The Canadian Centre on Disability Studies
Discussion Paper on
Seniors with Disabilities
for the Office of Disability Issues (ODI)
for their proposed
Advancing the Inclusion of Seniors with Disabilities Report

(Third edition to be published December 3, 2005)

Authors: Laurie Ringaert and Colleen Watters
Canadian Centre on Disability Studies

Submitted to ODI July 19, 2005

The Canadian Centre on Disability Studies Discussion Paper on Seniors with Disabilities for the Office of Disability Issues (ODI) For their proposed Advancing the Inclusion of Seniors with Disabilities Report

(Third edition to be published December 3, 2005)
Submitted July 19, 2005

Introduction

This discussion paper was prepared by the Canadian Centre on Disability Studies (CCDS) (Winnipeg, MB) and represents the incorporation of several documents into the Proposed Outline of the Advancing the Inclusion of Seniors with Disabilities. These documents included: a large concept paper on Aging and Disability (CCDS, June 17, 2005) commissioned by ODI, a short summary paper on Aging and Disability (CCDS, June 18, 2005) and an Executive Summary (June 19, 2005) commissioned by ODI and information from Draft Notes of a Round Table on Conceptualizing Disability held June 23, 2005 in Ottawa by ODI.

CCDS was asked to take the information and attempt to organize it into the draft outline categories that ODI had created for its proposed report. This paper deals with only Part 2 of the proposed report. CCDS understands that the information provided is suggestions for ODI to use in its report and this document does not represent ODI's final report. In some cases, information is lacking as these particular headings were not included in the original assignment given to CCDS (i.e.Chapter 7: Health and Well-Being and Chapter 6: Income). As well, some of the previous information that CCDS gathered is not included as it does not fall into the present outline. For instance, some information regarding current research and recommendations for research have been omitted as they did not fit into the outline. However, ODI has access to this information in the previous papers. This document also contains a comprehensive reference list. CCDS is pleased to have this opportunity to work with ODI to contribute to the forth coming document.

PART 2 – OUTCOMES AND INDICATORS FOR SENIORS WITH DISABILITIES

Chapter 4 –SENIORS WITH DISABILITIES

Who is the Population?

With our aging population, there are an increasing number of people who are aging into disability. At the same time, there are an increasing number of people with long-term disabilities who are aging due to better health and community supports. These two groups have remained distinct even though they share many commonalities. There is a distinction between Aging into Disability and Aging with a long-term disability in terms of time of acquiring the disability and in some cases, the type of disability. However in terms of functional outcomes and barriers and facilitators in the environment, many of the needs and gaps are similar. What is different is the length of time of acquiring the disability and the resultant skill development in living with the disability. For instance, those aging into disability could perhaps learn lessons from those who have lived a long time with a disability in terms of dealing with day to day life experiences.
The increasing demographic of an aging population is a well known trend across the country and internationally. What is not well recognized is the relationship to the aging population with respect to disability: both in terms of Aging into Disability and Aging with a Disability. While there has been a trend that "disability" and "aging" are two distinct areas of study and policy, the fact is that there is an overlap where many seniors have disabilities and many people with disabilities are aging. As we age, most of us will experience some type of disabling condition. The rate of disability increases to 10% among working-

age adults (aged 15 to 64). Seniors have the highest rate of disability in Canada-four times the rate of working-age adults and more than ten times the rate of children. More than three in ten younger seniors (aged 65 to 74) have disabilities, as do more than half of older seniors (75 and over).

At What Age are we Considered to be a Senior?

The question of the age for seniors has been a long term debate. The underlying premise is that there are formal and informal dimensions in defining this population. The formal one is related to governmental eligibility criteria and official age of retirement, while the other is generally linked to the social roles (regarding supports for example). For the purpose of eligibility to programs, the federal government has to use some form of categorization. Using the formal 65+ label is appropriate in this context, but it does not take into account the informal realities and different aging processes. A complete definition should include the informal dimension and consider seniors to be persons 55 years of age and over. For example, membership in some community seniors' organizations such as the Canadian Association of Retired Persons (CARP) is open to individuals 50 years of age and over. In many cases, those over the age of 55 are eligible for seniors housing facilities, and some Canadian banks have plans for seniors under the age of 65.
One view is to see aging a process or life journey rather than a point in time. Aging and disability can be seen as part of a life cycle journey, which begins at birth and ends at death. There are three dimensions of this process: the biological, chronological and social dimensions. "There is the need to see aging with a disability as a journey. Our present process makes it seem like a person mysteriously becomes older at some particular point in their life." (Hunsberger, 2005)

It is also crucial to recognize that seniors are not a homogeneous group and due to different aging experiences, it remains challenging to have an 'age threshold' defining when people become seniors. The key to defining who seniors are is really to understand how people define themselves.

Aging into Disability

It is well known that disability increases with age. There is a natural decline in all human functioning as the body ages. Some people will experience actual disability as a result of the aging process and some as a result of age-related disease and accidents. However, it must also be recognized that with increased personal health strategies (proper diet, fitness and activity programs, stress reduction), disability can also be lessened and in many countries people are living longer with less disability. Many countries are concerned about the economic burden and the public health and quality of life implications of an aging population that is becoming more disabled. A literature review showed references from Thailand, Sweden, United Kingdom, Germany, USA, Canada and others (see reference list). Although it has been recognized that changes in function and disability increase as we age, there is a need to address this topic in more detail. Worldwide, there is an acknowledgement of this topic and of its impending impact over the next several years. According to Guralnik, Fried, Salive (1996) as a greater proportion of the population survives to increasingly older ages, the public health impact of the burden of disease and disability and related utilization of medical care and need for supportive and long-term care has becomes an important concern. In particular, the ability of the older person to function independently in the community is a critically important public health issue.

Internationally it is recognized that the necessary changes have not taken place in the design of the built environment or in services to address these needs. There is also little epidemiological data on the development of disability over time in older persons. Ferrucci, Guralnik, Simonsick, Salive, Corti and Langlois (1996) Most of the studies that have occurred to date have dealt with medical aspects of aging and disability. Individuals may not always be prepared for the aging process. Research on safe driving differences among seniors with disabilities by Guerts, Shaw and Miller (2004, unpublished) noted that seniors ages 55-64 were not as well prepared for the changes in driving methods that occurred as a result of age as were those 65 years of age and older.

Aging with a Disability

We are now facing a situation where people with long term disabilities are living longer lives due to better medical care, nutrition, supports, societal changes, and other aspects. For instance, in the past, the average life span of a person with Downs Syndrome was 40 years. This has now increased to 55 years (Janicki, Dalton, Henderson and Davidson 1999). We know very little about the life trajectory of persons aging with long-term disabilities and about the supports and services they require. Further research, programs and related policies are indicated. It is important to look at the changing nature of health and functionality when discussing aging with a disability. There is actually very little research on living with a specific disability and aging. For instance, we know little about the life trajectory of persons with rheumatoid arthritis, or spinal cord injury, or cerebral palsy as they age. Some research exists related to aging with spinal cord injuries (see reference list) but very little work has been done on aging with other disabilities.

For persons living with a long-term disability, entering the aging process implies adaptation. But this adaptation may be eased compared to people who are aging into disability. The age-related limitations may be "accepted" more easily. Awareness of existing supports and services, as well as having an existing support network (although not always robust), may smooth the transition. In contrast persons aging into disability may be prone to denying their condition. Lessons can be learned from those who have lived with long-term disabilities.

One of the consequences for persons aging with a disability is accelerated aging. There is evidence that people with disabilities develop secondary conditions and disabilities and those they may age at a different rate than their non-disabled peers. This has implications for healthcare services and societal planning. For example, in research relating to aging with cerebral palsy, the Roeher Institute indicated that those with this disability age sooner than their non-disabled peers. (Roeher Institute, 1996). According to the RRTC on Aging with a Disability (Isaacson, 1998) whereas typical aging is not accompanied by a high rate of medical and functional problems until after 70-75 years of age, people with disability show these higher rates 20-25 years sooner. People with disabilities also have 3 to 4 times the number of secondary health problems compared to their age-matched peers without disabilities.

Disability as a Social Issue Versus Loss of Capacity: Two Perspectives

Disability as seen from the disability movement perspective is a social issue whereas disability from the aging perspective is seen as loss of capacity. These two perspectives have implications on how disability is viewed and addressed. In both perspectives, there is a perception of greater acceptance of disability if it comes gradually. The sudden or progressive onset of a disability is a key variable (in terms of timing, but also how it happens) in the self-identification with disability status. For persons with disabilities entering their senior years, there is a redefinition and questioning of self-identification. There might be an identity crisis, harder fights, or even burnout. However, there are similar issues that affect both seniors and persons with disabilities: vulnerability, safety and security, fraud and exploitation, supports and healthy living, economic viability, assets and poverty, social isolation, access to housing and the public built environment, etc. It is clear that in both cases, the environment and support systems have tremendous impact on these issues

There are different notions that society has in relationship to aging and to disability. There are well known stigmas associated with aging (that one will necessarily be disabled which is not true) and with disability itself (unattractive, unable to work, to live independently, etc). The Federal government recently conducted a study entitled Canadians Attitudes Toward Disability, 2004 that discusses some of these issues. Many people who are growing older fear the prospect of the onset of disability and experience stigma around the possibility of aging with a disability and how this might impact their lives. These individuals may not feel comfortable with using disability-related services, advocacy groups, etc. Most seniors do not accept the label of disability, even when formal structures and systems tell them they have a disability. Although such labels are sometimes necessary for people to access supports, there is a complex social stigma associated with both aging and disability (double stigma). Variables such as cultural differences, religion, language, family role, age, gender, and social environment all play a role in how a person will accept to self-identify as a senior with disabilities. Some people may be reticent in associating with seniors with disabilities

because it may symbolize loss of independence and dignity and raise the issues related to the acceptance of mortality. Time is also an issue, as there is less time for seniors to accept and deal with disability. In some cases, seniors may refuse to take on "disability" as a label, but will take on the impairment itself (recognizing for example, a loss of hearing but not accepting to be qualified as a person with a disability). The obvious consequence is that many seniors under-report disability. But disability is a natural part of life. Although younger population with rights-based attitudes might accept it more than seniors – and we might see a difference in attitudes in 5 to 10 years due to that -, disability status needs to be re-valued among seniors.

Stigma about disability and aging is not only an Individual Issue: Many organizations for seniors specifically shy away from notions of disability and discuss "healthy aging" as if disability is unhealthy, whereas in the disability movement, disability is a healthy state where a person with a disability can live a full productive life. For example, some seniors believe that disability aids and devices such as wheelchairs are signs of frailty. In contrast, the disability community feels that use of these types of aids and devices can lead to greater pride and independence. In another example of stigma, more seniors are using scooters to move around in public spaces such as malls. "This appears to be because there is stigma associated with using a wheelchair. It is more socially acceptable to use a scooter. People who would previously been isolated due to their "disability" are now going shopping together. Having a scooter is not associated with disability but rather with aging" (Ringaert, 2005) Various terms have been used in relationship to aging such as "successful" aging, which refers to living with dignity despite limitations and "active aging", a notion that parallels the idea of "full participation" in society, however these terms and those who use them often do not recognize the presence of disability as part of the equation.

Stigma is thus not only about attitudes but it is systemic as well. There are assumptions regarding mental and physical capacities of seniors, and various issues related to the health care system and services (over-prescribing, inadequate medical attention by healthcare professionals (nothing to worry about just age or nothing to worry about just your disability).

With communities playing a stronger role in increasing inclusion and recognizing "interdependence", there could be a more positive focus on abilities and sensitizing citizens to change their perception of "normality". In any case, this raises the question of how to turn stigma around or eliminate it altogether. Is it a policy issue? The self-perception and perception and attitudes of others need to be part of a strategy.

Distinctions between Disability Policy and Health Policy

While there has been a trend that "disability" and "aging" are two distinct areas of study and policy, there is an overlap where many seniors have disabilities and many people with disabilities are aging. As people with disabilities age, it may be necessary for them to move from one system of health/home care to another as they reach certain age restrictions in their area of care. In the past, many assistive devices and services were provided only in the "disability system", it is important to ask whether the same services are available in the system dealing with older adults without disabilities. It is also necessary to address how people cope as they move from system to system.

The growing number of seniors and those aging with a disability have important implications for policy and service delivery. Currently the research field, the voluntary sector, government departments, and advocacy groups tend to be structured into two separate streams: aging as one and disability as another. The issue is, what lessons can be learned from these separate groups and how can we deliver services in a most cost-effective way to both groups? Steen (2004) advocates a "double lens" approach. Steen (2004) suggests four main questions to address the challenge of providing supports to seniors with disabilities:

- How will seniors-focused policy and services need to be adjusted to account for the growing number of people with disabilities among this population?

- How will disability-focused policy and services adjust to the increasing number of seniors in the disability community?
- Will new policies or services need to be developed specifically for the large and growing number of seniors with disabilities in the community?
- Are there ways to integrate seniors and disability policy to provide the most effective and efficient programs and services?

When examining healthcare services, disability supports and income programs, it is important to consider what models are being utilized to develop programs in these areas, determine eligibility for services, undertake implementation and evaluate outcomes. Many of these programs operate primarily on the basis of the medical model whereby medical aspects of disabilities are the primary determinants of service eligibility and provision. Although medical aspects of disability should be considered, programming for seniors with disabilities should make every effort to integrate a social model of disability into programming. There is need to develop a holistic model, which combines philosophies, programs, and policies from both the aging and disability fields. It is important to explore how independent living values (autonomy and control, peer support) can be translated into aging/seniors programs
The model should be based on a social perspective of, disability and aging but also include features to address the health and functional limitations, which result from increased disability. There is the need for the disability and aging communities, non-profit organizations; policymakers, governments, researchers etc. develop new ways of responding to the needs of seniors with disabilities that take a **double lens** (Steen, 2004) approach to development of policies, programs and services. When discussing and developing policy, vocabulary can also be different across sectors (GOC, provinces, academia, disability organizations, seniors' organizations, Aboriginal communities, etc.). The use of words such as dependency, independence and interdependence may refer to different things. So terms to be used must be discussed amongst groups to clarify meaning.

Upcoming Challenges: ODI to add demographic information from PALS and other data sets here

Key Population Groups

There are several key population groups to address with respect to seniors with disabilities. These include differences in gender, visible minority groups, and aboriginal groups, types of disability (mental health, developmental disabilities, and invisible disabilities; isolated seniors and the different realities of urban and rural settings; various age groups (younger to older seniors). ODI: to add information they have on the other key groups.

> **Gender Issues of Older People with Disabilities:** Older women consistently have a higher prevalence of disability than men of the same age. This difference does not result from women developing disability more often than men, but rather because they survive longer with their disabilities. Guralnik, Leveille, Hirsch, Ferrucci, Fried (1996) We know very little about specific gender issues facing older people with disabilities and what sorts of health disparities are they facing. We know that women with disabilities generally lack access to healthcare providers and health screening (PAP smears, mammography) due to lack of accessibility of facilities and equipment, and insufficient training of healthcare professionals. Yet, we actually know very little about what is being done to address these issues. We also need to know if disparities are increased for older women with disabilities. Men with disabilities also face health disparities in many of the same ways (screening for prostate cancer), but have received even less attention than women with disabilities. Further research is needed to explore these gender differences as well as to determine if there are any differences as to how women and men age with a disability or age into disability.

Government Actions: This portion of the chapter should present the key research projects that federal departments and agencies have been conducting or sponsoring in the fields of seniors with disabilities,

ageing and progressive loss of capacity, as well as specific issues related to persons with disabilities entering their senior years. It will be important to acknowledge the divide that has traditionally existed in much of the research in the areas of disability and aging and the importance of undertaking research related to seniors with disabilities which melds the two fields and utilizes a double lens approach (Steen, 2004).

CHAPTER 5 – SENIORS WITH DISABILITIES IN THE COMMUNITY

Seniors with disabilities are important contributors to the community and to society. They are entitled to having meaningful participation in all aspects of the community including relationships, leisure opportunities, access to assistive devices and access to transportation. Many seniors with disabilities however, are socially isolated due to issues such as lack of physical accessibility, lack of financial resources, lack of transportation and disability supports, inadequate community policies to accommodate their needs and negative societal attitudes, etc. It appears that are there are many common key issues that converge for seniors and people with disabilities. The Society for Manitobans with Disabilities (Steen, 2004) conducted a review of major policy documents from government and voluntary sector (both national and provincial) for people with disabilities sand seniors. They found the following common key issues:

- Social isolation
- Home care
- Technology supports
- Income supports
- Case management
- Pharmaceutical compliance
- Transportation
- Affordable housing
- Accessible primary health care
- Access to government
- Abuse, neglect, and discrimination

The following additions are suggested by CCDS:

- Accessible private housing
- Home modification support
- Design of health care and assistive living
- Barriers in the public built environment
- Gender and minority issues
- Quality of Life/psycho-social issues
- Employment supports and transitions from employment
- Training of professionals
- Caregiver issues
- Attention of the other issues by specific agencies

Profiles: Profiles of seniors with disabilities: To be added by ODI

Removal of Community Barriers to Full Participation

To enable the full participation of seniors with disabilities in society and in the community, the barriers to participation need to be removed. Barriers include the inaccessibility of the built environment, recreation and community programs that are inaccessible or do not meet the support needs of seniors with disabilities, inadequate transportation, lack of awareness on the part of professionals, stigma by community organizations and seniors with disabilities themselves around the notions of successful aging, the scope of employment, voluntary and community activities in which they can participate and how to facilitate community participation for seniors with disabilities who are home-bound.

Built Environment: There are many issues that have not been addressed concerning the built environment and its lack of accessibility. The built environment encompasses everything from housing, to urban design, neighbourhood design, to parks and recreation, to public and private buildings, the design of rural environments to the design of transportation systems. Many people with disabilities and seniors are socially isolated due to lack of accessibility of various aspects of the built environment. As people with disabilities age, it is important to consider whether they are able to access the same services and opportunities that other older people access? Are seniors with disabilities able to access parallel transportation systems and services that are provided for "disabled people" in situations where these systems are only available to persons up to age 60 for instance? Research suggests that neighbourhood environments may influence functional health of those who are growing older. (Balfour and Kaplan, 2002). The design of homes both in new construction and in renovations is extremely important to community living. At the present time there is a low stock of even minimally accessible homes available in the community. According to Cooper and Shaw (2004) who evaluated a safe living guide for seniors, seniors are at greater risk for falls in their homes than younger individuals. Visitable homes (minimally accessible), universally designed homes and home modification incentives and programs are needed to ensure community participation. Environmental and universal design solutions to address those aging with disabilities should be examined within the context of a holistic perspective. Efforts should be made to increase the accessibility of facilities and the built environment for those aging with disabilities as these design solutions will benefit everyone.

Many seniors with disabilities do not live in their own homes in the community, but rather live in congregate and assistive living situations. These living facilities can also be designed to encourage active participation in the community. These must be designed both physically and programmatically to accommodate seniors with disabilities. For instance, do they accommodate the equipment that an older person with a long-term disability may need such as a reclining power wheelchair, a scooter, and an augmentative communication system? How are these facilities designed to treat people who are used to autonomy? Are there innovative less institutional systems that could work such as cooperative housing?

Inclusive Communities

There is a need for communities to be designed to play a stronger role in increasing inclusion and recognizing "interdependence. There is the need to look at the following issues from a community perspective: caregiving, home care and affordable assisted living/"aging in place", transportation, housing, the cities agenda and community/universal design. Support to community initiatives should be enhanced to improve accessibility and availability of supports and services. This could lead forward much needed inclusive community models and communal support studies. These issues must be included and integrated into community and health planning design initiatives. Planners, designers, architects and health planners and the seniors and disability communities must be brought together to design inclusive active, participatory, multi-generational communities.

Universal Design: A Promising Trends to Bring Aging and Disability Together to Build More Inclusive Communities

The whole concept of universal design: the design of products, services and environments to be more usable by all people regardless of age, size or ability addresses the needs of both seniors and persons with disabilities. Many of the designs that have been advocated by this movement including Visitable housing, power sliding doors at main entrances of commercial and public buildings, captioning on television, are all examples of how a universal design approach makes design more usable by all people especially including seniors and persons with disabilities. One of the newest trends in universal design is the trend toward universal design and tourism. The aging population who desires to travel is requiring more accessible tourism sites. This movement toward tourism will translate into increased accessibility for the residents of the location. The Canadian Standards Association has recently completed and published its latest barrier-free standard (CSA-B651 2004), which refers both to seniors and persons with disabilities as well as other citizens as benefactors. The Standard is required by all federally owned or leased properties. The National

Building Code serves as a model code fro the provinces and ensures accessibility of newly constructed buildings for both seniors and people with disabilities. The latest code (2005) has incorporated aspects of universal design.

The built environment and community programs can be redesigned in accordance with universal design principles and active aging concepts to facilitate the meeting of the needs of seniors with disabilities. Community planning should be undertaken to facilitate community involvement, the provision of increased resources and disability supports to facilitate community participation, awareness training among program staff, professionals, family members and seniors with disabilities themselves about active aging and the range of options for community participation. Information barriers such as the provision of material in alternative formats (such as tape and large print), culturally sensitive and plain language information etc. should be available.

Community Capacity and the Dynamics Between the Disability and Seniors Movement

Disability and Seniors organizations have a great deal of influence on the design of inclusive communities. However, most disability specific agencies (including research, policy or service organizations) have not yet addressed the issues of aging with disabilities and aging into disabilities. As well, many agencies/NGO's dealing with aging do not address disability head-on. Rarely do the two agency groups meet to discuss issues. According to one disability advocacy agency, many of their efforts have indeed assisted more seniors than younger people, although this fact was not formally recognized by either group. It is important to consider whether service agencies have begun to address these issues in terms of services to clients and if research organizations are conducting research on issues related to seniors with disabilities. In addition, it is important to examine whether advocacy groups are including the needs of seniors with disabilities in their work with government and the community to monitor service provision and advocate for improved services and programs. Advocacy efforts should combine policy recommendations from both the aging and disability fields.

The "Advancing Inclusion 2002" report discussed the community capacity of organizations within the disability community to carry out their mandates, address the increasing needs of their consumers/members/clients, conduct public awareness activities, carry out research, etc. The information in this section was based on research conducted by the Canadian Centre on Disability Studies in 2001. Many groups believed their organizational capacities had decreased or stayed the same in 2001. The funding climate prevented them from carrying out their mandates in advocacy, research and service and communicating with members/constituents. Directly tied to human resource capacity is financial resource capacity. Of the 18 organizations surveyed, only one said it had both the financial and human resources it needed to do its part in policy development. Without financial resources, a disability organization is severely limited in its ability to carry out its mandate. While many organizations in the voluntary sector have to some degree been able to diversify their sources of funding (government, foundations, private sector, fundraising), the sector as a whole still relies heavily on government funding. Disability organizations, which represent a largely marginalized population, may depend on government funding more than the average volunteer organization. Organizations within the voluntary sector which address the needs of seniors are also likely to be limited in their capacities to carry out their mandates for the same reasons that disability organizations are. If capacity issues are to be addressed, it will be important for the government to facilitate the provision of monetary and non-monetary resources to increase the capacity of the disability and seniors communities to respond to the needs of seniors with disabilities and take a "double lens approach" or universal design approach to development of policies, programs and services.

<u>Participation in Community: Indicators</u>

- Involvement in community organizations
- volunteerism
- Social isolation and mental health
- Active living
- Accessible housing

- Accessible communities
- Participation in shopping
- Participation in community development
- Participation with religious pursuits
- Life long learning participation
- Paid or volunteer work
- Leisure pursuits
- Environmental barriers
- Involvement in seniors and disability groups
- Access to government
- Gender and minority issues
- Quality of Life/psycho-social issues
- Employment supports and transitions from employment

.

Government actions: Information about the Canadian Human Rights Commission's initiatives and the voluntary Communication Code of Practice currently being implemented by the Canadian Transportation Agency will most likely be included here. Possibilities of Melding of Services: How can programmatic elements from the aging and disability sectors be melded to develop accessible and affordable long-term and community design options to meet the needs of seniors with disabilities?

CHAPTER 6 – DISABILITY SUPPORTS

Disability supports are vital to assist seniors with disabilities to participate fully in family and community life and in leisure and volunteer activities. These types of supports include assistance with everyday activities, access to transportation and aids and devices, obtaining appropriate home modifications, and securing information in alternate formats. Within the seniors' movement, supports and services are not necessarily called "disability supports" and can be provided by different suppliers. In any case, persons aging into disability may be less able to draw on support networks and may be unaware of how to access the supports traditionally available in the disability community.

There are a range of support options available for persons with disabilities (including traditional models, self-managed options, assisted living choices, etc). However, there are cost barriers to securing disability supports, gaps in the provision of services and innovative solutions to meet support needs. A gaps analysis as was done by Fawcett et al, Canadian Council on Social Development (2004) regarding younger persons with disabilities (age 5-14) and revealed issues in terms of supports received and supports needed but a gaps analysis is needed regarding older persons with disabilities. The Council of Canadians with Disabilities conducted a study of home support programs across Canada (Kraw and Ennis, 2005), and this document could also contribute to the above-mentioned gaps analysis.

Formal Supports:

ODI to add: Comparison between disability and aging Programs and Services: the "Advancing Inclusion" 2005 report should offer an overview and comparison of the programs and services for seniors and persons with disabilities including how the government of Canada and community organizations provide services for this population in areas such as housing, community and residential care supports, health programming and services, income support, support to families caring for older persons, etc. The common features and differences between the two types of programming could then be delineated. **Differences in Types of Supports across Provinces:** Homecare and home support policies differ from province to province in terms of aspects such as eligibility for support, the range of disability support options available, (traditional models of home care, self-management models, shared service options in assisted living housing facilities for persons with disabilities and/or seniors, etc.) the quality and quantity of support available, how services and supports are funded, etc. Thus, it will be important for the 2005 federal disability report to point out these differences, provide an overview of the range of supports and services available in various locations across Canada and delineate how jurisdictional differences affect programming for seniors with disabilities.

The Council of Canadians with Disabilities (CCD) undertook a national study of homecare policies and programs across Canada, and this document (which will be released shortly) and other studies could inform the discussion and contribute to the information available with respect to supports and services for seniors with disabilities. Different jurisdictions across Canada have different policies with respect to providing medical equipment and other aids and devices to people with disabilities. It will be important for the report to point out these differences and how these impact the lives of seniors with disabilities. Models of long-term care, assisted care, personal supports in both the disability and aging community will vary from province to province, and an overview of the range and types of options provided could be included in the report. Lessons could be learned from each. Further research is needed to develop methods for melding policies from the aging and disability fields which meet the needs of both populations. The report could pose questions, which will guide this research.

Informal Supports

For seniors with disabilities, the informal support network is crucial to maintain quality of life and to meaningfully participate in the community. This network includes social supports, families, friends, and community. These supports will differ somewhat depending upon the nature of the disability. These networks will changes as a person with a disability ages. For instance for people with developmental disabilities, the role of families and support workers changes over their life journey. As parents die or are no longer capable of providing caregiver support, new sources of support will be crucial for those seniors with developmental disabilities who are aging. Marlene MacLellan and Deborah Norris et al (2002) conducted research in Atlantic Canada on the importance of providing community supports to aging parents who are caring for sons or daughters with developmental disabilities and developed training materials to assist professionals in providing supports to these families. The found that the parents were dealing with their own age-related changes such as decreased energy levels, increased chronic illness as well as responding to the changing future care. The research indicates that future planning can be difficult and emotionally trying compounded by lack of services and suitable options, restrictive policy eligibility, previous experiences with service delivery system, perceptions of formal support, and family dynamics arising from caring for sons/daughters with lifelong disabilities. MacLellan et al's study (2002) suggests viewing care giving from a "family lens".

Lessons can be learned by examining both spouses and families that live with and provide support for people with disabilities and seniors. The 2005 report should examine whether those relationships change as all parties age. A family caregiver may have provided support for years. Are these issues taken into account by the current healthcare/homecare system and by community organizations that provide support to those with disabilities? More research is needed to examine how informal and formal community-based care supports the independence and autonomy of older persons attempting to cope with chronic illness and disabilities in community settings and in long-term care facilities. (Penning, Chappell, Stephenson, Tuokko, & Rosenblood, 1998) The issue of providing support to caregivers of persons with a variety of disabilities is an important one, however, there is very little research on the provision of caregiver support to families caring for seniors with disabilities, and more work is needed in this area.

Eligibility for Services

A key issue in this dialogue is eligibility for services and supports in terms of age, ability to work and other criteria. Both the 2002 and 2004 Advancing the Inclusion of Persons with Disabilities reports define seniors with disabilities as individuals aged 65 years and over. This is based on information contained in the 2001 Participation and Activity Limitation (PALS) survey (PALS, 2001). The 2004 version of the report also refers to "younger seniors" as those between the ages of 65 and 74 and "older seniors" as individuals 75 years and over. This includes seniors with disabilities. To qualify for many government programs, individuals must be 65 years of age and over. Examples of these programs include: The Home Adaptation for Seniors Independence Program operated by Canada Mortgage and Housing Corporation to assist seniors in making minor modifications to their homes to enable them to continue to live there independently and the Old Age Security and Guaranteed Income Supplement. It is important to note, however, that the definition of "senior" is not always a person who is 65 years and over. For example, membership in some

community senior's organizations such as the Canadian Association of Retired Persons (CARP) is open to individuals 50 years of age and over. In many cases, those over the age of 55 are eligible for seniors housing facilities, and some Canadian banks have plans for seniors under the age of 65.The above-mentioned examples illustrate that a senior is not always a person 65 years of age and over, and this is also the case with seniors with disabilities.

With respect to income, seniors 65 years of age and over are eligible for Old Age Security or OAS providing they complete the application forms and meet eligibility criteria. Those with limited or no income are also eligible for the Guaranteed Income Supplement or GIS. Partners or survivors of those on OAS are also eligible for an allowance if they are between the ages of 60-64 and if they have limited incomes. Given the increased needs for disability supports, aids and devices, etc. are these benefits adequate to meet the needs of seniors with disabilities who may have extra costs associated with obtaining aids and devices not covered by disability-related programs? What are the policy gaps with respect to these benefits and how can these be addressed? In the case of veterans who are seniors with disabilities (eligible to receive coverage for such things as homecare support, dental care, eye glasses, aids and devices, drugs and transportation to treatment through the Veterans Independence Program), are these supports adequate to meet identified needs? Do eligibility criteria for these benefits exclude persons who could benefit from these supports? A key issue in terms of eligibility of services is the prioritization of younger people over older people in the system. For instance, many cities are currently facing a major issue of supply and demand for parallel transit systems (i.e. Handitransit) as more and more seniors are needing to use the system. However, the way the systems were originally set up was for priority for younger people going to work. In many cities, there is talk of "abuse" of the system by seniors. Instead, there is the need to recognize the need to re-look and re-think the systems.

Another important issue in terms of eligibility is the move from a state of independence (or interdependence) to a state of a higher level of dependence and an increasing need for disability supports and services. For people with disabilities who have had control over their lives and their caregivers, reaching the age of 65 or 70 places them into a different care support model where they may no longer be eligible for previous services (i.e. power wheelchairs, parallel transit services). The question is, how is our health/home care system responding to these needs? Are people with disabilities able to maintain the same level of control and autonomy as they move from one system to another? What happens as a person with a disability moves from an independent living perspective to a system that is set up to deal with more dependence? It is important to integrate models of independent living, models of care, housing and support from the disability field with aging perspectives. This will enable the provision of a fuller range of supports and services to maximize independence for those with disabilities who are growing older. In addition, this will assist in linking the support models from the disability and aging fields.

Core indicators:

- Aids and devices :
- Help needed for everyday activities:
- Home modifications
- Supports for informal caregivers (ageing caregivers; parents or spouses).
- Transportation
- Information in multiple formats.

Supplemental Indicators

- Housing
- Medication support.
- Institution and Community Support

Note: Information in Multiple Formats: This area should be broadened to include access to technology and the provision of professional training to assist seniors with disabilities in utilizing technology to access information from community and government sources and from the World Wide Web.

Government Action

This government action section should provide a discussion of selected policies or programs focusing on disability supports for seniors with disabilities. CMHC's Home Adaptation for Seniors' Independence and Maintaining Seniors' Independence Through Home Adaptations programs could be described here, as well as their research on special housing needs for persons with dementia.

CHAPTER 7 – HEALTH AND WELL-BEING

Seniors with disabilities have the same desire for good health and well-being as other Canadians. Health is more than the absence of disease. It includes physical, mental, emotional and spiritual aspects which will contribute to a fuller life. Factors such as human biology, the health care system, individual behaviour, and social and economic conditions, the presence or absence of chronic conditions all impact health and well-being. (Advancing Inclusion, 2004). This 2005 report uses the World Health Organization approach to define health as not merely the absence of disease but also relates to mental, physical and social well-being, as well as the ability to function at an optimal level in the environment.

ODI: to add information on wellness and seniors, also information on active living and seniors with disabilities, "successful aging", healthy living, healthy aging, etc and tie into disability as many of these movements do not address disability as part of the equation. Here lies the difference between the disability (independent living movement and the seniors' paradigm of disability). Any info from data sets would also be interesting here. CCDS was not commissioned originally to collect information on Health and Well-Being.

Quality of Life/Psycho-Social Issues: There is the need to examine and compare QOL & psycho-social issues. Research indicates that quality of life (QOL) is negatively affected by age-related changes in function and health. Gerhart, et al. (1993) found that persons with spinal cord injury who had decreased function rated their lives as less satisfying than persons who had not changed function. Krause (1990) showed that life satisfaction normally increases as one ages with a disability as long as major functional changes do not occur. Similarly, Fuhrer et al., (1992) and Dijkers (1996) demonstrated that life satisfaction was only slightly lower among persons with disabilities compared to people without disabilities. Existing differences were due to health, mobility, work and social problems. Overall rates of depressive disorder are 2-3 times higher among persons aging with disability compared to age-matched non-disabled persons (Fuhrer et al., 1993; McColl and Rosenthal, 1994; Kemp et al., 1997). This finding is of major importance because depression itself is a disabling condition and in conjunction with a physical disability can cause excessive health, functional and family problems. Contrary to popular belief though, depression is not a "natural" consequence of disability or age and does not correlate with the severity of impairment, or even with the level of disability (Fuhrer et al., 1993; Reinhardt, 1996; Tate, et al., 1994; McColl and Rosenthal, 1994). However, depression correlates with difficulty coping with changes in health, function and social roles that accompany age. Kemp, Adams and Campbell et al. (1997) found that among persons aging with polio, depression scores were higher only if individuals had more post-polio changes and/or had poor family cohesion. Penninx, Guralnik, Bandeen-Roche, Kasper, Simonsick, Ferrucci and Fried, (2000) found that emotional vitality in older women with disabilities reduces the risk for subsequent new disability and mortality. These findings suggest that positive emotions can protect older persons against adverse health outcomes.

Abuse: People who are aging (both with disability and into disability) may become vulnerable to violence and abuse for a variety of reasons. Risk factors include: negative stereotypes about disability; economic dependence and poverty; reliance on others to provide for needs; lack of control in decision making and over life chances; social isolation and lack of adequate support for care providers. (Brunch, 2000). According to the Roeher Institute, many aging people with disabilities live in long-term care facilities. These individuals may be at greater risk of harm than younger people with disabilities. Provincial governments are increasingly making efforts to support individuals to live in small living arrangements or in communities rather than in institutional settings. However, there have been difficulties developing housing options for older people with disabilities that are affordable, available and accessible, and which

provide for efficient coordination and delivery of support services. Lessons can be learned from both areas of research and both systems of support.

Healthcare Issues

Seniors with disabilities (both those aging into disability and those aging with a disability) need full access to accessible, appropriate, and affordable healthcare support. (Health Canada, March 1999). This includes the provision of healthcare in both community and long-term facilities. The report could examine the range of community and long-term care options available to seniors with disabilities and whether these are appropriate, innovative, accessible, and affordable to meet individualized needs and how gaps in services can be eliminated. It will be important for the 2005 report to address the differences in health status between those aging with already existing disabilities versus those aging into disability. **Need for Training of Healthcare Professionals:** There is evidence of a need for increased training of healthcare professionals in the area of seniors and disability. One study specifically addressed intellectual disability and aging and training of health care professionals. (Janicki, Dalton, Henderson and Davidson, 1999). Seniors with disabilities require accessible healthcare in hospitals, doctors' offices, community clinics, dental facilities, etc. Are the services accessible to meet a range of needs of persons with a variety of disabilities? Are health care professionals appropriately trained to provide accessible services to seniors with disabilities? Is information about services made available in alternative formats to regular print, such as large print, on disk or in Braille, etc.? Are brochures written in plain language for those with developmental or other types of disabilities requiring this type of support? Are ASL interpreters available when needed to assist people who are deaf or deaf-blind to access healthcare services or emergency treatment? Are examining tables and other equipment accessible? Are staff well informed about the needs of seniors with disabilities and support requirements? What about end of life issues, living wills, rights to refuse treatment, etc?

Core Indicators

- Health Status
- active living status
- Impact of chronic conditions
- Impact of mental conditions
- Impact of violence.
- Impact of injuries
- Impact of individual behaviour factors
- Impact of environmental factors.

Supplemental Indicators

- Impact of neglect
- Case management related to healthcare services
- Pharmaceutical compliance
- Cost barriers to obtaining prescription drugs and other health-care services not covered by the public system
- Accessible, primary health care and eligibility for service
- Life satisfaction and quality of life indicators.
- Training of health care professionals.

Government Action

To be added by ODI, plus: Need to also discuss: innovative technologies, health and end of life care (palliative), healthy living strategy, active living strategy, programs to address poverty, abuse and neglect,

safety and security, the Aboriginal agenda and the Northern strategy, and of course the national seniors agenda.

CHAPTER 8 – INCOME

To fully participate in society, people need an adequate and secure source of income. For some individuals, this means the ability to pay bills and to have enough money to cover food, shelter, clothing, transportation, healthcare, etc. For others, it enables them to participate in community or leisure activities, attend school or university, be gainfully employed to support themselves and their families or undertake volunteer work. For many people with disabilities, obtaining adequate income is not possible, and this can affect all aspects of their lives.)"Advancing Inclusion, 2004). Seniors with disabilities over the age of 65 are more likely to depend on government transfer payments (such as Canada Pension Plan, Old Age Security and the Guaranteed Income Supplement) as their primary source of income. It will be important for the report to consider whether these benefits are adequate to meet the needs of seniors with disabilities who have extra disability-related costs not covered by existing programs. What are the policy gaps with respect to these benefits and how can these be addressed?

Aging into disability and aging with a disability presents different challenges and issues with respect to income. In many cases a person who is aging into disability has had life-long employment (greater income) than a person with a disability who has been unable to work. Upon retirement from work, the previously non-disabled worker will then in many cases have money saved and own property such as a home. For many people with disabilities who have been unable to work this is not the case Income, housing, services, unmet needs for aids and devices can also certainly differ for people who have lived with a long-term disability compared to people who are experiencing disability with aging. More specifically, people who for example experience disability starting at age 70 will probably have quite different income issues from people who have had disabilities from birth. In life transitions such as retirement for example, issues may differ for people with a disability that are aging, as they might have less labour market attachment, have different retirement choices based on their own experiences. These experiences are very much dependent on the age at the moment of disability onset, as stated previously.

Older Workers with Disabilities and Transitions from Employment to Retirement: There has been very little work done on older workers with long standing disabilities. As well there has been little attention to the many older workers who are staying in jobs longer due to various reasons such as economics. Questions could be asked as to whether seniors with disabilities have found it necessary to make further workplace accommodations to deal with the effects of aging. The 2005 federal report could explore the decisions they make to retire and the dynamics of the transitions from employment to retirement. Are these transitions different for non-disabled people? Employment seems to be a functional activity especially vulnerable to the effects of aging. Because employment is such a valued and important activity, many persons aging with disability who experience problems with fatigue, pain and weakness try to maintain work roles above all else. Studies conducted by the Rehabilitation Research and Training Center on Aging with Disability at Rancho Los Amigos Medical Center, McNeal, Somerville, and Wilson (1996) indicate that individuals decrease recreation, get more help with activities of daily living and try to get more rest in order to preserve their work capacity. However, these efforts may not suffice. These researchers also found that over 50% of persons with post-polio had to adjust work roles, reduce effort and hours, or else retire altogether by the age of 50 because of increasing disabilities. Over one-third of persons with spinal cord injury showed similar results. However, the persons with spinal cord injuries were 10 years younger on average than those with polio and they may eventually reach the same degree of change. James Hunsberger and Lynn Shaw, London, Ontario are currently carrying out research on transitions from work to retirement of persons with disabilities. Lynne Shaw pointed out that Ontario is talking about eliminating mandatory retirement and there is a need to conduct research on that.

Core Indicators

- Household income
- Employment income
- Persons living in low-income households
- Major source of personal income
- Food security
- Net worth

Government Action: to be added by ODI

CHAPTER 9 –ABORIGINAL SENIORS WITH DISABILITIES: TO BE ADDED BY ODI

Government Action: to be added by ODI

APPENDIX A – Reporting on the Labour Market

Although there is no significant link between seniors and the labour market, the Government of Canada has committed to annual reporting under the Labour Market Agreements for Persons with Disabilities (LMAPD). This appendix will be serving this purpose. Such an appendix would also appear in the 2006 report on children and youth.

APPENDIX B – Key acronyms
APPENDIX C—POPULATION PROJECTIONS (SENIORS WITH DISABILITIES)
APPENDIX D– Contributing Departments and Agencies
Endnotes

REFERENCES

Abyad A, Boyer JT. (1992) "Arthritis and aging". Curr Opin Rheumatol. Apr 4 (2) pp:153-9.

Balfour J.L & Kaplan, G.A. (2002) "Neighborhood Environment and Loss of Physical Function in Older Adults: Evidence from the Alameda County Study" American Journal of Epidemiology Vol. 155, No. 6: 507-515

Bauman, W.A. and Spungen, A.M. (1996). Disorders of carbohydrate and lipid metabolism in L Ferrucci, JM Guralnik, E Simonsick, ME Salive, C Corti and J Langlois

Canadian Council on Social Development (2005). Supports and Services for Persons with Disabilities in Canada: Requirements and Gaps. Canadian Council on Social Development.

Chappell, N.L. and Reid, R.C. (2002). "Burden and Well-Being Among Caregivers: Examining the Distinction." The Gerontologist 42(6), 772-780.

Chappell, N.L. and Penning, M.J. (2001). "The Sociology of Aging in Canada: Issues for the Millennium." Canadian Journal on Aging Vol.20, Suppl.1, 82-110.

Cooper, Kim and Shaw, Lynn (2004). The Utility of the Safe Living Guide: A Guide to Home Safety for Seniors. London Ontario: University of Western Ontario.
Crawford, Cam (1996). Aging, Well-being and Cerebral Palsy. (Report prepared for the Ontario Federation of Cerebral Palsy). Toronto Ontario: The Roeher Institute.

Dijkers, M. (1996). "Quality of life after SCI". American Rehabilitation, 22, pp.18-23.

Ferrucci,L, Guralnik JM, Simonsick E, Salive ME, Corti C & Langlois J (1996) Progressive versus catastrophic disability: a longitudinal view of the disablement process.

Fuhrer, M.J., Rintala, D.H., Hart, K.A., Clearman, R., and Young, M.E. (1992). " Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community". Archives Phys. Med. Rehab., 73, 552-557.

Fuhrer, M., Rintala, D., Hart, K, Clearman, R., and Young, M. (1993). "Depressive symptomatology in persons with spinal cord injury who reside in the community". Archives of Physical Medicine and Rehabilitation. 74, 255-260.

Gerhart, K.A., Bergstrom, E., Charlifue, S.W., and Menter, R.R. (1993). "Long-term spinal cord injury: Functional changes over time". Archives Phys. Med. Rehab., 74, 1030-1034.

Guralnik JM, Leveille SG, Hirsch R, Ferrucci L, Fried LP. (1997). "The impact of disability in older women". J Am Med Womens Assoc. 1997 Summer;52(3):98, 106.

Guralnik JM, Fried LP, Salive ME. (1996) "Disability as a public health outcome in the aging population". Annu Rev Public Health.;17:25-46

Guests, Karen, Lynn Shaw and Jan Miller (2004 unpublished). The Use of Safe Vehicle Features and Needs for Safe Transportation: Perspectives of Seniors with Disabilities. London Ontario: University of Western Ontario.

Government of Canada. (2002). Advancing the Inclusion of Persons with Disabilities: A Government of Canada Report. Ottawa, Ontario: Human Resources Development Canada (HRDC).

Government of Canada. (2004). Advancing the Inclusion of Persons with Disabilities: A Government of Canada Report. Ottawa, Ontario: Human Resources Development Canada (HRDC).

Health Canada (1999). Innovations and Best Practices in Continuing Care for Seniors. Ottawa Ontario: Health Canada.
Isaacson Kailes J, (1998) Dissemination Specialist, Rehabilitation Research and Training Center on Aging with Spinal Cord Injury Rancho Los Amigos National Rehabilitation Center 7601 East Imperial Highway, Downey, California 90242 http://www.jik.com/awdrtcawd.html

Janicki MP, Dalton AJ, Henderson CM, Davidson PW. (1999). "Mortality and morbidity among older adults with intellectual disability: health services considerations". Disabil Rehabil.May-Jun;21(5-6):284-94.

Kemp, B.J. and Thompson, L. (1997). Long-term functional changes in a sample of persons aging with spinal cord injury. Rehabilitation Research and Training Center on Aging with Spinal Cord Injury, Rancho Los Amigos National Rehabilitation Center, Downey, CA.

Kemp, B. J. and Campbell, M. (1993). Health, functioning and psychosocial aspects of aging with disability. Final Report. Rehabilitation Research and Training Center on Aging. Downey, CA.: Rancho Los Amigos Medical Center.

Kemp, B.J., Adams, B.M., and Campbell, M.L. (1997). "Depression and life satisfaction in aging polio survivors versus age-matched controls: Relation to post-polio syndrome, family functioning, and attitude toward disability". Archives Phys. Med. Rehab., 78, 187-192.

Krause, J.S. (1992). "Longitudinal changes in adjustment after spinal cord injury: A 15-year study". Archives Phys. Med. Rehab., 73, 558-563.

Kraw, K. and Ennis, Mary (2005). A National Shot of Home Support Through the Consumer Perspective. Document prepared by Jon Johnson and Victoria Bowman in collaboration with the Research Team and the Data Analysis Team. Council of Canadians with Disabilities.

MacLellan, Marlene and Deborah Norris (2002). Age-Related Transitions: Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities. Halifax, Nova Scotia: Nova Scotia Centre on Aging, Mount St. Vincent University.

Mactavish, J. and Mahon, M. (In Press). "Leisure Education and Later Life Planning: A Conceptual Framework." Journal of Policy and Practice in Intellectual Disabilities.

McColl, M. A. and Rosenthal, C. (1994). "A model of resource needs of aging spinal cord injured men". Paraplegic, 32, 261-270.

McNeal, D., N. Somerville and Wilson, D. (1996). Use of technology services to maintain employment among people aging with a disability. Final Report on the Rehabilitation Research and Training Center on Aging with Disability. Rehabilitation Research and Training Center on Aging with Disability, Rancho Los Amigos Medical Center, Downey, CA.

Penning, M.J., Chappell, N.L., Stephenson, P.H., Rosenblood, L., and Tuokko, H.A. (1998). "Independence among Older Adults with Disabilities: The Role of Formal Care Services, Informal Care giving and Self-Care", Final Report submitted to NHRDP.

Penninx BW, Guralnik JM, Bandeen-Roche K, Kasper JD, Simonsick EM, Ferrucci L, Fried LP. "The protective effect of emotional vitality on adverse health outcomes in disabled older women". J Am Geriatr Soc. Nov;48(11):1525-6.

Reinhardt, J. (1996). "The importance of friendship and family support in adaptation to chronic vision impairment". Journal of Gerontology: Psychological Sciences, 51, 268-278.

Ringaert, L. (2005). Disability and Aging: Canadian Centre on Disability Studies Concept Aging. Canadian Centre on Disability Studies, Winnipeg, Manitoba.

Statistics Canada (2002). Participation and Activity Limitation Survey 2001: A Profile of Disability in Canada. Ottawa: Statistics Canada.

Steen, D. (2004). Aging and Disability in Manitoba: Converging Opportunities. Society for Manitobans with Disabilities.

Tate, D., Kirsch, N., Maynard, C., Peterson, C., Forchheimer, M., Roller, A. and Hansen, N. (1994). "Coping with the late effects: Differences between depressed and non-depressed polio survivors". Archives of Physical Medicine and Rehabilitation, 83, 27-35.

Veterans Affairs Canada (2004). A Guide to VAC Health Benefits and the Veterans Independence Program. Halifax Nova Scotia: Veterans Affairs Canada.

Research on Aging with Spinal Cord Injury

Charlifue SW, Weitzenkamp DA, Whiteneck GG. (1999) "Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being". Arch Phys Med Rehabil. Nov;80(11):1429-34.

Fried LP, Bandeen-Roche K, Kasper JD, Guralnik JM. (1999) "Association of co-morbidity with disability in older women: the Women's Health and Aging Study". J Clin Epidemiol. 1999 Jan;52(1):27-37.

Gerhart KA, Bergstrom E, Charlifue SW, Menter RR, Whiteneck GG. (1993). "Long-term spinal cord injury: functional changes over time". Arch Phys Med Rehabil. 1993 Oct;74(10):1030-4.

Krause JS. (1998). "Aging and life adjustment after spinal cord injury". Spinal Cord. May;36(5):320-8.

Krause JS, Kemp B, Coker J. (2000). "Depression after spinal cord injury: relation to gender, ethnicity, aging, and socioeconomic indicators". Arch Phys Med Rehabil Aug: 81(8):1099-109.

McGlinchey-Berroth R, Morrow L, Ahlquist M, Sarkarati M, Minaker KL. (1995) "Late-life spinal cord injury and aging with a long-term injury: characteristics of two emerging populations". J Spinal Cord Med.Oct;18(4):255.

McColl MA, Arnold R, Charlifue S, Glass C, Savic G, Frankel H. "Aging, spinal cord injury, and quality of life: structural relationships". (2003) Arch Phys Med Rehabil. 2003 Aug;84(8):1137-44

McColl MA. (2002) "A house of cards: women, aging and spinal cord injury". Spinal Cord. Aug;40(8):371-3.

McColl MA, Rosenthal C (1994). "A model of resource needs of aging spinal cord injured men". Paraplegia. Apr;32(4):261-70.

Menter RR, Whiteneck GG, Charlifue SW, Gerhart K, Solnick SJ, Brooks CA, Hughes L. (1991). "Impairment, disability, handicap and medical expenses of persons aging with spinal cord injury". Paraplegia. Nov;29(9):613-9.

Krause JS. (2000) "Aging after spinal cord injury: an exploratory study". Spinal Cord. Feb;38(2):77-83.

Crawford Research Institute, Shepherd Center, Atlanta, Georgia, USA.

Pentland W. , Walker J., Minnes P., Tremblay M., Brouwer B. & Gould M. (2002) "Women with spinal cord injury and the impact of aging" August 2002, Volume 40, Number 8, Pages 374-387

Weitzenkamp DA, Gerhart KA, Charlifue SW, Whiteneck GG, Savic G. (1997) "Spouses of spinal cord injury survivors: the added impact of care giving". Arch Phys Med Rehabil. Aug;78(8):822-7.

Selected International References on Aging and Disability

Beekman AT, Deeg DJ, Braam AW, Smit JH, Van Tilburg W. (1997). "Consequences of major and minor depression in later life: a study of disability, well-being and service utilization". Psychol Med. 1997 Nov;27(6):1397-409.Department of Psychiatry, Free University, Amsterdam, The Netherlands.

Doblhammer G, Kytir J. (1998). "Social inequalities in disability-free and healthy life expectancy in Austria". Wien Klin Wochenschr. 1998 Jun 5;110(11):393-6.Institute for Demography, Austrian Academy of Sciences, Vienna, Austria

Ferrucci L. , JM Guralnik, E Simonsick, ME Salive, C Corti and J Langlois (1996) "Progressive versus catastrophic disability: a longitudinal view of the disablement process" Journals of Gerontology Series A: Biological Sciences and Medical Sciences, Vol 51, Issue 3 Geriatric department I Fracticini, National Research Institute (INRCA), Florence, Italy.

Giles LC, Cameron ID, Crotty M. (2003) "Disability in older Australians: projections for 2006-2031". Med J Aust. 2003 Aug 4;179(3):130-3.Department of Rehabilitation and Aged Care, Flinders University, Adelaide, SA.

Graham P, Davis P. (1990). "Life expectancy free of disability: a composite measure of population health status". Community Health Stud. 1990;14(2):138-45.Department of Community Health, School of Medicine, University of Auckland, New Zealand.

Jacobzone S. (2000). "Coping with aging: international challenges". Health Aff (Millwood). 2000 May-Jun;19(3):213-25.Organization for Economic Cooperation and Development (OECD), Paris.

Jagger C, Goyder E, Clarke M, Brouard N, Arthur A. (2003). "Active life expectancy in people with and without diabetes". J Public Health Med. 2003 Mar;25(1):42-6.Department of Epidemiology and Public Health, University of Leicester, 22-28

Jitapunkul S, Kunanusont C, Phoolcharoen W, Suriyawongpaisal P, Ebrahim S. (2003)."Disability-free life expectancy of elderly people in a population undergoing demographic and epidemiological transition". Age Ageing. 2003 Jul;32(4):401-5.Department of Medicine, Faculty of Medicine, Chulalongkorn University, Bangkok 10330, Thailand.

Kliebsch U, Siebert H, Brenner H. (2000). "Extent and determinants of hospitalization in a cohort of older disabled people". J Am Geriatr Soc. 2000 Mar;48(3):289-94.University of Ulm, Department of Epidemiology, Germany.

Melzer D, McWilliams B, Brayne C, Johnson T, Bond J. (2000). "Socioeconomic status and the expectation of disability in old age: estimates for England". J Epidemiol Community Health. 2000 Apr;54(4):286-92.Department of Public Health and Primary Care, University of Cambridge.

Paccaud F. (2002). "Rejuvenating health systems for aging communities". Aging Clin Exp Res. 2002 Aug;14(4):314-8.Institute of Social and Preventive Medicine, Faculty of Medicine of Lausanne and Cantonal Hospices, Lausanne, Switzerland.

Sauvaget C, Tsuji I, Aonuma T, Hisamichi S. (1999). "Health-life expectancy according to various functional levels". J Am Geriatr Soc. 1999 Nov;47(11):1326-31.Tohoku University Graduate School of Medicine, Department of Social Medicine, Sendai, Japan

von Strauss E, Aguero-Torres H, Kareholt I, Winblad B, Fratiglioni L. (2003). "Women are more disabled in basic activities of daily living than men only in very advanced ages: a study on disability, morbidity, and mortality from the Kungsholmen Project". J Clin Epidemiol. 2003 Jul;56(7):669-77.Aging Research Center, Division of Geriatric Epidemiology and Medicine, Neurotec, Karolinska Institutet, Stockholm, Sweden.

Schroll M. (1992). "Does increased life expectancy imply active life expectancy?" Dan Med Bull. 1992 Jun;39(3):258-61. Geriatric Department HL, Kommunehospitalet, Copenhagen.

Tobias M, Cheung J. (2000). "Independent life expectancy in New Zealand", 1996-97. Aust Health Rev. 2000;23(2):199. Ministry of Health, Wellington, New Zealand.

Other Works of Interest

Campbell, M., Sheets, D., Moulton, H., Kemp, B. and Leibig, P. (1998). "New Discoveries About Aging With Disability". Presentation at American Society on Aging. San Francisco, CA.

Olsen, R.V. and Hutchings, B.L. (1998). Issues and concerns of people aging with a developmental disability. Presented at the American Society on Aging Conference, San Francisco, CA.

Holicky, R. (1996). "Caring for the caregivers: The hidden victims of illness and disability". Rehabilitation Nursing, 21, 247-252.

Richards, J. S., and Shewchuk, R. M. (1996). "Caregivers of persons with spinal cord injury: A longitudinal investigation". Research Update: Annual Publication of the Spain Rehabilitation Center, University of Alabama at Birmingham.

Some Projects that May Take a More Social Model of Disability/Aging Approach (although only examined by the title)

Campbell, M., Sheets, D., Moulton, H., Kemp, B. and Leibig, P. (1998). New Discoveries About Aging With Disability. Presentation at American Society on Aging. San Francisco, CA.

Crawford, Cam (1996). Aging, Well-being and Cerebral Palsy. (Report prepared for the Ontario Federation of Cerebral Palsy). Toronto Ontario: The Roeher Institute.

Dijkers, M. (1996). "Quality of life after SCI". American Rehabilitation, 22, pp.18-23.

Fuhrer, M.J., Rintala, D.H., Hart, K.A., Clearman, R., and Young, M.E. (1992). "Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community". Archives Phys. Med. Rehab., 73, 552-557.

Guerts, Karen, Lynn Shaw and Jan Miller (2004 unpublished). The Use of Safe Vehicle Features and Needs for Safe Transportation: Perspectives of Seniors with Disabilities. London Ontario: University of Western Ontario.

Guralnik JM, Leveille SG, Hirsch R, Ferrucci L, Fried LP. (1997). "The impact of disability in older women". J Am Med Womens Assoc. 1997 Summer;52(3):98, 106.

Guralnik JM, Fried LP, Salive ME. (1996) "Disability as a public health outcome in the aging population". Annu Rev Public Health.;17:25-46

Health Canada (1999). Innovations and Best Practices in Continuing Care for Seniors. Ottawa Ontario: Health Canada.

Holicky, R. (1996). "Caring for the caregivers: The hidden victims of illness and disability". Rehabilitation Nursing, 21, 247-252.

Isaacson Kailes J, (1998) Dissemination Specialist, Rehabilitation Research and Training Center on Aging with Spinal Cord Injury, Rancho Los Amigos National Rehabilitation Center 7601 East Imperial Highway, Downey, California 90242 http://www.jik.com/awdrtcawd.html

Krause JS. (1998). "Aging and life adjustment after spinal cord injury". Spinal Cord. May;36(5):320-8.

Kemp, B. J. and Campbell, M. (1993). Health, functioning and psychosocial aspects of aging with disability. Final Report. Rehabilitation Research and Training Center on Aging. Downey, CA.: Rancho Los Amigos Medical Center.

MacLellan, Marlene and Deborah Norris (2002). "Age-Related Transitions: Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities". Halifax, Nova Scotia: Nova Scotia Centre on Aging, Mount St. Vincent University.

McColl, M. A. and Rosenthal, C. (1994). "A model of resource needs of aging spinal cord injured men". Paraplegic, 32, 261-270.

McColl MA, Arnold R, Charlifue S, Glass C, Savic G, Frankel H. "Aging, spinal cord injury, and quality of life: structural relationships". (2003) Arch Phys Med Rehabil. 2003 Aug;84(8):1137-44

McColl MA. (2002) "A house of cards: women, aging and spinal cord injury". Spinal Cord. Aug;40(8):371-3.

McColl MA, Rosenthal C (1994). "A model of resource needs of aging spinal cord injured men". Paraplegia. Apr;32(4):261-70.

McNeal, D., N. Somerville and Wilson, D. (1996). Use of technology services to maintain employment among people aging with a disability. Final Report on the Rehabilitation Research and Training Center on Aging with Disability. Rehabilitation Research and Training Center on Aging with Disability, Rancho Los Amigos Medical Center, Downey, CA.

McNeal, D., N. Somerville and Wilson, D. (1996). Use of technology services to maintain employment among people aging with a disability. Final Report on the Rehabilitation Research and Training Center on Aging with Disability. Rehabilitation Research and Training Center on Aging with Disability, Rancho Los Amigos Medical Center, Downey, CA.

Olsen, R.V. and Hutchings, B.L. (1998). Issues and concerns of people aging with a developmental disability. Presented at the American Society on Aging Conference, San Francisco, CA.

Penning, M.J., Chappell, N.L., Stephenson, P.H., Rosenblood, L., and Tuokko, H.A. (1998). Independence among Older Adults with Disabilities: The Role of Formal Care Services, Informal Care giving and Self-Care, Final Report submitted to NHRDP.

Penninx BW, Guralnik JM, Bandeen-Roche K, Kasper JD, Simonsick EM, Ferrucci L, Fried LP. "The protective effect of emotional vitality on adverse health outcomes in disabled older women". J Am Geriatr Soc. Nov;48(11):1525-6.

Pentland W. , Walker J., Minnes P., Tremblay M., Brouwer B. & Gould M. (2002) "Women with spinal cord injury and the impact of aging August 2002", Volume 40, Number 8, Pages 374-387

Reinhardt, J. (1996). "The importance of friendship and family support in adaptation to chronic vision impairment". Journal of Gerontology: Psychological Sciences, 51, 268-278.

Richards, J. S., and Shewchuk, R. M. (1996). Caregivers of persons with spinal cord injury: A longitudinal investigation. Research Update: Annual Publication of the Spain Rehabilitation Center, University of Alabama at Birmingham.

Weitzenkamp DA, Gerhart KA, Charlifue SW, Whiteneck GG, Savic G. (1997) "Spouses of spinal cord injury survivors: the added impact of care giving". Arch Phys Med Rehabil. Aug;78(8):822-7.