

**A Concept Paper on
Issues Concerning Seniors with Disabilities
and
Comments on Indicators Proposed by
ODI for *Advancing Inclusion 2005***

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Canadian Council on Social Development (CCSD)

309 Cooper St., 5th floor, Ottawa, ON K2P 0G5
◆ Phone: 613-236-8977 ◆ Fax: 613-236-2750
◆ Internet: www.ccsd.ca ◆ E-mail: council@ccsd.ca

Introduction

This short ‘concept paper’ is intended to stimulate the discussion of ideas and the development of reporting options in support of the 2005 edition of *Advancing the Inclusion of Persons with Disabilities* (Office for Disability Issues). For the 2005 edition of *Advancing Inclusion*, ODI has announced plans to focus some sections on seniors and to organize the population of seniors with disabilities into two separate groups: ‘those who are ageing *with* a disability’ and ‘those who are ageing *into* a disability’. Given the differences between the literature on ‘seniors/ageing’ and the literature on ‘disability’, this may be a ‘natural’ division and one well-suited to future challenges in defining and operationalizing ‘disability’. This paper is divided into three sections.

In Section I, we provide a summary discussion of the impact of an ageing population, including a brief introduction to the demographic changes anticipated in the Canadian population in the coming years, the implications of these changes for our population of persons with disabilities, and some of the issues that may need to be addressed as a result. In Section I, we also raise the issue of the definition of disability—in particular, we introduce some of the tensions that might arise from the anticipated increases in the numbers of seniors with disabilities. The literature on disability differs somewhat from that on seniors and ageing. As well, the two groups (persons with disabilities and seniors), despite a tremendous overlap, often operate within different cultural contexts. Finally, the two groups often access different resources and programs for very similar supports and services. We conclude our discussion in Section I with some ideas regarding important factors that might be considered when identifying potential ‘cleavages’ within the population of seniors with disabilities.

In Section II, we provide a methodological discussion of some possibilities for examining different groups of seniors with disabilities and developing profiles. We address the feasibility of data sources such as PALS, the CCHS, the NPHS, and GSS Cycle 16 in terms of identifying different sub-populations of seniors with disabilities. We introduce a conceptualization of disability for this group which recognizes age, age of disability onset, and underlying cause (in particular “natural ageing” as opposed to other causes). We believe that there are important differences between those who are ageing *with* a disability and those who are ageing *into* a disability. However, we also believe that among those ageing *into* a disability there is likely to be a further division worth considering—those ageing fairly slowly into disability (where the underlying cause is considered the natural ageing process) and those ageing more suddenly into disability (where the underlying cause is an illness or accident, for example).

Finally, in Section III, we provide brief comments on some of the indicators proposed by ODI.

Section I: The Implications of an Ageing Population on Disability

A. *The statistics on ageing:*

The significance of Canada's ageing population to the study of disability cannot be ignored. According to Statistics Canada (Cansim Data, 2003), the number of Canadians aged 65 and older in the total population will nearly double from 3,935,000 in 2001 to a projected 7,753,000 by 2026. If we look only at older seniors, we find that there were about 444,000 Canadians aged 85 and older in 2001; Statistics Canada estimates that this figure will likely grow to 930,000 by 2026 (Statistics Canada, Cansim Data, 2003). This projected increase in the number of seniors is not expected to be balanced by a similar increase in younger persons. The proportion of persons aged 65 and older in the total population is expected to rise from 12% in 2001 to 21.5% in 2026 (Statistics Canada, Cansim Data, 2003). These projections are of particular concern to anyone involved in the study of disability since it has been well established that the rate of disability increases with age. In 2001, for example, the disability rate in Canada among adults aged 15 to 64 was 9.9% (PALS, 2001). Among those aged 65 to 74, the disability rate was 31.2%, and among those aged 75 and older, the disability rate was 53.3%. Given these two trends – an ageing population and increasing rates of disability with age – the overall rate of disability in Canada is likely to increase fairly dramatically over the next 25 years and seniors will play a key role in that rise.¹

B. *Tension between the literature on ageing and the literature on disability:*

Despite the obvious overlap between the study of 'seniors/ageing' and the study of 'disability', there has often been a different focus when examining these two areas. Much of the literature on seniors and ageing has focussed on health, in particular examining issues related to illness and health care. In Canada, for example, the National Advisory Council on Aging was created to assist and advise the Minister of Health on issues related to the ageing of the Canadian population—there is an obvious health focus.² The Canadian Initiative on Frailty and Aging "seeks to improve the understanding of the causes and trajectory of frailty, promote wellness and improve the quality of health care and life for older Canadians".³ The World Health Organization adopted an *International Plan of Action on Ageing* in 2002 in response to world population ageing with the goal of "optimizing opportunities for health, participation and security in order to enhance quality of life as people age".

Ageing is typically viewed as being multi-dimensional. It is most often associated with some concept of frailty; although, there appears to be no true consensus regarding a

¹ See also: forthcoming *Age Waves* (prepared for CARP by the Canadian Council on Social Development <http://www.50plus.com/carp/files.cfm>); *Interim Report Card, Seniors in Canada 2003* (National Advisory Council on Aging http://www.naca-centa.ca/report_card2003/rptcard2003_index_e.htm); *Ageing and Health* (World Health Organization <http://www.who.int/hpr/ageing/>)

² <http://www.naca-centa.ca/>

³ <http://frail-fragile.ca/e/index.htm>

definition of frailty. “Frailty is an emerging, controversial and enigmatic concept. There is agreement that frail older adults are vulnerable and at high risk for a range of adverse health outcomes (acute and chronic illness, falls, disability, mortality) . . . ⁴ The Canadian Initiative on Frailty and Aging describe one model of ageing as a “dynamic complex process” and an “interaction of biological, psychological, cognitive and social factors”. In a very similar model of ageing, The Victorian Accommodation & Ageing Committee (Australia) considers three dimensions of ageing: “physiological changes, psychological changes and/or social expectations”.⁵ The physiological changes are linked to some notion of frailty (“reduced stamina, less efficient circulation”, “vision and hearing impairments, increasingly frail bones and increased risk of chronic disease and medical problems”). Psychological changes can include changes to “motivation, learning and personality”. As well, “dementia, depression and personal loss” can produce psychological changes. Social expectations are rooted in culture and can dictate how individuals act when they enter old age. In the literatures on ‘ageing’, disability is typically viewed as a potential, negative outcome of ageing—something that people ‘age into’. In addition to frailty, illness and disease are associated with ageing—certain illnesses/diseases being linked with old age (Alzheimer disease, Parkinson disease, arthritis, etc.) and others considered to be a risk of frailty. Regardless of the definition of frailty or the number of dimensions that are considered to be a part of ageing, the literature ultimately revolves around ‘health’.

The disability literature, on the other hand, has evolved from a focus on health/illness to a focus on ‘activity limitation’ and on social constructions of disability while being strongly influenced by the disability rights movement. As noted by ARCH: A Legal Resource Centre for Persons with Disabilities⁶: “Traditionally, disabilities were viewed through a medical lens only, and defined as a 'health problem' or 'abnormality' that must be cured. . . . Most people are familiar only with this outmoded "medical model" of disability . . .” ARCH further notes the adoption of a “social model” of disability by the Supreme Court of Canada:

In *Mercier*, the Supreme Court of Canada adopted a *social model* of disability. As described by Justice L'Heureux-Dube at paras. 77 and 79, “[b]y placing the emphasis on human dignity, respect and the right to equality rather than a simple biomedical condition, this approach recognizes that the attitudes of society and its members often contribute to the idea or perception of a 'handicap' [the term used in the Quebec statute at issue]. In fact, a person may have no limitations in everyday activities other than those created by prejudice and stereotypes... Thus, a 'handicap'

⁴ <http://www.frail-fragile.ca/docs/Background-CIFA.pdf>

⁵ <http://www.acrod.org.au/divisions/vic/thirdage.doc>

⁶ ARCH: A Legal Resource Centre for Persons with Disabilities is a Canadian specialty legal aid clinic dedicated to defending and advancing the equality-rights of persons with disabilities. <http://www.archlegalclinic.ca/>

may be the result of a physical limitation, an ailment, a social construct, a perceived limitation or a combination of all of these factors."

The Supreme Court expanded upon this model in *Granovsky* at paras. 29-30, stating that there are three aspects to disability: physical or mental impairments; functional limitations, whether real or perceived, and the "problematic response of society to th[e individual's] condition. A proper analysis necessitates unbundling the impairment from the reaction of society to the impairment, and a recognition that much discrimination is socially constructed."

The social model recognizes that functional limitations associated with disability are often not intrinsic to an individual, but are the consequence of socially created *barriers*

Within the disability community, in Canada and around the world, there has been a rejection of the 'medical model' of disability and a general acceptance of the 'social model' approach. While disability is widely conceptualized within a 'social model', it is more difficult to operationalize it in those terms in order to provide concrete data to monitor progress and provide indicators of problem areas that need attention. In Canada and in many other countries around the world, survey data are typically gathered using a methodology that relies on 'activity limitations' to operationalize disability. 'Activity limitations' are a little bit 'medical' and a little bit 'social'. There is room for interpretation. However, the understanding of 'activity limitations' as a proxy for disability is heavily steeped in a 'social model' or 'rights based perspective'.⁷

There are a number of sources which attempt to combine both ageing and disability. These sources might be organized into at least two different strands. One strand is situated within the literature on ageing and views disability as a potential negative consequence of the ageing process (as noted earlier); within this strand, the focus is on persons ageing *into*

⁷ For various sources on the definition of disability internationally and in Canada: *New Zealand Disability Strategy, 2001* (Office for Disability Issues, New Zealand: <http://www.odi.govt.nz/publications/nzds/>); Australian Institute of Health and Welfare, Functioning and Disability website (www.aihi.gov.au/disability/index.cfm) ; European Union Disability Strategy, 1993 (http://europa.eu.int/comm/employment_social/soc-prot/disable/strategy_en.htm) ; The Standard Rules on Equalization of Opportunities for Persons with Disabilities (<http://www.nottingham.ac.uk/law/hrlc/hrnews/march96/disab.htm>) ; Disabled Peoples' International, *Position Paper on the Definition of Disability* (<http://v1.dpi.org/lang-en/resources/details.php?page=74>) ; *What Does Disability Mean?* Catherine Frazee, Abilities Magazine, Issue 38, Spring 1999, also on EnableLink (<http://www.enablelink.org/include/article.php?pid=&cid=&subid=&aid=770>) ; CAILC (http://www.cailc.ca/CAILC/text/whatisil/diagram1_e.html) ; *Disability Rights Commission, UK* (<http://www.drc-gb.org/knowyourrights/definition.asp>) ; <http://www.umich.edu/~uminds/disability-definition.html> ; *The Definition of Disability*, by Deborah Kaplan, Director of the World Institute on Disability (<http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm>) ; <http://www.arts.ualberta.ca/cjscopy/reviews/difdis.html> ; <http://www.disabilitykar.net/pdfs/perspectives.pdf>; http://secure.cihi.ca/cihiweb/en/downloads/icf_jun02_NACC2002_e.pdf .

disability. There is often a rejection of the introduction of the social model of disability into studies of ageing⁸

Another strand, gaining popularity, tends to focus heavily on individuals ageing *with* a disability. Margaret Campbell (Research Director, Rehabilitation Research and Training Center on Aging, Rancho Los Amigos Medical Center) refers to the study of ageing with a disability as a “hot topic”.⁹ The primary focus of this literature is on persons with life-long or early-onset disabilities who are ageing; however, also included are those with “mid- to later-life onset of disability, such as stroke”. She describes two approaches to studying ageing with a disability: the ‘rehabilitation perspective’ and the ‘life course perspective’. The ‘rehabilitation perspective’ is described as building upon the World Health Organization’s ICIDH model. This model views disability as a functional limitation, but fails to provide “an integrated framework that combines the bio-psycho-social theories of aging and adult development from gerontology with the disability models and functional assessment tools of medical rehabilitation”¹⁰ The ‘life-course perspective’ has been proposed as a solution to this problem. As explained by Campbell:

Within this framework, the long-term effects of disability are seen as a complex process involving the intersection of individual or chronological aging, social aging, and historical time, all of which are superimposed upon the unique features of the ‘disability timeline.’¹¹

The term ‘life course approach’ seems to be gaining in popularity and has been adopted by researchers in a variety of countries around the world.¹² However, there seem to be a number of conceptualizations of ‘life course’; and, as with the concept of frailty, it is difficult to find a consensus and to find a coherent operational definition. What is clear, however, is that chronological age alone may be inadequate to determine who is ‘ageing’ and that time of onset of disability can be critical in determining social identification.

In *Advancing the Inclusion of Persons with Disabilities* (2002 and 2004), the difficulties in defining ‘disability’ are noted. It is noted that the International Classification of Functioning, Disability and Health (ICF) may offer a useful framework for future research in the area of disability. As noted in *Advancing the Inclusion* (page 12, 2004): “A framework of the World Health Organization, the ICF combines the major models of disability. It recognizes individual impairments and health conditions, as they interact with

⁸ Oldman, Christine. “Later Life and the Social Model of Disability: A Comfortable Partnership?” *Ageing and Society* (2002, 22: 791-806.

⁹ http://codi.buffalo.edu/graph_based/aging/conf/life

¹⁰ <http://www.usc.edu/dept/gero/RRConAging/ALTD.html>

¹¹ <http://www.usc.edu/dept/gero/RRConAging/ALTD.html>

¹² *From Womb to Tomb, Disability Social Policy and the Life Course*, by Mark Priestly (<http://www.leeds.ac.uk/disability-studies/projects/lifecour.htm>) ; *Aging with a Disability, A Life Course Perspective*, by Margaret Campbell (http://codi.buffalo.edu/graph_based/aging/conf/life) ; *Symposium on Disability and the Life Course*, by Mark Priestly (http://www.dsqsds.org/articles_pdf/2003/Spring/dsq_2003_Spring_02.pdf) ; http://policyresearch.gc.ca/page.asp?pagenm=v7n2_art_16 .

environmental factors, as either facilitators or barriers to the participation of persons with disabilities.” Yet, this framework does have an undeniable focus on health and during the 8th North American Collaborating Centre Conference on ICF, in 2002, there was a call for the ‘placement of disability within the overall framework of health’. This focus is contrary to the social model of disability embraced by so many of the organizations within the disability community in Canada.

Among seniors with disabilities in Canada, particularly older seniors, their disability was acquired later in life. For example, among the oldest seniors with disabilities (aged 85 and older), 71% reported disability onset *after* age 74 (11% reported onset between age 65 and 74 and 18% reported onset before age 65). Among older seniors aged 75 to 84, 31% reported disability onset after age 74 (39% reported onset between age 65 and 74 and 30% reported onset before age 65). Among young seniors (aged 65 to 74), 32% reported onset after turning age 65 with 68% reporting onset before age 65 (36% reported onset within the decade before turning 65).¹³

As the population ages, there will likely be an increasing proportion of disabled persons who might be thought of as having ‘aged *into* disability’. These individuals may be more likely to identify with seniors and issues related to ageing in general than with the disability community. Those who have aged *with* a disability may be more likely to identify with the disability community. These differences could, potentially, create tensions within the ageing population. We believe that it is essential that the 2005 report on disability not lose the focus on disability.

C. Conceptualizing seniors with disabilities—important factors:

When examining the impact of an ageing population on issues related to disability, it is important to keep in mind that the expected increase in the number and overall proportion of seniors with disabilities does not mean that there will be a large homogenous group of older disabled persons. There is likely to be much diversity within this group. A number of factors are likely to be important in determining the important cleavages that need to be identified. Based upon a summary review of the literatures on ageing and disability, we propose the consideration of at least three key factors: the ***age or state of ageing*** of the individuals; the ***age of onset of the disability***; and the ***underlying cause of the disability***.

Age or state of ageing--when does ageing begin? The age of the individual is, obviously, central to the intended focus on seniors with disabilities. However, this may not be as simple as focusing on persons with disabilities aged 65 and over. There are a number of issues that need to be considered. It may be wise to consult the stream of the literature which focuses on a ‘life course’ approach. While the term “life course approach” has been adopted by researchers in a variety of countries around the world, there appear to be a number of conceptualizations of “life course” expressed in the literature and a great deal of

¹³ Percentages calculated by the CCSD using PALS 2001.

work to be done in the area of operationalizing these concepts. Nonetheless, this literature provides some valuable ideas when it comes to examining seniors with disabilities. In particular, it calls into question the meaning of ‘ageing’. Going beyond the concept of chronological age, ageing should be viewed in a multi-dimensional fashion. In *Towards a Positive Third Age for People with Disabilities*, 2002, the Victorian Accommodation & Ageing Committee considers three dimensions of ageing: “physiological changes, psychological changes and/or social expectations”. The choice of viewing seniors as persons aged 65 and older fits squarely within the dimension of ‘social expectations’. Age 65 is defined as the entry point into the ‘senior years’ both culturally and in terms of social policy and program entitlements. However, some of the literature on ageing (particularly with respect to disability) cautions against a rigid adherence to age 65 as the portal into ageing.

There is a growing body of research which provides evidence that the physiological and psychological changes associated with ageing (such as increased frailty, decreasing energy levels, changes in motivation and emotional outlook) occur earlier for certain groups of individuals and may occur later for others. Margaret Campbell (1996), for example, outlines two populations likely to experience early onset of ageing (in terms of physiological changes): “those aging with developmental or early-life onset of disability, including cerebral palsy, mental retardation, polio and multiple dystrophy” and “those aging with young adult onset of disability such as spinal cord injury, traumatic brain injury and rheumatoid arthritis”. She notes that an estimated 5 – 10 million Americans are ageing within these two populations and will experience the complications of ageing sooner than the general population. The Australian Institute of Health and Welfare in *Disability and Ageing, Australian Population Patterns and Implications*, 2000, (page 38-43) describes findings from a variety of countries indicating that the ‘ageing process’ can begin in the 30s, 40s, and 50s for individuals with certain types of developmental disabilities (such as Down syndrome), as well as for individuals with early spinal cord injuries and polio. As well, consistent findings in Australia, the U.S.A, and the U.K. indicate that individuals with cerebral palsy experience physiological and psychological symptoms of ageing earlier than average.

These findings need to be considered in any comparative focus of seniors ageing *with* a disability and those ageing *into* a disability. Adhering simply to chronological age (i.e., 65) to define ‘seniors’ may fail to capture important groups of individuals ageing *with* a disability. While it would be difficult to completely eliminate the role of chronological age in the operationalization of seniors ageing *into* and *with* a disability, it would be prudent to expand the focus to include ‘near seniors’—particularly when identifying those ageing *with* a disability. Similarly, some individuals aged 65 and over may not ‘fit’ our traditional view of ‘seniors’ (for example, they may opt to continue labour force participation and may display none of the physical, psychological, or social characteristics associated with ageing). As the size of this age group grows in the population, methodologists may have to develop new strategies to reflect this.

Further complicating this discussion around chronological age and disability are two additional points that come up in the literature. First, there is now an increased life expectancy among certain populations with early onset disabilities. While some of these individuals may enter the ageing process earlier than most (as noted in the previous discussion), they may also be more likely to live longer than in previous generations due to medical advances and improvements to social programs (Australian Institute of Health and Welfare, 2000: 38). When considering the impact of an ageing society on disability, this must be recognized as it has implication for program planning.

Second, it may be wise to also consider the situation of ‘near seniors’ and ‘young seniors’ without disabilities who may be vulnerable to disability as they enter into natural ageing. As noted by Todd McDonald and Henry Harder of the University of Northern British Columbia (“Older Workers and Disability Management” in the *International Journal of Disability, Community & Rehabilitation*, Volume 3, No. 3), the ageing population has serious implications for Canada’s workforce making older workers and those over age 65 an important pool of labour. There will likely be an increased effort to encourage older workers to continue working. However, ageing can make older workers vulnerable to certain types of disabling injuries. While younger workers have a higher incidence of injuries on the job, older workers, when they are injured, are more likely to sustain a long-term or disabling injury. The implications of such a trend (near seniors and young seniors entering into disability prematurely due to extended labour force involvement) should also be considered in a focus on seniors with disabilities.

Age of onset of disability: Returning to the discussion of factors that impact on how we define seniors with disabilities, it is important to focus on differences in age of onset of disability. If there is to be a comparison of persons ageing *with* a disability and persons ageing *into* a disability, age of onset is obviously an important element in defining these two groups. As already mentioned, certain types of disabilities with early onset can result in early ageing—somewhat complicating our conceptualization of these two groups. But there are additional reasons to be concerned about age of onset of disability. Age of onset of disability can have a significant impact on the environment that one faces when ageing. There are implications for the availability of resources as well as one’s social identity. Those with lifelong disabilities or early onset disabilities may be more likely to enter into ageing with very different life experiences than those ageing into a disability later in life: less likely to have had significant labour force attachment, likely to have lower accumulated assets and lower levels of income, less likely to have a spouse and children (i.e., potential informal caregivers), less likely to have secure housing, and likely to have a more restricted social network (Victorian Accommodation & Ageing Committee). These differences can have an obvious impact on how these two groups experience ageing.

Culturally, these groups may be quite different as well. Those ageing *with* a disability may be more likely to identify with the disability community than with seniors’ groups. This

might result in a preference for turning to agencies associated with disability for assistance (The Australian Institute of Health and Welfare in *Disability and Ageing, Australian Population Patterns and Implications*, 2000). It might also result in a pattern of accessing programs for persons with disabilities and a reluctance to access programs for seniors. On the other hand, those ageing *into* a disability may be more likely to identify with seniors' groups and be reluctant to turn to disability organizations. These differences have implications for service delivery, communication, and overall well-being.

Underlying cause of disability: A third factor which impacts on how we might define important cleavages among seniors with disabilities is the underlying cause of disability. As already mentioned, certain underlying causes of early onset or lifelong disabilities have implications for the ageing process itself. We might also focus on those ageing *into* disability and further sub-divide this group into those *ageing slowly into* disability through natural ageing and those *ageing more rapidly into* disability through illness or accident. While those *ageing more rapidly into* disability may have certain advantages over those *ageing with* a disability in terms of available resources, they may also have more difficulty navigating their way to and through social programs designed for those with disabilities. They may be less likely to find the supports they need within the 'seniors community' with which they have identified but have no prior experience with the disability community. For these individuals, communication barriers may be more significant.

Building upon this discussion, in Section II, we turn to some ideas for conceptualizing different cleavages of seniors with disabilities—we begin an investigation of some potential options for operationalizing existing data sources to provide information for the December 2005 report.

Section II: Methodological Options and Data Sources for the 2005 *Advancing Inclusion*

In order to provide profiles and indicators using quantitative data for seniors ageing *with* disability and seniors ageing *into* disability, a data source which provides information about the time of onset of the disability is essential. While a number of data sources are listed in the proposed chapter outlined for Chapters 4 and 5 (CCHS/NPHS 2002, GSS 2002, PALS 2001) only PALS 2001 provides the information required to establish time of onset of disability in order to separate those ageing *with* a disability from those ageing *into* a disability.

The CCHS: The CCHS contains the new screening questions for disability (those established for PALS 2001). However, there is no follow-up question regarding time of onset. The only options that present for operationalizing persons ageing *into* disability and those ageing *with* disability using the CCHS appear to be those regarding underlying cause (injury, disease or illness, ageing, existed at birth or genetic, work conditions, other). Using this information (from Question RACCG5), one might consider isolating those

whose conditions existed at birth or were genetic to represent a group of individuals with lifelong disabilities. In the sample of 134,072, only 4,315 fall into this category and 3,284 are between the ages of 12 and 54. In the sample of focus (ages 55 and over), the following sample breakdown exists for those with a ‘lifelong disability’ (using this category of this question as a proxy): **530** aged 55 to 64; **178** aged 65 to 69; **133** aged 70 to 74; **97** aged 75 to 79; and **75** aged 80 and over.¹⁴ While this underlying sample size might be considered ‘healthy enough’ to support some analysis, it is essential to understand that only a segment of the population ageing *into* disability would be captured using this as a proxy.¹⁵ This would fail to capture individuals with early or even mid-life onset (not present at birth) who should be categorized as individuals ageing *with* a disability.

One might also isolate those listing “ageing” as the underlying cause of their disability in an effort to develop a proxy for persons ageing *into* a disability. However, this would isolate only a very select group of individuals ageing *into* disability—those with disabilities that might be considered a natural loss of function due to ‘frailty’. The underlying sample size for this is quite ‘healthy’: **1,466** aged 55 to 64; **1,040** aged 65 to 69; **1,381** aged 70 to 74; **1,538** aged 75 to 79; and **2,679** aged 80 and over.¹⁶

While there may be some value in comparing these two select groups of individuals, there remains the dilemma of ‘what to do with the huge number of people found under ‘injury’ and under ‘illness’ (as well as ‘work related’ and ‘other’)’.

The NPHS: The NPHS is one of the only databases to maintain the ‘old screening’ question for disability (similar to that which was used on the Census before 2001 and many other surveys prior to the late 1990s). Presumably, the reason for retaining this ‘old question’ is the longitudinal nature of the NPHS. The NPHS poses problems similar to that discussed for the CCHS in that there is no question directly inquiring about time of onset. There is a question concerning underlying cause (RA_Q5) (although with somewhat different categories: injury at home; injury in sports or recreation; injury in motor vehicle accident; injury work-related; existed at birth; work environment; disease or illness; natural ageing process; psychological or physical abuse; and other).¹⁷ The larger sample size of the CCHS makes it a better choice if one is considering using this question to identify two select groups as noted previously.

However, the NPHS may have one advantage over the CCHS—due to its longitudinal nature, it also inquires about change over time with respect to the disability screening

¹⁴ Weighted counts for this are: **82,570** aged 55 to 64; **23,840** aged 65 to 69; **18,220** aged 70 to 74; **11,490** aged 75 to 79; and **11,990** aged 80 and over (existed at birth or genetic).

¹⁵ These estimates are not ‘in line’ with similar information derived from the PALS.

¹⁶ Weighted counts for this are: **260,440** aged 55 to 64; **145,830** aged 65 to 69; **195,960** aged 70 to 74; **191,960** aged 75 to 79; and **312,840** aged 80 and over (due to ageing). Also note that these estimates are not ‘in line’ with similar information derived from PALS.

¹⁷ Without access to this restricted file, we are unable at this time to provide numbers concerning sample size breakdowns by age.

question itself. If one has access to the longitudinal file of the NPHS across all years, one could identify a population of persons in transition *into* disability.¹⁸ Again, this would involve examining only a very select population, but could prove useful to determine the immediate impact of acquiring a disability due to the reasons listed (i.e., how do those entering into disability due to illness differ from those entering into disability due to accident or ageing, etc.). This would provide no information on persons ageing *with* a disability (except that select group which could be isolated using ‘existed at birth’); however, it might provide some useful information about initial transitions.

The GSS 2002: The GSS 2002 (cycle 16 – Survey on Ageing and Social Support) provides extensive information on many interesting aspects of ageing (including retirement planning, care giving and care receiving, housing, living arrangements, and social contacts). While it contains a series of questions about specific activity limitations (in the area of speech, vision, hearing, mobility, etc.), there is no obvious method of determining time of onset. Even questions regarding how long ago the individual began receiving assistance from a long term care provider (for example, CR_FR_Q300) provide only a very short-term frame of reference (2 years or more being the longest period). It is difficult to understand how ODI intends to identify the two populations outlined (those ageing *with* disability and those ageing *into* disability) using the GSS 2002. It would be useful for providing general information on the age group of focus that is not found elsewhere; however, it isn’t clear that the groups outlined can be operationalized.

The GSS 2002, however, does provide some very useful information on care giving that isn’t found elsewhere. This can be useful for context. Much information of interest has already been published in this area and could prove useful in the 2005 report (see, for example, an article by Kelly Cranswick, Statistics Canada, *Caring for an Ageing Society*).¹⁹ In particular, much can be made of the findings that older individuals with disabilities or long term health problems are providing a surprising amount of care to others.

The PALS 2001: PALS 2001 provides information on the time of onset of disability as well as the underlying cause of the primary and secondary disability. While there are concerns regarding sample size for some groups and challenges regarding how to address the ‘life course approach’, PALS 2001 contains enough elements that it could be used to provide data on the two populations outlined with the possibility of even further divides along the lines discussed in the previous section.

In the previous section, we proposed that the identification of important cleavages of seniors with disabilities (with respect to those ageing *into* disability and those ageing *with* disability) depends upon at least three factors: the ***age or state of ageing*** of the

¹⁸ However, experience with the longitudinal SLID and LMAS suggest that this may not be a simple task due to the rather high rate of individuals who seem to be involved in the ‘turnover phenomenon’.

¹⁹ <http://www.statcan.ca/english/freepub/89-582-XIE/>

individuals; the *age of onset of the disability*; and the *underlying cause of the disability*. Put more simply, if we want to look at seniors ageing *with* a disability and seniors ageing *into* a disability, we need to be able to identify what we mean by ‘seniors’, whether they had the disability before becoming seniors or are acquiring it as seniors, and if the disability is considered to be a ‘natural part of ageing’ (this factor actually allow us to further sub-divide our population ageing *into* disability into those whose disabilities might commonly be considered the natural impact of frailty and those being plunged more suddenly into disability as a result of illness or accident).

As outlined in Section I, it may be ill advised to select the population of seniors by simply examining those aged 65 and over. While a ‘life course approach’ would be ideal, operationalizing it is problematic. Given data limitations, we cannot simply abandon chronological age as a method of identifying the ‘senior or ageing population’. However, we propose that we examine age ranges beginning with near seniors aged 55-64; 65-74; 75-84; and 85+. Within these ranges, we can further sub-divide based upon onset of disability and underlying cause information to attempt to capture a quasi ‘life course approach’.

Age of onset of disability is important in order to determine who is ageing *with* or *into* disability. Those ageing with life-long or early-onset disabilities have been the focus of much of the international research in this area. The treatment of those with mid-onset is less established. Following a life course approach, the importance of onset is really somewhat relative to where the individual is in their life-course. For this reason, we investigated a number of options for categorizing individuals to identify the populations in question (seniors ageing *into* and *with* disabilities). The following categories were developed²⁰:

Ageing with a disability:

- (1) aged 55-64 and disabled before age 35 (near seniors with early-onset – estimated at **96,780** persons according to PALS 2001)
- (2) aged 55-64 and disabled between 35-54 (near seniors with mid-onset - estimated at **331,760** persons according to PALS 2001)
- (3) aged 55-64 and disabled between 55-64 (near seniors with recent-onset - estimated at **149,020** persons according to PALS 2001)
- (4) aged 65-74 and disabled before age 55 (young seniors with early-onset - estimated at **191,200** persons according to PALS 2001)
- (5) aged 65-74 and disabled between 55-64 (young seniors with mid-onset - estimated at **220,000** persons according to PALS 2001)

Ageing into a disability:

- (6) aged 65-74 and disabled between 65-74 (young seniors with recent-onset - estimated at **194,720** persons according to PALS 2001)

²⁰ Estimates calculated by CCSD using PALS 2001.

Ageing with a disability:

- (7) aged 75-84 and disabled before age 55 (older seniors with early-onset - estimated at **76,170** persons according to PALS 2001)
- (8) aged 75-84 and disabled between 55-64 (older seniors with mid-onset - estimated at **90,270** persons according to PALS 2001)

Ageing into a disability:

- (9) aged 75-84 and disabled between 65-74 (older seniors with onset as young seniors - estimated at **213,370** persons according to PALS 2001)
- (10) aged 75-84 and disabled after 74 (older seniors with onset as older seniors - estimated at **171,360** persons according to PALS 2001)

Ageing with a disability:

- (11) aged 85+ and disabled before 65 (oldest seniors with early to mid-onset - estimated at **31,850** persons according to PALS 2001)

Ageing into a disability:

- (12) aged 85+ and disabled between 65-74 (oldest seniors with onset as young seniors - estimated at **19,350** persons according to PALS 2001)
- (13) aged 85+ and disabled after 74 (oldest seniors with onset as older seniors - estimated at **127,260** persons according to PALS 2001)

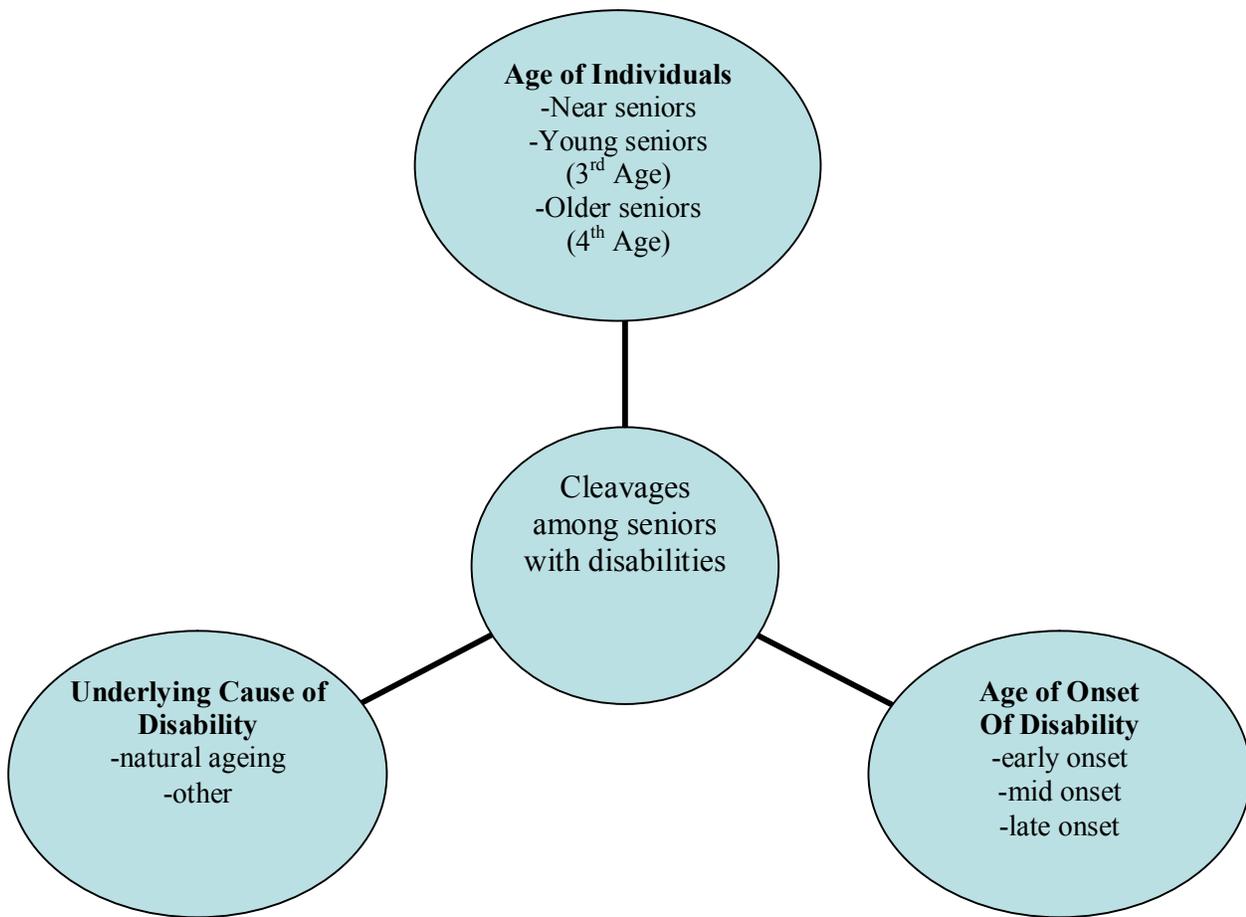
While the estimates provided here all meet release guidelines (Statistics Canada) without cautions attached, not all these categories are ‘viable’ in terms of providing estimates that can be used in an analysis with other characteristics. However, options for collapsing these categories can be considered—this should be dictated both by underlying sample size and important theoretical conceptualizations of the populations under investigation.

An additional factor was introduced into our preliminary analysis: underlying cause of disability. While a number of causes are provided in the PALS (similar to the CCHS) for both the primary and secondary disabilities (most primary and secondary causes are the same and certain other particular ‘combinations’ tend to occur more often than not)²¹, our initial investigation revolved around primary cause. The motivation for including this factor was to separate out those individual who were ageing *into* disability somewhat slowly by virtue of the natural ageing process. This information could also be used to identify those ageing *with* a disability (primary cause not ageing) who are also experiencing secondary disabilities due to ageing (possibly to capture the early ageing of those with early onset or lifelong disabilities). We dichotomized underlying cause into:

²¹ For example, of those who listed ‘illness’ as the underlying cause of their primary disability and had a secondary disability, over 58% listed ‘illness’ as the secondary cause. Among those listing ageing as the primary cause who had a secondary disability, 46% listed ageing as the secondary cause as well. Rarely do we find the combination of ‘existed at birth’ and underlying cause due to ‘natural ageing’. The combination of “due to ageing” and “due to illness” is the most likely combination where primary and secondary causes are not the same.

‘ageing’ and ‘not ageing’. The addition of this third factor into our earlier groupings can provide a further basis for collapsing those categories. Initial data runs suggest that all these factors may be important in terms of determining who has a requirement for supports and services and who has an unmet need. However, preliminary analysis indicates that age of onset data must be combined with ‘underlying cause data’ (i.e., using the dichotomy of ‘due to ageing’ and ‘not due to ageing’) in order to separate seniors into meaningful cleavages (when examined separately, the impact of age of onset and of underlying cause is often obscured). The challenge at this point is to collapse these data into meaningful categories which can provide ‘releasable’ estimates. While a typology based upon all three factors ultimately provides valuable data that can help us understand seniors with disabilities and provide valuable information for program and policy development, care must be taken when arriving at a final functional model. The December 2005 report may not be the appropriate vehicle to introduce these complexities. If only one of these three factors is to be used to divide up the population of seniors with disabilities, present age (at the time of the survey) provides the most explanatory value and is the easiest to present to a wide audience.

The following diagram depicts this overall model:



Section III: Comment on Selected Indicators and Overall Direction of 2005 Report

Overall, given the demographic changes facing Canada, a focus on seniors in the 2005 report is an excellent idea. Care needs to be taken, however, to provide a solid ‘disability’ angle rather than a focus on health which is found in so many other publications on ageing and seniors (i.e., this is the place to ‘come at it’ from a solid disability perspective and not replicate what is found elsewhere). However, the importance of health for this population cannot be denied.

Chapters 4 and 5 appear to follow a nearly identical set of indicators for the two groups of seniors targeted by ODI for this report—those ageing *with* a disability and those ageing *into* a disability. In the discussion leading up to the proposal for these two chapters (PART

2), there is mention of a focus on two major ‘age’ groups—‘younger’ and ‘older’ seniors. It is unclear how this was intended to combine with the two groups: ‘ageing *into* a disability’ and ‘ageing *with* a disability’. There may be some suggestions found in Section II that could be used to address this in a quasi ‘life-course’ fashion. Perhaps more in need of explanation is how any source other than PALS can be used to generate data separating those ageing *with* a disability from those ageing *into* a disability. Certainly, the other data sources listed (CCHS, NPHS, GSS Cycle 16) could provide data for ‘younger’ and ‘older’ seniors—but dividing the population on the basis of time of onset can reasonably only be done using PALS (and many, but not all, indicators listed could be generated using PALS).

It is also not clear how each of these indicators (18-19 listed under 3 headings) are to be compared. With the two groups separated into different chapters, a comparison between the two groups on the basis of these indicators might be unwieldy. Perhaps consideration might be given to a chapter design that focuses on indicator groupings and provides a comparison of the two groups (or more) within (rather than the other way around). Without more understanding regarding why these indicators are considered to be important, it is difficult to determine how best to introduce them. It is important to determine from the outset which comparisons are important and why.

In our preliminary investigation of requirements for aids/devices, comparing groups based on the typology presented in Section II (chronological age group, age of onset, and underlying primary cause due to ageing or not), some interesting findings (although not all of them ‘releasable’ without some collapsing as described in Section II) suggested that it may well be useful to make a comparison of different groups with respect to an individual indicator—particularly if the intent is to examine particular program/policy areas and determine how diverse the needs are among the different populations.

Another alternative to be considered might be to increase the number of chapters (reducing the length of each). Chapter 4 and 5 might present a very basic profile of the two groups (those ageing *into* and those ageing *with* disability)—no indicators, just basic profiles using the PALS. This could be supplemented with qualitative data (possibly gathered by a variety of organizations within the community) to provide a feel for each group and their experience with disability. These profile chapters could then be followed by indicator chapters organized by major area (i.e., health, disability supports and income, and others as deemed necessary)—comparing indicators for the different groups and the implications of this for programs and policies.

In terms of the indicator areas themselves, all three have merit. However, it might send a more ‘disability focused’ message to place health indicators somewhere other than first. We believe that disability supports is the most important group of indicators for all populations being studied and would recommend placing it first. Consideration might be given to adding in indicators of unmet need for supports and reasons for unmet need (all of which are available in PALS).

With respect to the proposed health and well-being indicators, it is worth discussing the importance of a number of the indicators listed here. This seems to follow the indicators in the previous report—most of which were taken from the CCHS. There are two issues that should be discussed. First, the focus of these indicators appears to be primarily on level of health rather than aspects of health important to persons with disabilities. The outcome indicators (each related to a different characteristic) are primarily based on the health utility index. We believe that it is important to discuss why this is an important thing to do in a report on persons with disabilities. While the first indicator listed, basic health status, is likely to be less problematic in terms of relevance to the disability community, the others could benefit from a discussion with stakeholders. Second, unless some methodology is developed to permit the identification of those ageing *into* disability and those ageing *with* disability using the CCHS, many of these indicators may not be viable using PALS data. Alternative indicators in the area of health might involve access to health care, prescription drugs, non-prescription drugs, etc. (all available in PALS). Alternative indicators in the area of well-being might involve data on social participation from PALS. In particular, one area that was mentioned fairly often in the literature concerned the size of one's social circle and chances to participate in leisure and volunteer activities. It has been suggested by some that some groups who are ageing *with* a disability may have smaller social circles and fewer chances to participate in other activities. Those ageing slowly *into* disability may be the most likely to have large social circles and opportunities for participation. All these have been considered important factors in well-being and might impact on psychological ageing.

With respect to the indicators on income, all the proposed indicators appear to be important to those in the disability community and those in the senior's community. Food insecurity (available on the CCHS and NPHS) is not available in the PALS. Similarly, information on net worth may be difficult to obtain. These indicators appear to address economic security; however, income is only one side of the equation. For persons with disabilities, increased expenses due to disability also threaten economic security. PALS can be used to provide data on various aspects of costs associated with disability.

Indicators that are suspiciously absent from this list include those related to housing and living arrangements—both of these are listed in the literatures as being critical factors for seniors and for persons with disabilities. Housing and living arrangements may be most critical to those ageing *with* a disability and should be addressed at some level.

Ultimately, the choice of indicators for the 2005 report must address the expectations of the stakeholders—the disability community.