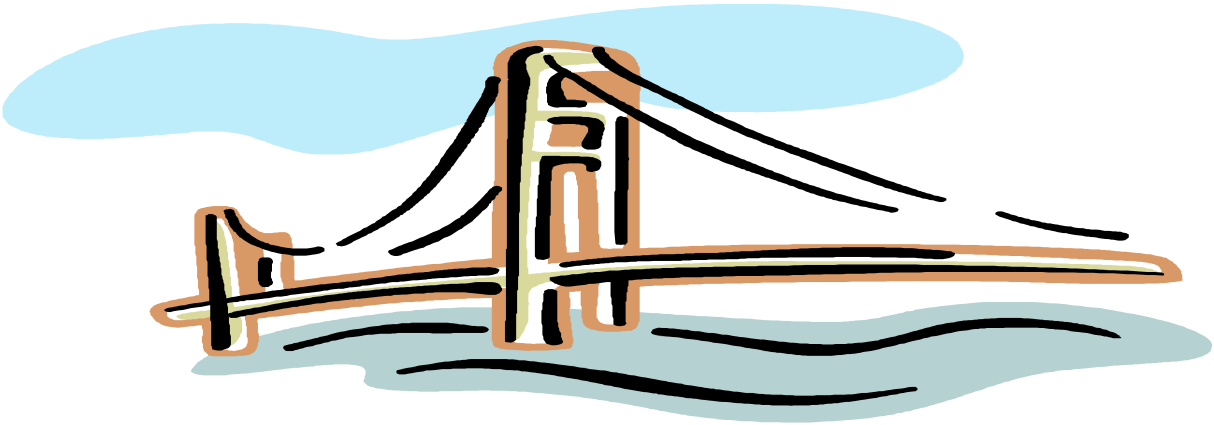
THE NEXT STAGE: RETIREMENT PLANNING FOR OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

FINAL REPORT

April 2009



This project has been made possible through a financial contribution from the Population Health Fund, Public Health Agency of Canada.

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April 2009

Prepared by:
Marlene MacLellan – Project Manager

The Final Report for the period from September 2005 – March 2009 incorporates and updates the Interim Report[1] prepared by Marlene MacLellan and Samantha Butler[2] (July 2008).

This project has been made possible through a financial contribution from the Population Health Fund, Public Health Agency of Canada.

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[1] The Interim Report was produced for the period from September 2005 – March 2008 and describes components of the project completed up to March 2008.

[2] Samantha Butler was Project Coordinator from December 2005 – March 2008.

ACKNOWLEDGEMENTS

Members of the Project Steering Committee offered sound advice, wisdom and unflagging support throughout the project. This was grounded in their unique knowledge bases and shared commitment to the need to respond to the changing needs of persons who are aging with developmental disabilities. Each Committee member took on specific roles at various stages of the project and also contributed to the overall project perspective.

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Pamela Fancey, Nova Scotia Centre on Aging, Mount Saint Vincent University
Dr. Aine Humble, Department of Family Studies and Gerontology, Mount Saint Vincent University
Anne MacRae and *Burke MacCallum*, Nova Scotia Disabled Persons Commission
Mary Rothman, Nova Scotia Association for Community Living
Cathy Deagle Gammon, DIRECTIO**NS** Council
Carol Anne Brennan, Regional Residential Services Society
Jeannine Jessome, Nova Scotia Department of Seniors
Kate Hemeon and *Kathy Greenwood*, Nova Scotia Department of Health, Continuing Care Branch
Mildred Colbourne, Nova Scotia Department of Community Services, Services for Persons with Disabilities
John Cox, People First Nova Scotia (Resource Member)
Tom Gunn, School of Health and Human Services, NSCC

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Carol Ann Brennan, Regional Residential Services Society (also President of Nova Scotia Residential Agencies Association)
Cathy Deagle Gammon, DIRECTIO**NS** Council
Mary Rothman, Nova Scotia Association for Community Living
Pamela Fancey, Nova Scotia Centre on Aging, MSVU (project evaluator)

Resource Members:
Anne MacRae, Nova Scotia Disabled Persons Commission
John Cox, People First Nova Scotia
Beth Saunders, Continuing Care Branch, Nova Scotia Department of Health
Margaret Ann Bruhier and *Valerie White*, Nova Scotia Department of Seniors

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Marlene MacLellan, School of Health and Human Services, NSCC

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THE NEXT STAGE: RETIREMENT PLANNING FOR OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

1. Project Overview

The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities had the primary goal of developing linkages between the disability and aging sectors in Nova Scotia. The primary purpose was to promote social inclusion of persons aging with developmental disabilities. In working to attain this goal, the project responded to a growing need for information to inform policy and programs relevant to retirement planning for persons with developmental disabilities. Service providers, educators, and policy makers recognize an imperative need to address the gaps in retirement planning for this population. Building links between the sectors is a primary step to creating inclusive social policy that will support healthy aging and community participation. In the Extension Year of the project (April 2008 – March 2009), the intent of the project goal remained the same with a specific focus on dissemination of the project's learnings to build capacity for building linkages between the aging and disability sectors to foster social inclusion.

The project was comprised of multiple components, each of which offered different perspectives and the opportunity to hear from many stakeholders. The approach used during the project was to generate and share information as well as to create opportunities for dialogue among the sectors. From September 2005 – March 2008, the project components included: focus groups and interviews for a needs assessment; an environmental scan which was the foundation for the development of a Resource Guide; community opportunities; policy discussion; preliminary meeting of a provincial network; development of an "aging in place" discussion paper; provincial newsletter updates; educational sessions for front-line workers in the disability sector; and presentations on project's key messages to organizations and groups around the province.

An Extension Year was granted to the project for the period from April 2008 – March 2009 for the purpose of disseminating the project learnings gleaned during the components completed in 2005 – 2008. The activities for this Extension Year included the continued delivery of educational sessions as well as the development of an educational resource manual, incorporating key messages from the project. The manual, consisting of 12 workshops organized around four themes, is designed for use as a professional development resource for both the disability and aging sectors. It was introduced to participants from both these sectors in Nova Scotia through provincial workshops.

Approval was received for the project from NSCC Research Ethics Board. The project evaluation was undertaken by the Nova Scotia Centre on Aging, Mount Saint Vincent University.

2. Project Issue

Excerpted from Building Bridges: Aging in Place Discussion Paper (p.1)[3]

Nationally and internationally, service providers and policy makers have identified an increasing impetus to respond to and plan for the changing needs of an aging population of persons with developmental disabilities. This aging population is placing new expectations and requirements on both the aging and disability service sectors. Historically, the aging and disability sectors have not been closely connected. They differ in many aspects: education, clientele, experience, programs, services, policies, funding streams and philosophies[4, 5]. Each sector has developed extensive expertise and knowledge about programs and services to meet the specific needs of their clients, which has served them well. However, with a growing population of aging adults with developmental disabilities who are living longer than ever before due to improved health care and services, program and service demands are changing. Each sector is exploring new opportunities while embracing new challenges. There is an emergent imperative for the aging and disability sectors to work together to share their expertise and knowledge. Also, there is increased recognition of the importance of a cross-sector approach for effective policy and program planning[6, 7]. Despite a broad societal commitment to inclusion, aging adults with developmental disabilities have not usually been included in programs and services planned for seniors in the general population, and so, continue to remain marginalized[8]. The outcome is that they may not receive services for which they are eligible. Policy makers and

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[3] MacLellan, M. & Butler, S. (in consultation with Project Steering Committee). (2008). *Building Bridges: Aging in Place Discussion Paper*. The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities. Halifax, NS: NSCC.

[4] Ansello, E.F. (2004). Public policy writ small: Coalitions at the intersection of aging and lifelong disabilities. *Public Policy and Aging Report, 14*(4), 1, 3-6.

[5] Bigby, C. (2004). *Aging with a lifelong disability.* New York: Jessica Kingsley.

[6] Campbell, M. (2007). *Public policy impacts on growing older with a disability.* Keynote session: Growing Older with a Disability Festival, FICCDAT.

[7] Ansello, E.F. (2004). Public policy writ small: Coalitions at the intersection of aging and lifelong disabilities. *Public Policy and Aging Report, 14*(4), 1, 3-6.

[8] National Advisory Council on Aging. (2004). *Seniors on the margins: Aging with a developmental disability. Ottawa, Ontario: Minister of Public Works and Government Services Canada.*

service providers in both aging and disability sectors are seeking pathways to support "aging in place".

2.1 Definitions

The **disability sector** consists of agencies, organizations and/or individuals that develop policies, provide services, and advocate for people with disabilities. The **aging sector** consists of agencies, organizations and/or individuals that develop policies, provide services, and advocate for older adults. Within the sectors, services are available to a range of ages and abilities[9].

3. Organization of Final Report

The Final Report for *The Next Stage* project provides a brief overview of the multiple components that were completed during the entire project term from September 2005 – March 2009, including key activities and observations. It contains information about the dissemination of information that occurred through various means including electronic distribution and educational workshops. The overall project findings, or learnings, are organized into a section called Key Messages. The findings described in this section were affirmed in more than one project component and are reflective of different perspectives. The discussion paragraphs in the Key Messages section briefly summarize the perspectives from participants in the project components.

4. Process, Learnings, and Dissemination

As stated, the project comprised several components which engaged diverse stakeholders in generating and sharing information relevant to the issue of aging with developmental disabilities. This section briefly describes the process for each of the multiple components, learnings, and the dissemination activities. The key messages, emerging from the learnings in the project, are discussed in detail in **Section 5**.

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[9] Definitions adapted from Butler, S., MacLellan, M. & Humble, A. (2006). *The next stage: Retirement planning for older adults with developmental disabilities: Needs assessment report*. Halifax, NS: NSCC and excerpted from MacLellan, M. & Butler, S. (in consultation with Project Steering Committee). (2008). *Building bridges: Aging in Place Discussion Paper*. The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities. Halifax, NS: NSCC. p.2.

4.1 Environmental scan

The objective for the environmental scan was to increase knowledge of existing resources on retirement planning options for aging persons with developmental disabilities and to use the information collected to inform both the needs assessment and the development of an annotated retirement planning resource guide (**Section 4.2 and 4.3**).

The starting point for the scan was the material already collected and referenced in the project proposal. This material generated further web sites, reference lists/bibliographies/suggested reading lists, and the identification of a number of key research centres in the U.S. and Canada devoted to aging with developmental disabilities. These included, but were not limited to:

a) SCE LifeWorks Inc. in Manitoba
b) Ontario Partnership on Aging and Developmental Disabilities (OPADD)
c) Rehabilitation Research and Training Centre (RRTC) on Aging with Developmental Disabilities, University of Illinois in Chicago.

The information gathered from OPADD proved to be significant in that it provided a model for the goal of *The Next Stage* project. This group has been involved in linking the aging and disability sectors for some time and received funding resources in Ontario to create partnerships between the sectors. Resources created by OPADD, specifically an information CD[10] and a guide for partnership development[11], became valued resources for this project, and with the approval of OPADD[12], were distributed within Nova Scotia to participants of the various project components. The CD produced by OPADD "*Guide to Accessing Seniors' Community Programs*" was developed for the Ontario population but contains very useful generic content of interest to service providers and educators in Nova Scotia. During the Extension Year, OPADD invited a presentation on *The Next Stage* project for their provincial conference held in Toronto, ON.

Four students in a NSCC Human Services Residential-Vocational Program contributed to the scan as part of their course work. The students' report helped to inform the development of the annotated retirement planning resource guide.

More than 200 documents were reviewed during the environmental scan by project staff and the students, generating a wide range of resources. Members of the project's Steering Committee also provided information on relevant websites and available resources familiar to them and their organizations.

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[10] OPADD (2006). *Guide on accessing seniors' community programs*. CD. Ontario: OPADD.
[11] OPADD (2007). *Building the Partnership: Guide to Planning Your Cross Sector Workshop*: http://www.opadd.on.ca/ Click on News/Resources section.
[12] Ron Coristine, Project Manager, Aging and Developmental Disabilities Project, OPADD.

4.2 Needs Assessment

A needs assessment was undertaken to gather information intended to guide retirement planning and policy discussion and to build links between the aging and disability sectors. There were two components of the needs assessment: interviews and focus groups. Discussion took place with service providers and decision-makers from both the aging and disability sectors through 14 interviews and 2 focus groups (21 focus group participants), and with persons with developmental disabilities through 3 focus groups (28 participants). Service providers and decision-makers were asked about the inclusive capacity of existing programs and about enablers and barriers to social inclusion, and persons with disabilities were asked to share their aspirations for retirement and community inclusion.

The needs assessment report makes 14 recommendations relevant to policy, practice and education. They are organized in categories of: 1) Transition planning from work to retirement; 2) Building capacity within the aging and disability sectors; and 3) Policy discussions. A plain language version of the needs assessment report was also created. The report has been widely distributed provincially and nationally (approximately 180 copies) to organizations in both the aging and disability sectors and is available on line through one of the project partners at http://www.msvu.ca/ARCFamilyWork/publications.asp. A member of the Steering Committee from the Nova Scotia Department of Seniors (formerly the Seniors' Secretariat) also sent the report electronically to the *Federal/Provincial/Territorial Ministers for Seniors* group.

Key findings supported the path of building links – or bridges – between the aging and disability sectors to enhance programs and services for people aging with developmental disabilities. A key message emerged that aging people with developmental disabilities wanted their voices to be heard in retirement planning. They valued meaningful activity, ongoing relationships with family and friends and adequate financial resources to support choices. It was clear that extensive education was needed at all levels in order to build a foundation for these bridges. Education was needed both within and across the sectors. As well, it appears that there is a willingness within the aging and disability sectors to respond to new needs in creative ways, but existing systemic and individual barriers must be addressed. The Executive Summary of the Needs Assessment report can be found in **Appendix A**.

4.3 Retirement Planning Resource Guide

Information from the environmental scan, project partners and others provided the content for the annotated Retirement Planning Resource Guide[13]. The first edition was distributed in March, 2007, and a second updated edition distributed in January, 2008. It was intended as a resource for older adults with developmental disabilities, their families, friends and service providers in both the aging and disability sectors. The Guide includes topics of retirement planning, financial information, recreation and leisure, healthy aging, inclusion, housing, transportation, seniors' organizations, community services, resource directories and centres, and advocacy/research organizations. It was designed to be an easy-to-use reference with contact information and brief descriptions of what the groups/organizations offered.

Members of the Steering Committee as well as three external stakeholders were invited to comment and offer input on the content. Prior to the distribution of the Guide, the organizations listed were contacted to obtain their permission to include their listing in the Guide and to confirm the accuracy of their information. A large print version of the first edition of the Guide was also developed.

The Guide, like the Needs Assessment report, has been widely distributed provincially and nationally in both print and electronic formats. Distribution included almost 175 print copies of the first edition and 350 print copies of the second edition. It is available electronically on the project partner's website mentioned above as well as on the websites of Regional Residential Services Society (http://www.rrss.ns.ca/CurrentIssues.htm) and Community Links (http://www.nscommunitylinks.ca/newsletter.php). The Steering Committee member from the Nova Scotia Department of Health also distributed the link to all Continuing Care Branch offices around the province as well as sending the link to representatives of the VON, Veterans' Affairs Canada, and Nova Scotia Department of Community Services.

4.4 Provincial Network Meeting and Updates

The preliminary Provincial Network Meeting was held on December 5, 2006 in New Glasgow for the purpose of beginning to build links between the aging and disability sectors in Nova Scotia. An underlying assumption of the project was that through building links, the emerging needs of persons aging with developmental disabilities can be effectively addressed.

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[13] Butler, S. (2008). *Retirement planning resource guide: For older adults with developmental disabilities, families, friends and service providers*. Second Edition. Halifax, NS: NSCC

Invitations to the meeting were sent to 167 representatives of organizations across the province from both the aging and disability sectors. Forty-five people registered for the day-long meeting but due to a winter storm, 23 were actually able to attend. A *meeting proceedings report* was prepared and distributed to the 45 people who had confirmed attendance. The report documented the meeting participants' feedback. Key points noted by participants included[14]:

- Commonality of issues and challenges facing both sectors
- Importance of increasing each sector's education and awareness
- Need for alignment between the interests of seniors and seniors with disabilities
- Need for inclusive programming for all seniors.

As a follow-up to the Provincial Network Meeting, two Provincial Network Updates (newsletter-type communications) were sent to those who had been involved in the meeting as well as others who participated in project activities. The Provincial Network Updates, produced in October 2007 and March 2008, were distributed to approximately 340 people, representing organizations in both aging and disability sectors, including those who participated in the front-line staff education workshops and in the educational resource workshops (described in **Section 4.8 and 4.10** respectively).

4.5 Community Opportunities

One component of *The Next Stage* project included working with two vocational settings in urban and rural areas of Nova Scotia to gain some understanding of the factors that enabled, or were barriers to, the participation of older adults with developmental disabilities in activities offered for retired people by local seniors' clubs. In one area, the local seniors' club had been including people with disabilities for some time so it was an opportunity to understand what promoted success in their model. In the second area, the vocational setting was intending to seek community opportunities for some clients so *The Next Stage* project was an opportunity to understand the process for becoming involved in a seniors' club. In both areas, the seniors' clubs were clear that their activities were open to all seniors in the community. Three clients (participants) participated in social and sports activities in two seniors' clubs. Because of the very small number of people involved, the intent in this component was only to provide general comments about what was learned. Findings in other components of *The Next Stage* project have supported the learnings described here, but it is important to recognize the limitations of information gathered from a very small component.

Key concepts that emerged were:

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[14] Excerpted from Evaluation Report, Year 2, p.7-8, based on information from Provincial Network Meeting Report.

- *Building Relationships:* Time is needed – and must be invested – to build relationships among the vocational setting, the participants, and the seniors' clubs. It is important to invest time to determine a "fit" between participant interests and available activities, to invite the support of families or residential support staff, to provide information on activities, and to link with the seniors' club to understand expectations and membership requirements.
- *Leadership:* Leadership is important in all sectors to champion and facilitate inclusion.
- *Alignment with interests or "fit":* This refers to the "fit" between the participant's interests and capabilities and the opportunity available as well as the opportunity to be included in meaningful roles that speak to people's abilities.
- *Limited retirement options:* Currently, there are very limited options for people with developmental disabilities who wish to retire and/or to participate in activities planned for seniors.
- *Retirement support:* Currently, there is no model of retirement planning in the sector. As vocational settings look to models of supporting retirement, they may be able to draw on elements of the job-coaching model to support community participation for retiring clients – that is, investing time upfront and gradually drawing away as comfort levels rise.
- *Outcomes of participation:* Participants seemed to genuinely enjoy their involvement in the seniors' clubs. The contact persons at the vocational settings acknowledged the value of the project because of its focus on building relationships between the sectors through community opportunities.
- *Role of vocational settings:* As vocational settings address the changing needs of their clientele, some new questions are emerging. What role does the vocational setting have in other aspects of people's lives, such as in supporting retirement planning?
- *What is needed:* Education to support retirement planning and community participation is needed for all groups – seniors' clubs, vocational settings, other service providers, client participants, and families.
- *Existing strengths:* Enabling strengths exist to build links between the aging and disability sector to promote community opportunities for inclusion. Change is happening in communities, as inclusion becomes the norm and as people let go of their images of old models of care and stereotypes.

Summary of key points:

- Building links between the aging and disability sectors is an important pathway to foster social inclusion for aging persons with developmental disabilities in retirement.

- Assistance and flexibility within the vocational settings to support community participation during work hours is one avenue for transition planning for retirement.

- Collaboration between vocational, residential and facility settings is needed to develop transition to retirement planning models for persons aging with a developmental disability.

- Opportunities for joint educational opportunities and planning sessions are needed for stakeholders in the aging and disability sectors to ensure that appropriate programs, services, and policies are available to support "aging in place".

A summary document can be found in **Appendix B**.

4.6 Policy discussion

As part of their commitment to the project, the Nova Scotia Disabled Persons Commission and Nova Scotia Department of Seniors (formerly known as the Seniors' Secretariat), collaborated on identifying two relevant policies within the jurisdictions of health and community services that affect the population of persons aging with developmental disabilities. On March 5, 2007, they brought together a small group from the provincial Departments of Health and Community Services to discuss the policies and enhance the understanding of issues related to aging with disability.

The policy makers discussed two policies relevant to aging with developmental disabilities: Self-Managed Care (Nova Scotia Department of Health) and Alternative Family Support (Nova Scotia Department of Community Services), using the Inclusion Lens[15] as a tool for viewing the two policies. The session was facilitated by Malcolm Shookner, the author of the Inclusion Lens. At the end of the session, there was a debriefing in terms of the usefulness of the session and of the Inclusion Lens as a tool. Participants also discussed whether the session helped them to look at policies differently from the perspective of those affected.

A synopsis report of the session was prepared by the Nova Scotia Department of Seniors (formerly the Seniors' Secretariat) and the Nova Scotia Disabled Persons' Commission and was distributed to participants of the March 7 session as well as to the Steering Committee. It noted that the policy makers appreciated learning about the Inclusion Lens and thought that the Inclusion Lens could be a useful tool to assist in the analysis of policy inclusiveness. They also appreciated the opportunity to discuss their policies with colleagues and advisory agencies face to face and discussed further meetings and collaborations.

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[15] Shookner, M. & Social Inclusion Reference Group (2002). *An inclusion lens: A workbook for looking at social and economic exclusion and inclusion*. Prepared for the Population and Public Health Branch, Atlantic Regional Office. Halifax, NS: Health Canada.

4.7 Presentations and Dialogue

As part of the dissemination strategy in the third year of the project (2007 – 2008), presentations highlighting the project's learnings were developed and delivered to community groups and organizations around Nova Scotia. The presentations also provided an opportunity to discuss potential for linkages as part of the sustainability plan.

During the summer of 2007, letters went out to 41 groups across both the aging and disability sectors in Nova Scotia, asking them to consider scheduling a presentation about *The Next Stage* project on one of their meeting agendas in the upcoming year. Nineteen letters were sent to organizations identified with the aging sector; 16 letters were sent to organizations identified with the disability sector and 6 letters were sent to organizations with joint membership. The intent was to reach groups with a provincial connection or a clear focus on a provincial issue (i.e. transportation).

As indicated in the chart below, 18 presentations to both the aging and disability sectors in Nova Scotia were conducted during the third year of the project (April 2007 – March 2008). A total of 291 people attended these sessions. Additional presentations are described below the chart. The brief evaluation feedback obtained from the participants indicated very strongly that the information presented was useful to them. Popular comments revolved around the importance and timeliness of the work, the importance of developing linkages between the aging and disability sectors, and how the presentation raised awareness of the issues relevant to aging with developmental disabilities.

When invited to write down any other comments, the most common response related to the theme of sustainability and how this is important work that needs to keep moving forward with leadership from the top. At all the groups, a website address was given to access materials. Copies of resource materials were brought to each group and shared as requested. The resources brought to the presentations included: OPADD CD[16]; *Strategy for Positive Aging in Nova Scotia*[17] produced by the Nova Scotia Department of Seniors; *Programs for Seniors*[18] produced by Nova Scotia Department of Seniors; *Retirement Resource Guide*[19] produced by this project; *Needs Assessment Report*[20] produced by the

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[16] OPADD (2006). *Guide on Accessing Seniors Community Programs*. CD. Ontario: OPADD.
[17] Nova Scotia Seniors' Secretariat (2005). *Strategy for positive aging in Nova Scotia*. Halifax, NS: Communications Nova Scotia.
[18] Nova Scotia Seniors' Secretariat (2007). 2007 *Programs for Seniors*. 18th Edition. Halifax, NS: Author
[19] Butler, S. (2008). *Retirement planning resource guide: For older adults with developmental disabilities, families, friends and service providers*. Second Edition. Halifax, NS: NSCC

project; and *Seniors on the Margins*[21] produced by National Advisory Council on Aging (NACA).

Summary of Project Presentations 2007 – 2008

Sector	Number of Presentations	Number of Participants	Groups
Disability	9	136	Membership-based associations; residential and vocational service providers; municipality committee; conferences; policy advisors
Aging	4	86	Community group; advisory group of seniors' organizations; service providers group; conference
Cross-sector	4	55	Membership-based association; conference; health care sector council; policy-makers
Academic managers	1	14	Educators
TOTAL	18	291	Time Period: 2007 - 2008

Additional Presentations

In addition to these presentations, a paper was presented at a small group session at the Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT) in Toronto (June 2007). During the *Growing Older with a Disability* component of the FICCDAT conference, speakers from many countries around the world voiced the need to build links in education, research and practice between the aging and disability sectors to support changing needs of clients.

[20] Butler, S., MacLellan, M. & Humble, A. (2006). *The next stage: Retirement planning for older adults with developmental disabilities: Needs assessment report*. Halifax, NS: NSCC.
[21] National Advisory Council on Aging. (2004). *Seniors on the margins: Aging with a developmental disability*. Ottawa, Ontario: Minister of Public Works and Government Services Canada.

In the Extension Year (April 2008 – March 2009), four additional presentations were made. Two presentations on *Building Partnerships for Change* were delivered in the Tools for Life Pre-Conference Workshop in the fall of 2008 and the same presentation delivered to the Tools for Life conference held the following day. A total of 41 people attended these presentations, primarily from the disability sector. In March 2009, a presentation was given to the Ontario Partnership on Aging and Developmental Disability (OPADD) provincial conference in Toronto (approximately 25 participants from both the aging and disability sectors were in this session).

4.8 Front-line Staff Education Workshops

A five-hour education workshop for front-line staff working in the disability sector in residential and vocational services was developed and delivered in four locations around Nova Scotia during the winter of 2008: Halifax, New Glasgow, Middleton and Sydney. As part of the Extension Year commitment, two additional sessions were delivered in Chester and Truro during the fall of 2008 for a total of six Front-line Staff Education Workshops. The education workshop was a direct response to the immediate need expressed as a consistent theme throughout all components of the project. Expressed was the need for front-line staff in the disability sector to obtain education about services and programs available in the aging sector to meet their clients' changing needs. Invitations for the workshops were distributed to service providers via DIRECTIO**NS** Council, Nova Scotia Residential Agencies Association, Adult Residential Centres/Regional Rehabilitation Centres Association and Support Services Group Co-operative and to educators via NSCC.

The objectives of the education workshop were three-fold:

1) To provide information for support staff in the disability sector about resources available for retirement planning for older adults.
2) To discuss bridges between the aging and disability sectors that can help to meet the changing needs of older adults.
3) To invite input on future education needs of front-line staff related to retirement planning for older adults.

The day's workshop agenda included:

a) Overview of *The Next Stage* project and key messages
b) Presentation on resources available in the aging sector relevant to retirement planning
c) Visioning exercise for a "picture" of retirement
d) Identification and discussion of potential bridges between the aging and disability sectors to work towards the vision
e) Participants' input on education components needed to respond to the needs of their aging clients

f) Opportunity to share success stories illustrating examples of links between the aging and disability sector which positively affected services.

A template for the Education Workshop for Front-line Staff agenda can be found in **Appendix C**.

In total, one hundred and thirty-seven (137) participants from 29 organizations attended the 6 workshops. The organizations represented included both residential and vocational service providers from community and facility sectors. As well, an educational institution was represented at three of the workshops. Participants received materials which included the *Retirement Planning Resource Guide*, *Guide to Seniors' Programs* (Nova Scotia Department of Seniors), Provincial Update newsletters, a sheet entitled *Words with Dignity*[22], and the OPADD guide for organizing partnership meetings between the aging and disability sectors[23]. The *Aging in Place Discussion Paper* (completed in March 2008) and the *Interim Report* (completed July 2008) were distributed at the two Fall 2008 workshops which were part of the Extension Year activities. A copy of the OPADD CD[24] was given to organizations represented at the workshops.

4.9 Aging in Place Discussion Paper

The key policy area "aging in place" was identified throughout the project by policy makers, service providers and people with disabilities. It arose as a theme early in the project during the focus groups and interviews and was affirmed as a key policy issue at the preliminary Provincial Network meeting. This issue became the focus of a brief discussion paper, *Building Bridges: Aging in Place Discussion Paper*[25], produced in March 2008. The paper was intended to help inform policy and program discussion between the aging and disability sectors. Steering Committee members provided expert review of the document prior to completion.

The selection of the "aging in place" issue was aligned with the focus on this topic seen in the *Strategy for Positive Aging in Nova Scotia*[26] (2005) document

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[22] Obtained from Laughie Rutt, Diversity Consultant, Organizational Development, Human Resources, Halifax Regional Municipality

[23] OPADD (2007). *Building the Partnership: Guide to Planning Your Cross Sector Workshop*. http://www.opadd.on.ca/ Click on News/Resources section

[24] OPADD (2006). *Guide on accessing seniors community programs*. CD. Ontario: OPADD

[25] MacLellan, M. & Butler, S. (in consultation with Project Steering Committee). 2008. *Building Bridges: Aging in Place Discussion Paper*. The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities. Halifax, NS: NSCC.

[26] Nova Scotia Seniors' Secretariat (2005). *Strategy for positive aging in Nova Scotia*. Halifax, NS: Communications Nova Scotia.

produced by the Seniors' Secretariat (now known as the Nova Scotia Department of Seniors) as well as the commitment of both the Nova Scotia Department of Health and the Nova Scotia Department of Community Services to adopt a common definition of "aging in place".

The *Aging in Place Discussion Paper* has been distributed to almost 500 individuals/organizations in both the aging and disability sectors around the province including a few contacts in other provinces. It is available in PDF format at http://www.msvu.ca/nsca/whatsnew.asp. (Click on "Aging in place for persons with developmental disabilities discussion paper").

4.10 Educational Resource Manual and Workshops

In every project component, the need for a variety of educational initiatives was identified. In response, a major project component during the Extension Year focused on the creation of professional development materials, utilizing adult education principles and incorporating learnings from all the project components. The result was an educational resource manual, with an accompanying CD, for use by service providers and other community members, including educators, in both the aging and disability sectors as a pathway for building links between the sectors.

The purpose of the educational resource manual is *"to generate some common understandings among participants from both the aging and the disability sectors, while recognizing the strengths inherent in each sector."*[27]

The educational resource manual, *Linking the Aging and Disabilities Sectors in Nova Scotia: Resources for Building Bridges,* was built around four key themes that were identified by the Extension Year Project Advisory Committee based on the learnings and key messages that emerged from the project components completed in the project years 2005 – 2008. Members of the Committee contributed their expertise to the design and content of the manual and reviewed materials. The four themes and workshops are:

Theme 1: Building Inclusive Communities

Theme 2: Accessing Community Resources

Theme 3: Toolkit for Positive Aging with Developmental Disabilities

Theme 4: Supporting Aging with Developmental Disabilities

[27] O'Regan, N. & MacLellan, M. (2009) *Linking the aging and disabilities sectors in Nova Scotia: Resources for Building Bridges*. The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities Project. Halifax, NS: NSCC. p. 10.

THEME	WORKSHOPS
Building Inclusive Communities	1. Linking the Aging and Disabilities Sectors in Nova Scotia 2. A Lens for Analysis 3. Listening to the Voices of People with Developmental Disabilities 4. Listening to the Community Voices 5. Journey to Community Inclusion
Accessing Community Resources	6. Services for People who are Aging with Developmental Disabilities in Nova Scotia 7. Positive Aging in Nova Scotia 8. Whose Job is it?
Toolkit for Positive Aging with Developmental Disabilities	9. Bridges for Retirement Planning
Supporting Aging with Developmental Disabilities	10. Responding to Changing Needs 11. Helping with Compassion 12. Diversity

The content of the manual is primarily designed to support service providers in building partnerships to respond to the changing needs of people aging with developmental disabilities while fostering social inclusion. It encourages collaboration between the aging and disability sectors in the implementation of the workshops. At the end of each theme section, there are brief suggestions as to how the resource might be utilized for individual professional development, for staff meetings or for community groups.

The manual is designed to be used in multiple ways, with flexibility in delivery plans. Service providers could custom design a delivery plan, selecting specific workshops from the manual to meet their educational goals. It is strongly recommended that any delivery of the resource material begin with Workshop 1: *Linking the Aging and Disabilities Sectors in Nova Scotia*, but the remaining eleven workshops may be offered as ‘stand-alones’, in sequence or clusters in

random order, depending on the educational needs. The manual also offers a valuable resource for human services students who could organize and facilitate a workshop(s) during their studies.

The twelve workshops integrate the learnings and key messages that emerged from the multiple project components. Introductory content for the themes and workshops includes excerpts from specific project materials relevant to the workshop topic. In addition to incorporating (and excerpting) materials generated as part of project activities, other materials which framed the project, or are relevant to the topic, are utilized. For example, a project partner, Nova Scotia Department of Seniors, gave permission for the document *Strategy for Positive Aging in Nova Scotia*[28] (2005) to be included in PDF format on the CD that accompanies the educational resource manual. They also provided a PowerPoint presentation which can be used in two of the twelve workshops (Workshops 7 and 9).

Early on in the life of the project, alignment with the *Strategy for Positive Aging in Nova Scotia* became integral to its focus. Released late in 2005, the *Strategy* document provides a guide for the development of policy, programs and services for all aging Nova Scotians and as such, offers a sound basis for planning for the changing needs of persons aging with developmental disabilities. "Aging in place" is promoted in the *Strategy*. The relevance of this document to the issues addressed in *The Next Stage* project can be seen in the educational resource manual in Workshop 9: *Bridges for Retirement Planning*. In this workshop, the goals and strategies outlined in the *Strategy for Positive Aging in Nova Scotia* are linked with the goals of Person Centered Planning as the basis for a planning discussion between the aging and disability sectors.

Each workshop in the manual contains a learning outcome(s), brief introduction to the topic, facilitator guide, handouts (if required), resource information, agenda, and a feedback form. The manual includes a CD containing a number of files in PDF format, including PowerPoint presentations associated with workshops.

One hundred copies of the educational resource manual (with CDs) were printed and will be distributed via Project Advisory Committee members, stakeholders and NSCC. The manual and contents of the CD will be available electronically on request from NSCC or through some partners' websites (as with other materials).

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[28] Nova Scotia Seniors' Secretariat (2005). *Strategy for positive aging in Nova Scotia*. Halifax, NS: Communications Nova Scotia.

Provincial Workshops: Introduction of Educational Resource Manual

During the Extension year, Workshops were held in four locations around the province -Yarmouth, Kentville, Port Hawkesbury and Halifax - for the purpose of sharing key messages from the project and introducing the educational resource manual. Workshop invitations were distributed through the distribution list networks of the Project Advisory Committee which proved to be a very effective strategy. The invitation can be found in **Appendix D**.

Objectives for the provincial Workshops were:

1. Provide an overview of key messages from *The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* project.
2. Engage participants in meaningful dialogue about building partnerships between the aging and disability sectors.
3. Introduce a new education resource designed to assist groups/organizations to build partnerships between the aging and disability sectors.

The provincial workshop design offered the opportunity to pilot test two of the workshops[29] from the educational resource manual. Each of two workshops from the manual was offered twice during the four provincial sessions, giving the opportunity to make immediate changes to the implementation based on participant feedback. The two workshops selected for piloting were Workshop 5*: Journey to Community Inclusion* and Workshop 8: *Whose Job is it?* Feedback from participants in the provincial workshops was incorporated into the content of the educational resource manual, resulting in modifications and enhancements to the design of some of the workshops in the manual.

One hundred and forty-five (145) people pre-registered for the provincial workshops with 123 actually attending. Project resource materials were distributed at all the workshops including the *Retirement Planning Resource Guide*; the *Aging in Place Discussion Paper*; the project Interim Report (2008); and the Provincial Updates for March 2008 and October 2007. Additionally other resource materials that have been referenced extensively in project activities were available including: the *Strategy for Positive Aging in Nova Scotia* (NS Department of Seniors); the *Building the Partnerships* paper and the *Guide on Accessing Seniors Community Programs* video (OPADD); the *Inclusion Lens* (M. Shookner and Social Inclusion Reference Group).

[29] Clarification on the use of "workshop" – depending on the context, the term refers to either the four provincial Workshops to introduce the educational resource manual or the actual contents of the educational resource manual (i.e. the 12 workshops in the manual).

The following chart shows the number of participants in the four provincial workshops as well as the sector represented.

Participants at Provincial Workshops (*Linking the Aging and Disability Communities in Nova Scotia: Resources for Building Bridges*) – *February 2009*

Four Locations	Pre-registered	Workshop Participants	Aging Sector	Disability Sector	Other
Yarmouth Kentville Port Hawkesbury Halifax	145	123	28	66	29
% of total Participants			(23%)	(54%)	(23%)

Description of sectors represented by workshop participants:

a) Aging sector: Includes service providers or senior-specific groups.
b) Disability sector: Includes service providers or disability-specific groups.
c) "Other" may be either affiliated with aging or disability sectors or both and includes:
    - Community Health Boards
    - Students/faculty
    - Community groups
    - Government
    - Membership based associations

The provincial workshops were successful with evaluation results indicating that 94% of the 110 participants who completed the workshop evaluation forms thought that the workshop format was appropriate to their learning needs. Ninety-two per cent (92%) felt that the material covered in the workshop provided a better understanding of the importance of linking the aging and disability communities in NS. Eighty-one per cent (81%) of evaluation respondents indicated that they had a better understanding of how to use the educational resource manual to build partnerships between the aging and disability communities.[30] A common response to the question of *what participants thought was the most important thing that they will remember*, was recognition of the similarities of needs/issues amongst those aging with and without disabilities. This is a significant outcome with potential to create the impetus to form new partnerships and to look at community opportunities.

[30] Evaluation Report Year 4 prepared by NSCA, MSVU.

5. Key Messages

The multiple components of *The Next Stage* project completed in the project term September 2005 – March 2008 generated a considerable amount of information. However, consistent themes emerged and these themes were organized into key messages. One criterion for determining key messages was that the theme emerged in more than one component of the project. In dissemination activities, the key messages were shared in presentations and workshops and they are incorporated in the workshops found in the educational resource manual. The key messages are in random order.

5.1 The concept of "aging in place" can be a bridge

The concept of "aging in place" can be a bridge for joint discussions between the aging and disability sectors.

Discussion

During the course of the project, it was clear that the concept of "aging in place" offered a natural bridge between the aging and disability sectors because it was a shared goal for programs and services. The *Strategy for Positive Aging in Nova Scotia* defines "aging in place" as *"…the diverse range of programs and housing options needed to ensure seniors maintain personal dignity and functional independence in their home, neighborhoods, or communities for as long as possible."*[31] Service providers in the disability sector repeatedly demonstrated their commitment to this concept through examples of accommodation or advocacy to support people's changing needs in their familiar environments.

Nova Scotia Department of Community Services and Nova Scotia Department of Health recognize the need to work together on this common issue to address the needs of people who bridge their services. As well, the Nova Scotia Department of Health's Continuing Care Strategy, a ten year plan to enhance and expand Nova Scotia's Continuing Care system, states that *"…the strategy aims to create a system that supports Nova Scotians in their desire to live well in a place they can call home."*[32]

In the 2007-2008 Nova Scotia Department of Community Services Business Plan, within **Section 5.4** on Services for Persons with Disabilities, it states *"The goal is to provide a range of programs that support people at various stages of*

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[31] Nova Scotia Seniors' Secretariat (2005). *Strategy for positive aging in Nova Scotia*. Halifax, NS: Communications Nova Scotia. p. 40.

[32] http://www.gov.ns.ca/health/ccs/ccs_strategy/default.htm. Retrieved April 8, 2008.

their development and independence." [33] All of these factors provide an unprecedented opportunity for cross-sector dialogue on what "aging in place" means for persons aging with developmental disabilities and how they can best be supported.

5.2 Willingness to respond to new emerging needs

There is a willingness within the aging and disability sectors to respond to new emerging needs of aging persons with developmental disabilities. However, the sectors are challenged by current systemic and individual barriers which need to be addressed.

Discussion:

Service providers in the disability sector across Nova Scotia are experiencing the aging of the populations whom they serve, consistent with the trend nationally and internationally. The direct effect is that the services they offer must adapt to meet changing client needs. The disability sector currently has limited knowledge of the aging process and of programs and services that are available in that sector and is eager to embrace new educational opportunities. While the need to adapt is recognized, additional resources are necessary to support new and adapted services.

In the aging sector, there has been little demand to date to include aging persons with developmental disabilities into the services and programs. As a result, the sector generally has limited knowledge about the program and service needs of this population. Groups in the aging sector readily acknowledged a need to reach out to the disability sector when they had an opportunity to hear about the issue. Many seniors' groups/individuals are unfamiliar with current inclusion practices. The aging and disability sectors differ greatly along many lines including educational preparation of staff, funding streams for services, philosophies, policies, programs and services, and clientele[34].

Both the aging and disability sectors currently have limited access to information needed to support those aging with developmental disabilities. Working together to meet the needs of aging clients offers unexplored opportunities for new services and also requires joint educational initiatives and discussions. New models of service will also require some revision to current funding and organizational practices.

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[33] http://www.gov.ns.ca/coms/department/Publications.html Retrieved April 8, 2008

[34] Ansello, E. F. (2004). Public policy writ small: Coalitions at the intersection of aging and lifelong disabilities. *Public Policy and Aging Report,* 14(4), 1, 3-6.

5.3 Intentional processes are needed to build bridges

Building bridges between the aging and disability sectors requires intentional processes of building relationships.

Discussion:

Few formal or informal links currently exist between the aging and disability sectors. There is a need to build bridges between the sectors in an intentional manner in order to build relationships among groups and individuals. Intentionality implies a focused approach with recognition of goals and success. During the presentations in the third year of the project, there was considerable discussion about the need to be intentional about building links and some groups suggested ideas that they could bring back to their communities. One example emerged from a person who was involved with a C@P site in the community and saw an opportunity to include aging persons with developmental disabilities in the computer education sessions offered to seniors at the site. This aligned with an interest area (learning to use computers) that was expressed by some people when they talked about what they wanted to do in retirement. Another example emerged from groups that included members from both the aging and disability sectors. They recognized that they could play a key role in building formal and informal links because of this joint membership.

Building relationships requires time and a variety of approaches to identify and include key stakeholders. It involves dialogue about opportunities and realities and about existing successful initiatives, as well as a willingness to share in respectful discussion. It begins with small steps. During the educational sessions with front-line workers in the disability sector, people were asked to share examples of success where the aging and disability sectors worked together to meet client needs. The common thread was the relationships that grew in the process.

Intentional relationships are needed among government departments as well. For a short time period, there was a position of an Executive Director of Strategic Social Policy who reported to both Deputy Ministers in the Departments of Health and Community Services and acted as a liaison between the two departments. This was a vehicle to address common issues. However, there was a reallocation of responsibilities and this position was changed.

During the project two Project Steering Committee members, who represented the Nova Scotia Department of Seniors and the Nova Scotia Disabled Persons Commission, brought a small group of people from the Nova Scotia Department of Health and the Nova Scotia Department of Community Services together to discuss a policy analysis tool with a specific focus on the population of persons aging with developmental disabilities. The group recognized the need to work

together to address common issues with clients who were aging and required a new mix of services.

The Nova Scotia Department of Seniors contributed to making information more accessible by adding a link on their website related to seniors with disabilities. They include a range of sites that encompass the needs of seniors who are 'aging into disability' – that is, acquiring a disability in their later years – and those who are aging with a lifelong disability. The web address is http://www.gov.ns.ca/scs/externallinks.asp, click on "Resources for Seniors with Disabilities".

5.4 Additional resources are required

Additional resources are required to support retirement planning for older adults with developmental disabilities.

Discussion:

The disability sector has developed a wealth of knowledge and expertise over many decades of responding to the needs of clients with developmental disabilities. They are well situated to move forward with retirement planning for aging persons with developmental disabilities. However, planning and support activities require additional resources to fund extra staff and programs. While the vocational and residential settings have been creative in seeking community opportunities for aging clients, they are truly limited by the current resources available to them. For example, in vocational settings, a portion of the operating funds comes from revenue generated by production of services/products. If they were to offer retirement programs, these programs would require a different funding model as there would not be the same capacity to generate revenue.

In the aging sector, programs are primarily run by volunteers and there is limited existing capacity to offer support, if needed, to participants in their programs. This sector has developed a wealth of expertise about aging and retirement planning/programs/services but to date, has had limited opportunities to interact with persons aging with developmental disabilities. Where there is paid staff, their educational preparation usually didn't include this population's needs.

In the beginning stages of building bridges, the aging sector requires resources for lay and professional education and capacity building to build an understanding of the population's needs and the opportunities that could exist in the community. Whereas the disability sector is poised to plan and implement retirement programs but requires additional resources for staff and programs. Education is also needed for the disability sector about healthy aging and age-related challenges associated with specific lifelong disabilities.

5.5 Education is needed for all stakeholders

Education is needed for all stakeholders across both aging and disability sectors to share unique knowledge and expertise, to raise awareness of the issue, and to develop common language.

Discussion:
Throughout the project, dialogue and information was accepted positively but it became very clear early on that comprehensive education at many levels was required as an essential bridge-building strategy to address emerging needs for the population of persons aging with developmental disabilities. Sector-specific education is needed about healthy aging; aging with developmental disabilities; decision-making; retirement planning and inclusion. While joint (aging and disability sectors) educational opportunities are needed to develop a common language and understanding of common issues.

An immediate need was addressed in the project by delivering six educational workshops to front-line staff working in residential, facility and vocational settings in the disability sector (137 participants in total). The workshops offered a combination of project findings, visioning, resource information and opportunities to share success stories as well as gather input on further specific education needs of the sector. This was only a first step in providing a range of educational options and was specific to one group. This step recognized and acknowledged the pivotal role of support persons in the lives of those whom they support. If someone is looking for information on a program or service and they seek information from a support worker, the breadth of knowledge that worker has is key to what opportunities may open.

As indicated earlier, 21 presentations to share the project's key messages were made to individuals/groups/organizations around the province during the years 2007 – 2009 and two presentations made at conferences outside NS. A common theme, emerging from discussions in these presentations as well as in the six front-line staff educational workshops, was the need for health care professionals to have more education on the health needs of persons aging with developmental disabilities.

Education must reflect a range of methods that include both intra- and inter-sector opportunities. People need to receive information specific to their work within their sectors but they also need to have opportunities for sharing information across sectors – an opportunity to learn from each other. A significant barrier to inclusion remains with the lack of a shared understanding of common issues and a common language. Language that is supported within a sector may not be part of the lexicon in other sectors or even in broader communities. General education that creates avenues for discussing how people communicate across sectors and services is needed every bit as much as more

detailed planning sessions. Education initiatives need to include persons aging with disabilities, families, support persons, service providers, volunteers, policy makers, municipalities, organizations and advocacy groups. Through dialogue, people grow in their awareness of complex issues.

5.6 Options for retirement are needed

People aging with developmental disabilities want to have options for retirement and to continue to participate in their communities.

Discussion:

In the three focus groups held with persons aging with developmental disabilities who were approaching retirement, a clear message emerged that they wanted to participate in planning for their retirement. This message was echoed in the focus groups and interviews with service providers, the provincial network meeting, the project presentations and the educational sessions for front-line workers. The message was also affirmed by the Steering Committee members. Focus group participants indicated that, in their retirement, they wanted meaningful activity, ongoing relationships with family and friends, and adequate financial resources to support choices. Because these goals align with goals of many other aging adults, they offer a bridge to seek community opportunities for social and leisure activities.

As emphasized in the Nova Scotia Department of Seniors' *Strategy for Positive Aging in Nova Scotia*[35], many people want to "age in place", that is, receive services in their home or neighborhood. This was affirmed in the voices of people with disabilities, service providers and support staff during the project. It is important that there be a fit between the person's interests and the options for services or programs that are available.

One area that is under-explored for providing options for activity in retirement is that of volunteer contributions. Volunteers underpin the organization and implementation of many activities across the province and there are myriad roles available to fit someone's interests. Some of the people working at Adult Service Centres (vocational settings) already volunteer in their communities. However, some support staff indicated that arranging volunteer placements was often very difficult and time-consuming. Again, the resource issue surfaced because while some saw volunteer contributions as being a potential source of meaningful activity in retirement, they often weren't able to support it within the vocational setting.

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[35] Nova Scotia Seniors' Secretariat (2005). *Strategy for positive aging in Nova Scotia*. Halifax, NS: Communications Nova Scotia.

5.7 Some opportunities exist

Existing community programs and services available for seniors in the general population may offer opportunities for community participation for some people aging with developmental disabilities.

Discussion

When seeking to respond to the changing needs of a growing population of adults aging with developmental disabilities, it makes sense to understand existing options. In the disability sector, there are few activities available specifically for aging and/or retired adults in terms of programs and services that are aligned with their interests. However, in the aging sector, there are many programs and services specifically focused on older adults and located in most communities across Nova Scotia. Programs and services are offered by a range of groups, including municipalities, seniors' clubs, provincial organizations, or government departments. Is there an opportunity to include adults aging with disabilities into these programs?

During the project, it was learned that community programs could be an option for some people if there was a 'fit' or alignment with interests. There are some challenges as well. The seniors' activities are primarily run by volunteers and they have very little capacity to offer support to participants. Furthermore, there can be a range of attitudes that stem from lack of knowledge and/or access to information to a welcoming openness to include persons aging with developmental disabilities. Clearly, attitudes can be either barriers or enablers to inclusion. Education is needed within the aging sector to embrace inclusion. Within the disability sector, education is needed on what community options are available. This sector is well situated to begin to build bridges in their communities, as they are most aware of their clients' interests. They are advocates of inclusion. Education is also needed in this sector to support clients in decision-making and planning.

5.8 Age criteria can be a barrier

Age criteria may be a barrier for people who need to access services based on functional need rather than age.

Discussion:

With the project focus on building links - or bridges - between the aging and disability sectors to foster social inclusion, it was important to understand where potential barriers could be. In the aging sector, programs and services sometimes have an age criterion to determine eligibility and they are often designed based on experience with a general adult population. For some people with developmental disabilities, life expectancy and the propensity to develop specific health conditions may differ from the general population. The questions

become: Is an age criterion a barrier to accessing community opportunities for the population of persons with developmental disabilities? Do programs and services have the capacity to look at functional need rather than simply age?

5.9 New models of cross-collaboration are needed

Models of cross-collaboration between the aging and disability sectors are needed to support retirement planning and provide program options for people aging with developmental disabilities.

Discussion

Clearly, messages from every component of the project spoke to the need for intersectoral collaboration – the need for the aging and disability sectors to work together to meet the changing needs of persons aging with developmental disabilities. How this is operationalized invites creative dialogue. It is recognized that each sector offers unique expertise and knowledge bases. The first steps in building bridges between the sectors are to find the common pathways. As mentioned, education and the concept of "aging in place" are elements that can provide pathways.

Through identifying shared goals, new models of collaboration can emerge. These models can draw on unique sector knowledge to support retirement planning and provide program options for people aging with developmental disabilities. Within the sectors, there is also a need to foster opportunities for cross-collaboration because traditionally service providers (within each sector) have not necessarily worked together. A model for collaboration exists with the Ontario Partnerships on Aging and Developmental Disability (OPADD). They have intentionally been fostering partnerships between the aging and disability sectors for the last number of years and have many resources available on their website.[36]

Pilot projects related to retirement planning and building capacity for social inclusion are needed to explore opportunities for cross-collaboration. There is no single answer to a broad range of needs. Collaborative initiatives vary substantively according to:

- *Geography* - Rural and urban locations differ significantly in access to available opportunities, including transportation.
- *Leadership* - Leaders within groups and organizations need to be open to inclusion and to provide needed education and support to help shape receptive attitudes.
- *Resources* - Available resources to support options differ from service to service.

[36] http://www.opadd.on.ca/ Retrieved April 8, 2008

- *Attitudes* - Behaviours are shaped by attitudes; achieving solutions to changing needs requires everyone involved to think in a different way - to be open to new opportunities.

5.10 Central role for service providers in disability sector

Service providers in the disability sector have a central role in identifying and enabling participation in community activities as clients approach retirement.

Discussion:

With their specialized knowledge of clients' needs and interests and their extensive experience with community inclusion, service providers in the disability sector play a central role in enabling social inclusion for adults aging with developmental disabilities. When people in the focus groups were asked to whom they would go for information on a new activity or an interest they had, they responded most often that they would ask a support worker. The knowledge that support workers have about services and programs is an important element in helping to create new opportunities for their clients in retirement.

Currently, there is no model for transition to retirement planning in the sector. Development of a model could offer new roles for service providers acting as liaisons between the aging and disability sectors.

5.11 Existing initiatives offer learning opportunities

Successful initiatives that currently exist provide a learning opportunity and offer building blocks for further growth.

Discussion:

For the disability sector, persons aging with developmental disabilities present a new and growing client group in communities. In responding to their needs, the sector can look to successful initiatives that grew from client needs over the life course. Existing initiatives provide learning opportunities and offer building blocks for further growth. The aging sector is continually reaching out to respond to unprecedented numbers of older adults who are seeking services that offer choice and flexibility aligned with unique interests. Both the aging and disability sectors have strengths in seeking creative and flexible options with limited human and financial resources. They have developed advocacy skills and strong understandings of community participation.

Service providers, planners and policy makers in both the aging and disability sectors can learn a great deal by looking at creative initiatives that address issues relevant to them. Some existing initiatives were mentioned in the discussion of the key messages above, such as the Nova Scotia Department of Seniors' *Strategy for Positive Aging in Nova Scotia* and collaboration between

the Nova Scotia Department of Health and Nova Scotia Department of Community Services. Examples of successful community partnerships also exist, such as the previously mentioned Ontario Partnership on Aging and Developmental Disability (OPADD). In Nova Scotia, some existing organizations such as Nova Scotia Association of Health Organizations and the Continuing Care Association of Nova Scotia include membership from both the aging and disability sectors, giving them readily available opportunities to exchange knowledge.

Key Messages Summary Statement

In summary, the key messages were heard from diverse participants across several components of the project and offer insight to both existing capacity and future potential. Overall, a broad societal commitment to social inclusion offers a strong platform for exploring inclusion in later life through building on what works well.

6. Sustainability

Man's mind, once stretched by a new idea, never regains its original dimensions.
Oliver Wendall Holmes

The relevance of this project to needs for current services and programs led to many comments about the need to sustain the activities, an observation that was particularly prevalent in discussions with groups following project presentations. A number of factors will contribute to the sustainability of the work.

Project was outcome of established group: In 2004, a group of educators, service providers, planners and advocates met to brainstorm on the issue of aging with developmental disabilities. This group developed a schematic of priorities. When the opportunity to apply for Public Health Agency of Canada (PHAC) funding arose, the group selected a component of their long range plan - specifically, retirement planning - on which to develop a proposal. Members of the group recognize the salience of the issue in regards to future development of programs and services.

Salience of issue: The issue of retirement planning for adults aging with developmental disabilities is extremely relevant to the disability sector. Currently, there are growing numbers of clientele who are aging and for whom better services and programs are needed. This sector has a long, well-established history of being effective advocates with the people they serve and they are not easily deterred by frequently encountered barriers. The issue is gaining public attention through other provincial and national initiatives, in addition to this project, that have begun in recent years. Late in 2007, Global TV ran a story

about the experience of a person who was aging with a developmental disability. While *The Next Stage* project was neither the focus nor the impetus for this Global story, it did serve to highlight the "aging in place" issues referenced throughout this project. Global included brief information about this project in the segment.

Nova Scotia Department of Seniors and Nova Scotia Disabled Persons Commission: During the life of the project, these groups collaborated on the policy discussion component and as members of the Project Steering Committee. Both recognized the need to reach out to the other group and to seek opportunities to include one another in ongoing activities. Both groups are connected to the policy functions of government and are able to represent their constituents in public discussion. While it is not possible to unequivocally state cause/effect relationships in most circumstances because myriad factors are at work, the project work may have fostered a climate that encouraged a more intentional understanding and commitment to collaboration. This is significant in that both of these organizations have been repeatedly identified as being in key positions to influence change.

Strategy for Positive Aging (2005): In 2005, the former Seniors' Secretariat, now the Nova Scotia Department of Seniors, released a guide for the development of policy and programs for aging Nova Scotians as a foundation for the coming years. The document expresses a vision that includes all seniors in Nova Scotia and as such, provides a framework for planning for the disability as well as the aging sector. The *Strategy* document was briefly discussed at the Provincial Network meeting in 2006 and was referenced in all the presentations and workshops, often with a quotation from the document. As well, copies of the document were available to participants. The *Strategy* offers an opportunity to build bridges between the sectors through joint discussion of the goals and societal actions, using common language. Information about the *Strategy* is included in the educational resource manual, further offering an opportunity to link its goals and strategies to planning for older adults with developmental disabilities.

Commitment to Education: A primary message emerging from the project was the need for education on many levels, including both inter- and intra- sectoral (aging and disability sectors) focus. The front-line educational workshops delivered to workers in the disability sector during the project met an immediate need and the content format is established and could be offered again. Participants who completed evaluation forms for the sessions indicated that the sessions were useful to them, and there was benefit in the opportunity to hear about other workers' experiences. The service providers have a strong commitment to providing education and recognize the need to offer specific information on the topic of aging with disabilities and retirement planning and they will seek opportunities to provide ongoing education.

NSCC's involvement as the lead partner for this project offers an opportunity to deliver some components of both pre-service and professional development education needed in conjunction with existing human services programming. The School of Health and Human Services consults with the service providers from the residential and vocational sectors and is aware of the need for additional education in the area of aging with developmental disabilities. The information gathered during the front-line educational workshops, about the specific topic areas needed to support clients' changing needs, offers a foundation for new educational offerings.

In response to sector demand (not related to the project), NSCC School of Health and Human Services is introducing a new one-year Certificate program in September 2009 entitled *Community Disability Supports*. This new program will include a required course on aging with disabilities which will draw on learnings from this project. In addition, there is discussion about the potential for an elective course for Human Services students that utilizes materials developed during the project.

Project Resource Materials: Project materials developed are available electronically in PDF format and can be sent out on request. Notably, the educational resource manual produced in the Extension Year 2008 – 2009 compiles the key messages and other learnings from the project years 2005 – 2008, presenting the information in a collection of twelve workshops which contain resource links, facilitator's guides, handouts, agendas and feedback sheets. This resource offers educational support to sectors that have limited budgets for professional development opportunities. It has a variety of possible uses and delivery can be configured based on educational needs: intra-agency or intra-sector; inter-agency or inter-sector; pre-service education in certificate or diploma programs; or community.

Summary Statement

In summary, there is growing recognition of this issue around the world. This, coupled with the provincial impact of *The Next Stage* project through increased awareness and availability of new resource materials, will help to support the building of new partnerships between the aging and disability sectors to respond to the changing needs of persons aging with developmental disabilities.

7. Overall Project Recommendations

1) It is recommended that groups, organizations and individuals seek opportunities to build bridges, in an intentional manner, between the aging and disability sectors as pathways for developing supportive policy, programs and services for older adults with developmental disabilities who are approaching retirement.

2) It is recommended that a planning and support model for transition to retirement for older adults with developmental disabilities be developed and piloted within the Adult Service Centres in collaboration with other stakeholders.

3) It is recommended that both sector-specific and joint education offerings be developed for the aging and disability sectors with a focus on aging with developmental disabilities.

8. Closing Statement

The purpose of the multiple components of *The Next Stage Project: Retirement Planning for Older Adults with Developmental Disabilities* was to build links between the aging and disability sectors to foster social inclusion through building capacity for new partnerships. Five "bridges" were identified as being key strategy areas for building partnerships between the aging and disability sectors:

- Education
- Healthy Aging
- Community Inclusion
- Aging in Place
- Leisure

The steps taken during the project period from September 2005 – March 2009 are the beginning of a long-term strategy that requires intentional processes of relationship building and information sharing. Through information gathered, resources created, and ongoing dialogue with many stakeholders, the outcome of the project is an enhanced understanding of the strengths and challenges that face the aging and disability sectors as they strive to respond to changing needs. The understanding provides underpinnings to help inform responsive policy development and programs to meet these emerging needs.

Appendix A

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The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities

Executive Summary[37]

The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities project, funded by the Public Health Agency of Canada, has the primary goal of developing linkages between the disability and aging sectors in Nova Scotia. The purpose is to promote social inclusion in retirement for the population of persons aging with developmental disabilities.

One component of this three-year project included a needs assessment. The primary objective of this phase was to elicit information to guide retirement planning and policy discussions in the aging and disability sectors. Several voices were included. Through focus groups and interviews service providers, planners and decision-makers from both sectors were asked about the inclusive capacity of existing programs and about the enablers and barriers to social inclusion. Through focus groups, persons with developmental disabilities were invited to share their aspirations for retirement and community participation.

The interview and focus group questions for service providers, planners and decision-makers were drawn from concepts included in the *Inclusion Lens* (Shookner & Social Inclusion Reference Group, 2002). They were designed to provide insight into the capacity and readiness of agencies and organizations to respond to the changing needs of an aging population of persons with developmental disabilities who are approaching retirement. Interview respondents were asked about existing opportunities that were available for persons with developmental disabilities and about current planning activities. They were also asked about their perceptions of the barriers and enablers to social inclusion. Focus group participants used the *Inclusion Lens* questions related to social exclusion and inclusion to frame their discussion and created an inclusion template from the results.

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[37] EXECUTIVE SUMMARY EXCERPTED FROM:
Butler, S., MacLellan, M. & Humble, A. (2006). *The next stage: Retirement planning for older adults with developmental disabilities: Needs assessment report*. Halifax, NS: NSCC. Pp.6-9.

For the focus groups with persons with developmental disabilities, questions were developed in conjunction with the project Steering Committee. Questions invited discussion on people's perceptions of retirement, including the types of activities they enjoyed now and would like to enjoy when they retire. They were asked about how they would access information about new activities and were invited to offer a key message to retirement service providers.

The framework for the initial analysis of the focus group data centered on responses given to the focus group discussion questions. As the analysis proceeded, additional themes emerged from the transcripts. For the interviews, the social inclusion factors from the *Inclusion Lens* (Shookner & Social Inclusion Reference Group, 2002) that framed the interview schedule were used to organize the results. Additional themes emerged from both the focus groups and interviews. These themes speak to interconnected issues relevant to the promotion of social inclusion as well as to retirement planning and policy discussions that need to occur between the aging and disability sectors. The additional themes identified include:

- Education
- Advocacy
- Valuing contributions
- Continuity of service through the life course (transition planning)
- Age eligibility criteria
- Centrality of service providers
- Meaning of work and retirement
- Retirement funding
- Cross-sector collaboration
- Leadership

A key message from the interview and focus group data is that aging persons with developmental disabilities value similar things in their retirement as does the general population. They want their voices to be heard so that they can share their experiences to help shape retirement options in communities. They want to have meaningful activity, relationships with friends and family, and adequate financial resources to support choices. Another important message relates to the need for in-depth education to prepare organizations in both the aging and disability sectors to respond to the growing population needs of aging persons with developmental disabilities who will be new retirees.

The report offers fourteen recommendations for translating the findings into action. The recommendations are organized under various headings:

Transition planning from work to retirement

It is recommended that:

1. The Project Steering Committee identify opportunities to inform policy, programs and services about the incorporation of a life course perspective, including social determinants of health, into planning and implementation stages of initiatives.

2. Funding be sought for a pilot project to explore the role of a Retirement Planning Coordinator to serve the needs of persons aging with developmental disabilities.

3. Structured retirement planning materials/workshops/resources, focused on healthy aging and retirement, be developed and implemented for persons with developmental disabilities nearing retirement, their support persons, and families.

4. Structured retirement planning materials/workshops/resources, focused on healthy aging and retirement, be developed and implemented for service providers in the aging and disability programs and services sectors.

Building capacity within the aging and disability sectors

It is recommended that:

5. Residential and vocational service providers review operations and programming policies to assess ability to meet the changing needs of aging people with developmental disabilities.

6. Service providers, educators, and policy-makers, in consultation with advocacy organizations, hold strategic planning discussions to determine their organizations' ability to respond to changing needs.

7. Advocacy organizations examine their capacity to work with the aging and disability sectors to respond to the changing needs of persons aging with developmental disabilities and their families.

8. Service providers, educators, and policy-makers, within their organizations, develop and implement cross-sector planning policies to foster partnerships to enable the provision of support based on individual needs.

9. Existing seniors' services, in collaboration with the disability sector, review their operations to assess their inclusiveness.

10. The disability services sector promote and seek opportunities for the participation of persons aging with developmental disability in generic community services.

11. A proposed Provincial Network focus on building links between existing service providers in the aging and disability sectors with the purpose of sharing information relevant to healthy aging and retirement.

12. Cross-sector professional development opportunities be integrated into operational planning for services and programs.

Policy discussions

It is recommended that:

13. The Nova Scotia Seniors' Secretariat and the NS Disabled Persons Commission proactively seek opportunities to develop collaborative strategies to build on the recommendations in the Strategy for Positive Aging in Nova Scotia (Nova Scotia Seniors' Secretariat, 2005).

14. During the Provincial Network meeting in November 2006, the following policy issues be discussed: “aging in place” and age eligibility criteria.

The recommendations offer myriad opportunities for innovative cross-sector collaboration between the aging and disability sectors, as well as meaningful opportunities for persons with developmental disabilities to be involved in learning and planning.

Appendix B

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The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities

Three-year project funded through a financial contribution by the
Population Health Fund, Public Health Agency of Canada

Community Opportunities

What is meant by "Community Opportunities"?
Community opportunities refer to activities in a community that are generally available to community members, based on interest or skills. In this case, there is a specific focus on programs and services directed to retired people. With an emerging population of people aging with developmental disabilities and for whom little or no retirement planning has occurred, it is timely to begin to understand what possibilities exist to include these new retirees in existing community programs.

When people retire, they often seek ways to stay active and connected to their communities. Across Nova Scotia, there are numerous social and leisure activities available for older adults. While these programs have been open to their general communities, the experience has been that very few older people with disabilities participate in these activities.

Role of *The Next Stage* project

The Next Stage project focused on building links between the aging and disability sectors to foster social inclusion for aging persons with disabilities. One component of this project focused on community opportunities for aging persons with developmental disabilities who were approaching retirement. Some key learnings emerged about the factors that can help to make participation in community opportunities successful and the factors that can be barriers to inclusion. A summary of these points is provided here. It is important to note that these points are general points only, based on information gathered from a few people, and is neither generalizable nor representative of all groups.

What helps to foster community inclusion?

PARTICIPANTS	VOCATIONAL SETTINGS	SENIORS' CLUBS
• Welcoming environment • Friendly people • Activities that are aligned to interests and skills • Proximity of activities • Ability to have time off during the workday • Understanding of expectations • Interest in social and community connections	• Large aging clientele and the need to seek social and leisure options in the community for people approaching retirement • Understanding that community opportunities open doors for clients • Commitment by the vocational settings to connect with seniors' groups • Genuine interest in fostering community opportunities such as volunteer, social or leisure activities for older clients • Staffing and funding resources to support planning	• Overall commitment to include all seniors in their community • Commitment of leadership to inclusion • Availability of multiple activities for differing interests • Need to expand membership base • Genuine desire to welcome new members • Meaningful roles available for members to fit different talents • Independence of participant • Potential to offer some support if needed

What can be barriers to community inclusion?

PARTICIPANTS	VOCATIONAL SETTINGS	SENIORS CLUBS
• Registration fees • Unfriendly or unwelcoming environment • Distance to programs • Timing of activity • Lack of transportation (particularly in rural areas) • Lack of enjoyment of group activities • Lack of "fit" with interests	• Current funding models for vocational settings that limit development of new programs • Lack of funding for retirement planning • Limited number of staff to seek out opportunities and to support community participation • Lack of information about programs and services for seniors: what is available and what is the process for participation? • Community opportunities do not meet the needs of all clients • Workplace and contract commitments that may limit client participation in the community during the workday	• Attitudes and stereotypes arising from lack of information and familiarity with persons who have developmental disabilities • Volunteer operated seniors' clubs have limited resources to offer support to participants • Club members usually have to take on various roles to ensure activities happen • Process for admitting new members differs from club to club and can cause delays • Current age criteria or other membership criteria • Some club activities are open only to members • Sports teams are competitive and are usually established for the year, requiring a

PARTICIPANTS	VOCATIONAL SETTINGS	SENIORS CLUBS
		consistent commitment (rather than a drop-in opportunity) • Clubs usually close over the summer so no activities available

For additional information on the project, please contact marlene.maclellan@nscc.ca

Disclaimer: The opinions expressed in this paper are those of the authors and do not necessarily reflect the views of the Public Health Agency of Canada.

Appendix C

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education that **works for you**
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THE NEXT STAGE: RETIREMENT PLANNING FOR OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES

Education Workshop for Front-line Staff

Workshop Objectives

1) To provide information for support staff in the disability sector about resources available for retirement planning for older adults
2) To discuss bridges between the aging and disability sectors that can help to meet the changing needs of older adults
3) To invite input on future education needs of front-line staff related to retirement planning for older adults

10:00 – 10:15	Welcome and Introductions
10:15 – 10:45	*The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* – Overview of Project
10:45 – 11:15	Where do I get information?
11:15 – 11:45	Creating a Future Priorities, Expectations, Collaboration, Leadership Small group discussions
11:45 – 12:00	Group reports – Creating a Future
12:00 – 12:45	Lunch

12:45 – 1:00	Key themes for Creating a Future
1:00 – 1:30	Building Bridges between the Aging and Disability sectors Small group discussion
1:30 – 1:45	Group discussion – Building Bridges
1:45 – 2:15	Educational needs to support retirement planning
2:15 – 2:45	Open discussion: Success Stories
2:45 – 3:00	Wrap-up and Evaluation

Thank you for your participation

Project funded through a financial contribution from the Public Health Agency of Canada

Appendix D

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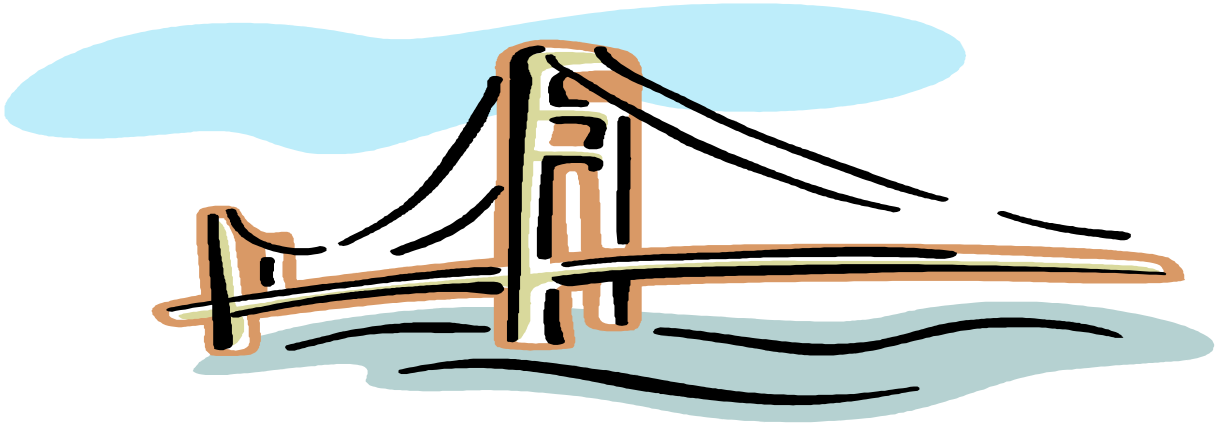
Workshop

Linking the Aging and Disability Communities in Nova Scotia

Resources for Building Bridges



Are you interested in building bridges between groups providing programs and services to aging Nova Scotians? If so, you may want to attend this workshop to explore how the aging and disability sectors can build new partnerships to support people aging with developmental disabilities.

Building bridges between the aging and disability sectors offers a pathway to creating new relationships and offering community options that support positive aging for **all** Nova Scotians.

This workshop is based on using new resource materials that will be available to help your group build partnerships. It provides practical information for program and service providers and volunteer organizations in both the aging and disability communities/sectors to assist them to:

- Recognize their unique strengths
- Share information and knowledge
- Understand each other's perspective
- Create new opportunities for community involvement
- Support persons aging with developmental disabilities
- Build inclusive communities

Who should attend?

People who have an interest in positive aging for persons with developmental disabilities….program planners, service providers, policy makers, educators, volunteer organizations, membership based organizations, board members of organizations ….

Where is the workshop being held?

The workshop is being offered at four locations in NS:

Yarmouth	February 9	NSCC Burridge Campus, Room B231
Kentville	February 10	NSCC Kingstec Campus, Room TBC
Port Hawkesbury	February 12	NSCC Strait Campus, Room 243
Halifax	February 16	NSCC IT Campus, Room B227

Workshop Time: 10am – 2pm

All refreshments are included.

There is no fee to attend the workshop but confirmation of registration is necessary by January 26, 2009.

Project funded through a financial contribution by the Public Health Agency of Canada

Workshop

Linking the Aging and Disability Communities in Nova Scotia

Resources for Building Bridges

Registration Form

Name: _____

Organization: _____

Mailing Address: _____

_____

Telephone: _____ Fax: _____

Email: _____

Please check the location that you will attend:

February 9, 2009	Yarmouth	☐
February 10, 2009	Kentville	☐
February 12, 2009	Port Hawkesbury	☐
February 16, 2009	Halifax	☐

Please fax, email or mail responses to:

Marlene MacLellan
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