

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

## Provincial Network Update



This edition of the *Provincial Network Update* is the last edition prior to the formal conclusion of *The Next Stage* project on March 31, 2008. The primary purpose of this project was to build links between the aging and disability sectors to foster social inclusion. This *Update* includes brief overviews of some relevant work undertaken by other groups that can contribute to building links. The project team gathered information from other projects and initiatives happening in Nova Scotia and elsewhere that address the issue of aging with disabilities. These projects all illustrate a commitment to meeting changing needs.



### Importance of *The Next Stage* Project to the Seniors' Sector in Nova Scotia

*The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* project has provided an invaluable forum for both the aging and disability sectors in Nova Scotia to come together to learn, share and discuss ways to ensure that persons with developmental disabilities participate fully in their communities and engage in retirement activities and opportunities.

It is exactly this type of project that the Department of Seniors envisioned when it prepared the Strategy for Positive Aging in Nova Scotia in 2005. The Strategy, a long-term guide to helping all sectors create senior-friendly communities and prepare for an aging population, ignores the boundaries that exist between each level of government, business, not-for-profit organizations, and community groups. Instead, it views the province as a whole and considers how all parts can work together in pursuit of a shared vision.

The opportunity for the aging and disability sectors to learn from one another will result in not only a better understanding of the issues but also, importantly, result in more opportunities for persons with developmental disabilities who are growing older. The Nova Scotia Department of Seniors has been pleased to participate on the project and commends both the

March 2008

#### Special points of interest:

- Retirement Planning Resource Guide (second edition) is now available (page 2)
- Development underway of a database to identify current and future health and service needs in Nova Scotia (page 4)
- Strategies are being discussed to improve primary health care by enhancing supports to Family Physicians (page 5)

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NSCC - School of Health & Human Services and the steering committee for their recognition and championing of the issue.

*Jeannine Jessome, Nova Scotia Department of Seniors*

## **The Next Stage Project Update on Activities**

### **Educational Workshop delivered to Front-line Staff in Disability Sector**

In late January/early February 2008 a five-hour educational workshop was delivered in four locations around the province (Halifax, New Glasgow, Middleton and Sydney) to a total of 111 staff representing 25 organizations (146 staff had actually confirmed attendance but 35 were unable to attend on their respective day due to either bad weather, work obligations or illness). The 25 organizations represented included 13 residential agencies, 11 vocational services and one education institution.

The workshop was enthusiastically received at all four locations. The objectives were to provide information about the resources available for retirement planning for older adults; to discuss bridges between the aging and disability sectors that can help to meet the changing needs of older adults; and to invite input on future education needs of front-line staff related to retirement planning.

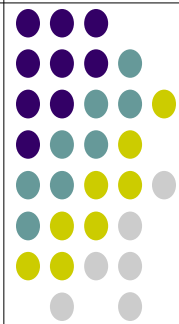
### **Retirement Planning Resource Guide—Second Edition (January 2008)**

The second edition, January 2008, of the Retirement Planning Resource Guide for older adults with developmental disabilities, families, friends, and service providers is now available at, and can be downloaded from, either of the following internet links (or if you would like a copy sent to you please refer to the contact information given on the back page):

[http://www.msvu.ca/ARCFamilyWork/pdf\\_files/Retirement\\_Planning\\_Resource\\_Guide\\_2nd\\_ed.pdf](http://www.msvu.ca/ARCFamilyWork/pdf_files/Retirement_Planning_Resource_Guide_2nd_ed.pdf)

Or: <http://www.msvu.ca/ARCFamilyWork/publications.asp>

The first edition (March 2007) of the Resource Guide was revised to reflect the Nova Scotia Seniors' Secretariat name change to the Nova Scotia Department of Seniors and to include its new website link to information for seniors with disabilities ([http://www.gov.ns.ca/scs/externallinks.asp#senior\\_disab](http://www.gov.ns.ca/scs/externallinks.asp#senior_disab)); to reflect the address change of the Disabled Persons Commission; to remove the National Advisory Council on Aging (NACA) as it has been disbanded; and to add four more organizations (ARC/RRC Association—Nova Scotia, Canadian Centre on Disability Studies—Manitoba, DIRECTIONS Council for Vocational Services Society, and the Independent Living Resource Centre Halifax).



**Educational workshops delivered to 111 front-line staff in the disability sector, representing 24 service providers and one educator around the province.**



## **The Next Stage Project Update on Activities continued ..**

### **Aging in Place Discussion 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” discussion paper has been developed to help inform policy and program discussions between the aging and disability sectors. This Discussion Paper will be widely distributed throughout the sectors.

### **Key activities from the project include:**

- \* Needs Assessment Report (also available in plain language)
- \* Retirement Planning Resource Guide, first and second editions (first edition also available in large print)
- \* Provincial Network Meeting, December, 2006
- \* Provincial Network Update communications, October 2007 and March 2008
- \* Education Workshops for Front-line staff
- \* Aging in Place Discussion Paper

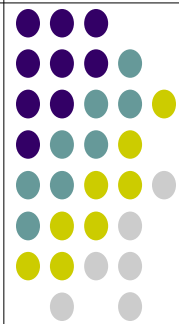
### **Ongoing activities include:**

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

The Needs Assessment Report, Retirement Planning Resource Guide (second edition), and Provincial Network Update (October 2007) 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 please contact the Project Manager ([marlene.maclellan@nsc.ca](mailto:marlene.maclellan@nsc.ca)).



“... an ‘aging in place’ discussion paper has been developed to help inform policy and program discussions between the aging and disability sectors.”



## Intellectual Disabilities Service Needs Research Alliance

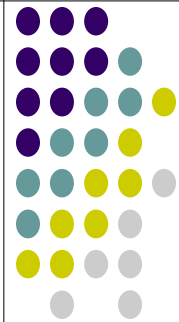
A diverse group of researchers, academics, service providers, advocacy organizations and family members of persons living with intellectual disabilities (ID), have come together to form the *Intellectual Disabilities Service Needs (IDSN) Research Alliance*. The aim of this three-year project, funded by the Nova Scotia Health Research Foundation, is to develop a comprehensive and sustainable database that will help to identify the current and future health and service needs of Nova Scotians living with intellectual disabilities and their families/caregivers. To date, there is no single database available that coordinates this information.

The IDSN Research Alliance feels that answering research questions about the health and social service usage of persons with intellectual disabilities is integral to understanding and improving the health of Nova Scotians with intellectual disabilities. The IDSN database will improve the quantity and quality of information on persons with intellectual disabilities enabling determinations of service needs and usage, satisfaction with services, and future needs. The database will be utilized for researching, planning, and evaluating services. Findings will be shared with community stakeholders such as persons with intellectual disabilities and their families, policy makers, service agencies, advocacy groups and researchers.

The research team includes Principal Investigator Dr. Deborah Norris, *Mount Saint Vincent University (MSVU)*; Co-Principal Investigator Dr. Kathleen MacPherson, *Dalhousie University (DAL)*; Co-investigators Dr. Gordon Flowerdew, *DAL*; Dr. Brian Hennon, *DAL*; and Dr. Janice Keefe, *MSVU*; and Project Associates Adele McSorley, *Center of Excellence on Children and Adolescents with Special Needs, Task Force on Early Intervention, MSVU* and Mark Smith, *Director, Population Health Research Unit, Faculty of Medicine, DAL*.

A key strength of the Alliance is the active participation of its community partners: Hilary Amit, *Nova Scotia Residential Agencies Association*; John Cox & Samantha Butler, *People First Nova Scotia*; Cathy Crouse, *Metro Community Housing Association*; Cathy Deagle Gammon, *DIRECTIONS Council for Vocational Services Society*; Suzan Jorgensen, *Disability Rights Coalition*; and Mary Rothman, *Nova Scotia Association for Community Living*. At every major point, the community partners ensure that that the project is moving in a direction that will ultimately address the needs of persons with intellectual disabilities in a practical, respectful, and inclusive manner.

The project is currently undergoing an ethics review at Mount Saint Vincent University and, upon approval, a survey for data collection will be piloted in Pictou County. A group of parents/caregivers of persons with



**“The IDSN Research Alliance feels that answering research questions about the health and social service usage ... is integral to understanding and improving the health of Nova Scotians with intellectual disabilities.”**



## IDSN Research Alliance continued ...

intellectual disabilities in Pictou County will assist in refining the survey through active participation and ongoing dialogue. This process will help to inform data collection in the Halifax Regional Municipality in Year 2 and Pictou County in Year 3.

While the IDSN Research Alliance has received three year funding from the NSHRF, the alliance is currently researching opportunities for supplemental funding to meet current project needs and long-term funding to promote the sustainability of this vital database. The vision of the alliance is to help people living with intellectual disabilities fulfill their potential for independence and community participation.

For more information on the project, please contact:

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Email: Deborah.Norris@msvu.ca

## A Consultation Workshop Concerning How Doctors Can be Supported in Providing Primary Care to Adults with Developmental Disabilities

On November 29, 2007, 28 individuals responded to an invitation by Dalhousie University's Department of Family Medicine to attend a consultation workshop regarding strategies for improving health care for adults with intellectual disabilities by enhancing supports to Family Physicians providing primary care. Families, self advocates, medical professionals, educators, administrators, service providers and representatives from the Department of Community Services participated. An overview of the Nova Scotia and Canadian situation regarding primary care for adults with intellectual disabilities positioned the need for this dialogue. Clinical Practice Guidelines for Primary Care to Adults with Developmental Disabilities (Canadian Family Physician, November 2006) and a proposal for a clinical and education support program to Doctors were presented.

Following the consultation, feedback was circulated to participants requesting further refining of the information gathered. A second consultation will be held early spring 2008.

*Carol Ann Brennan, Executive Director, Regional Residential Services Society*



**“An overview of the Nova Scotia and Canadian situation regarding primary care for adults with intellectual disabilities positioned the need for this dialogue.”**



## Aging with Disability and Dignity in Nova Scotia Project

In November, the Independent Living Resource Centre (ILRC) began a four month study on aging with disability. The focus of the research is an examination of the service needs of people who are aging with a disability. (What is being done well, what needs to be improved, and gaps in available services). Canada has an aging population. By 2026, 18% of the population of Nova Scotia will be over age 65. Persons with disabilities are among that group, with an 80% growth rate in the province the same year.

The project's name "Aging with Disability and Dignity in Nova Scotia", speaks to this reality. Cheryl Campbell, co-research coordinator says: "This project is an opportunity to have their [people who are aging with a disability] voices and their reality heard."

Research into the effects of aging on life-long disability is a very recent issue. Because of advances in medicine, social conditions and economy, persons with disabilities are living well into old age. However, research shows that the effects of aging that appear at age 70, occur sometimes 20-25 years earlier for a person with a disability. This has profound implications for social planners in the coming decades. "It is an opportunity to influence policy, best practices, and improved services," Campbell says.

Funded by the Office of Disability Issues and supported by the Independent Living Resource Centre in Halifax, the project's team consists of Cheryl Campbell and Judy Hughes, who jointly coordinate research activities from Pictou County and research assistant Craig MacKinnon based at the ILRC. Pictou County's Let Abilities Work Partnership Society is acting as the project's advisory committee.

The research team has been conducting focus groups and collecting individual survey returns from across the province during January and February. The schedule included group visits in Halifax, Kentville, Amherst, Pictou, and Sydney. A remote site visit is also planned in the First Nation's community of Pictou Landing. The findings of this study will be unveiled at a Roundtable Event taking place in the auditorium at the CNIB building in Halifax on March 18<sup>th</sup>.

Persons who are interested in participating are encouraged to contact the Aging with Disability and Dignity project team either by e-mail at [disabilityandagingns@gmail.com](mailto:disabilityandagingns@gmail.com), or by phone at (902) 446-3430 before February 29, 2008.

*Craig MacKinnon, Research Assistant, Aging with Disability and Dignity, Independent Living Resource Centre*



**"This project is an opportunity to have their [people who are aging with a disability] voices and their reality heard."**



## Canadian Centre on Disability Studies Research Project

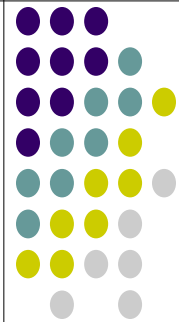
*Development of a Comprehensive Knowledge-based Framework to Address the Needs of Canadians with Long-Term Disabilities who are Aging*  
 Project Update: Research project by the Canadian Centre on Disability Studies, Manitoba, funded by Office for Disability Issues, Human Resources and Social Development Canada

By January 2008 we completed 3 roundtable discussions in each of the target provinces of British Columbia, Manitoba and Nova Scotia with our provincial advisory committees, service providers and consumer groups. A wealth of information was collected and topics such as Language, Attitudes and Identity, Poverty and Income were raised in addition to the 3 topic areas of Housing, Transportation and Home Supports and Care Giving. The differences between rural and urban programs were also discussed. Participants identified current programs and policies, opportunities for change, steps on how to move forward and how to measure success of current and future initiatives.

CCDS is planning our Inter-Provincial Forum on Aging with Disabilities on March 10-11 that will link BC, MB and NS as well as national advisory committee members, service providers and consumers to share, learn and establish next steps to improve the current situation for people with disabilities who are aging. Information and outcomes on this will be available on our website [www.agingwithdisabilities.com](http://www.agingwithdisabilities.com) after the project is complete March 31, 2008.

For more information, please contact: [ccds@disabilitystudies.ca](mailto:ccds@disabilitystudies.ca)

*Laura Rempel, Project Coordinator, Canadian Centre on Disability Studies*



**“CCDS is planning our Inter-Provincial Forum... that will link BC, MB and NS as well as national advisory committee members, service providers and consumers to share, learn and establish next steps to improve the current situation for people with disabilities who are aging.”**



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The project's Steering Committee members include:

- \* School of Health and Human Services, NSCC (lead partner)
- \* Nova Scotia Centre on Aging, 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)



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