

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

## Provincial Network Update



### Presentation prepared by John Cox, People First Nova Scotia

I must admit I am having a hard time with thinking about retirement planning for people with disabilities. Why? Because most people I know don't have anything to retire from AND more importantly, nowhere to retire to.

#### PEOPLE ARE NOT ALLOWED TO RETIRE



All people on Social Assistance have to be a part of a day program to, at the very least, receive a bus pass. One [person] retired earlier this year and has been told by the social worker that s/he needs to get another [type of day program]. S/he cannot get a bus pass that would allow for the freedom to get out and enjoy retirement. S/he is housebound and cannot enjoy retirement to its fullest.

#### PEOPLE DO NOT HAVE HOMES

If you are in a group home or small options home, you need to be a part of a day program. Part of this is that most places will not be staffed during the day. So it is not possible to even relax and stay home during the day. For example, last Saturday I slept in until 4pm. If I were in a group home or small options home, that would not be possible. One [name of organization] member, who works nights and doesn't get home until 2am, was expected to get up at 8 because that's when most people start their day.

#### PEOPLE HAVE PROGRAMS NOT LIVES

People who receive services have to have some sort of plan that runs their lives. And usually there is no flexibility built in. In a report to the renewal initiative, one person, who used to be the ED of [a disability sector organization], talked about someone who worked evenings who was forced to leave their job

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#### Special points of interest:

- Minimal retirement planning for people with developmental disabilities to date
- Building links between the aging and disability sectors is key
- "Aging in place" is a major issue

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## Presentation prepared by John Cox continued ...

because there was no funding to have staff in the home during the day. This person is not unique in this province. People need to be supported in what they do. And the program has to be flexible to meet the needs on an individual basis. After all, without us to provide services for, you'd all be out of a job.

### COMING OF AGE

I remember when I went to the Coming of Age conference. That was a national conference on retirement planning for people with an intellectual disability. I believe this project sprang from that conference. One person from [name of province] was living with their mother in a senior home. This person was worried that when their mom passed on, they would be moved from their home in [one town] to [another]. The facilitator asked the person to think about 10 or 20 years in the future. Their words stuck with me: "I don't give a gosh darn about 20 years from now, I am worried about today". And that's what it boils down to. How can we even begin to plan for retirement after 65 when people with intellectual disabilities cannot live as full citizens from age 0 – 65? In order to begin to plan for our futures, we need to give a gosh darn about today.

### CONCLUSION

The assumption in retirement planning is that people are adequately supported and are a part of their communities in the first place.

Before you can think about retirement planning for people with an intellectual disability you need to think about community inclusion.

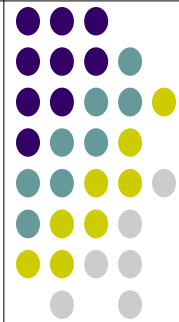
Community inclusion is not just about placing people in homes, but providing the right supports that are both supportive and nurturing that allow people to meet and interact with others in their community.

Government policies, especially those that deal directly with people's lives, need to have a flexibility that enables a person to have complete control over their lives.

These policies need to reflect that the ones in charge of these supports are the person with an intellectual disability.

So, before you can truly think about retirement planning, you most certainly have to advocate for community supports and inclusion.

*Presentation printed with permission from John Cox.*



**“How can we even begin to plan for retirement after 65 when people with intellectual disabilities cannot live as full citizens from age 0–65?”**



## The Growth of a Provincial Network

In the fall of 2004, a group of service provider and advocacy organizations, educators, and policy groups from both the aging and disability sectors met to discuss the opportunities and challenges of aging with developmental disabilities. Service providers in the disability sector had observed that many of their clients were growing older and that needs were changing. Meanwhile, the aging sector was continuing to respond to a growing need for community activities/supports for a diverse range of older adults. The impetus to meet grew from a recognized need to establish links between the aging and disability sectors to begin building bridges for sharing information and services. Recognition of the need to link the aging and disability sectors in response to aging populations is actually happening around the world.

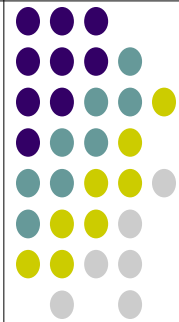
Both the aging and disability sectors have long histories of being responsive to client needs. They have clearly defined philosophies of service, well-utilized services and information links, specific educational standards, and a strong commitment to advocacy. What they don't currently have are pathways for the sectors to share their expertise with each other.

In the disability sector, service providers are facing new experiences such as applying for Old Age Security and responding to new health care needs. They are beginning to consider the idea of retirement which has not been a key focus to date in vocational settings. Many clients are growing older and wanting to cut back on their work time but the support structures in place are not making that an easy transition. Service providers and advocates have little awareness of the aging-related services and information available to them in their communities.

In the aging sector, services and information are usually directed to all older adults in the community – they don't exclude a particular group. However, the aging sector services don't have many requests, as yet, to include persons with developmental disabilities in their programs. In many ways, this is an 'invisible' population for their services. When a request has occurred, they realized that they didn't have much information to help them serve this population.

The original group recognized an opportunity to carry out their work through the Public Health Agency of Canada; a proposal was submitted with NSCC as the lead partner. The proposed project focused on retirement planning because of the immediate and obvious need and was successful in obtaining funds.

The project has several components in recognition of multiple routes to inform policy and practice and the need for different types of information



**“Recognition of the need to link the aging and disability sectors in response to aging populations is actually happening around the world.”**



## The Growth of a Provincial Network continued...

to fuel change. One component was preliminary work to explore the development of a Provincial Network to build links between the aging and disability sectors. The project hosted an exploratory forum in December 2006 as a first step with the hope of initiating some communication to help build interest and commitment.

The session was held in New Glasgow. While 45 people had confirmed attendance, on the day of the event only 23 were present because of a severe winter storm the previous night. Good discussion occurred and a report was circulated to all who confirmed. There was consensus about the need to share information between the sectors.

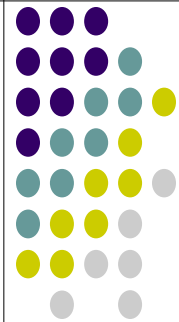
*“The participants felt that a provincial network to link the sectors would be valuable for information sharing and for raising the profile of the issues. .... The participants also pointed again to the need for the sectors to learn more about each other in order to network effectively.”* (p. 5. Provincial Network Meeting Proceedings Report)

Key areas were identified at this meeting if the Network was to come alive – leadership must emerge from both the aging and disability sectors.

*“Participants discussed the need for the network to have responsive and accountable leadership....., and for terminology to be defined and clarified to enable a common understanding of terms between the aging and disability sectors. ....To be inclusive, the network needs to be representative of the people involved in each sector who are committed to creating an experience of “positive aging” for all seniors.”* (p. 7. Provincial Network Meeting Proceedings Report)

It is important to note that this first step of preliminary discussion about a Provincial Network is intended to be a catalyst for ongoing development. If a cross-sector network is to come into being and be sustained, it requires leadership beyond the life of the project.

The concept of a Provincial Network is a positive approach to addressing the “aging in place” issues that emerged as a priority area in the December discussion. This aligns with priorities expressed in the Seniors’ Secretariat Strategy for Positive Aging in Nova Scotia (2005). As well, the Departments of Community Services and Health recognize the growing implications of changing needs and are committed to working together.



**“The participants also pointed again to the need for the sectors to learn more about each other in order to network effectively.”**



## The Growth of a Provincial Network continued ...

It is timely for a Provincial Network of aging and disability sector groups to carve out leadership in this shared area of client concern. However – in order to be vibrant and sustainable, the growth and direction of a Network must emerge from its members' commitment.

## Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT)

*The Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT) offered five conferences simultaneously in Toronto (June 2007), drawing people from around the world. Of particular relevance to our retirement planning project was the conference on *Growing Older with a Disability*. We presented a paper there that shared information about our project, specifically about the needs assessment phase. The growing imperative to link aging and disability sectors in response to changing client needs was a common theme among presenters from many countries. Both sectors have much expertise to offer. Innovative collaborations can create new opportunities and capacities, resulting in improvements to policy and programs.*

During the conference, we learned of other groups with similar interests to ours, particularly the Canadian Centre on Disability Studies (CCDS) in Manitoba and Developmental Disabilities Association in BC. Both groups have addressed aging issues in their work. The CCDS is currently conducting an aging with disabilities project that includes people from NS, including some members of our project Steering Committee.



**“Both sectors [aging and disability] have much expertise to offer.”**



## Importance of Project to Disability Sector

The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities is such an appropriate title for this project. Retirement planning is indeed the next stage as we struggle to ensure that people with developmental disabilities lead full, participating lives in their communities and it is largely uncharted territory.

Families and advocates have worked to create inclusive schools, post secondary opportunities, employment, and supported living in their communities but, until recently, we have not considered how we will support people with developmental disabilities in their retirement years. We also had not begun the discussions with, nor created the liaisons needed with seniors' groups. This project has enabled us to come together with many partners to begin this much needed work and the lessons learned will guide us in the future.

*Mary Rothman, Nova Scotia Association for Community Living*

## Nova Scotia Seniors' Secretariat: Strategy for Positive Aging

In 2005, the NS Seniors' Secretariat released an excellent framework entitled "Strategy for Positive Aging in Nova Scotia". This document provides a foundation to guide programs, policies and services in the coming years, identifying goals and the societal actions needed to achieve them. It speaks to the well-being of all seniors in Nova Scotia, recognizing the significance of choices and community options. The Strategy became a 'guiding beacon' for this project, celebrating all seniors and embracing a path of 'aging in place'.

## Nova Scotia Departments of Health (DOH) and Community Services (DCS) working together

Continuing Care is recognized as being provided by the Continuing Care Branch, DOH and Services for Persons with Disabilities, DCS, therefore, there is a need for the departments to work together to ensure a range of services is available to meet people's changing needs. Susan Logue is the Executive Director of Strategic Social Policy and she is the liaison between the two departments which includes issues relating to 'aging in place'.



**“Retirement planning is indeed the next stage ... and it is largely uncharted territory.”**



## Calendar of Project Events

The project is now in its third and final year and there are still new, action-oriented initiatives to come.

### Education

The project team is beginning to plan an education initiative to reach front-line staff in the disability sector. The purpose is to share information learned in the project and to hear about what education is needed to support planning for the retirement of persons aging with developmental disability.

### Issue paper

“Aging in place” has been identified as a key policy issue by policy makers, service providers and people with disabilities throughout this project and, as a result, an “aging in place” issue paper will be developed to enable policy discussions with decision-makers.

### Key outcomes to date from the project include:

- \* Needs Assessment Report (also available in plain language)
- \* Retirement Planning Resource Guide (also available in large print)
- \* Provincial Network Meeting, December, 2006

### Ongoing activities include:

- \* Provincial network development
- \* Community opportunities
- \* Presentations and dialogue with the aging and disability sectors

The Needs Assessment Report and Retirement Planning Resource Guide can be viewed at the following website:  
[www.msvu.ca/ARCFamilyWork/publications.asp](http://www.msvu.ca/ARCFamilyWork/publications.asp)

For more information about the project contact the Project Coordinator, Samantha Butler, at the contact information given on the back page.



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# **nsc**

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This project is funded through a financial contribution by the Public Health Agency of Canada.

The project's Steering Committee members are:

- \* School of Health and Human Services, NSCC (lead partner)
- \* Maritime Data Centre for Aging Research and Policy Analysis, Mount Saint Vincent University
- \* Department of Family Studies and Gerontology, Mount Saint Vincent University
- \* Nova Scotia Disabled Persons Commission
- \* Nova Scotia Association for Community Living
- \* **DIRECTIONS** Council for Vocational Services Society
- \* Regional Residential Services Society
- \* Nova Scotia Department of Seniors
- \* Nova Scotia Department of Health, Continuing Care Branch
- \* Nova Scotia Department of Community Services, Services for Persons with Disabilities
- \* People First Nova Scotia (Resource Member)

