devolved delivery of home care and continuing care to the regions. Nova Scotia intends to do so. Single entry access has now been instituted in every Atlantic province, again with variations of historical context, model, and time of implementation. Terminology in the continuing care field is sometimes province-specific.

The feature that establishes the Atlantic provinces as different from other Canadian jurisdictions is the cost to residents of long term facility-based care. In the Atlantic provinces, long term care is uninsured; full costs of facility-based care are assumed by all residents if they can afford it, and government assistance is determined by province-specific income/asset tests. In other Canadian jurisdictions, residents of long term facilities are charged a co-payment; what is generally considered to be the cost of room and board is assumed by residents. The other services, generally considered as the care portion, are paid for by the provinces.

In relation to residential long term care, differences among the provinces are evident in regulations and standards, assessment procedures, and rates of utilization. There are differences in the degree of government control over the delivery system and in the public–private role in service delivery (i.e. whether the facilities or the organization providing the services are publicly or privately owned).³

Regarding home care, differences among the provinces are evident in areas including definition of terms, organizational models, fee structures, eligibility for service, 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 requirement is similar in terms of having a provincial health card (residency); NB requires physician referral for its Extra Mural Program.
- Similarities in home care services provided include: assessment, nursing, personal care and home support in the four provinces. Differences include: adult day care 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.
- Service is provided using a public provider model in PEI, and a mixture of public and private in NS, NB and NL. Typically professional workers are public employees, and home support/personal care workers are from private agencies - although NS contracts with the Victoria Order of Nurses (VON) to deliver nursing services in urban areas.

³ Terminology defined by Deber, Lutchmie, Baranek, Sharpe, Duvalko, Zlotnik-Shaul, Coyte, Pink, and Williams.

- Fees paid by care recipients are determined uniquely: In PEI and NS, income testing is used to determine the home support payment fee; in NS, user fees are not paid for the acute care program; nor are there user fees for the Extra Mural Program in NB. In NB's long term care home support program and for home support services in NL, fees for services are determined by both income and asset testing.
- Although there is a lack of consistency in the definitions of services included in home care budgets, there remains apparent variation in per capita expenditures among the provinces.

Next Steps

Our vision is that this workshop will move us towards the identification of research that will make a substantive, relevant contribution to regional policy development. In so doing, we want to create an ambience that will enable sustainable linkages among researchers and policy-makers to prevail in the Atlantic continuing care sector.

We conclude on what may be considered a note of solidarity, not just in the Atlantic region but in Canada. It is a quote, taken from the final report of Hollander Analytical Services' set of reports on the continuum of care (Hollander & Prince, 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.

We anticipate - and look forward to - lively, creative and productive discussion. Thank you for joining us.

Terminology

Continuing Care – for the purposes of this workshop, continuing care is defined as a system of service delivery (formal and informal) to persons with functional limitations who require assistance to live in their communities, whether in their own homes or in residential facility settings. In their definition of continuing care, Hollander and Prince 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 (Hollander and Prince, 2002, p.2).

Continuum of care – a goal that refers to the myriad components of the health care system to ensure the provision *of the right services, in the right place, at the right time.*

Home Care – describes those services that are professional in nature and include such services as nursing, homemaking and personal care. These services are provided to people within the community, in the home or occasionally in a facility. These services are provided to help individuals stay within their homes and communities for as long as possible.

Long Term Care – describes the formal services that are provided to people who are limited in their capacity to function independently and whose informal network is insufficient to meet their needs. These services are provided in the community, in the home or facility.

New Brunswick's Extra-Mural Program – a provincial program that delivers all publicly funded home health care services. The program includes service by seven disciplines - clinical nutrition, nursing, occupational therapy, physiotherapy, respiratory therapy, social work and speech language pathology. Support services, primarily homemaking services, are delivered through a contracted service arrangement to a limited number of clients.

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Appendix B: Workshop Agenda

Building Capacity in Continuing Care
Bridging Researchers & Decision Makers in the Atlantic Region
Ramada Plaza Hotel, Dartmouth, NS
October 7-8, 2002

Agenda

Monday, October 7, 2002

- 1:00 pm Welcome & Registration
- 1:15 pm Opening Remarks
Dr. Sheila Brown, President, Mount Saint Vincent University
Krista Connell, Executive Director, Nova Scotia Health Research Foundation
- 1:30 pm Introductions & Orientation to the Workshop
- 2:15 pm Mapping the Issues: Presentation of the survey findings
- 2:35 pm Break
- 2:45 pm Phase I: What's Missing from the Survey?
- 3:30 pm Report on Group Discussion
- 4:15 pm Phase II: Choosing Priority Issues
- 5:00 pm Wine & Cheese Reception
- 6:00 pm Dinner

Tuesday, October 8, 2002

- 8:00 am Continental Breakfast
- 8:30 am Report on Prioritizing Activity: Four topic areas
- 9:00 am Phase III: Small group discussion on one topic area of participant's choice
- 10:15 am Break
- 10:30 am Phase IV: Small group discussion on one topic area of participant's choice
- 11:45 am Report on Four Topic Areas
- 12:15 pm Lunch
- 1:30 pm Phase V: Mapping the process
- 2:45 pm Report on Group Discussion
- 3:30 pm Next Steps
- 4:15 pm Wrap-up: Evaluation & Closure

Appendix C: Introduction and Rationalization

Appendix D: Summary of Survey Results

**Bridging Researchers & Decision Makers in the Atlantic Region
Building Capacity in Continuing Care
Workshop Survey**

1. Please indicate your province _____ Prince Edward Island
_____ Nova Scotia
_____ New Brunswick
_____ Newfoundland

Your organization _____

2. From the perspective of your organization, what are 3 key issues in facility-based long term care in your province?
3. From the perspective of your organization, what are 3 key issues in home care in your province?
4. Where can research fill gaps in knowledge and contribute to an understanding of the above issues?

Facility-based:

Home care:

5. Please identify the continuing care research initiatives in which your organization is involved.

Facility-based:

Home care:

THANK YOU

Your input is very much appreciated. Please forward your reply to hc_policy@msvu.ca or fax to (902) 457-6134 by September 18, 2002.

Department of Family Studies & Gerontology and Nova Scotia Centre on Aging, July 2002

Research Initiatives Identified in Survey

New Brunswick

Facility-based research initiatives

- Conducting a pilot ethnographic study with nursing staff in four Long Term Care facilities in NB to determine strengths & learning needs of RNs, RNAs & RAs

Home care research initiatives

- Implemented a new data collection system in 2000. This information generates many reports that assist managers to do analysis.
- Building a new nest: the experience of older women relocating to senior designated apartment buildings
- Canadian home care human resource study; Training in medication management for caregivers of seniors at home (CACC); Home support: will it be there when you need it.
- A study on conditions effecting home support workers, with a comparison of Health Regions 2 & 3 and have completed a report that was sent to all MLA's in the province & premier
- Healthy Aging in Rural Places project
- CMHA Seniors' Home Care Project

Prince Edward Island

Facility-based research initiatives

- Colleagues began work in areas of interest including institutional respite
- Centre for Aging conducting several projects
- National Dementia Care Initiative (of which there are research components)
- Province is involved in research on assessing population needs based on nurse human resources through a CHSRF funded project for 3 years with ACRUN; A nursing sector study led by HRDC
- Determine acuity needs and develop programs to meet those needs; Determine specific gaps-develop programs; Determine what skill mix work well

Home care research initiatives

- The PEI center for Study of Health and Aging is coordinating the PEI portion of "Aging Well in Rural Places"; Colleagues began work in areas of interest including seniors preferences for formal home care providers; Funding from PEI portion of Health Canada/VAC Falls Prevention Initiative-focused on trying to keep seniors, caregivers and veterans healthy and active and living in their own homes as long as possible.
- Research about falls
- Integrated Palliative Care Initiative funded through Primary Care Redesign Fund.
- Determine acuity needs and develop programs to meet those needs; Determine specific gaps-develop programs; Determine what skill mix work well; Creative education program development

Newfoundland

Facility -based research initiatives

- Participation in the Aging Well in Rural Places project
- Regional review of long term care (LTC) sector (incidence of new clients entering sector, time to placement, characteristics and resource use by clients in system and demand for institutional care)

Home care research initiatives

- Survey of informal caregivers to identify needs

Nova Scotia

Facility-based research initiatives

- Goal attainment scaling as a measure of clinically important change in nursing homes; Outcome measures in the rehabilitation of older adults; Canadian Geriatrics: from where to where?; Frailty: help or hindrance?
- LTC infrastructure management; Challenging behavior project; Resident Assessment Instrument
- Research on volunteerism in LTC; Joint research project with Nova Scotia Centre on Aging and Dalhousie on Functional Fitness in LTC (grant proposal in progress)
- Funding methodologies ; Approaches to integration; Healthy workplace initiatives including occupational health & safety; Performance management; Attendance management
- Past-HR issues study in continuing care; Current-HHR study of NS. Prior learning assessment & recognition: current models for Continuing Care; Entry level competencies for CCR's in LTC; Needs Assessment: IT Resources in Continuing Care
- Leisure needs of residents and family caregivers in long term care.
- Human resource (HR) issues in LTC; Family involvement in LTC responsibility of family versus staff
- Development of audit tool for HR issues in LTC; Education initiatives that cover continuing care; ADOCC revision; Initiative for action in Health Education with the Alzheimer's Society.
- Looking at the impact of different contributions to cost of care on everyday life and financial situations of spouses, comparing 3 provinces in Canada

Home care research initiatives

- Evaluation of traveling geriatric clinic; An evaluation of specialized geriatric care for rural dwelling, frail older people
- Recruitment & retention; Training of continuing care assistants to home support; Ongoing profile of home support workers in NS
- Wellness in the Workplace: Understanding Wellness & Health Promotion in NS's Continuing Care sector; Factors impacting PCW/CCA recruitment & retention in LTC in NS
- Rural communities, helping patterns and health services; Ethical issues in delivery of home care services - accessibility in rural areas, demand versus supply; Increasing gap in accessing homemaker services by income availability.
- Healthy Balance (informal caregivers); Policy initiatives to support families caring for adult sons/daughters with disabilities.

Appendix E: Detailed Group Summaries

Detailed Group Summaries

The following is a detailed chronology of the work accomplished in the proceedings. It has been transcribed with a minimum of editing from the flip charts used in small group discussions, and intended to capture the authenticity of the processes.

Issues identified through survey: (Please refer to Appendix D for details of the survey)

Continuing Care:

- HR Issues (recruitment and retention, wages, training)
- Standards
- Acuity of care

Home care:

- Informal caregivers
- Cost of program
- Access in rural areas

Facility-based care:

- Financial assessment
- Supportive/alternative housing
- Capital costs

Monday Afternoon

Orientation and introductions were followed with small group discussion to identify any issues or gaps in continuing care that were not identified in the survey responses.

Additional issues identified by participants and categorized by organizers into specific research areas:

Over-arching considerations for all topics:

- Diversity (rural/urban, poverty/wealth, culture, ethnicity)
- Demographics (gender, aging, future projections)
- Dissemination of current research
- Promotion and knowledge transfer (Atlantic region research and continuum of care of service delivery)
- Systemic issues (standardization of data and terminology, assessment of LTC needs within each province)
- Paradigm shift (medical to ecological model, move to evidence-based decision making, increased emphasis on determinants of health and health promotion, home care shift from maintenance and support to acute care substitution)
- Ethics

- How do systemic factors influence requests for service (example factors of language, financial resources)?

Service Delivery: Organizations, Models and Alternatives:

- Client-focused/patient autonomy (including challenging the assumptions of choice, such as happier at home, women as caregivers, supportive families, and healing faster in the home; impact of shift to perception of residents as tenants)
- Adult day programs
- Aging in place (multi-leveled facilities, barriers (cost, licensing, access and HR issues), “in-between” individuals/clients, end of life care)
- Alternative housing (impact of reallocation of expenditures to supportive housing from nursing homes)
- Respite care
- Impact of shift in family structures on availability of informal caregivers
- Under what condition is home care not effective
- Holistic/seamless/integrated services as opposed to fragmentation of programs and service delivery
- Home care - selection of core services from service menu including respite, palliation and adult day care
- Inclusion of mental health services in home care

Human Resources:

- Recruitment and retention, training, wages, turnover, staff abuse
- Effective team composition and building, effective scope of practice
- Need to value continuing care as a career choice
- Best practice models (for dementia and all specific groups in the continuing care sector)
- Continuing education
- Quality of care provided
- Out-migration, differences between rural/urban
- Gender issues
- Scope of practice, core competencies
- Home care - consistency/continuity of caregiving, need for educating informal caregivers

Cost Effectiveness:

- The spectrum of continuing care-informal caregivers, home care, assisted/ supportive housing, nursing homes
- Cost benefit analysis of various living arrangements
- Apropos financial assessment- risk of intrusion (wait)
- Financial assessment, non-insured services
- Funding models/ accountability
- Home care cost benefit analysis-looking at the cost and benefit analysis from who's perspective

And:

- Identification, intervention, prevention of elder abuse (not categorized)

Tuesday Morning

Small Group Discussions- Phase III and IV

Participants self-selected, based on interest, two of four morning theme groups to participate in:

- Models/ Organizations of Service Delivery- integration vs. fragmentation, evaluation of best practices, underlying philosophy
- Human Resource- R&R, wages, training, education, entry to practice, core competencies, scope of practice
- Cost Effectiveness of Home Care- Comprehensive perceptions (all players), home care versus facility care, home care vs. informal care, future ability to be cost-effective (shift in family structure, out-migration), at what ethical risk
- Alternatives along the Continuum- Cost benefit (home care, assisted living, etc.)

For each of the 4 themes, the following 5 questions were addressed:

1. What are the gaps in this topic area (i.e. projects or knowledge areas that need to be filled-what is known and unknown)?
2. Why do these gaps exist? What are the barriers to filling the gaps?
3. Identify practical research projects in this specific topic area (being undertaken or that could be undertaken).
4. What are the enablers, which will facilitate the development of project proposals and lead to successful outcomes?
5. Who are the potential partners for projects in this topic area?

Overall Lens:

Gender, diversity, jurisdictional issues, socio-economic and rurality

1. Models/ Organizations of Service Delivery- integration vs. fragmentation, evaluation of best practices, underlying philosophy

Groups 1 and 2

Gaps:

- Lack of knowledge
- Fiscal decision making
- Political
- Currently under-researched in Atlantic Canada
- Characteristics of ideal model of quality continuing care

- What is the best way to serve adults with disabilities?
- The values and philosophy- public and decision makers
- Self-managed models versus service provision model
- Integration of continuity into current system and processes
- Evaluation of current practices (e.g. user pay models, continuing care as a non-insured service)

Enablers:

- Leadership
- Will buy in
- Funding, including pre-project
- An “Atlantic team”

Partners:

- Researchers (expert and Atlantic based), government (federal and provincial), consumers, service providers, system administrators, non-government organizations, project specific, private sector?

Barriers:

- Values of decision makers
- Money
- Lack of resource allocation
- Silo protection
- Ageism

Research Questions:

- What are the indicators of quality continuing care for seniors in rural Atlantic Canada? What are the values, philosophies, resources required?
- Evaluation of the user pay model in Atlantic Canada.
- Integration of known best practices into continuing care (measure and evaluate), at the policy/system and delivery/practice levels.
- Deinstitutionalization –does it work for persons with physically disabilities and persons who are mentally challenged? What should it be to meet consumer needs?
- Are current service models sensitive to location, culture and poverty levels of specific consumers?

2. Human Resource- R&R, wages, training, education, entry to practice, core competencies, scope of practice

Group 1

Research Areas:

- Determining the needed amount of continuing education: topics, method, time, technology
- What makes an effective continuing care team? How do we transplant it? – Collaborative model; impact of the various disciplines on the team
- How do we recruit/maintain staff- how do we shift public image of it, what makes students chose?
- Who is the best person/what is the best role for safe and effective practices?
- Wage issues (& benefits) – public versus private, how does it affect R&R? aging workforce?

- Core curriculum, what needs to be the basics for all caregivers?
- Family caregivers-what are their needs to be a member of the care team? What training and support do they need?
- Effective assessment tools versus life satisfaction ratings.

Group 2

Gaps:

- Continuing care services mean different things to different provinces
- Lack of consistency: in title, terminology, deployment, training
- Lack of basic demographic data, lack of consistency in occupational title
- Lack of understanding of core competencies
- Recruitment: How to attract personnel to these careers
- Retention: valuing, career laddering, career development
- Structure of the system- funding, wages, lack of benefits, scheduling- all support the status quo.
- Lack of qualitative research
- Lack of capacity to participate in quantitative research

Why gaps:

- Funding
- Cutbacks
- Lack of valuing
- Community based delivery vs. bureaucratic decision making

Enablers:

- Work has begun
- Area is gaining attention from funders, decision makers, public
- Communication is happening
- Successful collaboration among professions, researchers, government
- Recent completion of demographic data collection
- MDS recognized, used in some jurisdictions
- Tele-health

Potential Partners:

- Health care sector council
- Individual stakeholder organizations
- Community (care recipients, support networks)
- Providers
- Occupation associations, professional associations
- Provincial departments-community service, health, education, labour and workmen's compensation
- Unions

3. Cost Effectiveness of Home Care- Comprehensive perceptions (all players), home care versus facility care, home care vs. informal care, future ability to be cost-effective (shift in family structure, out-migration), at what ethical risk.

Group 1

- At what point is home care no longer cost effectiveness

- How does the client move through the continuum of care, with particular regards to transition points, - through a longitudinal study
- Human costs of formal and informal systems - what is the cost of home care on the family caregiver in Atlantic vs. other provinces.
- Flexibility of choice for seniors
- Case management
- Preventive aspect/health promotion- is it going to cost more if they don't involve preventative component; proof that lifestyle issues impact utilization of other services
- Accessibility to primary health clinics in rural communities- impact on service utilization (home care, facility care...)
- Partners: Regional boards, community health boards, doctors, government and seniors

Group 2

Research Questions:

- What is the cost effectiveness of providing home care to post acute clients (cost of care to families, to volunteers, home support, etc.- What does cost effectiveness mean- holistic approach
- Cost benefit analysis of each area (function) of home care (preventative/maintenance, acute)- Downloading costs to families/informal caregivers- focusing dollars away from "soft-services"
- Policy direction –primary healthcare- what is the cost effectiveness of doing secondary prevention
- Comparison of interventions (assisted living, enriched housing, ambulatory care)

Issues

- Data system- fragmented

Barriers

- Expectations-shift of care to informal caregivers
- IT costs
- Short term perspectives as a result of political mandates
- Increasing acuity
- Limited financial resources
- Absence of national framework
- Impact of cultural and social values
- Value placed on long term care
- Risks to workers

Enablers

- Networks, funding (foundation and research institutes), federal and provincial money, budgeting processes, marketing/visibility, lobbying-public pressure, identify champions/ spokespersons

Partners

- Not-for-profit/private business, families/consumers, researchers, consumer groups, provinces, professionals/employers

4. Alternatives along the Continuum- Cost benefit (home care, assisted living, etc.)

Group 1

Gaps

- Level I-Level II- gaps in services
- Not enough options in community - leads to increase pressure in acute care.
- Do people know options?
- Do we know enough about the 40-60% who need supportive housing and what the options should be?
- What is the cost benefit of each option?
- What options are best suited to which clients?
- How can these options increase client autonomy and independent living?
- Are seniors feeling more isolated because of changing demographics?
- What are the benefits of volunteer adult day care – traveling program in NB?
- What encourages youth and other older volunteers to volunteer, rural/urban comparison?

Gaps exist because:

- Changing family structure
- Desire to remain at home
- Increase demand on system
- National view may not fit local areas
- Shifting demographics
- Lack of political will
- Lack of funding partnerships (feds)
- Marginalized group- low income
- Need of different facility options
- Needs changing in facilities
- Options not “insured” services

Research topics:

- An evaluation of what exists and what is needed to maintain seniors within the community? What programs and services are needed to meet demands?
- Rural/urban home care model -should we expand this option?
- Identify those in facilities that are appropriate for other types of care.
- KPMG projections on need for LTC beds in future with different options in community- application in other areas.
- Create Atlantic “lens” for community and alternative options.
- CMHC and CMHA Smart housing options to support aging in place.
- Financing/funding to promote wellness.
- Legislation –national and provincial i.e. Good Samaritan – volunteer protection.
- Collaboration between health and community social services.

Enablers/Partners:

- Health Canada, Atlantic provincial government, CIHR, CHSRF, NSHRF, Statistics Canada, universities, provincial regional boards, volunteer, not-for-profit groups, service clubs, community health boards, municipalities.

Group 2

Gaps:

- Availability (program, staff, facilities).
- What do people need, want and what can we afford?
- Inequity of service based on geography and personal resources.
- Why do people relocate?
- Borderline clients (financial).
- Stigma of accepting welfare assistance.
- Language/terminology.
- Matching resources to choice.

Barriers:

- Expectation to provide care (gender)
- Families and out-migration
- Volunteer base shrinking/ liability
- Rural communities shrinking
- Transportation to day programs-a liability issue
- Funding
- Need to move to global thinking

Research Areas:

- How does the system influence refusal to service when seniors qualify for them (that is using own resources, language, “welfare stigma”)
- How does the way we finance services impact decisions to accept care?

What are the inequities that exist in availability of services throughout Atlantic Canada-between provinces, rural/urban, and ability to pay, between health regions?

Tuesday Afternoon

Small Group Discussions- Phase V

The potential research areas identified in the morning session were further framed by the organizing team; coming up with 6 specific practical research areas for small group discussion:

- Organizations of service delivery: What are the characteristics of quality continuing care for seniors in Atlantic Canada?
- Models of service delivery: Evaluation of user pay models in Atlantic Canada including an assessment of how these funding models impact on decisions to accept continuing care.
- Evaluation of Service Models- Self-managed (funding) vs. service provision in the Atlantic region context. What is the sensitivity within these models to specific consumer groups (culture, poverty, etc.)?
- Human Resources: Issues included recruitment & retention, training & education, entry to practice, core competencies, and scope of practice.
- Cost effectiveness: A longitudinal study of consumers to understand how clients move through the continuum of care - including transition points of prevention, maintenance, and acute services; home care, facility care, and acute care; and cost effectiveness, including human cost.
- Alternatives along the continuum of care: Estimating the need for facility-based services and alternative supports in Atlantic Canada, including comparisons of supports such as assisted living, enriched housing, and ambulatory care.

For each specific practical research area:

1. What is the key research question to address?
2. What projects can be developed and go forward?
3. Are there pre-tests/exploratory studies that would enhance future proposals?

1. Organizations of service delivery: What are the characteristics of quality continuing care for seniors in Atlantic Canada?

Research:

- Step 1: Complete literature/ best practice in rural areas in continuing care (focus on continuing care for seniors and include rural health delivery models).
- Step 2: Identify and define “continuing care” (using Atlantic and rural lens) start with definition from this workshop. Develop a survey. Include what services are available in Atlantic region (see Parent and Anderson). Asset Map, compare best practices
- Principals to guide the framework: P.H.C. principals, capacity building, community development, social marketing
- Step 3: Employ qualitative research: key informants’ scan of best practice in rural continuing care, focus groups, etc.

- What are the models, questions or meanings/indicators? Client satisfactions and wait lists vs. health outcomes, response time standards, access to services, barriers, ease of use, public participation, appropriate technology, intersectoral collaboration, prevention & health promotion, cost efficiency and effectiveness, utilization of services and primary health care lens.

Resources:

- The Yarmouth Stroke project (upcoming publication, AHPRC)
- Presentation to Senator Carstairs, project on rural palliative care project, October 2002.
- Aging Well in Rural Places (upcoming publication, AHRPC)
- Caregiving in rural communities (2002)
- National study on home care (Parent & Anderson, 2002)
- Mental health issues in home care (Parent & Anderson, 2002)
- F/P/T document on best practices in Mental Health

2. Models of service delivery: Evaluation of user pay models in Atlantic Canada including an assessment of how these funding models impact on decisions to accept continuing care.

Research question to address:

- Evaluation of funding policies. Evaluation of the user pay model
- How do these funding policies impact on decisions to accept continuing care?
- Describe “what is” regarding home care, long term care, and other programs in the 4 provinces (describe assessment process, intrusiveness, stigma of welfare. Policy analysis?). Note: We have some background information (see Hollander) Build on this.

Hypothesis:

- More intrusive assessment/more client contribution will: prevent people from accessing needed services, creates inappropriate care arrangements, delays service use until crisis, increases level of risk, increases use of (unregulated) private services, and increases use of acute care, early discharge, physician care and other insured services or crisis interventions.

Data Sources:

- Clients, seniors groups, family, assessors and care coordinators, hospital discharge planners, service providers.
- Policies and people implementing them.

3. Evaluation of Service Models: Self-managed (funding) vs. service provision in the Atlantic region context. What is the sensitivity within these models to specific consumer groups (culture, poverty, etc.)?

- No one participated in this discussion group.

4. Human Resources: Issues included recruitment & retention, training & education, entry to practice, core competencies, and scope of practice.

Research Topics:

- Impact of de-skilling and de-professionalization on client health outcomes (What type of training is required? Does well meaning equal well skilled/competent?)
- Does credentialing work? Across disciplines from home support workers to physicians?
- Quality issues in human resources need to be addressed as well as quantity issues? What are they and how do you measure them?
- How to understand the “magnet team” in continuing care? What is its professional composition? Its dynamics? What is the effectiveness of the patient navigator? What are the barriers /enablers to effective continuing care teams, for example, administration, how does the customer regard to team approach? Provision of team in rural areas? How to maintain the well being of the team? Cost effectiveness of team approach? Multi-disciplinary versus interdisciplinary teams?

Profile of continuing care workers-by increasing the profile, value and respect for these staff, we can increase recruitment and retention issues. Valued member of “team” is one piece of this profile.

5. Cost effectiveness: A longitudinal study of consumers to understand how clients move through the continuum of care - including transition points of prevention, maintenance, and acute services; home care, facility care and acute care; and cost effectiveness, including human cost.

Research questions to address:

- How cost effective are informal caregivers to the overall care plan?
- How can we show that services are cost effective and are making a difference?
- Is it the right level of care provider?
- How does the preventative component help maintain and sustain caregivers and the independence of care receivers?

Projects:

- In terms of how cost effective informal caregivers are to the overall care plan, one may be able to access data from the M.D.S. that would give a researcher a good idea of what needs the family will be supplementing in the care plan, and also what family members are included in the care plan. Therefore you could test this question using M.D.S. Start by doing a pilot in a region within Nova Scotia. Other provinces do not have M.D.S. system, so would have to see if their assessments would give similar information to be comparable.
- In terms of how does the preventative component of home care help maintain and sustain the independence of the care receiver, you could have demographers chart, in terms of a increment and decrement table, the onset of transitional events within the persons life, such as when they enter and exit acute care, home care, long term care, etc. In hopes that it would become a predictor of future needs and

may be able to see what the implicators are - may be health status. Address questions such as what was the need? Were you able to meet those needs at that point? What created the need?

6. Alternatives along the continuum of care: Estimating the need for facility-based services and alternative supports in Atlantic Canada, including comparisons of supports such as assisted living, enriched housing, and ambulatory care.

Research questions to address:

- What kind of services do we require in Atlantic Canada to meet the needs of persons requiring continuing care?

Project:

- Develop a standardized language for continuing care
- What are the existing services in continuing care in each project by region, by rural/urban areas?
- Scan literature, internal document for community care services available in other countries/other provinces
- Survey (a) users of services (nursing homes), (b) potential users (baby boomers) of perception/satisfaction, (c) retrospective by family members
- The results from survey would include areas to focus on, which would lead to pilot project that would apply demographic data and would result in interventions.
- Pilots on (a) existing delivery and (b) alternatives i.e. assisted living.
- Measure outcomes

Appendix F: Evaluation Form

EVALUATION

Participants - Continuing Care Workshop

October 7 -8, 2002

Thank you for your contributions to the "Building Capacity in Continuing Care Workshop". As part of our project evaluation, we would appreciate you taking a few moments to complete this survey. Please check the appropriate response with an explanation or comments if you wish. Your comments are welcomed.

Your Background

" Government " Researcher " Association " Service Provider " Other

1. Was the background information helpful for orientation to the workshop?

Very helpful

Somewhat helpful

Not enough

Comments: _____

2. Was the process conducive to achieving the identified goals and outcomes?

Effective

Somewhat effective

Ineffective

Comments: _____

3. Were your expectations met?

To a great extent

Somewhat

Not at all

Comments: _____

4. To what extent did the workshop provide an opportunity to network with others with similar interests?

To a great extent

Somewhat

Not at all

Comments: _____

5. From your perspective, was this workshop an effective way to develop partnerships for research?

Effective

Somewhat effective

Ineffective

Comments: _____

6. Through this process, were you able to identify areas where your particular skills and interests were best suited?

To a great extent

Somewhat

Not at all

Comments: _____

7. In addition to the work to be undertaken by MSVU, is there potential for research in continuing care to emerge in your province as a result of this workshop?

Potential exists

Uncertain

See no potential

Comments: _____

8. Could we have done something different to facilitate the outcomes?

Yes

No

Uncertain

Please explain: _____

9. Please identify and describe the most effective aspect of the workshop.

10. Please identify and describe the least effective aspect of the workshop.

Additional Comments:

Thank you for your input.

Appendix G: Workshop Participant List

Workshop Participant List

Arsenault, Anne-Marie
Professeure
Ecole de Science Infirmiere
Universite de Moncton
Moncton, NB
E1A 3E9
Tel:(506) 858-4259
Fax:(506) 858-4017
Email:arseneam@umoncton.ca

Arseneau, Catherine
Executive Director
Health Care Human Resources Sector Council
45 Alderney Dr.
Suite 815
Dartmouth, NS
B2Y 2N6
Tel:(902) 461-0871
Fax:(902) 461-0372
Email:arseneau@hcsc.ca

Boudreau, Debra
Committee Member
Atlantic Health Promotion Research Centre
Tel:(902) 742-0589
Fax:(902) 742-0686
Email:boudreda@gov.ns.ca

Conrad, Patricia
PhD (Cand.) Health Policy
University of Toronto
Faculty of Medicine
Department of Health Policy, Management & Evaluation
1150 Wellington St.
Halifax, NS
B3H 2Z8
Tel:(902) 422-4842
Fax:(902) 494-1396
Email:pconrad@ns.sympatico.ca

Cruttenden, Kathleen
Assistant Professor
Faculty of Nursing
University of New Brunswick
P.O. Box 4400
Fredericton, NB
E3B 5A3
Tel:(506) 458-7627
Fax:(506) 453-4519
Email:kcrutten@unb.ca

Davis, Donna
National Nursing Officer
Health Service Policy Directorate
Rm 427
DJ MacDonald Building
Box 7700
Charlottetown, PE
C1A 8M9
Tel:(902) 368-0225
Fax:(902) 566-8890
Email:dldavis@vac-acc.gc.ca

Dill, Donna
Director of Continuing Care- Western Region
NS Department of Health
1690 Hollis Street
P.O. Box 488
Halifax, NS
B3J 2R8
Tel:(902) 424-1590
Fax:(902) 424-3559
Email:dilldm@gov.ns.ca

Doody, Linda
Manager
Seniors Program
Department of Health & Community Services
P.O. Box 8700
St. John's, NFLD
A1B 4J6
Tel:(709) 729-5246
Fax:(709) 729-0730
Email:ldoody@mail.gov.nf.ca

Gammon, Greg
Director
Community Supports for Adults
NS Department of Community Services
P.O. Box 696
Halifax, NS
B3J 2T7
Tel:(902) 424-8263
Fax:(902) 424-0502
Email:gammonga@gov.ns.ca

Greenwood, Kathy
Regional Director
Continuing Care Capital District
NS Department of Health
3845 Dutch Village Rd.
Halifax, NS
B3L 4H9
Tel:(902) 424-7242
Fax:(902) 424-3559
Email:greenwka@gov.ns.ca

Hancock, Doris
Regional Planner
Strategic Social Plan
1 Union Street
P.O. Box 2006
Corner Brook, NF
A1B 4A4
Tel:(709) 637-2937
Fax:(709) 637-2921
Email:dhancock@mail.gov.nf.ca

Higgins, Trudy
Executive Director
Home Support Services Inc.
41 Budd Ave.
P.O. Box 239
St. Stephen, NB
E3L 2X2
Tel:(506) 466-1759
Fax:(506) 466-5012
Email:hss@nbnet.nb.ca

Ipson, Nila
School of Health and Human Performance
Dalhousie University
6230 South Street
Halifax, NS
B3H 3J5
Tel:(902) 494-3391
Fax:(902) 494-5120
Email:nila.ipson@dal.ca

Kennedy, Marilyn
Community Care Facility/ Nursing Home
Coordinator
Acute & Continuing Care Division
Department of Health & Social Services
P.O. Box 2000
16 Garfield St.
Charlottetown, PE
C1A 7N8
Tel:(902) 368-4953
Fax:(902) 368-6136
Email:mekennedy@ihis.org

Knowles, Ruby
Director of Continuing Care- Northern Region
NS Department of Health
82 Esplanade St.
Truro, NS
B2N 2K3
Tel:(902) 893-0368
Fax:(902) 896-2227
Email:knowlrm@gov.ns.ca

Leigh, Debra
Chief Operating Officer
Continuing Care Association of Nova Scotia
119-2786 Agricola St.
Halifax, NS
B3K 4E1
Tel:(902) 453-2977
Fax:(902) 453-2967
Email:ccans@ns.sympatico.ca

Lefort-Jost, Sandra
PEI Department of Health & Social Services
16 Garfield Street
Charlottetown, PE
C1A 7N8
Tel:(902) 368-6717
Email:salefort-jost@ihis.org

Leonard, Andrea
Chairman of the Board of Directors
Home Support Nova Scotia Association
287 Lacewood Dr.
Unit 103, Suite 349
Halifax, NS
B3M 3Y7
Tel:(902) 421-6317

Lepine, Andre
Director
Services to Adults with Disabilities & Senior
Services
NB Dept. of Family & Community Services
P.O. Box 6000
Fredericton, NB
E3B 5H1
Tel:(506) 457-6856
Fax:(506) 453-2082
Email:andre.lepine@gnb.ca

MacDonald, Jackie
Memorial University of Newfoundland
Faculty of Medicine
STJ Campus
St.John's, NF
A1C 5S7

MacDonald Connolly, Debye
Coordinator Continuing Care
McGill Community Mental Health Centre
Mona Wilson Building
61 McGill Avenue
P.O. Box 2000
Charlottetown, PE
C1A 7N8
Tel:(902) 368-4911
Fax:(902) 368-6189
Email:damacdonald@ihis.org

McInnis Perry, Gloria
Director of Psychogeriatric Programming
Queens Health Region
Health & Community Services
P.O. Box 1929
Charlottetown, PE
C1A 7N5
Tel:(902) 368-5914
Fax:(902) 368-5411
Email:gloria.mcinnis@pei.sympatico.ca

Menzies, Keith
Executive Director of Continuing Care
NS Department of Health
1690 Hollis Street
P.O. Box 488
Halifax, NS
B3J 2R8
Tel:(902) 424-7233
Fax:(902) 424-0558
Email:menziek@ns.ca

Murnaghan, Donna
Associate Director
PEI Health Research Institute
University of Prince Edward Island
550 University Avenue
Steel 112
Charlottetown, PE
C1A 4P3
Tel:(902) 894-2812
Fax:(902) 894-2811
Email:dmurnaghan@upei.ca

Nyiti, Claire
Director of Continuing Care- Eastern Region
NS Department of Health
360 Prince St.
Suite 15
Sydney, NS
B1P 5L1
Tel:(902) 563-3701
Fax:(902) 563-5602
Email:nyitici@gov.ns.ca

Powell, Colin
Director
Centre for Health Care of the Elderly
QEII Health Sciences Centre
5955 Veterans' Memorial Lane
Suite 2650
Halifax, NS
B3H 2E1
Tel:(902) 473-8603
Fax:(902) 473-4867
Email:peggy.hobbs@cdha.nshealth.ca

Rennie, Charles
Board Chair
Seniors Resource Centre
Suite W 100
280 Torbay Road
St. John's, NFLD
A1A 3W8
Tel:(709) 737-2333
Fax:(709) 737-3717
Email:seniorsresource@nf.aibn.com

Richards, Judy Lynn
Professor
Department of Sociology and Anthropology
University of Prince Edward Island
550 University Avenue
Main Building, Room 428
Charlottetown, PE
C1A 4P3
Tel:(902) 566-0433
Email:jrichards@upe.ca

Rogers, Wendy
Director of Long Term Services
Mental Health Division
Department of Health & Wellness
P.O. Box 5100
Carleton Place
Fredericton, NB
E3B 5G8
Tel:(506) 444-4559
Fax:(506) 453-8711
Email:wendy.rogers@gnb.ca

Scott, Lauren
Researcher/ Policy Analyst
Nova Scotia Association of Health
Organizations
2 Dartmouth Road
Bedford, NS
B4A 2K7
Tel:(902) 832-8532
Fax:(902) 832-8505
Email:lauren@nsaho.ns.ca

Singleton, Jerry
School of Health and Human Performance
Dalhousie University
6230 South Street
Halifax, NS
B3H 3J5
Tel:(902) 494-1166
Email:jerome@is.dal.ca

Stadnyk, Robin
School of Occupational Therapy
Dalhousie University
5981 University Avenue
Halifax, NS
B3H 1W2
Email:Robin.Stadnyk@dal.ca

Taper, Janet
Professor
Mount Saint Vincent University
Applied Human Nutrition
166 Bedford Highway
Halifax, NS
B3M 2J6
Tel:(902) 457-6256
Fax:(902) 457-6134
Email:janette.taper@msvu.ca

Weeks, Bev
Coordinator
Harvey Outreach for Seniors
2019 Route 3
Harvey Station, NB
E6K 3E9
Tel:(506) 366-3017
Fax:(506) 366-2927
Email:hofs@nbnet.nb.ca

Weeks, Lori
Assistant Professor
Department of Family & Nutritional Sciences
University of Prince Edward Island
550 University Avenue
Charlottetown, PE
C1A 4P3
Tel:(902) 566-0528
Fax:(902) 628-4367
Email:Lweeks@upepei.ca

Wells, Judith
Nurse Educator
Western Regional School of Nursing
P.O. Box 2005
Corner Brook
Corner Brook, NF
A2H 6J7
Tel:(709) 637-5000 ext.5588
Fax:(709) 637-5161
Email:jwells@swgc.mun.ca

Organizing Committee

Hawkins, Glenda
Mount Saint Vincent University
Department of Family Studies & Gerontology
166 Bedford Highway
Halifax, NS
B3M 2J6
Tel:(902) 457-6782
Fax:(902) 457-6134
Email:hc_policy@msvu.ca

Keefe, Janice
Associate Professor
Family Studies & Gerontology
Mount Saint Vincent University
Halifax, NS
B3M 2J6
Tel:(902) 457-6466
Fax:(902) 457-6134
Email:janice.keefe@msvu.ca

Langille Ingram, Ethel
Project Coordinator
Nova Scotia Centre on Aging
Mount Saint Vincent University

Halifax, NS
B3M 2J6
Tel:(902) 457-6573
Fax:(902) 457-6508
Email:ethel.langille@msvu.ca

MacLellan, Marlene
Associate Director
Nova Scotia Centre on Aging
Mount Saint Vincent University
Halifax, NS
B3M 2J6
Tel:(902) 457-6546
Fax:(902) 457-6508
Email:marlene.maclellan@msvu.ca

Manning, Marlie
Mount Saint Vincent University
Department of Family Studies & Gerontology
166 Bedford Highway
Halifax, NS
B3M 2J6
Tel:(902) 457-6782
Fax:(902) 457-6134
Email:mmanning@hfx.eastlink.ca

McEvenue, Shannon
Project Researcher
NS Department of Health
1690 Hollis Street
P.O. Box 488
Halifax, NS
B3J 2R8
Tel:(902) 424-2753
Email:shannonmcevenue@hotmail.com

Weagle, Susan
Senior Policy Analyst
Policy Planning & Legislation Branch
NS Department of Health
1690 Hollis Street
P.O. Box 488
Halifax, NS
B3J 2R8
Tel:(902) 424-2632
Fax:(902) 424-2814
Email:weaglesj@gov.ns.ca