

# The Next Stage

## Retirement Planning for Older Adults with Developmental Disabilities

Needs Assessment Report  
November 2006

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School of Health  
& Human Services

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

# **The Next Stage: Retirement Planning For Older Adults With Developmental Disabilities**

## **NEEDS ASSESSMENT REPORT**

November 2006

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# Executive Summary

*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 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.

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 also 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. 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 identifies 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' abilities 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 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.

# Section I: Introduction

## Statement of Purpose

Since their inception, the aging and developmental disabilities service sectors have run in parallel with respect to philosophy, knowledge, and expertise, and sources of funding (Ansello, 2004). As well, personnel in each sector have followed different educational paths. As a result, few alliances exist among organizations that provide programs and services to seniors and those that serve people with disabilities (Bigby, 2004). With a growing population of persons aging with developmental disabilities and nearing retirement, there is increasing recognition that existing services and policies must adapt to meet changing circumstances, ensuring a continued quality of life for those who are “aging in place”. However, there is currently little information available to help service providers in either the aging or disability sectors understand the needs of this population, much less information that will help them understand where the barriers and opportunities lie.

There is also a growing recognition that the aging and disability sectors must work together, sharing their unique knowledge, and jointly planning responses to new needs. *The Next Stage* project focuses on building links between the aging and disability sectors as a pathway to building capacity in response to changing service needs. It is a small step forward in generating information to inform policy and program needs.

## About the Project

*The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* has the primary goal of developing linkages between the disability and aging sectors in Nova Scotia. The purpose is to promote supportive social policies for the inclusion of persons aging with developmental disabilities into established community activities for seniors. In working to attain this goal, the project responds 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 have recognized 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.

A needs assessment, which is the subject of this report, is one objective of *The Next Stage* project (from here on referred to simply as the project). In this phase, persons with developmental disabilities and service providers were invited to share their knowledge through either focus groups or interviews.

The term developmental disability is used synonymously with intellectual disability in this project. The definition of developmental disability was adopted from the National Advisory Council on Aging’s (NACA) 2004 publication: *Seniors on the Margins: Aging with a Developmental Disability*:

A developmental disability is associated with many conditions that originate prior to birth, at birth or in early adulthood but the primary disability is intellectual. The

conditions present varying degrees of intellectual deficiency, along with other physical and/or sensory incapacities and health risks. (p. 2)

For this project, the population of people with developmental disabilities over the age of 40 is considered as aging and potentially facing retirement.

Over a three year period, the project objectives also include an environmental scan, policy discussions, pilot inclusion projects, provincial network development, materials development, and presentations. A variety of methods are being employed to achieve these objectives.

The project supports values of equity, sustainability, and social justice in its commitment to realize full citizenship for aging persons with developmental disabilities. It strives to address glaring gaps in policies that guide programs and services, specifically in retirement planning and options, and seeks to offer opportunities for community participation.

### **Needs Assessment Project Objectives**

The primary objectives for undertaking a needs assessment were to elicit information to guide retirement planning and policy discussions and build links between the aging and disability sectors. Several voices were included. Service providers and decision-makers from both sectors were asked about the inclusive capacity of existing programs and about enablers and barriers to social inclusion. The Inclusion Lens (Shookner & Social Inclusion Reference Group, 2002) provided a framework for this discussion. Persons with developmental disabilities were invited to share their aspirations for retirement and community participation.

### **Needs Assessment Method**

The needs assessment component of the project included focus groups with persons with developmental disabilities and service providers, and interviews with key informants (see Appendix A for details of the method).

# Section II: Interviews

## Background

To enhance community opportunities for persons aging with developmental disabilities who are nearing retirement, it is necessary to first understand where some potential “bridges” between the aging and disability sectors may be. Via interviews, service providers and others were invited to share their perceptions of social inclusion and exclusion and to share their insights into existing and future service capacities. Interviews were conducted with fourteen service providers, advocates, and decision-makers representing organizations and agencies in both the disability and community-based aging sectors (9 and 5 respondents respectively). Members of the Project Steering Committee identified key informants to be included in the interviews. They indicated services, programs, and individuals to ensure a comprehensive cross-section of informants. The types of organizations represented were provincial and municipal governments, advocacy groups, residential service providers, and seniors’ centres. The interview schedule can be found in Appendix B.

The disability sector comprises those agencies and/or individuals that develop policies, provide services, and advocate for people with disabilities, and within the context of this project, specifically people with developmental disabilities. The aging sector comprises community-based groups that perform these functions for older adults; the services are available to a wide age range.

## Results

*At the retirement end of the spectrum at the sheltered industries, people go to work all through their careers but it is not the same kind of work that exists outside sheltered industries, so the whole idea of “one day I’ll retire from all this and do what I like” – it is not the same thing, so there is not the planning for it. (Interview, disability sector)*

The interview questions were drawn from concepts included in the Inclusion Lens (Shookner & Social Inclusion Reference Group, 2002) and were designed to provide insight into the capacity and readiness of agencies and organizations, in both the aging and the disability sectors, to respond to the changing needs of an aging population of persons with developmental disabilities who are approaching retirement. Respondents were asked about existing opportunities that were available for persons with developmental disabilities and about preparation that they may be doing to meet new needs. They were also asked about their perceptions of the barriers and enablers to social inclusion.

Responses to the interview questions are organized under the following headings for both the community-based aging and disability sectors:

- A. Services or programs currently offered
- B. Current strategies
- C. Community opportunities
- D. Agency capacity
- E. Social inclusion

## **A. Services or Programs Currently Offered**

*There is no one right now who is really pushing the limits to get new services for people with developmental disabilities in any way, at any age; it is a non-issue.*  
(Interview, disability sector)

Interviewees were invited to share specific characteristics of their services or programs, including whom they serve and how their populations are supported.



## Aging Sector

Table 1 describes the services or programs offered to retired people as indicated by the respondents from the five aging sector organizations represented in the interviews.

Table 1

<b>Types of services offered</b>	<ul style="list-style-type: none"> <li>• In-house recreation and fitness programs/centre</li> <li>• Lounge</li> <li>• Day trips</li> <li>• Lunch club</li> <li>• Book club</li> <li>• Bingo</li> <li>• Fund raising activities</li> <li>• Outreach programs (medical transportation, meal delivery, home helpers)</li> <li>• Information</li> <li>• Communication</li> <li>• Consultations</li> <li>• Referrals and links to other seniors' organizations</li> <li>• Swimming programs</li> <li>• Special events</li> <li>• Foot care clinic</li> <li>• Income tax clinic</li> </ul>
<b>Services are mandated</b>	<ul style="list-style-type: none"> <li>• Three respondents indicated yes</li> <li>• Two respondents indicated no</li> </ul>
<b>Population served</b>	<ul style="list-style-type: none"> <li>• Seniors (50+)</li> <li>• Ages range from 50 - 80</li> <li>• Other age groups may contact agencies to get information for older family and friends</li> </ul>
<b>Numbers served in past year</b>	<ul style="list-style-type: none"> <li>• Some organizations were member-based, some were drop-in, others offered particular services such as meals on wheels, luncheon programs, and information; respondents offered a range of numbers of participants</li> <li>• Numbers varied according to services and could be hard to pinpoint because events drew additional people</li> <li>• Information: 500 calls per month</li> <li>• Membership: 600 - 800</li> <li>• Programs: about 200 participants</li> </ul>
<b>Supports available to assist when needed</b>	<ul style="list-style-type: none"> <li>• Staff available to answer questions about seniors' issues</li> <li>• Financial assistance program for hearing aids, glasses, and dental work for those on a low income</li> <li>• Financial assistance to access programs or pay for a membership</li> <li>• Staff who can adapt and develop programs specific to individual needs</li> <li>• Physical accessibility (wheelchair ramp, elevator, accessible parking)</li> </ul>

## Disability Sector

Table 2 describes the services or programs offered to retired people as indicated by the respondents from nine disability sector organizations represented in the interviews.

Table 2

<b>Types of services offered</b>	<ul style="list-style-type: none"> <li>• Residential (apartments and small option homes)</li> <li>• Liaison with government and disability community to improve programs and services</li> <li>• Development of plain language documents</li> <li>• Professional health care services</li> <li>• Residential rehabilitation</li> <li>• Information and referral</li> <li>• Social events (dances)</li> <li>• Public awareness and educational activities</li> <li>• Advocacy</li> <li>• Support for individual development</li> </ul>
<b>Services are mandated</b>	<ul style="list-style-type: none"> <li>• Five respondents indicated yes</li> <li>• Four respondents indicated no</li> </ul>
<b>Population served</b>	<ul style="list-style-type: none"> <li>• People with developmental disabilities of all ages (however, most of the clientele were adult populations)</li> <li>• People with health and disability issues including, but not limited to, developmental disabilities</li> </ul>
<b>Numbers served in past year</b>	<ul style="list-style-type: none"> <li>• Numbers varied according to type of services</li> <li>• Clients were primarily non-retired persons</li> <li>• Numbers ranged from less than 100 to several hundred</li> <li>• Public sector services reach many thousands of Nova Scotians</li> </ul>
<b>Supports available to assist when needed</b>	<ul style="list-style-type: none"> <li>• Staff provide whatever support is needed to help people access work, education, or recreation</li> <li>• Equipment support</li> <li>• Staff make things happen based on the need of the individual</li> <li>• Information/referral</li> </ul>

## Discussion: Current Programs and Services

A primary difference between the services offered by the community-based aging and disability sectors, as identified by the respondents in this project, is evident in the nature of the services. The disability sector provides community-based residential and vocational services to adults of all ages who have disabilities. The aging sector generally provides community-based social and recreational services in non-residential settings to people, using an age criterion for eligibility. Moreover, the supports available in the disability sector center on individual needs and life goals, whereas the supports available through the aging sector are more program-based, meaning that in most cases the individual must fit into what exists. Both sectors are clearly committed to supporting the needs of their clientele.

### **B. Current Strategies**

Respondents from both sectors were asked to share information about the availability of their programs and services to diverse populations and whether they had received requests to provide services to retired people with developmental disabilities.

#### **Aging Sector**

The five respondents from the aging sector indicated that their programs and services are open to everyone. The openness ranged from making the person feel welcome to meeting with the individual to ensure they have the supports to participate. One of the respondents said that his/her agency had received calls expressing concern about what activities and housing will be available to people with developmental disabilities as they age: *“Questions around growing concern, what is and what will be available for these folks as they age, where they will live.”* Another respondent had been asked to provide support for people with developmental disabilities. In the latter case, the response was to meet with the individuals on a one-on-one basis to discover the type of supports required, and to implement them, often in partnership with other agencies. This enabled participation in the activity of the individual’s choice.

One of the five respondents reported that s/he had some discussion within his/her agency about the types of services and programs that will be needed as the population of persons aging with developmental disabilities grows. The transitions from the vocational agency environment to retirement and living arrangements during retirement were discussed. This discussion was prompted by the respondent attending educational sessions and meeting with people who work with people with developmental disabilities. In general, however, it would appear that retirement inquiries are not in reference to individuals with developmental disabilities.

#### **Disability Sector**

The majority of agencies in the disability sector currently provide services and programs to retired people with developmental disabilities within their residential and/or social settings. The respondents with the agencies that do not provide services had not received, in their knowledge, requests to provide such services.

The majority of respondents indicated that there has been some discussion within their agencies about the types of services and programs that will be needed as the population of persons aging with developmental disabilities grows: “...we talk about people’s rights to stop work if they choose, and [the] right to age in place, to continue to find things that people like to do and how are we going to help people be part [of their community] and have activities to do that they particularly enjoy.” These discussions were mainly prompted by the increasing age of each agency’s clients. The factors discussed included:

- how to support the aging population
- few advocacy groups to influence government
- how to ensure that resources will be there for people to “age in place”
- the need for retirement transition coordinators in the community
- the right of people with developmental disabilities to retire and participate in activities they enjoy
- the medical community’s lack of knowledge about the aging process for persons with developmental disabilities
- the effect of retirement on existing funding

The salience of “aging in place” was discussed by most of the agencies in terms of people having a choice to stay in their homes as long as possible.

### **Discussion: Current Strategies**

Due to the increasing age of their clients, more of the respondents from organizations in the disability sector than those in the aging sector had some discussion about the types of services and programs that will be needed as the population of persons aging with developmental disabilities grows. However, both sectors recognize that this is an emerging issue. An aging sector respondent discussed two factors that were also identified by disability sector respondents: retirement transition planning and housing options. These have specific relevance to aging in place. “Aging in place” refers to being able to age within one’s community, with appropriate supports available as needs change. The Nova Scotia Seniors’ Secretariat *Strategy for Positive Aging in Nova Scotia* describes “aging in place” as:

...the diverse range of programs and housing options needed to ensure seniors maintain personal dignity and functional independence in their homes, neighborhoods, or communities for as long as possible. (p. 40)

The topics of transition planning and housing appear to be salient to both sectors and may offer opportunities for cross-sector education and “bridge-building”. The disability sector agencies also discussed advocacy, the right to a meaningful retirement, and the need for more knowledge about the aging process for persons with disabilities.

### **C. Community Opportunities**

Respondents were asked about the existing integration opportunities in their communities for those aging with a developmental disability.

## Aging Sector

Respondents indicated minimal awareness of what was available in their respective communities for retired people aging with developmental disabilities: *“I don’t think there are many opportunities for them to socialize and take part in activities where they would feel accepted.”* However, respondents believed that, generally, staff who run programs and services for the mainstream aging population would try to accommodate people with developmental disabilities. They felt that a lack of funding for trained support staff might pose the biggest obstacle to inclusion. One person noted that the attitudes of other participants in the program or service may also pose a potential barrier to someone feeling welcome in community activities.

In response to whether services and programs for those aging with developmental disabilities are open to the general population, the respondents felt that they would be open but that the general population would not necessarily access them.

In terms of the programs and services that the respondents would like to see in place, there was general agreement that people aging with a developmental disability should have the same opportunities as everyone else during retirement and not be constrained by transportation, recreation, and/or housing issues.

## Disability Sector

The majority of the disability sector respondents had minimal awareness of general community programs and services available for people aging with a developmental disability: *“As far as anything specific in the general community, I am not aware of anything.”* As well, differences were noted in rural and urban areas: *“Right now people are having to move into the larger centres because the services are not there [in rural areas].”*

On the one hand, when asked if they thought the services and programs available to the general population were open to people with a developmental disability, the majority of respondents said that they might appear to be open but that in reality barriers such as lack of awareness and understanding among staff and other participants would prevent inclusion in many cases. One respondent commented that: *“Generally, people in the community are not sure how to deal with people with disabilities, how to approach them and communicate.”* On the other hand, it was felt that disability sector service providers do not tend to consider generic programs as options for their clients as much as they should. As a result service providers in the aging sector are not challenged to examine their inclusiveness as much as they could: *“We, as service providers, might not be looking at generic service possibilities as much as [we] should be.”* Another respondent commented on the reality that people may not be aware of persons in their community who may like to participate: *“People just aren’t aware, say you have a group like the Lion’s Club, maybe they just don’t know that there are people [with developmental disabilities] out there who would just love to be part of it.”*

In response to whether the general population access services and programs planned for those aging with developmental disabilities, most of the respondents said that such services and programs

would be open to the general population but that the general population may not access them: *“Sure, but I don’t see anyone coming to ask if they can participate.”*

The following is a list of the programs, services, and opportunities that the respondents would like to see available for persons aging with a developmental disability and contemplating retirement:

- access to existing retirement planning workshops
- volunteer opportunities in the community
- retirement transition coordinators
- generic seniors’ programs and services fully inclusive with knowledgeable staff
- adult day centers
- supports for “aging in place”
- the right to retire from a job with a pension (government or otherwise)
- residential and vocational services working together to provide retirement opportunities
- increased government awareness of these issues and the need to address accessibility

### **Discussion: Community Opportunities**

Nova Scotia is an inclusive society of caring communities that supports the well-being of seniors and values their contributions. (Nova Scotia Seniors Secretariat, 2005, p. 25)

Respondents from both sectors had minimal awareness of what is available in their respective communities for people who are aging with a developmental disability during retirement. However, it seems that very few options exist so the minimal awareness could be a reflection of this reality rather than an indication that they lack knowledge of existing services.

Both sectors indicated that a lack of trained support staff (due in some cases to a shortage of funds) and a lack of awareness and understanding amongst program participants are two of the biggest obstacles to generic seniors’ programs and services being open and inclusive to people with developmental disabilities. The first obstacle coincides with the findings of the Persons with Developmental Disabilities Calgary Region Community Board Advisory Committee (Biersdorff, 2000) in its analysis of the service delivery system to aging individuals with developmental disabilities. It found that generic seniors’ programs do not provide enough support to allow persons with developmental disabilities to participate (Biersdorff, 2000). In addition, as Bigby (2004) found in her Australian research, significant barriers to access to formal and informal community leisure programs still exist. Moreover, these barriers exist to some degree even in programs that have as their key operating principle the inclusion of people with disabilities. Bigby (2004) goes on to say that:

Both organizations and individual people with intellectual disabilities require an array of different resources to support access. Such resources range from staff training, effective transport systems and attendant care to individual support to select and participate in activities. (p. 156)

All of the respondents felt that people aging with a developmental disability should have the same retirement opportunities as the general population including access to: mainstream retirement planning/transition workshops, volunteer work options, housing options, income, and meaningful recreation/leisure opportunities. This is consistent with the strategic framework outlined by the Nova Scotia Seniors' Secretariat in their recent document *Strategy for Positive Aging in Nova Scotia* (2005).

## **D. Agency Capacity**

In order to better understand capacity for integration, respondents were asked about their organization's ability to respond to new needs.

### **Aging Sector**

Of the five representatives, one said that their agency currently has the capacity and is ready to respond to a growing population of persons aging with a developmental disability: *"We are ready as we offer the wide range of programs and services; we recognize there is a need."* Another representative thought that their agency would be ready because *"...we have a good group of people here that would be willing to help out"*. Yet another respondent said that their agency recognizes that this is an issue and hopes to work with other agencies to formulate solutions: *"We are very open to working with or collaborating with other agencies or people working on behalf of disabled persons."* The remaining two representatives reported that their agencies are not ready to respond due to their current mandates, but recognized a need: *"We have seen in other areas where there are lots of folks out there that we should be providing services for but I am sure that it is something that will come up as we continue to constantly review and change mandates."*

One agency currently provides opportunities for people with disabilities to have input into the design or implementation of their programs and services. Two agencies have the capacity to offer these opportunities in the future because the respondents said that they already have a strategy of consulting with the public prior to developing programs and services. The final two respondents do not provide these opportunities directly but members of their agencies are able to have input through a voting procedure.

To be better prepared to respond to a growing population of persons aging with developmental disabilities and hence increase their agencies' capacity, the respondents indicated that they need to:

- conduct brainstorming sessions to identify the priority needs of the population
- take advantage of professional development opportunities to increase their own knowledge and awareness
- conduct a community needs assessment
- secure the funding to be able to hire additional staff to support people with developmental disabilities in their programs and services

## Disability Sector

Five of the nine agency representatives indicated that their agencies have some capacity and are ready to meet the changing needs of a growing population of persons aging with a developmental disability with a major caveat – additional resources are needed. Education was also identified as important: *“If you think of enablers, education is key, we need to be out there advocating and educating people about what this population is about and how we enable them to be part of the community.”* Although concern was expressed regarding who will cover the additional costs associated with an aging population, some respondents indicated that they could react quickly if resources were more readily available. The remaining representatives felt that currently their agencies are not ready to respond but recognize that the needs of this growing population will need to be addressed.

All of the respondents’ agencies are committed to offering opportunities to people with disabilities to have input into the design or implementation of programs and services and most do so currently. One respondent commented: *“We are getting better at it and in the day-to-day planning of people’s lives; we are really trying to make sure that people do have input into that so that they can see their wishes take shape, including those in retirement.”*

To be better prepared to respond to a growing population and hence increase their agencies’ capacity, the respondents indicated that they need to:

- increase awareness about their services and the sector in general, and celebrate successes
- have more of an ability to create the options people need
- work together with the provincial departments of Health and Community Services to find ways to finance programs
- understand the demographics of this population, research, and create a strategic plan
- create more awareness in society that people with developmental disabilities need jobs in the mainstream workforce
- empower persons with developmental disabilities to speak for themselves
- acquire more resources, funding, and information
- advocate for and create a continuum of services
- involve younger people
- advocate for better medical intervention (doctors who are more knowledgeable about aging and developmental disability issues)

## Discussion: Agency Capacity

Some respondents from the disability sector agencies indicated that they have the capacity and are ready to respond now to a growing population of persons aging with a developmental disability. However, they also note that in order to do so, additional resources must be available. The remainder of the disability agencies, while not yet ready to respond, recognized that the needs of the growing population will need to be addressed. As yet, there is not widespread recognition from the aging sector of the need to respond to this population. It appears that the aging sector has not received frequent requests for this service so it has not been a central area of development.



To respond effectively to new needs input must be requested and received from the persons with developmental disabilities themselves and then integrated into the design or implementation of programs and services. The disability sector agencies interviewed request and receive such input. The aging sector also has opportunities for input from persons with disabilities based on membership status or specific programs. At times, organizations who represent people with disabilities may be a conduit to inform particular programs.

To increase the capacity of their agencies to respond, both the disability and aging sector respondents pointed to a general need for more funding, research into the needs of the population, and professional development opportunities to better understand the aging issues for persons with developmental disabilities. The disability sector respondents also indicated the need to advocate for better medical intervention and a continuum of services, to empower persons with developmental disabilities to self-advocate, and to raise awareness of the need for an income in retirement acquired through mainstream workforce employment allowing for a Canada Pension Plan (CPP) contribution.

## **E. Social Inclusion**

Although social inclusion has been a desired societal goal for policy, services, and programs across the country, in reality, it has not been fully achieved. One respondent commented: *“The opportunities need to be there, there have to be activities in the community that are available...”* (Interview, Disability Sector). An understanding of the barriers as well as the enablers to social inclusion is needed.

### **Aging Sector**

Most respondents from the aging sector indicated that social inclusion has not been achieved in their communities, *“We are trying, we still have a few challenges...”* One respondent felt that it had been achieved within their agency community due to the myriad of different services offered through the agency: *“I would say yes because of the different services we are able to offer, but at the same time, [we] can’t meet all the needs...”*. Another expressed that: *“I would like to think so but I could see how it wouldn’t necessarily feel like that if you were the person with the developmental disability.”*

Barriers to social inclusion, according to the respondents, include:

- lack of opportunities for involvement in community activities for people with developmental disabilities
- negative attitudes of some of the general population due to a lack of understanding and awareness
- limited housing options
- lack of funding for agencies to assist them to become inclusive
- the reality that some people with developmental disabilities do not self-identify and ask for services

Enablers to social inclusion include:

- information gained from research into community inclusion
- professionals (such as social workers, health professionals, teachers) committed to making things better
- Special Olympics, which raises awareness of the needs
- changing attitudes in the general population
- inclusive policies for programs and services within agencies
- awareness within agencies of community needs
- efforts of people who advocate for change

## Disability Sector

Most respondents from the disability sector believed that social inclusion has not been achieved in society, and two respondents indicated that progress was being made. A question was posed whether or not “inclusive” activities were actually inclusive “... *is it true social inclusion? I would say no...*” Another respondent referred to the devaluation of persons with disabilities within society: “*Devaluation – I believe that society, [those] who are not working with people with developmental disabilities, [do] not want to see it, know about it, they don’t understand it.*”

Barriers to social inclusion, according to these respondents, include:

- the stigma associated with mental health issues
- information not written in plain language
- lack of inclusive policies, practices, and programs that lead to social exclusion
- lack of infrastructure resources for accessible programs, transportation, and housing
- negative attitudes of some of the general population due to a lack of understanding, awareness, education, and a fear of the unknown
- lack of transition planning throughout the life course, particularly for retirement
- isolated services (lack of connections among services)
- a shortage of powerful advocates
- lack of visibility in the community of people with developmental disabilities
- the way in which the work performed by people with developmental disabilities is viewed by society as different to and/or less valuable than work performed by the general population
- a lack of recognition of people’s abilities

Respondents also identified enablers to social inclusion including:

- the distribution of information to the general public, particularly young people, and the resulting increase in awareness of the general public through education
- inclusion of all types of services throughout the lifecycle
- greater cooperation among the provincial departments of Community Services, Health, and Education for continuity and transition planning
- visibility and connection within the community, such as staff accompanying clients to community activities

- strong advocacy by the Disabled Persons Commission, Nova Scotia Seniors' Secretariat, community advocacy organizations, church, and families
- availability of inclusive activities in the community
- job coaches to enable more people to work in the mainstream workforce and earn minimum wage, thus providing some access to government pensions and, in some cases, private and/or workplace retirement pensions
- a commitment to share with the rest of the community, including the medical community, the knowledge acquired in the disability sector about the aging process of people with developmental disabilities

### **Discussion: Social Inclusion**

Full inclusion is a societal goal and as such, needs to be a guiding beacon for all services and programs. However, it is not easy to achieve: "Reaching the goal of full inclusion is a major challenge for all Canadians" (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000, p. xiv).

A definition of social exclusion highlights the elements that are needed for inclusion:

Social and economic exclusion happens when people don't have – and can't get – the education, jobs, decent housing, health care and other things they need to live comfortable, to take part in society and to feel that they are valued and respected members of their community. (Catano & Rhymes, 2004, Tool Kit, Slide #1)

An understanding of the enablers and barriers to social inclusion is important to further our understanding of community participation. Although full participation in community for persons with disabilities is an accepted goal, it remains elusive. The overriding feeling amongst the respondents in both the aging and disability sectors was that social inclusion has not been achieved in society. The barriers appear to fall under the following broad headings:

- Negative stereotypes and attitudes found among some of the general population including professionals, service providers, and the government due to:
  - stigma associated with mental health issues
  - lack of understanding, awareness, and education
  - lack of knowledge in the medical community
- Devaluing of contributions through:
  - lack of recognition of people's abilities
  - less value being placed on the work performed by people with developmental disabilities
  - "pigeon-holing" people with developmental disabilities into services designed for much older people (because of the lack of other options if health needs change)
- Not enough advocacy and self-advocacy leading to:
  - lack of visibility and connections in the community

- lack of resources for accessible recreation programs, transportation, and housing
- Lack of inclusive policies and practices within and across all sectors and jurisdictions due to:
  - lack of connections among services throughout the life course
  - lack of transition planning at all stages of life, particularly retirement
  - lack of information written in plain language
  - programs that foster social exclusion

The enablers to social inclusion given were basically the opposites of the barriers and included:

- raising the awareness of society through education
- valuing contributions
- encouraging more advocacy and self-advocacy initiatives
- developing inclusive policies and practices

# Section III:

## Focus Groups - Persons With Developmental Disabilities

## **Background**

The “first voice” of aging persons with developmental disabilities is essential in helping to understand the expectations and aspirations of persons who are nearing retirement. This population often has limited access to information about retirement and is seldom asked for their views about this stage in life. Thus, in this project, employed persons with developmental disabilities were invited to participate in focus groups to discuss their perceptions of retirement.

These focus groups took place in Halifax, Kentville, and Sydney (one at each site). The Kentville and Sydney focus groups were hosted by the vocational setting where the people were employed, and the Halifax focus group was hosted by a residential service provider.

Focus group participants were invited from various vocational workshops. Nineteen women and nine men participated in the focus groups. Of the 28 persons with developmental disabilities who participated in the three focus groups, 20 worked full-time and of those individuals, 19 worked in vocational workshops (one worked elsewhere in the community). Eight participants worked part-time and seven of these individuals worked in vocational workshops (again, one worked elsewhere in the community). Twelve persons were in the 41 - 50 age group; fourteen were in the 51 - 60 age group; and two were in the 61 - 70 age group.

## **Results**

The questions for the focus groups (Appendix C) were developed with considerable input from the project Steering Committee. The questions invited discussion on people’s understandings of retirement, including the types of activities they enjoyed now and would like to enjoy when they retire. A definition of retirement was not provided because the intent was to elicit the participants’ perceptions of what it meant to them. Participants were also invited to talk about where they would go to access information about new activities. Questions were posted on the walls to provide a visual guide to the discussion.

Results from the three focus groups are organized under the following headings, relevant to the focus group questions:

- A. Perceptions of retirement
- B. Current community activities and hopes for the future
- C. Access to information
- D. Key messages for retirement service providers

### **A. Perceptions of Retirement**

To begin discussion, participants were asked about their perceptions of retirement, specifically related to activities they thought retired people engaged in and the meaning of retirement to them. The majority of the focus group participants knew people who retired. They mentioned family members, people from their church, or former fellow workers.

The participants generated an extensive list of home and community based activities in which retired people, whom they knew, engaged. Some of the activities involved physical activity, such as work around the house, building items like tables and rocking chairs, gardening, walks, swimming, bowling, and skating. Other identified activities were more sedentary such as watching movies and TV at home, relaxing, playing computer games, sleeping, and knitting. They also identified many social engagements including visiting grandchildren, going out for lunch, meeting friends, and going to Tim Horton's. Community participation included movies, flea markets, seniors' clubs, playing cards and pool, drives, shopping, Bingo, and paid or volunteer work. Many also mentioned travel (specifically cruises).

The word "retirement" elicited a range of thoughts and images, often based on the experiences of people they knew. A few people from the focus groups opted not to answer this question, saying they did not know people who were retired. Most frequently, the participants' images were of relief from obligations: "*won't have to get up early*", "*... take it easy and go for walks and read*", or "*not having to take the bus to work*." Some identified retirement as "*... a time that you have to move on for yourself*" and a time for rest and relaxation. The break from work was acknowledged: "*No work. I've been here 22 years [clapping] I'd be happy [to retire],*" and "*I'm looking forward to my retirement and not going to work*". Enjoyment of activities was a key concept, "*... going on trips .... or recreation, more like recreation... doing things that keep you busy and that you enjoy like a fire in the backyard in the summertime*". Comments indicated a link between age and retirement – as a stage in later life, "*I think of an elderly person*" or "*... getting too old to work*". Choice emerged as important, "*I wouldn't want to take retirement... [People] should have the choice if they want to retire, they should have the choice to stay home*". Participants also indicated the importance of keeping active and continuing to connect with family.

Not all comments had a positive focus however; one participant said: "*I think it [retirement] is ridiculous. I think people should stay at work or just cut their work down to volunteer... [work] is better than staying at home*". Another commented: "*I would hate to retire; I would like to work until I am 100 years old*". Often, people saw work as their way to contribute to society. Several respondents were concerned about finances and source of income during retirement, "*Where will the money come from? How are we going to save it?*" There seemed to be very little information among the groups as to what financial resources were available to them in retirement. One person commented: "*I wouldn't want to retire until I knew that I had enough money put away.*"

### **Discussion: Perceptions of Retirement**

In general, individuals who participated in the focus groups have clear perceptions of retirement and view it as something positive. The few negative comments revealed an underlying concern of having to leave their work and a concern of how their retirement would be funded if they did retire. The concern appeared to be related to not knowing what would take the place of work.

Many of the people in this project have positive perceptions of retirement, but it is important to note that they are not yet retired. Other studies that have interviewed persons with developmental disabilities during their retirement years have had reverse findings. In a study by Rogers, Hawkins,

and Eklund (1998) for example, just a few of the retired persons with developmental disabilities were positive about retirement and said that they enjoyed it and the majority indicated that they would like to return to work to improve their quality of life. Those who enjoyed their retirement were involved in meaningful leisure activities in the community that they had chosen. Those who were dissatisfied felt that they had little control over their retirement and had been ill-prepared; they were not involved in meaningful leisure activities but rather in diversionary activities deemed to be socially appropriate (Rogers et al., 1998). These findings offer insight into what could contribute to positive retirement experiences. People in the focus groups for this project recognized the importance of meaningful activity after work.

The range of activities identified illustrates an understanding of the diverse range of possibilities in the physical, social, and affective arenas in which retired people engage. Because individuals approach retirement in different ways, they also will be affected by it in different ways, and retirement preparation needs to recognize this range of experiences and reactions. Some retirement researchers have attempted to note this variation and their insights into various typologies can be useful in preparing informational materials. For example, Hornstein and Wapner (1985) created a typology of retirement experiences: Retirement could be experienced as a "...transition to old age, as a new beginning, as a continuation of pre-retirement life structure, and as an imposed disruption" (p. 291). Each category differed in factors such as the meaning of retirement, main emotions felt during the transition, attitudes toward employment, and the overall extent of change in one's life as a result of the retirement. In particular, the way in which retirement is experienced (gradual or quick/voluntary or involuntary transition) can have a profound effect on individuals. The level of choice and self-determination that persons with developmental disabilities have in the retirement transition needs to be addressed. Moreover, in addition to what persons with developmental disabilities are leaving behind (employment), they also need to have a good understanding of and preparation for what they are moving toward.

## **B. Current Community Activities and Hopes for the Future**

Participants were asked about activities that they like to engage in currently, in their communities. Their responses can be grouped into social activities, including hobbies – "*I like to listen to music, watch tapes, and put models together*"; physical activities; community involvement; and learning opportunities. In terms of social activities, they mentioned fun with friends and family ("*I want to go back down to the country with my family*"); going to the movies, concerts or other events; going out for coffee and meals; shopping; attending church; and travel. References were made to varied physical activities such as bowling, swimming, baseball, curling, playing pool, walking, gardening, and camping. For some, the Special Olympics provide opportunities for physical activity as well as community involvement. Additionally, several people indicated an engagement in community activities including participation in community groups. A theme of helping people came out in reference to volunteer work, including being involved at church, the hospital, and selling tickets to events. Others indicated participation in learning opportunities such as pottery class, reading (library visits), and literacy classes.



Participants were then asked to imagine that they were currently retired and they were invited to identify activities in which they would like to engage. Not surprisingly, the categories were similar with social activities/hobbies, physical activities, community involvement, and learning opportunities. In addition, a few people mentioned relaxation. Within the categories, there was an emphasis on spending time with family and friends. More than half of all the activities mentioned fell in the social/hobbies category, acknowledging the availability of more time for personal pursuits such as listening to music, working on puzzles, shopping, visiting, and traveling. Reading and taking classes were also identified.

Finally, a clear theme was evident in community involvement – that of helping others: “[Homeless people need] *good family, to love them, to cherish them, to love. That’s why I want to do [work with homeless people]*”; *“I’d like to be doing more volunteering”*; and *“I would like to work [as a volunteer] with the soup kitchen over there in [town].”*

### **Discussion: Hopes for the Future**

Participants expressed their desire to have fundamental needs met in their retirement. They want to: (a) be part of their community with friends and family, (b) have meaningful activities, and (c) have income for other types of spending (beyond basic shelter needs), which offers choices. These wishes are consistent with what most people would like to see in their retirement, thus reinforcing the possibilities for integration of persons aging with developmental disabilities into existing community activities focused on retired persons. As Bigby (2004) notes in her research, aging persons with developmental disabilities want to remain active and engaged.

The results from this project also confirm previous research findings (Edgerton & Gaston, 1991; Factor, 1989, cited in Factor, Preston, & Conte-Ennis, 1997) that individuals with developmental disabilities are just as diverse as the general population with respect to their adaptation and adjustment to old age. As with all retired people, they differ in the recreation/leisure activities they choose, in the types and ages of people they want to mix with, and in their attitudes toward retirement. Comments from participants in the focus groups demonstrate a range of recreational, social, and community interests that speak to the need for a diverse range of options to be available to meet their expectations and to offer meaningful opportunities for community participation.

### **C. Access to Information**

How people access information is an important consideration for program and services planners in terms of preparing and distributing notices and materials. In the focus group, respondents were asked whom they would approach for information if they wanted to find out about a new activity. Participants were very specific in their responses, often naming an individual: *“I would say go to the right person and ask questions. Find out all you can about it.”* Generally, they indicated that they would ask someone they lived with, often a staff person or supervisor, the organizer of an activity whom they would call, vocational workshop staff, the Nova Scotia Seniors’ Secretariat, friends and family, and their advocate. When probed further as to how they would find out about something they wanted to do they indicated additional community contacts such as the library, a government source, the Internet, staff, a bulletin board, caseworkers, calling for information, and asking at

classes that are being attended (one example given was a night class on use of computers). One person offered a specific example: *“If I wanted to do yoga, I would check out with the lady that does the yoga. Call her up on the phone and find out what time’s her exercise.”*

### **Discussion: Access to Information**

Respondents tended to access information through the people with whom they live whether in a group home, small options home, or family home, or through professionals who work with them. They also utilize libraries and the Internet. They indicated a genuine willingness to seek information and would not hesitate in asking questions to find out what they wanted to know. This knowledge offers valuable information in the development of dissemination strategies for education about aging and retirement. It also reinforces the need for diverse messages and formats.

### **D. Key Messages for Retirement Service Providers**

Participants were asked what their most important message is for people who are planning services for retirement. This question posed some challenges; only a few of the participants responded with a message they wanted to share with planners. Many indicated that they did not have a message or did not know how to respond. Moreover, many directed their message at retired persons rather than the service providers: *“Live your life to the fullest. Do the things you want to do. Enjoy life.”* They encouraged retired people to relax and enjoy their retirement. However, those who responded indicated a need for providers to help people plan their retirements, *“Try to help the people retiring as much as they can.”* Reference was made to financial resources in retirement – the need to have information about income sources: *“Before they retire, or think of it, they should ask the government for a little bit of money first.”*

A few people asked that they be listened to and be asked for their feedback about retirement: *“If people listen to us more, they get more feedback”* and *“I’m asking the government to listen carefully to what we are saying.”* In the group where this comment was made, all participants expressed agreement with this message. Another person commented on the focus group session: *“We should have more, if only we could have more discussions like this, it would be a hundred per cent more better and we are sitting here listening to each other.”*

### **Discussion: Key Messages for Retirement Service Providers**

The predominant message that these respondents wanted to give retirement service providers is for the service providers to talk to and listen to them regarding their wishes for retirement. The second most common message is for service providers to help them plan for their retirement both socially and financially. The people in this project echoed the sentiments of those who attended the “Coming of Age: Securing Positive Futures for Seniors with Intellectual Disabilities” conference held in Winnipeg in 2004. These self-advocates told service providers that: “You have to listen to us... allow us to do what we want to do”, “Let us have choices!”, and “Don’t plan for me... I just want a life with support when and where I need it!” (Crawford, 2004, pp. 37 - 38).

The fact that many of the persons with developmental disabilities participating in the focus groups were not able to answer this question suggests two issues. First, in asking them for a message

addressed to program planners, the question may have been an unfamiliar format that gave them pause for thought. They may not have had the necessary skills, education, and/or life experience to frame a response to such a question in a short time period. Second, they may not have been provided in the past with enough opportunities to offer input and experiences to give them the confidence to give messages to service providers and planners. In other words, they may not have been given enough opportunities for self-determination in a system that plans for them. This highlights the importance of offering opportunities for input as well as support to participate in an environment that is familiar and comfortable to the participants.

# Section IV:

## Focus Groups - Service Providers

## Background

The primary goal in *The Next Stage* project is to link the aging and disability sectors in an effort to build capacity for responding to the emerging needs of persons with developmental disabilities who are approaching retirement. Planning for this retirement context in a manner that promotes social inclusion requires the participation of service planners and providers as well as policy makers. To this end, service providers (planners and policy makers) were included in focus groups in which they could share information about existing capacity as well as discuss components relevant to social inclusion. A key outcome of the service provider focus groups was this opportunity to bring people from both the aging and disability sectors together in a forum with a common purpose. The focus group agenda can be seen in Appendix D. Twenty-one service providers participated in two focus groups in Halifax and Sydney (one at each site). They represented agencies from both the aging and disability sectors, including advocacy groups, seniors' centres, recreation departments, vocational workshops, residential services, and churches.

The format for these focus groups was framed by portions of an Inclusion Lens document (Appendix E) developed by Malcolm Shookner and colleagues (Shookner & Social Inclusion Reference Group, 2002). The Inclusion Lens was designed as a tool for use in the in-depth analysis of elements of social inclusion (and exclusion) in policies and programs and it is contained in a workbook available on Health Canada's website (see reference list). Participants were provided with a copy of the Inclusion Lens workbook that was mailed out to them prior to the focus group. At the beginning of the focus group, an introduction to the Lens was provided. Prior to seeing it in conjunction with this project, most of the participants had no previous familiarity with the document. Participants used the questions related to social exclusion and inclusion to frame their discussion and created an inclusion template from the results. Three policy topics were identified for discussion during the focus group: housing, transportation, and recreation. These topics were identified by the Steering Committee as key policy areas with the potential for significant impact on the quality of the retirement experience. At the end of the focus group, participants developed an Inclusion Lens template for each of these three areas, summarizing the results of their discussions (Appendix F).

## Results

As indicated in the section above, the Inclusion Lens (Shookner & Social Inclusion Reference Group, 2002) framed the focus group discussions with the service providers. The primary focus of the discussion was social inclusion (exclusion) and the factors that mitigate this: *"If individuals have valid choices, then they're included. That's belonging, being valued and a sense of independence so that people have choice..."*. The need to have discussions between the aging and disability sectors to serve the needs of persons aging with developmental disability was acknowledged. One service provider focus group participant poignantly stated that: *"But just realizing that there's a real disconnect in our knowledge of the issues in need, and the way our populations are now being served. You know, we might have knowledge in our population of people but there's a real disconnect in what else is being done and what are their needs – cause we don't cross-sector often enough."*

The information obtained from the service provider focus groups is organized in the following tables that address the key policy areas of recreation, housing, and transportation respectively.

Tables 3, 4, and 5 list the key points of the discussion for each of the topics from the perspective of social exclusion and Tables 6, 7, and 8 illustrate the discussion for the topics from the perspective of social inclusion.

### Elements of Social Exclusion - Recreation

Table 3

<b>Sources of exclusion</b>	<ul style="list-style-type: none"> <li>• Seniors not a priority</li> <li>• Lack of funds and communication</li> <li>• Limited access to transportation</li> <li>• Society’s attitude toward people with disabilities</li> <li>• Lack of self-advocacy, sometimes due to illiteracy</li> <li>• Recreation not a priority for other service providers (e.g., transportation services may not prioritize recreation)</li> </ul>
<b>How current programs and policies promote exclusion</b>	<ul style="list-style-type: none"> <li>• Not being proactive or drawing in people</li> <li>• Not hiring staff to support people with disabilities who need help to participate</li> </ul>
<b>How exclusion impacts people</b>	<ul style="list-style-type: none"> <li>• Loneliness</li> <li>• Isolation</li> <li>• Boredom</li> <li>• Frustration</li> <li>• Loss of social skills</li> <li>• Passivity</li> <li>• Development of negative behaviors</li> <li>• Long-term health difficulties</li> <li>• Depression</li> <li>• Possible hospitalization</li> </ul>
<b>Costs of exclusion</b>	<ul style="list-style-type: none"> <li>• Increasing health care and social service costs borne by society as a whole</li> </ul>
<b>Who benefits from exclusion</b>	<ul style="list-style-type: none"> <li>• Nobody</li> </ul>
<b>Who has the responsibility to address sources of exclusion</b>	<ul style="list-style-type: none"> <li>• Politicians at all levels of government but everyone has some responsibility</li> </ul>

## Elements of Social Exclusion - Housing

Table 4

<b>Sources of exclusion</b>	<ul style="list-style-type: none"> <li>• Lack of knowledge</li> <li>• Lack of resources, especially funding</li> <li>• Programs not designed with the individual in mind</li> <li>• Bureaucracy</li> <li>• Limited housing options (increase in congregate living arrangements)</li> <li>• Housing stock not keeping up with needs of older adults</li> <li>• New homes built in suburbs (leads to isolation if transportation system inadequate)</li> </ul>
<b>How current programs and policies promote exclusion</b>	<ul style="list-style-type: none"> <li>• Practices of the past are not keeping up with future needs (e.g., housing needs of the past are not meeting the future needs)</li> </ul>
<b>How exclusion impacts people</b>	<ul style="list-style-type: none"> <li>• Decline in both physical and mental health and an acceptance that their situation is inevitable</li> <li>• Isolation, depression, boredom</li> </ul>
<b>Costs of exclusion</b>	<ul style="list-style-type: none"> <li>• A lack of healthy integration</li> <li>• Discrimination</li> </ul>
<b>Who benefits from exclusion</b>	<ul style="list-style-type: none"> <li>• Money may be saved in the short term by not adjusting programs to people and not trying to fit the people in but no one really benefits</li> </ul>
<b>Who has the responsibility to address sources of exclusion</b>	<ul style="list-style-type: none"> <li>• Everyone</li> </ul>

**Elements of Social Exclusion - Transportation**

Table 5

<p><b>Sources of exclusion</b></p>	<ul style="list-style-type: none"> <li>• Inflexible policies and programs (e.g., fixed criteria to access services)</li> <li>• Poverty</li> <li>• Lack of cross-sector planning</li> <li>• Lack of responsibility for ensuring physical accessibility (e.g., snow removal on sidewalks)</li> </ul>
<p><b>How current programs and policies promote exclusion</b></p>	<ul style="list-style-type: none"> <li>• Restricts participation in social and recreational activities, and in community life in general</li> <li>• Deters people from retiring for fear of being stuck at home with no social contact</li> </ul>
<p><b>How exclusion impacts people</b></p>	<ul style="list-style-type: none"> <li>• Isolation</li> <li>• Loss of skills</li> <li>• Loss of social contacts</li> <li>• Loss of identity</li> <li>• Loss of independence</li> <li>• Loss of opportunities upon retirement</li> <li>• Pressure on families</li> <li>• Decrease in physical and mental health</li> <li>• Depression</li> <li>• Feelings of helplessness</li> <li>• Early admission to assisted care</li> </ul>
<p><b>Costs of exclusion</b></p>	<ul style="list-style-type: none"> <li>• Increased costs to society borne by everyone, including the next generation</li> </ul>
<p><b>Who benefits from exclusion</b></p>	<ul style="list-style-type: none"> <li>• No one benefits in the long term</li> </ul>
<p><b>Who has the responsibility to address sources of exclusion</b></p>	<ul style="list-style-type: none"> <li>• Everyone: all levels of government, community advocacy groups, self-advocates</li> </ul>



## Elements of Social Inclusion - Recreation

Table 6

<b>Sources of inclusion</b>	<ul style="list-style-type: none"> <li>• Accessible programs</li> <li>• Healthy lifestyle programs</li> <li>• Human Rights organizations</li> <li>• Inclusion training programs</li> </ul>
<b>How current programs and policies promote inclusion</b>	<ul style="list-style-type: none"> <li>• Current programs and policies have limited impact on promoting inclusion except financial assistance policies to enable recreation participation</li> </ul>
<b>Measures of inclusion</b>	<ul style="list-style-type: none"> <li>• Feedback from persons with developmental disabilities about access and enjoyment</li> <li>• Increase in participation levels</li> <li>• Public recognition of existing programs, promoting practice</li> <li>• Increase in quality and quantity of inclusive programs</li> </ul>
<b>Who benefits from inclusion</b>	<ul style="list-style-type: none"> <li>• Everyone, especially persons with developmental disabilities and their families</li> </ul>
<b>Who needs to be involved in solution</b>	<ul style="list-style-type: none"> <li>• Recreation service providers</li> <li>• Family and caregivers</li> <li>• Persons with developmental disabilities</li> <li>• Government and policy makers</li> <li>• Educational institutions to teach young people about the benefits of inclusive recreation</li> <li>• Community groups</li> </ul>
<b>Processes needed to make solutions work</b>	<ul style="list-style-type: none"> <li>• Partnerships</li> <li>• Referrals</li> <li>• Collaborations</li> <li>• Resource sharing</li> <li>• Discussion with persons with developmental disabilities</li> <li>• Leadership with vision</li> <li>• Communication system</li> </ul>

**Desired outcomes of inclusion**

- *For the individual:* increased participation, increase in quality of life, health and wellness, positive energy, sense of belonging, and more opportunities to contribute to society
- *For society:* improved communication among/between organizations in different sectors, more diverse communities where people with disabilities are valued, government programs and policies that are participant centered and effective, equality and availability of services

## Elements of Social Inclusion - Housing

Table 7

<b>Sources of inclusion</b>	<ul style="list-style-type: none"> <li>• Flexible eligibility around age for services</li> <li>• Recognition of equal rights, respecting diverse abilities</li> <li>• Equitable pay and increased program funding to attract more trained staff</li> <li>• Aging policies for housing with funding to develop options and ensure access</li> <li>• Housing funding to individuals and their families for renovations to improve access</li> </ul>
<b>How current programs and policies promote inclusion</b>	<ul style="list-style-type: none"> <li>• The provincial Department of Health's Self-Managed Care program by assisting people to age in place</li> <li>• Willingness of provincial Department of Community Services to achieve inclusion</li> <li>• Cultural sensitivity programs through education</li> </ul>
<b>Measures of inclusion</b>	<ul style="list-style-type: none"> <li>• Individual awareness of community activities and access to their activities of choice</li> <li>• Individuals answer positively about their life reality</li> <li>• The availability of funding for promoting inclusion</li> </ul>
<b>Who benefits from inclusion</b>	<ul style="list-style-type: none"> <li>• All lives are enriched with a greater view of reality</li> </ul>
<b>Who needs to be involved in solution</b>	<ul style="list-style-type: none"> <li>• Everyone needs to take ownership at all levels: policy makers, families/caregivers, persons with developmental disabilities, service providers</li> </ul>
<b>Processes needed to make solutions work</b>	<ul style="list-style-type: none"> <li>• Focus groups with service providers, persons with developmental disabilities, and other interest groups to identify the needs</li> </ul>
<b>Desired outcomes of inclusion</b>	<ul style="list-style-type: none"> <li>• <i>For the individual:</i> appropriate, affordable and accessible housing available based on needs, richer quality of life, greater health and well-being, sense of belonging in community, and an awareness of resources available to them</li> <li>• <i>For society:</i> policies, programs, practices, and legislation designed and implemented to improve accessibility, and increased cross-sector planning and cooperation</li> </ul>

## Elements of Social Inclusion - Transportation

Table 8

Sources of inclusion	<ul style="list-style-type: none"> <li>• Vision is necessary as well as a mandate for an inclusive transportation system</li> <li>• A policy whereby all newly purchased vehicles are accessible to all</li> <li>• Flexible schedules for accessible and regular buses</li> <li>• A greater number of accessible buses</li> </ul>
How current programs and policies promote inclusion	<ul style="list-style-type: none"> <li>• Community-based committee is working for change</li> </ul>
Measures of inclusion	<ul style="list-style-type: none"> <li>• Individuals have transportation choices</li> <li>• More diverse transportation system</li> <li>• Greater visibility of people with developmental disabilities in the community</li> </ul>
Who benefits from inclusion	<ul style="list-style-type: none"> <li>• Everybody</li> </ul>
Who needs to be involved in solution	<ul style="list-style-type: none"> <li>• Persons with developmental disabilities, policy makers, transportation service providers, families/caregivers</li> </ul>
Processes needed to make solutions work	<ul style="list-style-type: none"> <li>• Cross-sector collaboration, cooperation, communication, understanding led by persons with developmental disabilities for more effective use of funding</li> <li>• Sensitivity training for service providers</li> <li>• Investing more money</li> </ul>
Desired outcomes of inclusion	<ul style="list-style-type: none"> <li>• <i>For the individual:</i> independence and freedom, increased confidence and well-being, better quality of life, greater sense of belonging as a result of being able to contribute to community, and lifestyle continuity</li> <li>• <i>For society:</i> healthy, inclusive communities</li> </ul>

### Discussion: Social Inclusion in the Areas of Recreation, Housing, and Transportation

Although the three policy topic areas of housing, recreation, and transportation were chosen specifically in the context of this project, these three topics also represent issues that affect all seniors regardless of ability. The Nova Scotia Seniors' Secretariat, in its *Strategy for Positive Aging in Nova Scotia* (2005) document states:

[In addition to adequate income] seniors must also have appropriate and affordable housing, and support services that meet their needs. To access services and

participate in their community, they need affordable and accessible transportation.  
(p. 11)

As can be seen from the results, policies and practices in the areas of recreation, housing, and transportation are exclusionary to varying degrees to older adults with developmental disabilities. In addition, each area cannot be looked at in isolation as each impacts another; it is not enough for one area to eliminate exclusion, all areas must do this for social inclusion to be achieved. As the Nova Scotia Seniors' Secretariat (2005) stresses, by creating a greater understanding of aging issues and by developing more positive attitudes toward seniors, the province will be better able to ensure that "affordable housing and transportation are accessible, safe, and provide services that meet varying ability levels and care needs" and "communities throughout Nova Scotia encourage the full participation of seniors" (p. 63). The Nova Scotia Seniors' Secretariat also notes that when housing is affordable and appropriate, seniors are more likely to remain healthy and independent, and that transportation is vital to ensuring seniors maintain a high quality and quantity of life. Recreation activities, in turn, allow for the continuation, expansion, and development of formal and informal social networks.

All of the service providers agreed that exclusion from these areas impacts people negatively, which in turn increases health and social service costs that the whole of society bears. The general sources of exclusion or, in other words, the barriers to social inclusion identified by the service providers in the two focus groups are similar to those identified in the interview data:

- lack of funds, knowledge, and support staff
- society's attitude toward people with disabilities
- lack of self-advocacy
- reactive, limited and inflexible policies and programs not designed with the individual and other services in mind
- lack of cross-sector planning and communication

The enablers to social inclusion given were:

- flexible age criteria for program eligibility
- recognition of equal rights no matter the disability
- adequate funding to hire and train knowledgeable support staff
- inclusive policies that ensure access for all
- proactive and flexible programs that put the individual at the center

The results show consensus in the belief that persons with developmental disabilities, families/caregivers, service providers, policy makers, educators, and community groups all need to be involved in the achievement of social inclusion. Similarly there was general agreement that the processes needed for social inclusion should include:

- cross-sector partnerships and collaborations
- resource sharing

- focus groups and discussions with persons with developmental disabilities and service providers
- visionary leadership that ensures inclusive policies are put into practice
- sensitivity training

The service providers indicated that the solutions for the social inclusion of older adults with developmental disabilities lie in many areas and that there is a wide net of responsibility to have social inclusion occur. At the end of the sessions, they created an Inclusion Lens profile incorporating the key points of their discussions. As stated earlier, the Lens for each of the three topics (housing, transportation and recreation) can be seen in Appendix F.

# Section V: Additional Themes

The first part of this report (sections II, III, and IV) is organized according to specific topics that were the foundation of the focus group and interview discussion guides. Thorough consideration of the interview and focus group data revealed that other themes emerged that encompass both systemic and individual issues. These themes offer important contexts for both understanding the issue of retirement planning for older adults with developmental disabilities and for underpinning the recommendations. In this section, these themes are briefly presented and the results and discussion of these themes are combined. These additional themes also suggest topics for further exploration.

## **Additional Themes: Interviews**

The themes of education, advocacy, valuing of contributions, continuity of service throughout the life course, and age eligibility criteria emerged in the interviews with service providers and decision-makers. These themes are salient to the concepts of social inclusion and citizenship:

The concept of citizenship is central to disability issues. Citizenship is the inclusion of persons with disabilities in all aspects of Canadian society – the ability of a person to be actively involved with their community. Full citizenship depends on equality, inclusion, rights and responsibilities, and empowerment and participation.  
(Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000, p. 7)

## **Education**

Many of the responses indicated the need for more education about aging with developmental disabilities as well as retirement planning. *“If you think of enablers, education is key, we need to be out there advocating and education people about what this population is about and how do we enable them to be part of the community”* (Disability sector). This education was needed by a diverse range of groups and individuals including the medical community, the general public, service providers, and policy makers in both the aging and disability sectors, and individuals and families.

*Medical community:* Service providers indicated that more knowledge was needed by the medical community to adequately respond to the changing needs of the population of persons aging with developmental disability. This need is recognized in the literature. To effectively provide support to this emergent population, Doka and Lavin (2003) stress the need for gerontologists and specialists within the field of developmental disabilities to have training and education about the population’s characteristics and needs, and for the needs of older persons with developmental disabilities to become a research priority. Likewise the National Advisory Council on Aging (2004) points out that there are few specialists with expertise in both developmental disability and psychogeriatrics. In addition, a 2005 project conducted by the USA Special Olympics found that physicians, dentists, and other health professionals do not receive adequate training to treat people with developmental disabilities at any age (Special Olympics, 2005).



*General public:* One of the barriers to social inclusion identified in the interviews was the existing negative attitudes of mainstream populations. Negative attitudes limit all members of society because they do not recognize potential and opportunity. There is a need to offer education that will challenge these images and attitudes. Attitudes that only see persons with disabilities as needing care have meant that interventions and support have been the major focus throughout adult life at the expense of personal development, growth, and capacity building (Llewellyn, Balandin, Dew, & McConnell, 2004).

*Aging sector:* Service providers in this sector require more education on how to make their organizations inclusive, including a greater understanding of the abilities and potential support needs of persons aging with developmental disabilities. Some help with this has recently become available. For example, the Nova Scotia Association for Community Living (McCallum, 2006) produced a new resource, *Belonging: Giving Value to Every Person: A Guide for Communities*, that offers guidance to communities, organizations, and individuals who want to become more inclusive. In addition, the aging sector requires information about healthy aging and age-related challenges for people living with various developmental challenges.

*Disability sector:* Aging with developmental disabilities is a relatively new issue for the disability sector, and they are challenged with adapting their services, policies, and programs to meet the changing needs. Some respondents in this project indicated that their organizations were beginning to consider what is needed but it is still a future activity. Some of the service responses are “just in time” to meet the changing needs of their current populations for aging persons. According to Bigby (2004), a lack of training and expertise with respect to aging with developmental disability has been identified by the disability sectors of many western countries but they have neither developed systematic partnerships with the aging sector to make use of its expertise, nor have they organized specialized training in this area. For example, as the Persons with Developmental Disabilities Calgary Region Community Board Advisory Committee found, training does not always prepare staff in the disability sector to recognize the indications of aging in this population (Biersdorff, 2000). Instead, the signs may be interpreted in other ways; for example, hearing and vision loss can present as behavioral changes. According to Biersdorff (2000), it is important for there to be “... service providers who are knowledgeable about the aging process as it affects people with developmental disabilities and who know how to secure supports from the relevant systems” (Knowledge of needs and supports, para. 1). She notes though that many service providers do not have this knowledge due to the high staff turnover in the disability sector.

*Individuals and families:* Persons with developmental disabilities described a network of contacts to whom they would turn for information. This network could also be a conduit for educational initiatives. For example, persons with developmental disabilities and their friends and families need information on aging processes, healthy aging, and retirement planning. In particular, people indicated that they had little access to financial information that could help them plan for the future.

To summarize, a broad spectrum of educational options is required for policy makers, service providers, the general public as well as persons with developmental disabilities and families. A variety of educational formats would be needed to meet diverse needs. As Rogers et al. (1998) indicate, such education is required to bring the lifestyles of older adults with developmental disability closer to the “commonly held views of retirement” (p. 129).

### **Advocacy**

Respondents spoke of the need for effective advocacy, including self-advocacy, recognizing the role it has played for many years in advancing the rights and freedoms of people with disabilities. Advocacy initiatives have led to changes but currently more advocacy groups are needed to stimulate action.

Also, more opportunities need to be created to hear the voices of people with developmental disabilities, to hear their opinions and wishes. Participants also spoke of a leadership role for the sector as advocates: “*The pressure on government is not as sustained as it used to be, until that pressure gets there, they won’t respond appropriately*” (Disability sector). According to Cohen (2004), it is necessary to re-educate “... advocates and advocacy, particularly in terms of more critical thinking about time frames for change and undertaking planning and advocacy strategies that go well beyond the customary political periodicity of two, four and six years” (p. 11).

### **Valuing Contributions (Recognition of Varying Abilities)**

Fundamental to social inclusion is the need to value people and their contributions to society: “*People don’t see people with disabilities as valued. In order to do that ... you need to put people in a valued position before their disability disappears*” (Disability sector). Documents like *In Unison* (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2002) describe basic Canadian values of inclusion for all and the opportunity, through appropriate supports, for all people to be full citizens. Achieving this requires multi-sector collaboration as well as explicit valuing of all people. As indicated in the report:

Citizenship for people with disabilities depends on having the supports necessary to take part in work and community activities. It also depends on having access to public and private facilities and to decision-making processes. (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000, p. 6)

Traditional approaches to aging people with disabilities have been to treat them as “... vulnerable, non-productive adults requiring care” (Sutton, Sterns, & Park, 1993, cited in Llewellyn et al., 2004, p. 367). Groups become marginalized when the focus is on protection and care because their members, even those who have contributed through employment, tend to be viewed as dependent and not able to contribute to society (Llewellyn, Dew, & Gorman, 2003, cited in Llewellyn et al., 2004). There needs to be greater understanding of the range of abilities of people with disabilities so that their potential to contribute to and use societal resources in their retirement years is recognized and planned for. Moreover, their contributions need to be valued. With this in mind there needs to be a range or continuum of services to support diverse abilities.

## **Continuity of Service Through the Life Course**

Government departments and community agencies in both the aging and disability sectors need to find new ways to work together to ensure continuity in each stage of the life course through appropriate planning: *“To include all types of services through the lifecycle, getting more cooperation between the departments of education, community services, and health to provide that continuity, I think that would make a big deal”* (Disability sector). According to Llewellyn et al. (2004) and Doka and Lavin (2003), pre-retirement planning is central to retirement and productive, healthy aging because it can help avoid being at risk of financial hardship and social exclusion during the retirement years. Therefore, according to Llewellyn et al. (2004), it is paramount to find opportunities to recognize and build on existing individual capabilities and foster new ones well before retirement arrives. For example, leisure participation can begin very early in the planning process if it is not already integral to an individual’s life, as it provides meaningful retirement activities, creates alternative opportunities to socialize, maximizes skill maintenance and growth, and maintains and improves health and physical well-being.

The need to address various aspects of retirement has been identified in recent years by some retirement planners. An emerging trend in the field of retirement planning is the concept of “life planning” (Anthes & Lee, 2001). In life planning, individuals are encouraged to approach retirement not only from a financial standpoint, but also a holistic standpoint that takes into account other aspects of the retirement experience such as leisure, identity, and relationships. As well, life planning, which is intended to be self-directed and intentional, starts early in individuals’ lives.

In particular, older adults with developmental disability need assistance as they move into retirement (Rogers et al., 1998). For example, they may need help in exploring the possibilities of different kinds of “work”, recognizing that volunteer work can be a part of retirement. To enable persons with developmental disabilities to effectively plan for retirement, vocational workshops and community employers need to offer transition planning workshops that consciously assist people with developmental disabilities to cope with and adapt to change (Doka & Lavin, 2003).

## **Age Eligibility Criteria**

Chronological age is often used as an indicator of eligibility for programs and services. How does this criterion affect persons aging with developmental disability? One respondent said: *“From a chronological age point of view, 65 and above is senior, and when you ask if there are any programs... I think people would have a good understanding if they knew what is normal aging for a person with a developmental disability. Age shouldn’t be the indicator”* (Disability sector).

It would be more useful to look at a person’s functionality rather than their age to determine eligibility for programs and services. This would ensure that these are more closely aligned with need. For some people with developmental disabilities, age-related changes (such as reduced stamina, increase in health problems and/or early stages of dementia) may appear earlier than in the general population. For example, some persons may experience changes even as early as their forties. As age-related changes for the general population are usually thought to occur well after

sixty or older, generic seniors' services, including social and health programs and services offered by federal, provincial, and municipal government, "do not always recognize middle-age people with developmental disabilities as fitting their service criteria" (Biersdorff, 2000, Characteristics and Needs of Older Individuals, para. 1). According to Doka and Lavin (2003), arbitrary ages of sixty-two or sixty-five are often used as benchmarks to determine eligibility for particular services, such as social security programs. These eligibility parameters do not reflect function or need. This is problematic for some individuals aging with developmental disabilities because they may need such entitlements earlier in life due to an accelerated aging process. Because of their health needs, people may have to access services designed for a much older population rather than services that would support their interests.

## **Additional Themes: Focus Groups - Persons with Developmental Disabilities**

In the focus groups with persons with developmental disabilities, salient themes of centrality of service providers in their lives, the meaning of work and retirement, retirement funding, and interest in computers emerged.

### **Centrality of Service Providers**

According to the National Advisory Council on Aging (2004) persons with developmental disabilities have few opportunities to make decisions for themselves. As a result of this lack of experience, even those who do have the capacity for self-determination may become unnecessarily dependent on others and not reach their full potential. As an illustration of this, Rogers et al. (1998) found that few opportunities were given to individuals with intellectual disabilities to freely choose leisure activities and that leisure choices were controlled by the care providers. Decisions were based on group management rather than individual needs, often because of limited staffing and transportation. It was evident in the responses from our participants in the focus groups that they relied primarily on support persons for information about new opportunities and events: "*Oh, I would ask somebody at the Centre where I work for information, if I want something, or I would ask someone from home.*" Therefore, it can be surmised that the openness or willingness of support staff and/or family members can be a key element in the range of opportunities that open for persons with developmental disabilities in their retirement. In other words, social inclusion is a value and concept that needs to be embraced by support staff and families, as well as the individuals themselves.

### **Meaning of Work and Retirement**

For many adults with developmental disabilities, as is the case for the general population, employment represents an important source of social support and interaction. It can often define a person's identity; it is a way to feel productive and useful and to maintain social contact which affects life satisfaction. Moreover, it offers routine to the day, which is important to people with developmental disabilities. If a person's identity is strongly connected to their job, however, such as in the case of individuals experiencing retirement as an "imposed disruption" (Hornstein & Wapner, 1985), the retirement transition may be especially difficult. Retirement for everyone, including people with developmental disabilities, according to Sterns, Kennedy, Sed, and Heller

(2000), "... causes a rift in one's social identity by changing the nature of one's role in society. It represents a transition to another phase of one's life, which one may or may not be completely prepared to make" (p. 182). Moreover, it may eliminate the main source of positive social interactions. As a result, some people prefer to continue working for as long as possible. In this project, participants were not specifically asked about the meaning of work to them; however, the salience of work in their lives emerged in their comments. Some commented on the need for choice: *"There's a lot of people that don't want to work at that age. Some people want to work [at] that age. It should be totally up to yourself if you want to work."* The meaning of work for individuals and how that affects their experience of retirement would be an important area for further exploration.

### **Retirement Funding**

Participants expressed realistic concerns about how their retirement will be funded: *"If a person went on their retirement, where are they going to get their money?"* The people involved in the focus groups participated in workplace settings where they did not have access to work pensions. This is very common in the lives of persons with developmental disabilities who, when working, are more likely to participate in work situations such as vocational settings or part-time entry level positions without pension opportunities. Evident also was a need for information about funding options available in retirement. This is consistent with the general seniors' population in which often people are not fully aware of their options. This is an area where agencies and service providers can offer joint education.

Lack of financial awareness regarding retirement planning is a concern for all individuals. It is possible that retirement planning information sessions for the general population may be opportunities for persons with disabilities to participate. However, differences in workplace participation must always be kept in mind because, of the three components of the public pension system – Canada Pension Plan (CPP), Old Age Security (OAS) and Guaranteed Income Supplement (GIS), older adults with developmental disabilities are least likely to have made CPP contributions during their working life. Nonetheless, there may be similarities between the groups in their need for information because of the centrality of the public pension system in most seniors' lives. Only 40% of the general population is covered by a private plan (Statistics Canada, 2003), therefore the public pension system is extremely important to most older adults, regardless of the presence of a disability. In addition, a lack of funding and/or difficulty understanding where funding comes from means that many older people with developmental disabilities are unable to access the resources to enable them to choose how to spend their time. Although the issue of retirement funding is not a central focus of this project, it is important to mention because it clearly emerged in the focus groups as a concern. Adequate funding offers choices across a range of options for housing, transportation, and recreation and as such, must be considered within the retirement transition planning process.

### **Interest in Computers**

A few participants in the focus groups expressed an interest in using computers and some were already doing so or in the process of learning. One person commented: "... [the teacher] *shows us*

*how to do our things on a computer, like reading and writing. I find it really interesting. Some of us are going to take it up soon, when we get help to learn how to use the computer there.*” In the community, computer education sessions are often offered to older adults and these often begin with very basic information. Moreover, the reasons that retired older people, with or without developmental disabilities, would use computers could be different than those who are in the workplace. This means that the needs of seniors may be more closely aligned in terms of motivations for learning about computers than in other age groups where it may be an essential part of the workplace and tied to specific activities. This is another area where there is potential for integration within existing programs.

## **Additional Themes: Focus Groups - Service Providers**

In the focus groups with service providers, strong themes of cross-sector collaboration and leadership emerged.

### **Cross-sector Collaboration**

As is evident throughout this report, there is a need for the disability sector and the generic aging sector to build system-wide, collaborative relationships to foster social inclusion. One participant said: *“There’s a lack of cross-sector planning. You know, we have many different groups here that have a lot of the same issues and if we all got together...”*. Effective solutions to meeting changing needs in communities lie in building on existing capacity – not creating new parallel sectors. Cross-sector partnerships and collaborations help members of the different sectors identify their roles in meeting the diverse needs of individuals (Biersdorff, 2000). This is congruent with the Nova Scotia Seniors’ Secretariat’s (2005) supportive communities’ goal to:

Encourage and facilitate participation in leisure, active living, social and cultural events for seniors by *identifying opportunities for community-based partnerships and maximizing the use of public facilities*, especially in rural communities [emphasis added]. (p. 60)

To build bridges and work together effectively, the Huron Trillium Partnership’s *New Challenges Handbook for Managers and Planners on Aging and Developmental Disabilities in Huron County* (2005) says that the aging sector needs to share its knowledge about aging so that the developmental disability sector can support people to age in place, and likewise, the disability sector needs to share its knowledge about developmental disabilities with the aging sector so the aging sector can support people who enter its programs and services. Respondents in the interviews and focus groups frequently referenced the need for collaboration.

### **Leadership**

Although it is recognized that there is a wide net of responsibility to implement solutions, the questions arise: Who will take the lead to make things happen? How will the knowledge that each sector requires be transferred, translated, and brought from the front-line care providers to the decision-makers? In both the focus groups and the interviews, service provider respondents indicated that leadership within both the aging and disability sectors, led by those who use the

services, is necessary to effect change and ensure responsiveness. A participant indicated: “... *where if we all come around the table together, then we could probably come up with solutions to these things, it would be much different than how [service] would think of it*”. Leadership can be formal in nature through agencies and organizations or it can be informal in the sense of community “champions”. Leadership must fundamentally embrace the value of full citizenship for all to achieve social inclusion. To ensure the development and implementation of comprehensive policies, it will be necessary, according to Bigby (2004), for one of the sectors to: “... take the initiative in tackling cross-sectoral boundary issues and ensuring the specific needs of this group [older adults with developmental disabilities] are adequately represented in the relevant service systems” (p. 254). Bigby suggests that the disability sector should adopt this leadership/advocacy role due to the inclusive focus of much of its policy and services. She asserts that in this way, through external advocacy, the needs of older adults with developmental disabilities are less likely to be overlooked or lost among competing demands.

## **Summary of Additional Themes**

In summary, the additional themes emerging from the interviews as well as persons with developmental disabilities and service provider focus groups are:

- 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

These themes are interconnected in that change in one area will foster change in another. They display a triangulation of perspectives that offer a sound base for recommendations and future initiatives. Translating the messages in the themes into action offers myriad opportunities for 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.

# Section VI: Recommendations



The goal of *The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* is to build links between the aging and disability sectors to foster and support the development of inclusive social policy to promote healthy aging and community participation for persons aging with developmental disabilities. This section proposes recommendations to help achieve that goal.

It is important to note that these recommendations are interim recommendations based on the themes emerging from the focus groups and interviews. As the various phases of the project are completed, new information may emerge that will set the priorities and directions for the recommendations that are contained in the final report.

## Key Messages

The most important message gleaned from the input of all participants 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. First and foremost, this knowledge segues into working towards full social inclusion. Another key message to emerge from the focus groups and interviews relates to the need for in-depth education to prepare organizations to respond to the growing population needs of aging persons with developmental disabilities who will be new retirees. Currently, there is willingness within the aging and disability sectors to respond to new needs but there are barriers that need to be addressed on both systemic and individual levels. Nevertheless, there are numerous enabling factors that can be drawn upon to build capacity.

The recommendations are organized into three sections that contain policy, practice, and education recommendations:

- A. Transition planning from work to retirement
- B. Building capacity within the aging and disability sectors
- C. Policy discussions

## Recommendations

### A. Transition Planning from Work to Retirement

#### Policy: Life Course Perspective

The basis for this perspective is the notion of continuity with the realization that aging is a lifelong process; the development of a healthy lifestyle and strong social networks earlier in life will impact the state of emotional and physical health and well-being of people as they begin to age (Bigby, 2004). The life course perspective recognizes that social determinants of health influence well-

being as well as considers how historical contexts may affect individual development. The choices that are available to individuals throughout their life, such as employment, have a profound influence on their retirement experiences in later years. The life course perspective has been particularly effective in looking at the effect of earlier life experiences on retirement for women (e.g., Berger & Denton, 2004; Moen, 1996), and this perspective can inform one's understanding of the retirement experience for other groups.

1. It is recommended that the Project Steering Committee identifies 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.

### **Practice: Pre-retirement Planning**

Successful pre-retirement planning should engage the community in meeting the needs of persons with developmental disabilities and as a result, it has to start very early when the worker is still active in the workforce (Llewellyn et al., 2004). This is consistent with the concept of “life planning” mentioned previously. It requires the efforts of several groups: “Researchers, employers, and employees with disabilities must work together to design, implement, and evaluate evidence-based workplace planning for healthy, productive post-retirement” (Llewellyn et al., 2004, pp. 368 - 369).

Although many individuals do not think about retirement planning until closer to the time (the “near phase”), retirement planning can begin much earlier (the “remote phase”), such as when a person begins her or his first job (Atchley, 1976). Workers with disabilities require either specific pre-retirement programs tailored to their needs (examples include the program created by Sutton, Heller, Sterns, Factor, & Miklos, 1994 or the one developed by Isfeld & Mahon, 1997) or support to access mainstream programs that are available in the community (Llewellyn et al., 2004). Specific pre-retirement program curricula could include such topics as “making choices, current and potential living arrangements, work options and roles, health and wellness, use of leisure time and recreation, use of informal and formal supports, setting goals, and making action plans” (Heller, Miller, Hsieh, & Sterns, 2000, p. 396). Transition plans could also draw on experience gained from some models in existence. In addition to the actual programs, opportunities need to be provided for transition training to cope with change.

Workplaces and residential homes are ideal settings for pre-retirement planning to take place. It will be necessary to develop models that utilize existing employee assistance programs and apply them to workers with developmental disabilities (Llewellyn et al., 2004). Government departments also must recognize that workers with a disability have the same right to access services as their peers without a disability (Llewellyn et al., 2004). Furthermore, retirement transition coordinators could act as facilitators for the individual and workplace or residence.

2. It is recommended that 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.

## Education: Transition Planning

Transition planning can strengthen the internal resources of older persons with developmental disabilities by giving them the skills to choose and evaluate choices. Planning for retirement then presents an opportunity for self-determination and with it the potential for self-advocacy. However, Sterns et al. (2000) and Rogers et al. (1998) stress that creating opportunities for self-determination is one of the biggest challenges facing those who work in the disability sector. Education is the bridge that spans the distance between the aging and disability sectors, offering a means to connect through sharing expertise.

3. It is recommended that 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. It is recommended that 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.

## B. Building Capacity Within the Aging and Disability Sectors

### Policy: Meeting Changing Needs

The process of retirement is different for each individual. In particular, for increasing numbers of individuals the process may involve “bridge jobs” and part-time work rather than an abrupt termination of full-time employment (Schellenberg, 1994). This varied process of retirement may also need to be applied to individuals with developmental disabilities. To allow people the opportunity to choose the type of retirement they would prefer, it is necessary for both residential and vocational disability service providers to offer the option of flexible, part-time working hours to some retirees who do not want to leave work completely. However, the disability sector may not be set up to accommodate such an option currently because for example, staffing at the residence may be an issue, as well as challenges with transportation from work to residence or recreational activity. In addition, other retirees may choose not to work but would still want the choice to remain at home during the day and choose the leisure and activities they wish to pursue either at home or in the community. Again, this option would require the service providers to offer that flexibility.

5. It is recommended that residential and vocational service providers review operations and programming policies to assess ability to meet the changing needs of aging people with developmental disabilities.

### Practice: Capacity

Although building capacity for inclusion of retired persons with developmental disabilities within communities by drawing on existing senior services is seen as an option to meet new needs, it does not necessarily follow that existing seniors’ programs are ready to respond. Aging and disability organizations that see themselves as offering inclusive opportunities in the community need to review all aspects of their programming to ensure that services are accessible and welcoming and

that appropriate support is available. Examples can be gleaned from cross-sector innovations such as seen in a partnership in Ontario between Midwestern Adult Day Centres and Huron County Associations for Community Living whereby protocols ensure access for older adults with developmental disability to the existing seniors' day program (Huron Trillium Partnership, 2005).

6. It is recommended that service providers, educators, and policy-makers, in consultation with advocacy organizations, hold strategic planning discussions to determine their organizations' abilities to respond to changing needs.
7. It is recommended that 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. It is recommended that 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. It is recommended that existing seniors' services, in collaboration with the disability sector, review their operations to assess their inclusiveness.
10. It is recommended that the disability services sector promote and seek opportunities for the participation of persons aging with developmental disability in generic community services.
11. It is recommended that 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.

### Education: Professional Development

Each sector embodies a wealth of knowledge about their client populations. An opportunity exists for the sectors to identify cross-sector educational sessions, drawing on each other's strengths.

12. It is recommended that cross-sector professional development opportunities be integrated into operational planning for services and programs.

## C. Policy Discussions

### Aging in Place

People aging with a developmental disability should have the same opportunity as other older people to "age in place" in their own homes if they choose to do so. Policies that support aging in place require clearly defined commitment and considerable forward planning to ensure that older adults can remain at home as long as possible (Bigby, 2004). As the Nova Scotia Seniors' Secretariat notes in its *Strategy for Positive Aging* (2005):

Aging in place promotes self-sufficiency, encourages interdependence between friends, family members and neighbours in the community, offsets social isolation and reduces the need for professional support. Maintaining friendships, familiar shopping, entertainment, and community supports enhance quality of life, personal control, and dignity. (p. 98) .... Aging in place requires coordination of policies and priorities *from a number of sectors*, while keeping in mind the fact that the

preferences and resources of older persons and their families vary considerably, as do the needs of particular communities [emphasis added]. (p. 105)

13. It is recommended that the Nova Scotia Seniors' Secretariat and the 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).

### Age Eligibility

Eligibility for services based on an age criterion may disadvantage older adults with developmental disabilities because some of them experience age-related changes at earlier ages than seen in the general population. To determine the impact of age criteria, an assessment of some existing policies will help to inform the discussion.

14. It is recommended that during the Provincial Network meeting in November 2006, the following policy issues be discussed: aging in place and age eligibility criteria.

Implementation of these recommendations calls for innovative collaborative initiatives. *The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities* offers some beginning steps towards creating opportunities for ongoing dialogue.

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<sup>1</sup> This document can be found on the website: [http://socialunion.gc.ca/In\\_Unison2000/iu011100e.html](http://socialunion.gc.ca/In_Unison2000/iu011100e.html)



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<sup>2</sup> This document can be found on the website:  
[http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Inclusion\\_lens/index.html](http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Inclusion_lens/index.html)

# Appendices

## **Appendix A: Needs Assessment Method - Focus Groups and Interviews**

### **Identification of Participants**

Participants for the two service provider focus groups and the key informant interviews were purposively identified by the project's Steering Committee. People were identified and/or invited because of their knowledge of the field and the fact that they represented specific agencies/organizations that have a role to play in retirement planning.

For the three focus groups with persons with developmental disabilities, Steering Committee members identified specific residential and vocational agencies in Halifax, Kentville, and Sydney that could host the sessions and recruit participants. The Project Coordinator worked with these agencies to coordinate the focus groups.

### **Ethics Approval**

Ethics approval was received from the Nova Scotia Community College (NSCC) Research Ethics Board for the focus groups and interviews prior to the start of these activities.

### **Pilot Focus Group and Pilot Interviews**

A pilot focus group with three people with developmental disabilities and two pilot interviews with key informants took place in January, 2006.

#### *Pilot - Persons with Developmental Disabilities Focus Group*

Participants for the pilot focus group were invited by an advocacy organization and the pilot was conducted at the organization's site. The pilot was facilitated by the Project Coordinator and the Project Manager. A graduate student (associated with a project partner) was present to take notes; the pilot was not audio-taped. The participants were advised that this pilot focus group was for the purpose of testing questions. The focus group questions were posted on the wall as a visual aid. Participants also reviewed the plain language Project Information Sheet. They found it readable, clear and useful; they suggested distributing it in hard copy and they suggested a larger font size for the print. Pilot participants liked the informal seating arrangement (circle format) and the small group size. They felt that the questions were clear and understandable, and that it helped to have them posted on the wall as well as to hear them. From the facilitators' point of view, there was some lack of clarity in the wording of question seven; clarification was provided during the subsequent focus groups.

#### *Pilot - Key Informant Interviews*

The two pilot interviewees were invited by telephone to participate and information was emailed to them. The pilot interviews were held at the key informants' workplaces, each took about 50 minutes, and they were not audio-taped. Both interviewees felt that the schedule was progressive and logical. The only concern expressed related to question number four. One of the interviewees found it to be too broad and felt that it should refer to community activities rather than to the

community in general. However, in committee discussion, there was a decision to keep the question as is because the intent was to elicit broad information.

### **Focus Group Process - Persons with Developmental Disabilities**

Focus groups with persons who have developmental disabilities were held in March 2006 at three sites (one at each site): Halifax, Kentville, and Sydney. The Halifax group took place at a residential service provider's main office and the Kentville and Sydney groups took place at vocational service provider's sites. Service providers were either members of the Steering Committee or affiliated with the members. The focus group participants were recruited by the staff at each of the three sites. Twenty-nine persons with developmental disabilities were invited to participate and 28 accepted. Of the 28, there were 8 participants in Halifax, 9 in Kentville, and 11 in Sydney.

The Project Coordinator facilitated each focus group for consistency with the Project Manager being present for two groups. An agency staff person was also present during the focus groups at each location. The graduate student recorded notes on a laptop computer and audio-taped the sessions. Project Information Sheets written in plain language were available to the participants as were copies of the National Advisory Council on Aging's (NACA) 2004 publication, *Seniors on the Margins: Aging with a Developmental Disability*.

### **Focus Group Process - Service Providers**

Two service provider focus groups were held in Halifax and Sydney in March 2006. Both groups were held at the same sites that hosted the focus groups with persons with developmental disabilities.

Service provider participants were identified by the project Steering Committee, ensuring that a range of services and groups were represented from both the aging and disability sectors. Potential participants were sent an invitation letter with the Project Information Sheet enclosed. If the invitation was accepted, the person was sent a confirmation letter with additional information, including the Inclusion Lens Workbook (Appendix E). Thirty-three service providers were invited to participate and 26 accepted (13 from each sector). However, 5 service providers were unable to attend the focus groups leaving a total of 21 who actually participated (10 from the disability sector and 11 from the aging sector). The service providers represented agencies that included advocacy groups, seniors' centres, recreation departments, vocational workshops, residential services, and churches.

These focus groups were facilitated by the Project Coordinator and Project Manager. The discussion format for the focus groups was framed by portions of the Inclusion Lens document. Three policy topic areas were discussed during the focus group: housing, transportation, and recreation. These topics were identified by the Project Steering Committee as key policy areas with the potential for significant impact on the quality of the retirement experience. Participants used the exclusion and inclusion questions and the lens format from the Inclusion Lens workbook to frame their discussion.

A Project Information Sheet and a copy of the National Advisory Council on Aging's (NACA) 2004 publication, *Seniors on the Margins: Aging with a Developmental Disability*, were provided to each participant.

### **Key Informant Interview Process**

The Project Steering Committee and project staff identified potential interviewees from the aging and disability sectors. Potential interviewees were e-mailed a letter of invitation, followed by additional information when they indicated acceptance. Twenty-one key informants were invited to participate in the interview and 14 accepted (9 from the disability sector and 5 from the aging sector). Interviews were conducted at a location convenient to the interviewee and were audio-taped. Two interviews were conducted over the phone due to geographical considerations.

### **Analysis**

Data from the focus groups were transcribed verbatim whereas only key comments and phrases from the interviews were transcribed. 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, social inclusion factors from the Inclusion Lens (Shookner & Social Inclusion Reference Group, 2002) framed the interview schedule and were used to organize the results. Again, additional themes emerged. A thematic analysis identified commonalities from the interview and focus group data.

### **Limitations**

Participants with developmental disabilities were all identified by service agencies. This means that persons with developmental disabilities living in the community with family and not known to the service sector were not included in the focus groups. As well, the technique of focus groups allows only for a cross-sectional perspective and is not designed to elicit a longitudinal understanding of issues that have salience for the individual or obtain in-depth information from each respondent.

Participants in the focus group for persons with developmental disabilities were still employed at the time of the discussion so their perspective of retirement was shaped by their current life experience. It is possible that their views about retirement may change when they become retired.

## **Appendix B: Interview Schedule**

### Interview Questions

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

This project is funded by the Public Health Agency of Canada

#### Preamble

The purpose of the interviews is to gather in-depth information about the services and opportunities that are available to people aging with developmental disabilities. The purpose of the project is to build links between the disability and aging sectors to respond 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 have recognized 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.

- 1) Does your agency/group offer services or programs to retired people?
  - a. What types of services or programs do you offer?
  - b. Are the services you offer mandated for your organization?
  - c. Can you describe the population that you serve?
  - d. How many people have used these services in the past year?
  - e. Are there supports available to assist people when needed?
  
- 2) Does your agency/group offer services or programs to retired people with developmental disabilities?
  - a. What types of services or programs do you offer?
  - b. Are the services you offer mandated for your organization?
  - c. Can you describe the population that you serve?
  - d. How many people have used these services in the past year?
  - e. Are there supports available to assist people when needed?
  
- 3) If your agency or group does not provide services to retired people with developmental disabilities, have you ever been asked to do so?
  - a. How did your agency respond?
  - b. What factors did you consider in responding to the request?
  
- 4) What is available in your community for people, during their retirement years, who are aging with developmental disabilities?

- 5) In a perfect world, are there programs or services that you would like to see in place for persons aging with a developmental disability?
- 6) Have you had discussion within your agency/group about the types of services and programs that are needed as the population of persons aging with developmental disabilities grows? What prompted the discussion? What factors did you discuss?
- 7) Are the services and programs that are available in your community for the general population open to aging persons who have a developmental disability? Please describe.  
If yes, what contributes to their success?  
If no, what are the barriers?
- 8) Are the services and programs that are available in your community to those aging with developmental disabilities open to the general population?
- 9) Has social inclusion been achieved in your community?
  - a. What are the barriers?
  - b. What are the enablers?
- 10) How ready is your agency/group to respond to a growing population of persons aging with developmental disability?
- 11) Does your agency/group offer opportunities to people with disabilities to have input into the design or implementation of programs and services?
- 12) What would help your group/agency to be better prepared?
- 13) Do you have any comments that you would like to add?
- 14) As part of this project, we would like to develop a provincial network of people interested in this topic. Would you like to be part of the network? (contact information)
- 15) Is there anyone that you can think of that we should call to get their views on this topic?

## **Appendix C: Persons with Developmental Disabilities Focus Group Questions**



School of Health & Human Services

Questions for Focus Group Discussion

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

This project is funded by the Public Health Agency of Canada

Welcome participants

Introductions

Housekeeping details

Preamble:

The purpose of the focus groups is to gather information about retirement hopes and plans for the population of persons aging with developmental disabilities. This information would be shared with people who develop programs and policies. The project wants to build links between groups who offer services to seniors and groups who offer services to people with disabilities. There is very little information available directly from persons with developmental disabilities and people who offer services to them, about retirement. There are also very few connections between services for seniors and services for people with disabilities. The project will listen to the voices of people with disabilities to help understand what they would like to do when they get older and retire. The project will also listen to the voices of groups who provide services to seniors and to people with disabilities.

Questions for discussion:

1. Do you know people who are retired?
2. What do you think that retired people do?  
Probe: activities, relationships, volunteer work



3. When you hear the word “retirement”, what do you think of?  
Probe: not working, age, health, social interactions
4. What kinds of things do you like to do in your community now?
5. Let’s pretend that you are retired...
  - a. What are the kinds of things you would like to do?
  - b. Are there things that you are not doing now that you would like to do?
6. If you wanted to do something new, who would you ask for information about that activity?
  - a. How would you find out about something you wanted to do?
7. What is the most important message you want to give to people who are planning services for retirement?
8. Is there anything you would like to add?
  - a. Did you have a chance to say what you wanted to say in this group?  
Probe: Comfort with the group

Note to facilitators: Please plan to include refreshments either before or after the discussion. You could plan on 1.5 hours for discussion and .5 hour for refreshments.

## **Appendix D: Service Provider Focus Groups Discussion Guide**



School of Health & Human Services

### **The Next Stage: Retirement Planning for Older Adults with Developmental Disabilities Service Provider Focus Group Agenda**

1. Welcome and Introductions.
2. Explanation of the Inclusion Lens in relation to project and plan for the session.
3. Participants split up into three groups of four, and each group chooses one issue topic from: housing, recreation, transport.
4. Each group answers the exclusion questions on page 7 of the Inclusion Lens Workbook (documenting on flip chart) – 20 mins.
5. Joint discussion on the exclusion questions – 20 mins.
6. Each group answers the inclusion questions on pages 8 and 9 of the Inclusion Lens Workbook (documenting on flip chart) – 20 mins.
7. BREAK – 10 mins.
8. Joint discussion on the inclusion questions – 20 mins.
9. Each group completes the Inclusion Lens Template for their issue topic (documenting on flip chart) – 15 mins.
10. Joint discussion on the Inclusion Lens Templates – 25 mins.
11. Provincial Network Information.
12. Inclusion Lens Evaluation Questions.
13. Thank you.

## **Appendix E:**

### **An Inclusion Lens Workbook For Looking At Social And Economic Exclusion And Inclusion - Use For Service Provider Focus Groups**

To ensure the social and economic inclusion of individuals, families, and communities, it is necessary to examine legislation, policies, programs, and practices that exist within society. The Inclusion Lens Workbook is a tool that enables such an examination (Shookner & Social Inclusion Reference Group, 2002). It offers a way for policy makers, program managers, community leaders, and activists to begin to plan for inclusion by looking at the conditions that exclude people from participating fully in society and at the solutions that promote inclusion (Shookner & Social Inclusion Reference Group, 2002). For the purposes of this project, the focus is on *social* inclusion; economic inclusion is a topic for future exploration. The project, *The Next Step: Retirement Planning for Older Adults with Developmental Disabilities*, is concerned with the elements of social inclusion that impact retirement planning for older adults with developmental disabilities.

To create an Inclusion Lens (the dimensions of a Lens include cultural, economic, functional, participatory, physical, political, relational, and structural), the Workbook requires readers to answer questions about exclusion and inclusion, using a process that involves people who are excluded. For the focus groups in this project, the Workbook was used to guide discussion on three issues (recreation, housing, transportation) rather than to analyze a specific policy, program, or practice. Therefore, only specific components of the Workbook were utilized for the discussion in the service provider focus groups. Further, for the interviews, the topics contained in the Inclusion Lens Workbook provided the backdrop themes for the interview schedule. The Workbook provides an Inclusion Lens Template so that readers can create their own lens (p. 12 of the Workbook).

The Workbook also includes an Action Plan that was not utilized in the focus groups. This plan was not used because it is tailored to how a specific organization might create a plan for inclusion, rather than being intended for general discussion as seen in the focus groups. For example, key action plan considerations include defining: who is responsible, roles of partners, resources needed, and measures of progress.

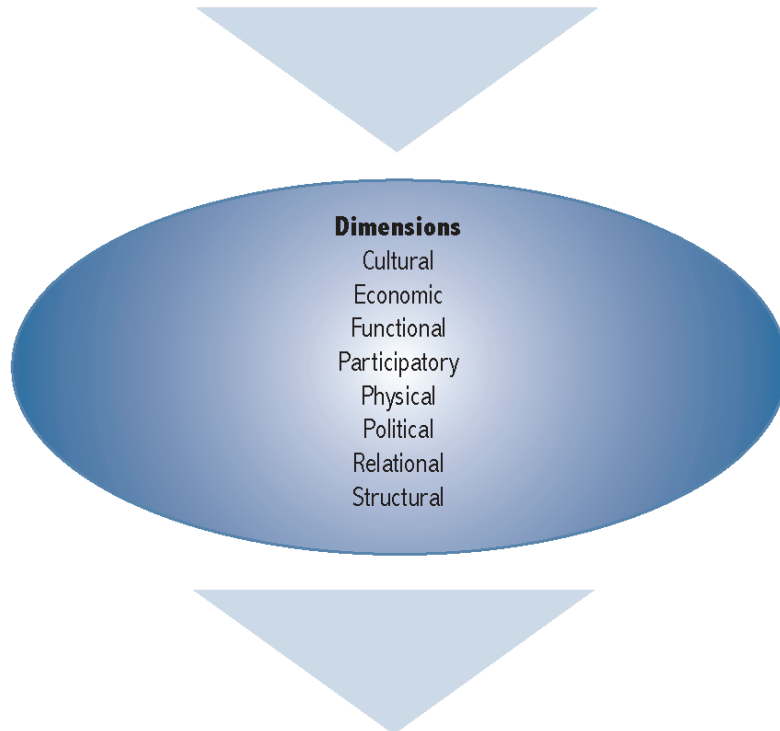
The Inclusion Lens Workbook can be found at the following website:  
[www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Inclusion\\_lens/index.html](http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Inclusion_lens/index.html)

**Appendix F:  
Service Provider Focus Groups' Inclusion Lens Templates Housing,  
Recreation, And Transportation**

# Housing

## Elements of EXCLUSION

Inadequate communication	No input from persons with developmental disabilities
Isolation	Restrictive policies
Limited resources	Lack of eligibility
Lack of affordable housing	Ableism
Barriers to access	Oppressive structure



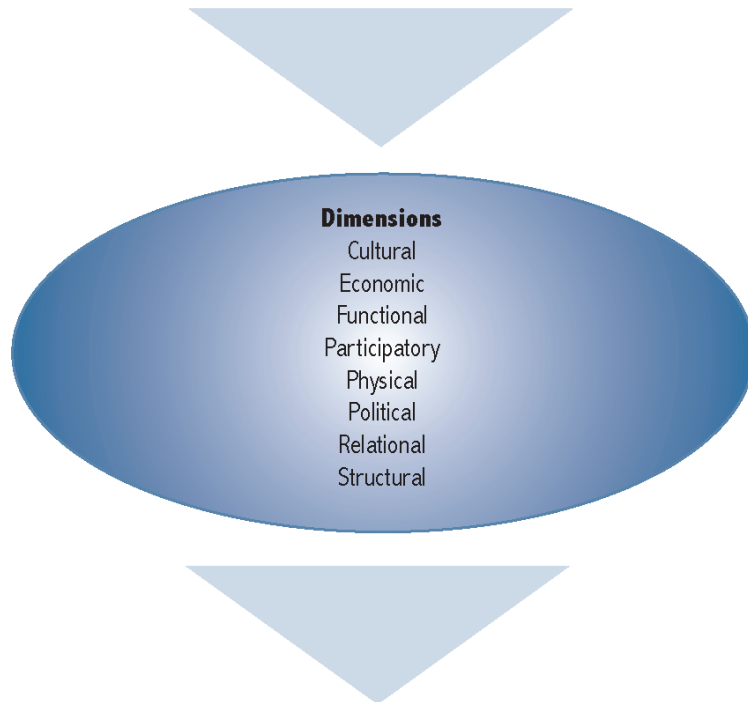
## Elements of INCLUSION

Acceptance of diversity	Public accessibility
Belonging to community	Persons with developmental disabilities involved in policy making
Adequate income	Flexible programs and policies
Funding for housing	Value-based education
More housing options	Recognition of varying abilities
Awareness of needs	

# Recreation

## Elements of EXCLUSION

Cultural deprivation (not on radar)	Lack of political will/voice
Poverty/lack of funds	Lack of policy development
Lack of appropriate supports	Programs unavailable
Lack of knowledge	Physical barriers
Lack of mobility	Mindset
Isolation	Illiteracy



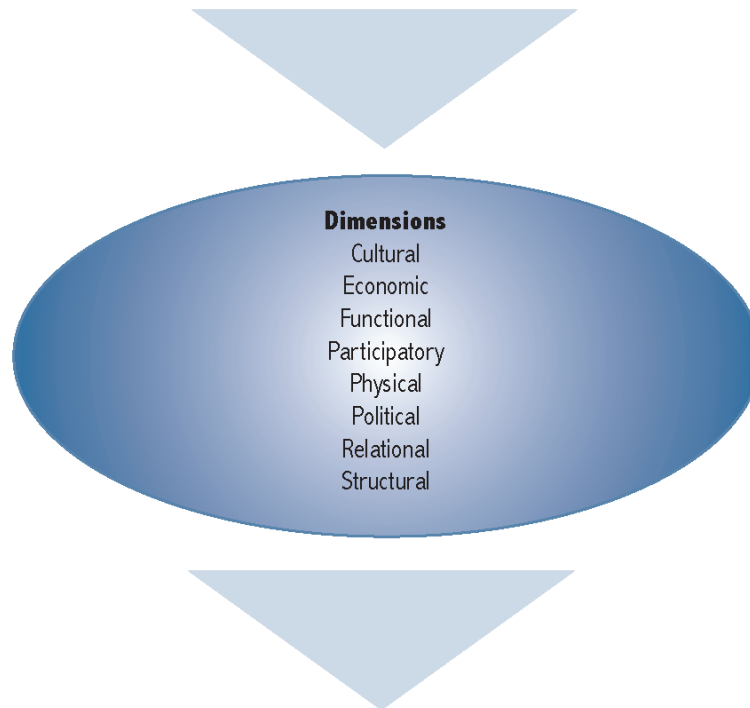
## Elements of INCLUSION

Acceptance and participation	Appropriate supports provided
Adequate funding and income	Policies and programs developed to include all
Accessible programs	Political will
Awareness	Literacy
Empowerment	Problem solving

# Transportation

## Elements of EXCLUSION

Funding and poverty	Isolation/segregation
Persons with developmental disabilities lack a voice	Physical barriers
Lack of accessible and affordable transport	No choices
Lack of collaboration	Restrictive policies and eligibility to programs
	Discrimination



## Elements of INCLUSION

Sustainable core funding	Access to choice of transportation resources
Persons with developmental disability involvement in all decisions	Inclusive policies-improve criteria for access
All new transportation purchases are adapted if not already accessible	Together
All municipalities mandated to provide accessible transportation	Empowerment-freedom to choose, to contribute to community, increase in friendships