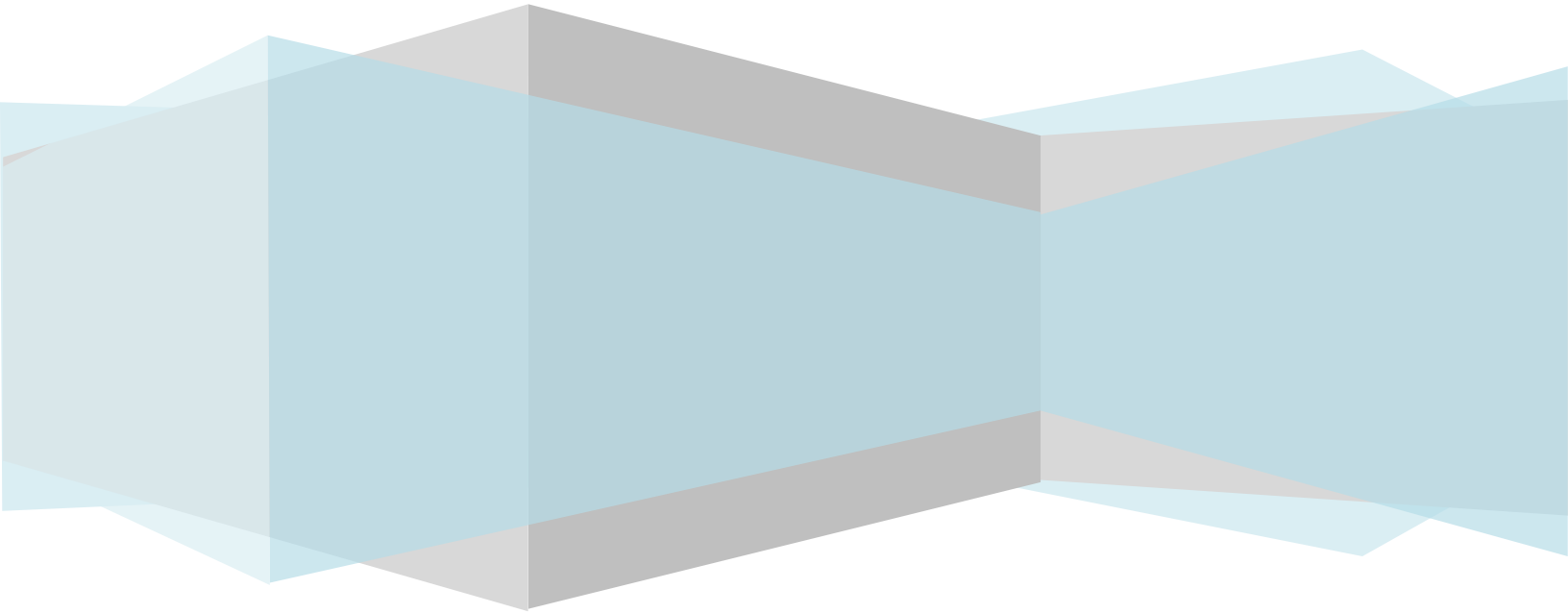
Validation of Research Elements on Episodic, Moderate and Short-Term Disabilities and Employment

Final Report
(Revised)

Adele D. Furrie
Adele Furrie Consulting Inc.



Contents

1. The Objectives of the Research

The mandate of the Federal/ Provincial/ Territorial (F/P/T) Persons with Disabilities Advisory Committee (PwDAC) includes the provision of evidence-based policy advice and options to F/P/T Deputy Ministers (DMs) regarding persons with disabilities. This Committee has developed a three-year research program to examine the labour force participation of, and the effects of income support programs on, persons with episodic, moderate or short-term disabilities. This report covers the first phase of the research and will act as a primer for the next phases. It involves four major activities including the following:

1. validation of the working definitions of the five terms – episodic disability, moderate disability, short-term disability, longer-term sustained employment and intermittent employment;
2. identification of potential sources of administrative data that cover the three sub-populations with disabilities (episodic, moderate and short-term), as well as their employment and income characteristics;
3. validation and refinement of the preliminary research questions for future research studies; and
4. identification of data gaps with suggestions as to how those gaps could be filled.

2. The Research Methodology

The methodology for Phase 1 of the research program is designed to provide the information necessary to identify the information required for Activities 1 and 2 above. The following diagram identifies the sources that are included in the research. The report is structured such that each source forms a section of the report. The details of the methodology used are described within each section as an introduction to that section.

The literature review and input from disability organizations and researchers provide the input to Activity 1 of the research. Information from selected income support programs (CPP-D, EI Sickness Benefits, ODSP and WSIB), along with an overview of Statistics Canada surveys that include the identification of persons with disabilities (Survey of Labour and Income Dynamics [SLID], 2006 Participation and Activity Limitation Survey [2006 PALS], Longitudinal International Adult Survey [LISA], Canadian Community Health Survey [CCHS], and the Canadian Survey on Disability [CSD]) provide the input to Activity 2. The international scan of countries (Ireland, Australia, New Zealand and the United States) and international organizations (European Union [EU], Organization for Economic Co-operation and Development [OECD], and the International Labour Organization [ILO] provides input for both Activities 1 and 2.

Finally, the information found in Activities 1 and 2 will be used to assess the validity of the research questions (Activity 3) that are proposed for the next phases of the research and will also identify any gaps in available data sources (Activity 4).

3. Literature Review

3.1 Objective and Structure of Literature Review

The purpose of this literature review is to validate and provide operational definitions of the five key terms outlined in the RFS: episodic disability, short-term disability, moderate disability, intermittent work capacity/intermittent employment and longer-term sustained employment.[1]

The information presented has been organized as follows:

- methodology
- validation and discussion of each key term
- annotated bibliography

The validation of key terms section contains a chart that includes the reference for each definition and the relevant content as it pertains to employment access (where applicable). Following each quote in the chart is a definitional category shown in brackets to clarify the nature of the information provided. The definitional categories include:

- *complete definition* – the author has developed working definition of the key term that may be used similarly in other sources that provides information on the nature of the disability and the anticipated time period of the disability
- *partial definition* – to suit the purpose of the source material, the author mentions the key term and provides some development of the meaning of the term; however, a portion of the definition is missing
- *reference only* – the author makes a direct mention of the key term without providing a definition of its meaning

"*Relevant context"* is another label in the chart; this label refers to other information that provides a context for the definition.

Following each key term is a discussion section that compares and contrasts the key terms, examining the similarities and differences and where there is definitional overlap and mutual exclusivity between the definitions provided by the authors of the articles. The discussion also includes additional insights from the author of this review.

Finally, the annotated bibliography provides a brief description of the journal articles and other web-based sources that contained relevant definitions or contextual information.

[1] The literature review was researched and written by Melissa Popiel.

3.2 Methodology

The literature review search included reviews of the following:

- academic literature
- grey literature (informally published material not located in academic journals)
- Google Scholar
- Advanced online search
- Provincial/territorial ministry websites

In addition to completing a search of the key terms, combinations of the key terms were also searched, as follows:

- episodic disability and intermittent work capacity
- episodic disability and longer-term sustained employment
- short-term disability and intermittent work capacity
- short-term disability and longer-term sustained employment
- moderate disability and intermittent work capacity
- moderate disability and longer-term sustained employment

A targeted search was also conducted of the ministry websites responsible for income support programming in all 13 Canadian provinces and territories for the presence of relevant definitions of the five key terms.

The terms “work” and “employment” are used interchangeably in this section, and refer to paid employment. In addition, to ensure that the search terms captured the intersections between major project themes, the three “disability” terms were also searched in conjunction with both “employment” and “work”.

The academic search was limited to developed countries, including Canada, the United States, Great Britain, Western Europe and Australia beginning in 2000 through to early 2013. The non-academic search was limited to Canadian content to limit the number of results generated; the time period was limited to the same range as mentioned previously.

The following academic database sources were used to conduct the key term search:

- AIS International (1914 - current)
- Alt-PressWatch (1970 - current)
- ASFA: Aquatic Sciences and Fisheries Abstracts (1971 - current)
- Biological Sciences (1971 - current)
- BioOne Abstracts & Indexes (1998 - current)
- Business Source Complete

- Canadian Newsstand Complete
- Canadian Research Index
- CBCA Complete
- Dissertations & Theses @ Wilfrid Laurier University
- EconLit (1969 - current)
- Environmental Sciences and Pollution Management (1967 - current)
- ERIC (1966 - current)
- GenderWatch
- Index Islamicus (1906 - current)
- International Index to Music Periodicals Full Text (1874 - current)
- MLA International Bibliography (1926 - current)
- Philosopher's Index (1940 - current)
- Physical Education Index (1970 - current)
- PILOTS: Published International Literature On Traumatic Stress (1871 - current)
- Proquest, including the following
    - ProQuest Business Collection (1951 - current)
    - ProQuest Dissertations & Theses (PQDT)
    - ProQuest Dissertations & Theses A&I
    - ProQuest Historical Annual Reports
    - ProQuest Historical Newspapers: The Globe and Mail (1844-2009) (1844 - 2009)
    - ProQuest Historical Newspapers: The New York Times (1851-2009)
    - ProQuest Nursing & Allied Health Source
    - ProQuest Political Science (1985 - current)
    - ProQuest Sociology (1985 - current)
- PsycARTICLES (1894 - current)
- PsycBOOKS (1806 - current)
- PsycINFO (1806 - current)
- RILM Abstracts of Music Literature (1967 - current)
- Social Services Abstracts (1979 - current)
- Sociological Abstracts (1952 - current)
- The Vogue Archive
- Worldwide Political Science Abstracts (1975 - current)

3.3 Validation of the Key Terms

3.3.1 Episodic Disability

SOURCE	DEFINITION
Anderson, J & Brown, G. (2005). HIV & disability insurance in Canada: An environmental scan http://backtolife.ca/EN/research/documents/HIV_Disability_Insurance_Canada_Environmental_Scan.pdf	"Characteristics of lifelong and episodic illness include: uncertainty, unpredictability, and alternating periods of being well/unwell/very unwell." (*partial definition)*
Antao, L., Shaw, L., Ollson, K., Reen, K., To, F., Bossers, A., & Cooper, L. (2013).Chronic pain in episodic illness and its influence on work occupations: A scoping review. *Work*, 44(1), 11-36 doi:http://dx.doi.org.remote.libproxy.wlu.ca/10.3233/WOR-2012-01559	"An illness that is permanent however can result in recurring and unpredictable periods of good health and poor health." Note: In this report, episodic disability and episodic illness are used interchangeably. (*partial definition*)
The Arthritis Society, Episodic Disability and Income Supports http://www.arthritis.ca/document.doc?id=156	"Episodic disabilities can result from lifelong and chronic conditions such as arthritis, HIV/AIDS, multiple sclerosis etc. People with these conditions may experience periods when their condition is controlled or when it may be unpredictably interrupted by periods when the disease worsens." (*complete definition*)
Beveridge S., Craddock, S.H., Liesener, J., Stapleton, M. & Hershenson, D. (2002). Income: A Framework for Conceptualizing the Career Development of Persons with Disabilities. *Rehabilitation Counseling Bulletin*, 45: 195-206doi:10.1177/00343552020450040201	"When considering episodic disabilities … it is important to consider the possible cumulative impact of exacerbations or the progression of episodic disability on the person (e.g., self-efficacy beliefs, work motivation, general endurance, psychological reserve), on the work environment … and on the employer and co-workers." (*reference only; relevant context*)
Boyd, V. (2012). Are some disabilities more equal than others? Conceptualising fluctuating or recurring impairments within contemporary legislation and practice. *Disability & Society*, 27(4)	The experience of episodic disability is "complex" and "unstable". (*partial definition*)

Canadian AIDS Society. (2003) HIV/AIDS as an Episodic Disability: Revising the CPP(D) Program. A Brief Prepared for the Sub-Committee on the Status of Persons with Disabilities http://www.cdnaids.ca/files.nsf/pages/hivasepisodicillness/$file/HIV%20as%20Episodic%20Illness.pdf	"Serious medical conditions that are recurrent, episodic or cyclical – be they different types of cancer, an assortment of musculoskeletal conditions, respiratory infections, multiple sclerosis or schizophrenia." (*partial definition*) "But may not meet the criterion of prolonged for the purposes of CPP disability." (*relevant context*)
Canadian Arthritis Patient Alliance. (2007). Re-examining the Role of episodic disabilities in the workplace, Fall edition http://www.arthritispatient.ca/index.php/resources/re-examining-the-role-of-episodic-disabilities-in-the-workplace/	"An episodic disability is defined as a physical or mental illness that is unpredictably recurrent and impacts on personal ability to actively engage in the social and employment environments. Examples of episodic disabilities include multiple sclerosis, HIV, lupus, hepatitis C and some forms of arthritis, cancer and mental illnesses." (*complete definition*)
Canadian Council on Rehabilitation and Work. ABC's of Disability http://www.ccrw.org/jas/?id=57	"Conditions such as multiple sclerosis, HIV/AIDS, lupus, Hepatitis C, and some forms of mental illness, cancers and arthritis. Features that distinguish episodic disabilities from 'traditional' disabilities are their unpredictability, and alternating episodes and degrees of illness and wellness." (*complete definition*) Periods of illness and wellness "can force people out of the workforce without warning and then resolve to once again allow people to return to work." (*relevant context*)
Canadian Mental Health Association (CMHA) Statement of Common Agenda on Disability, Full Participation and Work http://www.cmha.ca/public_policy/statement-of-common-agenda-on-disability-full-participation-and-work/#.USJdqqUqan8	"In Canada today, many people live with recurrent or episodic disabilities that are characterized by alternating periods of illness and wellness." (*partial definition*)

Canadian Working Group on HIV and Rehabilitation. (2012). Promoting Accessibility to Employment for People Living with Episodic Disabilities http://www.hivandrehab.ca/EN/resources/documents/Promoting_Accessibility_2009-2012_Final_Report.pdf	"Episodic disabilities are lifelong conditions that are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and frequency from one person to another. Some common examples of episodic disabilities include multiple sclerosis, diabetes, HIV/AIDS, hepatitis C, chronic fatigue syndrome, migraines, chronic pain, and some forms of arthritis, cancer and mental illness." *(complete definition)*
Disabled Women's Network (DAWN) Canada, (2011). Women with Disabilities and Abuse: Access to Supports – Report on the Pan-Canadian Focus Groups. Canadian Women's Foundation http://www.canadianwomen.org/sites/canadianwomen.org/files/PDF%20-%20VP%20Resource%20-%20DAWN-RAFH%20Canada%20-%20Focus%20Groups%20WWD_201.pdf	"Increasing numbers of Canadians are living with episodic disabilities, including multiple sclerosis, arthritis, cancer, HIV/AIDS, diabetes and some forms of mental illness…A person can simultaneously live with both permanent and episodic disabilities; however, there are clear distinctions. An episodic disability is marked by fluctuating periods and degrees of wellness and disability. In addition, these periods of wellness and disability are unpredictable." (*complete definition*) "As a consequence, a person may move in and out of the labour force in an unpredictable manner." (*relevant context*)
1) Episodic Disability Network (EDN). (2011). Statement of Common Agenda on Episodic Disability, Full Participation and Employment http://www.hivandrehab.ca/EN/episodic_disabilities/documents/StatementofCommonAgenda10January2011FINAL.pdf	"Because it is often difficult to predict when episodes of disability will occur, how severe they will be and how long they will last, some people must leave the workforce without warning for indeterminate lengths of time, resulting in serious impacts on health, employment participation, income stability, coordination of care and social inclusion. There are also many systemic and practical barriers that prevent people with episodic disabilities from participating in the labour force, in communities and in society in a meaningful way." (*reference only; relevant context*)

Similar definitions noted for: 1)Episodic Disabilities Employment Network (EDEN), What are episodic disabilities http://edencanada.ca/en/episodicdisabilities (CWGHR hosted) 2)BC Coalition of Persons with Disabilities, (2010). HIV/AIDS and Episodic Disabilities: Keys to Healing http://www.bccpd.bc.ca/docs/healgd-episodicweb.pdf	"Episodic disabilities are long-term conditions that are characterized by periods of good health interrupted by periods of illness or disability. These periods may vary in severity, length and predictability from one person to another. Some common examples of episodic disabilities include multiple sclerosis, arthritis, diabetes, HIV/AIDS, hepatitis C, chronic fatigue syndrome, migraines, chronic pain, some forms of cancer and mental illness. Unlike permanent disabilities, episodic disabilities are periodic — the episodes of illness come and go." (*complete definition*) "Because they are also unpredictable, they can often be more difficult to manage with regard to employment. (*relevant context*)
Furrie, A. (2010). Towards a better understanding of the dynamics of disability and its impact on employment. Adele Furrie Consulting Inc. http://www.adelefurrie.ca/PDF/Dynamics_of_disability.pdf	Episodic disability is defined in terms of the "underlying health problem or condition that results in the disability." (*partial definition*) As a result of the underlying condition(s), they are "often or sometimes limited in the workplace." (*partial definition*)

Government of Canada Response to "Listening to Canadians: a First View of the Future of the Canada Pension Plan Disability Program": The Fifth Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities (2003). *Human Resources and Skills Development Canada* http://publications.gc.ca/collections/Collection/RH4-22-2003E.pdf	The Government of Canada response to a report by the Standing Committee on Human Resources Development and the Status of Persons with Disabilities: "The Government shares the Committee's view of the importance of CPP Disability covering a wide variety of conditions, including cyclical and degenerative mental and physical conditions. Recurrent and episodic disabilities are becoming more prevalent in Canadian society." (*reference only*) "Because the determination of disability for CPP is based on the functional limitations that prevent a person from working, and not simply on a medical diagnosis or prognosis, the adjudication process is able to take into consideration the short- and long-term impacts of recurrent or episodic medical conditions on the client's ability to function in the workplace." (*relevant context*)

Government of Canada. (2006). Out of the Shadows at Last. Transforming Mental Health, Mental Illness and Addiction Services in Canada - The Standing Senate Committee on Social Affairs, Science and Technology (e-resource) http://www.parl.gc.ca/Content/SEN/Committee/391/soci/rep/rep02may06part3-e.htm	Unlike other disability groups, people with mental illness are rarely ill continuously; rather, they tend to cycle between periods of illness and wellness. When they are symptom-free, they are usually able to work and carry out the normal tasks of life." (*partial definition*) "The episodic and cyclical nature of most mental illnesses is another factor that makes it harder to assess the impact of mental illness in the workplace. It creates additional difficulties in making the necessary accommodations at work for people living with mental illness. During episodes of psychiatric illness, however, they may be incapable of functioning at a level that would permit them to work in regular, full-time employment…The cyclical, episodic, and unpredictable nature of serious mental illness can impede the establishment of a long-term and stable employment history. Having unexplained work-gaps on one's resumé poses a formidable challenge when seeking to return to employment." (*relevant context*)
Government of Manitoba Response to Recommendations of the Accessibility Advisory Council for a Made-in-Manitoba Accessibility Act http://www.gov.mb.ca/dio/pdf/white_paper-january8final.pdf	The Government of Manitoba developed a white paper response to recommendations made by the Manitoba Accessibility Advisory Council of an inclusive definition of disability. The Council recommends the Act should "define barrier as anything that interacts with an impairment in a way that may hinder the person's full and effective participation in society on an equal basis with others. This definition is intended to embody an inclusive, broad meaning of impairment, including long-term physical, mental, intellectual, invisible, episodic or sensory impairments." (*reference only; relevant context*)

1)Government of Manitoba, Employment and Income Security http://www.gov.mb.ca/dio/openingdoors/employment.html 2)Canadian Council on Disability (CCD), Disability Community Priorities and Expectations http://www.ccdonline.ca/en/international/un/canada/disability-community-priorities-march2011 3)Commission for the Review of Social Assistance in Ontario, (2012). What we heard: A summary of discussions on social assistancehttp://www.socialassistancereview.ca/uploads/File/What-We-Heard---A-Summary-of-Discussions-on-Social-Assistance(1).pdf 4)University of Toronto Scarborough. Accommodating Students with Disabilities http://www.utsc.utoronto.ca/~ability/faculty_accommodate.html	There were a number of instances where the term episodic disability appeared in text, but there was no clear definition. These include the Government of Manitoba Employment and Income Security paper that expressed a commitment to addressing employment barriers faced by people living with episodic disabilities or illnesses. (*reference only*) The Canadian Council on Disability (CCD) made mention of the term, as did the Commission for the Review of Social Assistance in Ontario in a background document and the University of Toronto in a policy on student accommodations. (*reference only*)
Government of Newfoundland and Labrador, Valuing Mental Health http://www.gov.nl.ca/publicat/MentalHealthPolicyPaper.pdf	Refers to mental illnesses as "episodic or cyclical in nature"; "a person may have episodes of acute illness, but also long periods of wellness." (*partial definition*) The health continuum is about the "presence or absence of symptoms of disorder." (*relevant context*)

Human Resources and Skills Development Canada, (2012). Definition of Disability http://www.hrsdc.gc.ca/eng/disability_issues/reports/disability_guide/page03.shtml	"Disability is a complex phenomenon, reflecting an interaction between features of a person's body and mind and features of the society in which they live. A disability can occur at any time in a person's life; some people are born with a disability, while others develop a disability later in life. It can be permanent, temporary or episodic. Disability can steadily worsen, remain the same, or improve. It can be very mild to very severe. It can be the cause, as well as the result, of disease, illness, injury, or substance abuse." (*reference only; relevant context*)
Interagency Coalition on AIDS and Development. (2009). HIV/AIDS as an episodic disability in the workplace http://www.icad-cisd.com/index.php?option=com_content&view=article&id=176%3Aguidelines-and-policies-hivaids-as-an-episodic-disability-in-the-workplace&catid=46%3Ahivaids-and-disability&Itemid=73&lang=en	"An episodic disability is characterized by unpredictable, intermittent and varying degrees of illness and wellness." (*partial definition*) "Specific challenges exist for individuals managing an episodic disability including for example the need to move in and out of the workplace or workforce in an unpredictable manner, workload management and/or income replacement options that respond to the episodic nature of the disability." (*relevant context*)
Lysaght, R. Krupa, T. & Gregory, A. (2011). Perspectives on Intermittent Work Capacity – What Can Qualitative Research Tell Us? *Queen's University* https://qshare.queensu.ca/Users01/lysaght/Rosemary/Employers'%20Perspectives%20-%20Final%20Report.pdf	"Disability can be temporary or episodic, meaning that people are not necessarily affected by disability constantly." (*partial definition*) "While episodic health conditions might lead to intermittent work capacity, it is neither necessary nor sufficient for these to be present." (*relevant context*)

Moore, L. (Director of Public Affairs, The Arthritis Society, Episodic Disabilities Network) at the Finance Committee on October 27th, 2010 http://www.parl.gc.ca/HousePublications/Publication.aspx?DocId=4734387&Language=E&Mode=1	"An episodic disabling condition or disease is lifelong, but it differs from persistent or progressive disabling conditions. The period of disability in an episodic condition can vary in severity and duration. There may be advance notice of an episode, or it may come on quite unexpectedly. Examples of conditions that can be episodically disabling include mental health disease, arthritis, HIV/AIDS, multiple sclerosis, Crohn's disease and colitis, and asthma." (*complete definition*)
Prince, M.J. (2008). Canadians Need a Medium-Term Sickness/Disability Income Benefit. *Caledon Institute of Social Policy* http://www.caledoninst.org/publications/pdf/670eng.pdf	"People can have quite serious medical conditions that are recurrent, episodic or cyclical – be they different types of cancer, an assortment of musculoskeletal conditions, respiratory infections, multiple sclerosis or schizophrenia." (*partial definition*) Chronic diseases which can include "recurrent, episodic and cyclical conditions such as arthritis, cancer, diabetes, heart problems and rheumatism." (*partial definition*) In spite of having one or more of these conditions they "may not meet the criterion of 'prolonged' for the eligibility purposes of CPP disability." (*relevant context*)
Smith-Fowler, H. (2010). Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario? *Social Research and Demonstration Corporation* http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf	Author references the Canadian Working Group on HIV and Rehabilitation (CWGHR) definition of episodic disability "people with multiple sclerosis, lupus, arthritis, cancer, diabetes, and certain mental health conditions, for example, may have —periods of good health…interrupted by periods of illness or disability, though be unable to predict when these episodes will occur or how long they will last." (*complete definition*) "It is increasingly recognized that even people with disabilities not usually considered episodic might nevertheless have the capacity to work - at least on an intermittent basis – if provided with appropriate supports." (*relevant context*)

Stapleton, J. & Tweedle, A. (2008). Navigating the maze: Improving coordination and integration of disability income and employment policies and programs for people living with HIV/AIDS – A discussion paper	"Periods of good health may be interrupted by periods of illness or disability. Often it is difficult to predict when these "episodes" of disability will occur or how long they will last…Increasing numbers of Canadians are living with lifelong episodic disabilities, which may include multiple sclerosis, lupus, arthritis, cancer, diabetes and mental and mood disorders." (*complete definition*) "People with episodic disabilities can face significant employment and income support challenges. Most income support programs are designed for people with disabilities who need to fully disengage from the labour force. Recurring periods of ill health make it difficult to work, especially full-time." (*relevant context*)
Treasury Board of Canada, Duty to Accommodate: A General Process for Managers http://www.tbs-sct.gc.ca/ee/dorf-eng.asp	A disability is a physical or mental condition that is permanent, ongoing, episodic or of some persistence, and is a substantial or significant limit on an individual's ability to carry out some of life's important functions or activities, such as employment. Disabilities include visible disabilities, such as the need for a wheelchair, and invisible disabilities, such as cognitive, behavioural or learning disabilities, and mental health issues." (*reference only; relevant context*)

Vick, A. (2012). Theorizing Episodic Disabilities: The Case for an Embodied Politics. *Canadian Social Work Review*, 29(1)	"Many persons with episodic disabilities experience considerable physical, cognitive, and/or social fluctuating limitations that interfere with activities of daily living (ADLs) such as personal care, community functioning, and/or employability. Such restrictions, either independently or in combination, may or may not reappear with the same symptoms, intensity, duration, or within the same contexts with each flare-up of a person's condition(s). Given this shifting materiality of the body, the magnitude of a person's disability and her/his functional restrictions become exceedingly problematic to corroborate as consistently substantial and stably recurrent." (*complete definition*)
Vick, A., & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. *Journal of Disability Policy Studies*, 21(2), 70-80. doi: http://dx.doi.org/10.1177/1044207309358588	"Fluctuating mental health issues that coexist with the volatility of physical health conditions in relation to changing bodily experiences, life circumstances, and physical environments…." "Living with a complex episodic disability implies embodying permutations of (dis)ability and (un)employability that arbitrarily shift depending on the body's physicality and situatedness from moment to moment and day to day." (*complete definition*)

Discussion

The term "episodic disability" is becoming increasingly prevalent both in Canada and internationally. Several papers noted a rise in the numbers of people living with episodic disabilities in the developed world with anticipated ongoing growth in coming years. Discussions on the topic of episodic disability are found amongst a variety of professional disciplines including the academy, the private sector, policy makers, the insurance sector and amongst people living with episodic disabilities.

Of note is the increase in the federal and provincial governments' acknowledgement of the term "episodic disability" in recent years. In most cases, this acknowledgement references only the term "episodic disability" but does not provide a definition of the term. In 2003, the term was also mentioned in the Human Resources and Skills Development Canada (HRSDC) review of the Canada Pension and Disability Plan, which, in the course of the development and usage of the term "episodic disability," was an early recognition by the Government of Canada of the importance of the term. The government of Manitoba paper on Employment and Income Security went beyond a mention of the term to express a commitment to address the unique barriers to employment faced by people living with episodic disabilities.

Among the differences noted between the definitions is the blurred usage of the terms "episodic disability" and "episodic illness." It is worth noting that it is common for the terms "episodic disability" and "episodic illness" to be used interchangeably, although each term can have a very distinct meaning. For the purposes of validating the key terms, instances where both terms are used have been noted. "Episodic illness" was sometimes used in a similar way to "episodic disability" including in terms of the way in which illness has an impact on the person and his/her ability to engage with the social world. It is important to select terms carefully and to provide definitions of terms used to avoid potential confusion/misinterpretation of the terms.

Episodic disabilities are comprised of a variety of health conditions that result in some form of physical or emotional limitation.

In several of the references listed above, the focus was on the barriers to employment people living with episodic disabilities may encounter because of the impact of their disability on their capacity to work. These impacts can vary from a change in the individual's capacity to perform his/her job duties, which may trigger internal workplace accommodation processes, to the movement of an individual in and out of the workplace when an episode of greater severity is experienced.

Overlap Among the Definitions

The hallmark characteristic of living with an episodic disability noted in all of the complete definitions is a change in health status due to recurring episodes of illness and wellness. These changes result in concomitant life impacts, such as to employment. Also common to the definitions is the notion of a time-limited episode of disability.

The episodic disability framework presents a helpful visual of these changes that occur over time — changes that are noted in the various definitions — including a period of illness, commonly occurring after some form of "trigger", a decline in health over a period of time (which could be over days, weeks or months) followed by an improvement in the level of disability, sometimes returning to the former state of health and sometimes returning to a state of health worse than what was previously experienced.

Among the definitions listed above, there are a number of commonalities. Seen across many of the definitions is the characteristic unpredictability in the occurrence of an "episode" of disability. Common disabilities noted were some forms of mental illness, mood disorders such as major depressive disorder and anxiety disorders, HIV, arthritis, and some forms of cancer. The chart in Annex D, compiled by Furrie (2010) in consultation with the Canadian Working Group on HIV and Rehabilitation, provides a much broader list of illnesses that are frequently termed to be "episodic".

Differences

Some of the definitions mention changes in the degree of severity of the disability episode (Episodic Disabilities Employment Network website; Moore, 2010) while others do not. Disability episodes may vary in terms of degree of impact on the individual's life. Mitigating factors, such as social supports or access to treatment, may help to reduce the severity of the disability episode (Smith-Fowler, 2010).

The concept of permanence came up in several of the definitions. Permanence of the disabling impacts of an episodic disability is generally at odds with the definition of episodic disability, as the disability itself is periodic in its presentation. Where the discussions vary on the topic of permanence is in whether or not the illness itself is an ongoing, persistent part of the life of the person living with the episodic disability. Persistence of the disability is commonly seen in definitions of both "chronic illness" (Antao, Shaw, Ollson, Reen, To, Bossers, & Cooper (2013) and "disability" in general; however, persistence of the disability was not a factor that was seen specifically in definitions of episodic disability.

The term "cyclical" was also used on occasion in the definitions. This term refers to repeating episodes of disability that may or may not be predictable. Cyclical could also refer to consistency in the severity and presentation of the episodes, which is different from many of

the definitions of episodic disability (Human Resources and Skills Development Canada, 2003; Government of Canada, 2006).

As noted earlier within the definitions, there are differences in the illnesses that are listed as episodic. This poses a particular challenge for decision makers who may seek to compile an exhaustive list. Disability results from the impacts of the illness on the individual and his/her ability to act as he/she desires. The way that an illness expresses itself within an individual can be physiologically quite different from its expression within another person. As well, this raises the potential for illnesses beyond the 27 listed to have episodic disabling impacts within some individuals and leaves the potential for a range of illnesses that are not part of the current list considered to be episodically disabling. As such, the list of illnesses should be considered to be a list of the more common episodic illnesses. Consideration should be given to examining other ways of defining episodic disability that involve a fixed list of illnesses.

The Vick and Lightman definitions reference the changes in self-conception that result from the diagnosis of episodic disability and the resultant changes to the body. Amongst the CWGHR literature, there is reference to increases in levels of depression.

3.3.2 Short-term Disability

SOURCE	DEFINITION
BC Public Service, Disability - Short Term Illness and Injury Plan (STIIP) https://www.bcpublicservice.ca/benefits/plan_details/disability_stiip.htm	"Inability to work due to illness or injury." Short-term disability (STD) may also be referred to as STIIP or short-term illness and injury plan. (*partial definition; relevant context*)
Dewa, C. S., Chau, N., & Dermer, S. (2009). Factors associated with short-term disability episodes. *Journal of Occupational and Environmental Medicine*, 51(12), 1394-1402. doi: http://dx.doi.org/10.1097/JOM.0b013e3181bc3f7c	"A sickness absence of five or more continuous workdays related to a medical diagnosis given by an employee's treating physician." (*complete definition*)

Fu, A.Z., Chen, L., Sullivan, S.D. & Christiansen, N.P. (2011). Absenteeism and short-term disability associated with breast cancer. *Breast Cancer Research and Treatment*, 130 (1)	Short term disability refers to "third-party payers" disability plans; "privately insured fee-for-service or capitated health plans." (*partial definition*)
Georgetown University Law Center, Workplace Flexibility 2010, "Episodic Time Off: An Overview" (2007). Memos and Fact Sheets. Paper 22 http://scholarship.law.georgetown.edu/legal/22	Using language similar to "episodic disability," this paper discusses concepts related to short-term disability leave as follows: "While some workers' needs for flexibility can be addressed by Short Term Time Off (STO) or by a Flexible Work Arrangement (FWA), there are other workers who need time off on a more episodic basis. These workers may have an illness, such as cancer or kidney disease, which requires them to attend numerous medical appointments on a relatively set basis or they may have a chronic condition, such as migraine headaches or fibromyalgia that flares up sporadically. Episodic Time Off or EPTO describes the type of workplace flexibility needed to address these types of needs. Under this definition, the provision of EPTO addresses the recurring need for time off – sometimes regular, sometimes sporadic, sometimes foreseeable, sometimes not – for which STO is insufficient and which an FWA cannot resolve." (*complete definition; relevant context*)
Lynk, S. Michael. (2007). Disability and Work: The Transformation of the Legal Status of Employees with Disabilities in Canada. Available at SSRN: http://ssrn.com/abstract=1068403 or http://dx.doi.org/10.2139/ssrn.1068403	"A short-term disabling condition would usually impose a duty upon the employer to maintain the relationship." (*relevant context*)

SunLife Financial. (2013). Employee Benefits http://www.sunlife.com/us/Service+center/How+do+I/Employee+benefits#std_considered	"Under the definition of STD, a claimant continues to receive benefits as long as the claimant meets the definition of totally disabled for their own occupation up to the maximum benefit period. Further definitions vary depending on the plan." (*relevant context*) "STD often begins when an employer's regular sick-leave runs out for a limited period of time varying from employer to employer – 15 to 26 weeks on average." (*complete definition; relevant context*)
The Workers' Compensation Board of Nova Scotia Summary of Financial Results Third Quarter 2012 http://www.wcb.ns.ca/app/DocRepository/5/About/Review/Reports/Summary_Final_Results_Q3_2012.pdf	"All income benefits during the initial period after the injury, before the injury has stabilized, reached a plateau, or consolidated. The time at which an injury stabilizes depends on the type of injury and the workers' condition. Short-term disability benefits include income benefits during a rehabilitation period." (*complete definition*)

Discussion

Generally speaking, short-term disability refers to the intersection of the disabling impacts of an illness or injury that may or may not have occurred within a workplace context and the absences from the workplace resulting from these disabling impacts. Reference to a specific time period is also key to this definition, although the exact period of time is somewhat variable, as discussed below.

The origin of the disability and previous instances of the illness are of less relevance in this context. The origin of the disability may be due to a chronic/episodic illness, a progressive illness, an injury or a temporary condition. The primary focus is on the current disability and the resultant impact on the workplace relationship (Lynk, 2007).

Medical definitions may refer to a period of disability limitation that may or may not involve impacts on the workplace (Dewa, Chau & Dermer, 2009).

Overlap Among the Definitions

Short-term disability is most commonly used within the insurance sector, referring to an income replacement benefit period for an individual unable to perform his/her job

requirements due to illness or disability. The benefits commonly run for 15 to 26 weeks. The definitions vary somewhat from plan to plan, but refer to a time-limited temporary income replacement.

Amongst the insurance-related definitions (SunLife Financial, 2013; BC Public Service) there is mention of the inability of the individual to perform job duties and the leave of absence that often results. The disability is considered "total" due to the significant impact on functionality within the workplace. This label of "total" disability refers only to a limited period of time that will be reassessed as outlined by the treating medical team.

There were some commonalities within the definitions of short-term disability from private insurance companies such as SunLife Financial, Manulife Financial, and the Canadian Life and Health Insurance Association. These definitions refer to leaves of absence resulting from a verified disability. It should be noted, however, that there were also differences among the definitions used by these companies.

Differences

Lynk's approach to short-term disability is framed from a duty to accommodate perspective that likely would require an employer to provide accommodation support to the employee. This definition is formed from a non-monetary perspective and focuses on the interactions of the individual within a workplace environment.

The Georgetown Law review discusses the concept of short-term time off, which is similar to short-term disability as outlined above. A unique conceptualization was that of episodic time off, which similarly refers to periods of time where an individual is away from the workplace. One difference related to episodic time off is the increased flexibility of the benefit grant period, where there is a possible but unpredictable requirement for a workplace leave of absence, for example due to a recurrent illness or family caregiving responsibilities. Although the parameters of short-term time off and/or episodic time-off are broader than are absences due to episodic disability, there is overlap in the use of this benefit to manage disability episodes.

3.3.3 Moderate Disability

SOURCE	DEFINITION
Buckup, S. (2009). The Price of Exclusion: The economic consequences of excluding people with disabilities from the world of work. *International Labor Organization*. Employment Sector: Employment Working Paper No. 43	Used as a category on survey questionnaires, moderate disability refers to responses to more than one question as having "some difficulties" but no questions with "a lot of difficulties." Although there was some variability in the questions used from country to country, common survey questions are as follows: (1) "Does anyone in this household have any difficulty in doing day-to-day activities because of a physical, mental or emotional (or other health) condition?" (2) "Does anyone in this household need assistance to do day-to-day activities?" Both questions allow for the answers "a lot/often", "a little/sometimes", and "no". (3) "Has this difficulty lasted, or is it expected to last, six months or more?" (*all of the above form a complete definition*)
DesMeules, M., Turner, L. & Cho, R. (2003). Morbidity Experiences and Disability Among Canadian Women. *Public Health Agency of Canada* http://www.phac-aspc.gc.ca/publicat/whsr-rssf/pdf/WHSR_Chap_9_e.pdf	Chronic conditions were categorized into "mild, moderate and severe according to level of impact on functional status." Disability was also categorized, as "moderate or severe." Individuals who had "activity limitation and dependency" were considered to have a "severe disability." (*partial definition*)

1) Human Resources and Skills Development Canada. 2006. Disability in Canada: A 2006 profile http://www.hrsdc.gc.ca/eng/disability_issues/reports/disability_profile/2011/page01.shtml 2) Statistics Canada. (2008). Profile of disability among adults http://www.statcan.gc.ca/pub/89-628-x/2007002/4183079-eng.htm	"Severity is a term that is used to discuss how serious people's disabilities are, or to what extent they are able to do everyday tasks. The severity of a disability can have profound effects on the types of limitations experienced by a person with a disability. The 2006 PALS separates the 4.2 million adults with disabilities into four levels of severity: mild, moderate, severe and very severe." "The level of severity depends on the frequency and intensity of limitations associated with each type of disability. For example, a person who has no difficulty walking and climbing stairs but cannot stand in line for more than 20 minutes would have a mild mobility-related disability. A person who can only move around in a wheelchair would have their mobility more severely limited, and one who is bedridden for a long-term period would have a very severe mobility related disability. The number of disabilities also has an impact on the overall level of severity." "The severity of a disability can be driven by two factors, the cumulative effect of multiple disabilities or the overall effect of one significant disability. For example, a person who has no difficulty walking and climbing stairs but cannot stand in line for more than twenty minutes would have a mild mobility-related disability." (*all of the above form a complete definition; relevant context*)
Mental Health Commission of Canada. (2012). At Home / Chez Soi Interim Report http://www.mentalhealthcommission.ca/SiteCollectionDocuments/AtHome-ChezSoi/AtHome_InterimReport_ENG.pdf	The definition of moderate disability used here is medically oriented and often includes scales of various kinds such as pain or life/activity limitations. (*relevant context*)

Osgoode Hall Law School. The Court. Financial Incentives and Efficiency Concerns: The Test for Catastrophic Impairment in Pastore v. Aviva Canada Inc. http://www.thecourt.ca/2012/10/14/financial-incentives-and-efficiency-concerns-the-test-for-catastrophic-impairment-in-pastore-v-aviva-canada-inc/	Moderate impairment: "identified impairments are compatible with some, but not all, useful functioning." (*partial definition*)
Prince, M.J. (2008). Canadians Need a Medium-Term Sickness/Disability Income Benefit. Caledon Institute of Social Policyhttp://www.caledoninst.org/publications/pdf/670eng.pdf	"Presently, the interruption of employment income and economic security due to a moderate disability and recurring illness is, to a large degree, a matter of individual responsibility with the possibility, for some people, of private insurance plans and, for others, provincial and territorial welfare programs." (*reference only; relevant context*) "People who may not qualify for CPP disability include workers with mild or moderate physical and mental disabilities, and probably workers with certain kinds of severe disabilities not well recognized by the medical community." (*reference only; relevant context*)
WCB of Nova Scotia – Policy Manual. (2008). Guidelines for the Assessment of PMI http://www.wcb.ns.ca/Policy/index_e.aspx?DetailID=1741	"In this category, the worker is still capable of looking after personal needs in the home environment but, at times insidiously, confidence will diminish and the worker will become more dependent on the members of the family in all extramural activities. The worker demonstrates a moderate, at times episodical, anxiety state, agitation with 'traumatophobia', and nurtures strong passive dependency tendencies." (*reference only; relevant context*)
World Health Organization. (2002). Towards a common language for functioning, disability and health http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf	Moderate disability also was seen to refer to disabling illnesses, activity limitations or participation restrictions as noted in the World Health Organization definition. (*complete definition*)

Discussion

Discussions involving the term "moderate disability" are more common within certain disciplines. Economic definitions were seen in the Buckup article, and usage was also common within the public sector as noted by the number of references to moderate disability coming from sources intended to inform policy decisions such as the HRSDC (2006) and Statistics Canada (2008).

A targeted search of current medical literature was conducted on the term "moderate disability;" however, use of this term was primarily in reference to measures used to describe the level of severity of a particular illness or injury such as the degree of disability associated with traumatic brain injury. Due to the limited relevance of the usage of the term "moderate" within this body of literature, the definitions have been excluded from this paper.

In the definitions above, the term moderate disability is often used comparatively in various types of scales to denote a degree of impact — in this case on an individual and/or his/her ability to engage with the surrounding environment, which can include an employment context (HRSDC, 2006 and Statistics Canada, 2008). Moderate disability is often situated between other terms such as "mild" and "severe".

It is worth noting that within an employment context that moderate disability is commonly associated with some form of impact on employment capacity or on the ability to function in the workplace.

Overlap Among the Definitions

Moderate disability is commonly used, particularly in public sector reporting within Canada. It was also seen to a lesser extent in the academic literature. The term "moderate disability" was frequently used as a self-report measure and often situated between terms similar to "mild" and "severe." As such, it is seen as somewhat manageable, while still having an impact on activities of daily life (Desmueles, 2003 and HRSDC, 2006). The most frequent uses of these terms were seen within the Government of Canada (Veterans Affairs, HRSDC) and from the Council of Canadians with Disabilities (CCD).

The nature of this type of self-report opens up a wide variety of subjective interpretation of the definition of "moderate". In addition to self-report measures individual levels of comfort with the terminology will also vary, such as with the use of the term "disability".

Differences

Moderate disability could also refer to any age range to both visible and non-visible disabilities and may or may not include fluctuations or a worsening of symptoms over time. Both web-

based and academic searches showed that moderate disability may refer to both static — meaning ongoing and relatively stable levels of disability — and episodic disabilities that vary over time (Buckup, 2009).

3.3.4 Intermittent Work Capacity/Intermittent Employment

SOURCE	DEFINITION
Antao, L., Shaw, L., Ollson, K., Reen, K., To, F., Bossers, A., & Cooper, L. (2013). Chronic pain in episodic illness and its influence on work occupations: A scoping review. Work, 44(1), 11-36	Intermittent work capacity is related to unpredictable illness episodes that result in "presenteeism and withdrawal from work. In contrast to absenteeism, where employees are completely absent from work, presenteeism occurs when employees are physically present in the workplace but are functionally unproductive". *(partial definition; relevant context)*
Lysaght, R. Krupa, T. & Gregory, A. (2011). Perspectives on Intermittent Work Capacity – What Can Qualitative Research Tell Us? *Queen's University*	"Has unexpected and/or periodically diminished capacity relative to the usual or unexpected workload because of a disability or health condition, or is absent from the workplace frequently or for extended periods of time because of disability or health condition." Capacity in this context refers to the following: "The actions that a person can perform and how the expression of capacity in life situations, including work, is affected by broader social and environment factors that support or challenge performance and participation." (*all of the above form a complete definition*) "Although intermittent capacity is not disability-specific, a number of disabilities and health conditions are considered to be episodic in nature." (*relevant context*) "The intermittent capacity is measured against the usual expected employee workload unrelated to the commonplace illnesses (flus, colds and so on) or other disruptions (sick child, death in the family, etc.)". (*relevant context*)

Malenfant, A., LaRue, A. & Vezina, M. (2007). Intermittent Work and Well-Being: One Foot in the Door, One Foot Out. *Current Sociology*, 55	"Workers who do not have any continuous employment relationship with a single employer" "Temporary workers" "Many factors can lead workers towards intermittent work….A layoff, a significant health problem, or life choices outside of work were among the common reasons cited." (*all of the above form a partial definition*) "In most cases lack of economic resources, lack of social support, lack of accomplishment and lack of self-esteem and esteem by others are all part of the intermittent work experience." (*relevant context*)
Smith-Fowler, H. (2010). Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario? Social Research and Demonstration Corporation	"Not being able to work predictable full-time hours because of a disability or health condition." "Needing to be absent from the workplace more frequently or for extended periods of time due to a disability or health condition." (*all of the above form a complete definition*)

Discussion

Intermittent work capacity describes the variable ability of people to engage in employment over time. Periods of employment are temporary with no predictable end to the period of employment due to unpredictable factors, including episodes of personal illness, disability or periods of caregiving. All of this has an impact on employment capacity.

Overlap Among the Definitions

Intermittent work capacity is not related to any particular form of disability; however, some definitions place more focus on the impact of episodic disabilities. Work capacity may be impacted by a reduction in work hours or an inability to work full-time hours for a period of time.

Several authors (Lysaght, Krupa, & Gregory, 2011; Malenfant, LaRue, & Vezina, 2007) indicated that this type of variable employment contract is likely to have an impact on the individual's access to stable income supports over time, access to extended drug and health benefits, personal emotional wellness, and other relationships, including familial relationships.

Differences

Antao et al. note that intermittent work capacity extends beyond movement into and out of the workforce and discuss a reduction in work hours and the concept of "presenteeism" as a limitation to work productivity that results from one or more of the factors listed above. Individuals continue to remain the workforce while unable to perform to the same capacity as at periods of optimal wellness.

Malenfant, La Rue and Venzina describe some of the challenges faced by those with intermittent work capacity in their discussion of what happens to those experiencing temporary work. This is an alternate way of approaching the topic of intermittent work capacity, as it focuses more on the lived experiences of those who are engaged in time-limited work. Individuals who experience health problems that result in intermittent work capacity face barriers to income support and have limited social connections due to their intermittent work status. Some of these barriers are also outlined in the definitions and discussion above on the three forms of disabilities: episodic, moderate and short-term.

This definition can be contrasted with that of Lysaght, Krupa and Gregory (2011) who describe intermittent work capacity as "unpredictable" or "periodic" and as interspersed with periods of improved health. Although Lysaght, Krupa and Gregory wrote with a focus on episodic disability, their paper highlights the impact this type of disability has on work capacity. This definition also highlights the individual's altered ability to engage in the other socio-environmental life activities that extend beyond the employment context. It is worth noting that this conceptualization of intermittent work capacity bears some similarity to the definitions of episodic disability.

3.3.5 Longer-Term Sustained Employment

SOURCE	DEFINITION
Becker, D., Whitley, R., Bailey, E.L. & Drake, R.E. (2007). Long-Term Employment Trajectories Among Participants With Severe Mental Illness in Supported Employment *Psychiatric Services*. doi: 10.1176/appi.ps.58.7.922 http://ps.psychiatryonline.org/article.aspx?articleid=98212&link_type=googlescholarrelated	"This study examines long-term employment trajectories over a period of 8 to 12 years for psychiatric survivors in supported employment. Employment here referred to any type of work-related activity, including paid work and volunteer work. Supported employment involves individualized supports that are provided as long as necessary to sustain employment." (*complete definition*)
Ontario Ministry of Community and Social Services. Ontario Disability Support Program – 5.1 Employment Supports Directives http://www.mcss.gov.on.ca/en/mcss/programs/social/directives/directives/ODSPDirectives/employment_support/5_1_ODSP_ESDirectives.aspx	The Ontario Ministry of Community and Social Services (MCSS) describes longer-term sustained employment as "focused on job retention and as a process of goal achievement in locating and sustaining employment, as opposed to a milestone. The definition guides employment counsellors and other service providers contracted to assist in the return to work process for people with disabilities who receive financial incentives at 6 weeks of continuous employment and then again at 13 weeks of employment." (*complete definition; relevant context*)
Doren, B., Gau, J.M. & Lindstrom, L. (2011). The role of gender in the long-term employment outcomes of young adults with disabilities. *Journal of Vocational Rehabilitation*, 34(1)	"Long-term employment is considered to be 1 year of employment retention, post-job placement." (*complete definition*)

Foster, S. & Casebourne, J. (2011). Integrated Employment and Skills: Maximising the Contribution for Sustainable Employment. *JHP Group* http://www.cesi.org.uk/sites/default/files/publications/CESI_IES_for_sustainable_employment.pdf	"Longer-term work sustainable is viewed as extended beyond the traditional 6 weeks to target goals of 6 months or even two years with financial incentives ongoing throughout this period." (*complete definition*)
International Labor Office. (2010). G20 Meeting of Labor and Employment Ministers. United Kingdom's Response to the Crisis http://www.dol.gov/ilab/media/events/G20_ministersmeeting/G20-uk-brief.pdf	This paper mentioned of the need to help workers who receive employment supports "move into long-term sustained employment." (*reference only*)
Education, Employment and Workplace Relations References Committee. (2011). The administration and purchasing of disability employment services in Australia http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id:committees%2Fcommsen%2F1f2e649e-7cc4-4826-9ff5-5a26707a17ce%2F0013	Reference is made to a "26 week employment outcome period" as long-term sustained employment. (*partial definition*)

1) Government of Saskatchewan. (2010). Plan for 2010-11. Ministry of Advanced Education and Labour http://www.finance.gov.sk.ca/PlanningAndReporting/2010-11/AEELPlan1011.pdf 2) Native Council of Nova Scotia. Aboriginal People's Training & Employment Commission (APTEC) http://ncns.ca/programs-services/aboriginal-peoples-training-employment-commission-aptec/	Long-term sustainable employment is listed as a "priority in regional strategic planning." (*reference only*)
Moran, J. R., Short, P. F., & Hollenbeak, C. S. (2011). Long-term employment effects of surviving cancer. *Journal of Health Economics*, 30(3), 505-514. doi: http://dx.doi.org/10.1016/j.jhealeco.2011.02.001	In examining the employment trajectories for those who experience one or more episodes of cancer, longer-term employment is described as "employed at a check-in point at least two years after diagnosis." (*partial definition*)

Discussion

The term refers to a period of time during which employment is sustained and does not refer to temporary employment through agency contracts that are limited to brief periods of time such as several months (Doren, Gau, & Lindstrom, 2011; Foster & Casebourne, 2011). From the perspective of the authors of this review, longer-term sustained employment does not take into account whether or not the position held is full-time or part-time, only that the position is maintained for a minimum period of time.

Overlap Among the Definitions

Based on the internet search, the term was more commonly used in the 1990s, and the use of the term seems to be on the decline, as indicated by the limited number of academic references shown in the annotated bibliography. In addition to searching the key term "longer-

term sustained employment," online and academic references were also searched more generally for "longer-term employment."

Longer-term sustained employment is used by both the Ontario Disability Support Program (ODSP) and the Ontario Works Employment Placement program. Public sector contexts that made use of the term included the government of Saskatchewan and the Native Council of Nova Scotia.

The Government of Saskatchewan and the Native Council of Nova Scotia have both acknowledged the need for longer-term employment and have even declared it a priority, although no definitions were provided.

Differences

The most noteworthy difference among the definitions is the period of time of sustained employment that is considered sufficient to be classified as "longer term." Vocational rehabilitation programs in Canada commonly used 13-weeks or 26-weeks (Ontario Ministry of Community and Social Services; Education, Employment and Workplace Relations References Committee). One program in Britain has an expanded definition that extends to two years (Becker, Whitley, Bailey & Drake, 2007; Foster & Casebourne, 2011).

The relative dearth of multi-year studies examining employment outcomes for people living with time-limited disabilities is also worth noting. Examinations of the employment trajectories of people living with episodic, moderate or short-term disabilities would be a useful tool to inform decision making for this growing group going forward.

3.4 Annotated Bibliography

This bibliography provides a brief description of the journal articles and other web-based sources that contained relevant definitions or contextual information. Please note that the sources that included definitions with little or no other relevant source material are not included in this annotated bibliography. These definitions appear only in section 3.3.

1. Anderson, J & Brown, G. (2005). HIV & disability insurance in Canada: An environmental scan.
   http://backtolife.ca/EN/research/documents/HIV_Disability_Insurance_Canada_Environmental_Scan.pdf
   Written from the perspective of HIV as an episodic disability, this paper consists of a literature review and a series of key informant interviews conducted with people living with HIV, policy makers, AIDS Service Organizations and health care providers on their experiences with income security and employment-related interactions with the Canada

Pension Plan – Disability program and private sector long-term disability plans. The paper outlines both real and perceived barriers to income support access and labour force engagement and recommends improved communication practices to better inform potential recipients of their income support options and the increasing limits on allowable earnings without claw backs or benefit reductions.

2. Antao, L., Shaw, L., Ollson, K., Reen, K., To, F., Bossers, A., & Cooper, L. (2013). Chronic pain in episodic illness and its influence on work occupations: A scoping review. *Work*, 44(1), 11-36. doi:http://dx.doi.org.remote.libproxy.wlu.ca/10.3233/WOR-2012-01559

   This international scoping review of 80 articles provides an overview of the current literature in chronic pain, episodic illness and work with the goal of examining how work or medical policy could be improved. The authors propose that policy changes are needed to facilitate work transitions and ensure individuals with intermittent work capacity do not fall outside of the realm of current return-to-work parameters and programming strategies. Currently, these strategies are designed to address issues of "presenteeism", where an individual is at work but not able to work to capacity. Accommodation for persons living with episodic disabilities needs to be considered.

3. Becker, D., Whitley, R., Bailey, E.L. & Drake, R.E. (2007). Long-Term Employment Trajectories Among Participants With Severe Mental Illness in Supported Employment. *Psychiatric Services*. doi: 10.1176/appi.ps.58.7.922

   http://ps.psychiatryonline.org/article.aspx?articleid=98212&link_type=googlescholarrelated

   Sustained competitive employment can be an option for people living with psychiatric disabilities if individualized supports are provided. This study is one of two long-term employment outcome studies conducted in the U.S. in the early to mid-1990s. At the time of the interview, 47% were involved in some form of supported employment services. Seventy-one percent of those involved in the follow-up worked more than 50% of the follow-up period. Ongoing employment supports were viewed as critical to facilitate the navigation of the employment transitions. Successfully managing symptoms and deploying appropriate coping skills appeared to also play an important role in individuals' finding and maintaining work.

4. Beveridge, S., Heller Craddock, S., Liesener, J., Stapleton, M. & Hershenson, D. (2002). Income: A Framework for Conceptualizing the Career Development of Persons with Disabilities. *Rehabilitation Counselling Bulletin*, 45(4).

   This paper examines the relationship between having an "episodic disability" and one's career path and acknowledges differences between the onset of the episodic nature of the disability occurring 'pre-career' and 'mid-career'. The paper examines this using INCOME (Imagining, iNforming, Choosing, Obtaining. Maintaining and Exiting) that is designed for rehabilitation professionals to assist them with career path projections. The authors recommend considering the cumulative effect of the unpredictable "episodes" of episodic

disability on the person, their environment and their co-workers. The authors also recommend that public and private policy examine long-term support options to allow people living with disabilities to maintain support, even after job placement is successful.

5. Boyd, V. (2012). Are some disabilities more equal than others? Conceptualising fluctuating or recurring impairments within contemporary legislation and practice. *Disability & Society*, 27(4).

   The paper introduces the concept that social theories of disability and current definitions of disability (permanent, severe and consistent) are different from with new conceptualizations of disability (flexible, multiple and contested), which include those disabilities that fluctuate or recur, such as episodic disability. The purpose of the paper is to further legitimize the presence of fluctuating disabilities to facilitate policy reform. The author thoroughly discusses the extent of episodic disability work completed in Canada, including the development of the Episodic Disability Framework (see O'Brien et al. below), the work of other researchers such as Lightman and Vick, and the CWGHR-led Episodic Disability Network and compares this with the United Kingdom context. The author sees both moral and legal obligations to respond to the many individuals who fall outside of traditional definitions of disability, including the need to work to harmonize the medical and social definitions of disability.

6. Buckup, S. (2009). The Price of Exclusion: The economic consequences of excluding people with disabilities from the world of work. International Labor Organization. Employment Sector: Employment Working Paper No. 43.

   This paper describes an exploratory study that examined the macro-economic costs of excluding people with disabilities (short-term, moderate and long-term) from the world of work in 10 countries across Asia and Africa. Guided by the World Bank Study (Metts, 2000), this paper creates a formula for the "price of exclusion," which includes factors pertaining to reduced productivity, the higher unemployment rate of people living with a disability compared with those not living with a disability and the higher labour market inactivity rate of people living with a disability versus those who do not have a disability. The data provided are primarily relevant to Asia and Africa. The category of moderate disability is widely used throughout the paper to describe individuals who experience disability to such a degree that their workforce participation is commonly impacted in some way. The paper notes that, in many countries, as the degree of disability increases from mild to moderate to severe and very severe, the percentage of participants in the labour force decreases.

7. Canadian AIDS Society. (2003) HIV/AIDS as an Episodic Disability: Revising the CPP(D) Program. A Brief Prepared for the Sub-Committee on the Status of Persons with Disabilities.

   http://www.cdnaids.ca/files.nsf/pages/hivasepisodicillness/$file/HIV%20as%20Episodic%20Illness.pdf

This brief uses the term "episodic illness" to describe HIV. Its goal is to ensure that "policy accurately reflects the realities of people living with HIV." The purpose of the brief is also to communicate a series of income support and employment recommendations relevant to people living with HIV. Recommendations include improving flexible access to CPP-D and addressing return to work challenges such as stigma and discrimination, part-time work options and access to rehabilitation.

8. DesMeules, M., Turner, L. & Cho, R. (2003). Morbidity Experiences and Disability Among Canadian Women. Public Health Agency of Canada. http://www.phac-aspc.gc.ca/publicat/whsr-rssf/pdf/WHSR_Chap_9_e.pdf
   The foundation of this study is the disproportionately higher rates of disability episodes and impacts among women in Canada. The purpose of the study is to examine the gap in gender in overall morbidity and disability for women in Canada. Women reporting disabilities, including chronic conditions, are more likely to be poor and disengaged from the labour market. Chronic conditions were categorized into mild, moderate and severe according to level of impact on functional status. The prevalence of disability was higher among women than men with moderate and severe chronic conditions. Disability was also categorized as moderate or severe. Women who report disabilities were also more likely than men to be poor and unemployed and to have little or no social support. The authors reinforce the need to use social factors both before and after disability to identify interventions to prevent disability and to improve quality of life and access to employment.
9. Dewa, C. S., Chen, M., Chau, N., & Dermer, S. (2011). Examining factors associated with the length of short-term disability-free days among workers with previous short-term disability episodes. *Journal of Occupational and Environmental Medicine / American College of Occupational and Environmental Medicine*, 53(6), 669-673. doi: http://dx.doi.org/10.1097/JOM.0b013e31821e5a0b
   The authors note that many people in the workplace with major depression remain at work rather than take short-term disability leaves of absence. For those who do take short-term disability leaves, they are at greater risk of a subsequent leave of absence. Additionally, there was a lower number of days between short-term disability episodes for this group than for those individuals with a physical disability. The authors consider that there may be other factors in addition to access to effective treatment options that have an impact on increased short-term disability episodes, including continuing work impairment after symptoms have lessened.
10. Dewa, C. S., Chau, N., & Dermer, S. (2009). Factors associated with short-term disability episodes. *Journal of Occupational and Environmental Medicine*, 51(12), 1394-1402. doi: http://dx.doi.org/10.1097/JOM.0b013e3181bc3f7c

Using administrative data to track short-term disability claimants over time, this article examines the prevalence and types of factors associated with mental health claims and physical disability-related claims. In addition to providing a definition of short-term disability, the authors also contribute to the current body of knowledge on why and how short-term disability claims are made. Previous disability episodes predict future disability claims for mental and physical health claims; however, repeat mental health claims were nearly seven times more likely to occur than were physical health claims. As well, a greater number of women experience disability episodes. Protective factors include return-to-work policies, marriage and social supports.

11. Dewa, C. S., Goering, P., Lin, E., & Paterson, M. (2002). Depression-related short-term disability in an employed population. *Journal of Occupational and Environmental Medicine / American College of Occupational and Environmental Medicine*, 44(7), 628-633.

    Addressing issues of mental health in the workplace has increasingly become a topic for discussion related to attendance management and insurance claims, as mental health claims continue to rise and present the largest number of short-term disability claims in the workplace. This study used administrative data from three major Canadian financial/insurance sector firms. Having one absence increases the likelihood of a subsequent absence. The authors note that people on short-term disability are not "homogeneous", but rather they have illnesses that varying in terms of severity. Comparing depression-related short-term disability with other mental health short-term disability leaves, depression "generally affected more employees, lasted longer and had a higher rate of recurrence."
12. Doren, B., Gau, J.M. & Lindstrom, J. (2011). The role of gender in the long-term employment outcomes of young adults with disabilities. *Journal of vocational rehabilitation*, 34(1).

    This article describes the outcomes of a youth employment placement in Oregon called the Youth Transition Program. The program serves youth with disabilities during the last two years of high school by providing assistance with career planning and life skills development, connecting them with local employers other support services, and providing follow-up support for one year after high school. The study examines the wage outcomes of 521 female and male participants in the program between 1990 and 1997. The study found that the wages of the youth increased initially and then decreased over time. For the six years over which wages were tracked, a gender gap in income persisted, with males earning significantly more than females.
13. Episodic Disabilities Network. (2011). The path forward: Addressing Episodic Disabilities in Canada. Brief to the Standing Committee on Finance. http://www.hivandrehab.ca/EN/episodic_disabilities/documents/ThePathForward_EpisodicDisabilityNetwork.pdf

This brief by the Episodic Disability Network, a "pan Canadian forum on episodic disability" that is comprised of a number of disability groups, defines episodic disability and examines the barriers to employment access experienced by people living with episodic disabilities. The intent of the brief is to make recommendations for policy change in Canada. A contributing impediment to employment access for people with disabilities results from the lack of integration of disability income support programs at the federal, provincial/territorial levels and within the private sector. Recommendations to better support Canadians living with episodic disabilities include making Employment Insurance benefits more flexible; developing an inter-jurisdictional body to oversee disability income support programming in Canada; and developing a program or system of programs to facilitate access to partial disability income support benefits with flexible access over time.

14. Foster, S. & Casebourne, J. (2011). Integrated Employment and Skills: Maximising the Contribution for Sustainable Employment. JHP Group.
    http://www.cesi.org.uk/sites/default/files/publications/CESI_IES_for_sustainable_employment.pdf
    The aim of this research report is to examine the role of the IES program — a vocational training program in Britain — in achieving sustainable employment, with a particular focus on those individuals who "cycle" between employment and unemployment. The purpose of the research is to explore the relationship between skills development and sustainable employment; identify and detail best practice examples; explore barriers to the integration of employability and skills; and to provide recommendations for further improvement to employability and skills integration policy, funding and practice. The report contains a series of recommendations to improve program functionality and maximize longer-term sustainable employment outcomes for participants, including a focus on ongoing skills development and the recognition that outcomes-based funding programs in Britain should be re-examined.
15. Fu, A.Z., Chen, L., Sullivan, S.D. & Christiansen, N.P. (2011). Absenteeism and short-term disability associated with breast cancer. *Breast Cancer Research and Treatment*, 130 (1).
    This study involved a review of the disability claims of approximately 150 U.S. companies, covering approximately 100 million employees. The study focused on absenteeism and the claims of working-age women between 18 and 64 who were diagnosed with cancer. The cost of absenteeism and disability claims related to cancer was estimated at $20,000 to $100,000 USD over an individual's lifetime. These outcomes reflect only the work-related costs due to days lost through absenteeism or short-term disability, not the costs associated with lost productivity.
16. Furrie, A.D. (2010). Towards a better understanding of the dynamics of disability and its impact on employment. Adele Furrie Consulting Inc.
    http://www.adelefurrie.ca/PDF/Dynamics_of_disability.pdf
    This report examines the complexities of defining "episodic disability" and examines the workplace impacts of employed Canadians living with disabilities. Using quantitative data

analysis techniques, the report identified that "19.7%, of Canadians report they are 'often' limited at work and/or school, while 32.1%, report they are 'sometimes' limited." The potential reasons why Canadians may be limited at work included both illness and work capacity. The study found that people with disabilities were more likely to be in precarious employment.

17. Georgetown University Law Center . (2010). Workplace Flexibility 2010, "Episodic Time Off: An Overview" (2007). Memos and Fact Sheets. Paper 22.
    http://scholarship.law.georgetown.edu/legal/22
    This memo discusses the concept of episodic time off as an alternative to short-term time off or flexible work arrangements for those who may need time off from work on an episodic or periodic basis. Short-term time off is thought to be insufficient for workers experiencing illness at unpredictable intervals, and episodic time off is discussed as an alternative avenue for benefits programs to consider under the "reasonable accommodation" legislation in the U.S.
18. Government of Canada Response to "Listening to Canadians: a First View of the Future of the Canada Pension Plan Disability Program": The Fifth Report of the Standing Committee on Human Resources Development and the Status of Persons with Disabilities (2003). *Human Resources and Skills Development Canada*.
    http://publications.gc.ca/collections/Collection/RH4-22-2003E.pdf
    This report focuses on the near term, examining both program and administrative issues of the CPPD program. It is a Government of Canada response to a series of 71 recommendations for the CPP-D program. Many of these recommendations had been addressed or were in the process of being addressed when this report was written. The report also acknowledges that the recommendation to expand eligibility and benefits would not be addressed as it had been reviewed five years prior in an effort to establish prudent limits that would maintain the long-term viability of the program.
19. Government of Canada. Out of the Shadows at Last. Transforming Mental Health, Mental Illness and Addiction Services in Canada - The Standing Senate Committee on Social Affairs, Science and Technology (e-resource).
    http://www.parl.gc.ca/Content/SEN/Committee/391/soci/rep/rep02may06part3-e.htm
    In examining the workplace and employment, the authors identify that mental illness is one of the most prevalent forms of episodic disabilities. Unemployment rates among those with mental illnesses are high, and exclusion from the workplace is common. Employment is a mitigating factor in reducing disability episodes for those living with mental illness. This paper is grounded in the perspectives of people living with mental illness. Though the recommendation to look at self-help mechanisms and peer supports, the article poses some challenges to the use of evidence-based research methodologies as a way to determine "best" outcomes in employment for people living with mental illness.

20. Lightman, E., Vick, A., Herd, D. & Mitchell, A. (2009). 'Not disabled enough': Episodic disabilities and the Ontario Disability Support Program. *Disability Studies Quarterly*, 29(3).
This article defines complex episodic disabilities as fluctuating mental health issues that coexist with the volatility of physical health conditions in relation to changing bodily experiences, life circumstances and physical environments. Using semi-structured interviews conducted with five women annually over a period of five years, the authors examined the experiences and realities of the women as they moved in and out of employment while coping with the realities of a complex episodic disability. The authors propose that there is a need to re-examine the prevailing paradigm that one "must be entirely sick, able or disabled, and employable or unemployable," in favour of one that allows for "more malleable descriptors" that facilitate the cyclic character of episodic disabilities.
21. Lynk, S. Michael, Disability and Work: The Transformation of the Legal Status of Employees with Disabilities in Canada (December 2007). Available at SSRN: http://ssrn.com/abstract=1068403 or http://dx.doi.org/10.2139/ssrn.1068403
The author outlines the legal changes to the definition of disability in Canada over the past 20 years, highlighting the movement from a primarily biological model toward a socio-political model. His definition of disability includes a reference to short-term disability that he states would "usually impose a duty upon the employer to maintain the relationship." Lynk discusses the "fluid" nature of disability, which is "transient" and "changeable", and estimates that this type of disability accounts for between 25-30% of the population with disabilities. In addition to citing the evolution of disability case law, the author outlines the principles associated with workplace accommodation, including re-bundling and modifying jobs, the intersections and impacts of mental illness and addictions, the ongoing nature of duty to accommodate, the need for access to medical information in the decision-making process, and the employee's duties. The author concludes by discussing the ongoing severity of disability discrimination, including workplace discrimination, as amongst "the most serious of human rights challenges in Canada today."
22. Lysaght, R. Krupa, T. & Gregory, A. (2011). Perspectives on Intermittent Work Capacity – What Can Qualitative Research Tell Us? Queen's University.
https://qshare.queensu.ca/Users01/lysaght/Rosemary/Employers'%20Perspectives%20-%20Final%20Report.pdf
This paper provides a definition of intermittent work capacity associated with cyclical or episodic illness episodes. The author completed a literature review of intermittent work capacity and episodic disability; this review resulted in very few findings. To obtain the perspective of the employer on factors that have an impact on intermittent work capacity, individual interviews were conducted with employers and employer-representatives, along with two employer focus groups.

23. Malenfant, A., LaRue, A. & Vezina, M. (2007). Intermittent Work and Well-Being: One Foot in the Door, One Foot Out. Current Sociology, 55.

Chronicling changes in the employment trajectories of 22 men and 30 women from the Quebec City region, this article examines health and wellness outcomes for people who have experienced intermittent work. The label of intermittent or temporary may be ongoing throughout the life of the individual and implies that all employment contracts will not be permanent. An additional variance is the use of "any one employer," meaning that individuals may move between employers, but it also leaves open the possibility of holding multiple part-time positions. The article notes a number of factors associated with intermittent work in addition to the strength of the labour market, including a layoff, a significant health problem or life choices outside of work. For some individuals, intermittent work had been a long-standing part of their employment history. The article describes the common negative social- and health-related repercussions, such as income instability, reduced access to drug and health benefits, and increased stress related to intermittent work that apply to many who do not self-select intermittent work as their preferred work option.

24. McKee, E. (2007). Re-examining the Role of episodic disabilities in the workplace. *Canadian Arthritis Patient Alliance,* Fall edition.
http://www.arthritispatient.ca/index.php/resources/re-examining-the-role-of-episodic-disabilities-in-the-workplace/

In addition to defining episodic disability, this article discusses the broader social benefits to improving inclusiveness and employment access for people living with episodic disabilities. The article highlights current barriers to this goal, such as the loss of health benefits when people living with episodic disabilities leave public income support providers to return to work and the lack of coordination among disability income support providers. The article also cites potential financial returns for employers who examine alternative options to help engage people living with episodic disabilities in the labour market.

25. Moran, J. R., Short, P. F., & Hollenbeak, C. S. (2011). Long-term employment effects of surviving cancer. Journal of Health Economics, 30(3), 505-514. doi: http://dx.doi.org/10.1016/j.jhealeco.2011.02.001

This study attempted to determine the effect of a cancer diagnosis on employment rates by surveying 1,800 working-age cancer survivors in Pennsylvania and Maryland annually over four years. The employment rates across gender are roughly equal for those who remain cancer-free at follow-up. The study showed a 7-8% reduction in employment at the second interview point. For those with new cancers at the follow-up, there was a 28-30% reduction in employment for females and a 19-21% reduction for males. This study shows that, in the long-term, for those who experience episodes of illness, such as from cancer. The intersection of gender and employment access is also an important factor to consider from a disability perspective.

26. O'Brien, K., Davis, K.K, Strike, C., Young, N.L. & Bayoumi, A.M. (2009). Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *Journal of the International AIDS Society*, 12(30). http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2788343/
This paper outlines the development of the episodic disability framework that was based on a series of qualitative research focus groups and face-to-face interviews conducted with adults living with HIV/AIDS in Toronto. This paper highlights how extrinsic factors such as social supports and stigma, as well as intrinsic factors such as living strategies and personal attributes have an impact on the experience of disability. The authors highlight the importance of considering both the dimensions of disability and contextual factors in assessing the impact of episodic disability on an individual. Although the project was conducted from the perspective of people living with HIV, it may have "broader applicability to individuals living with similar life-long illnesses who share a similar episodic disease trajectory."
27. Prince, M.J. (2008). Canadians Need a Medium-Term Sickness/Disability Income Benefit. Caledon Institute of Social Policy. http://www.caledoninst.org/publications/pdf/670eng.pdf
The author notes that there are a variety of types of disability, including mild, moderate, episodic, cyclical and severe. He also states that there is an absence of income security options for people living with medium-term illnesses and moderate disabilities, including episodic disabilities. Those who are unable to work for a period of time often experience significant challenges to accessing CPP-D or EI benefits at the federal level and are, therefore, compelled to apply for provincial/territorial social assistance. The author views these public policies as "somewhat outdated" and recommends a response to the changing employability of Canadians, including the development of more flexible and responsive national income support programming.
28. Smith-Fowler, H. (2010). Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario? Social Research and Demonstration Corporation.
http://www.srdc.org/uploads/IntermittentWork_report_EN.pdf
In discussing barriers to employment, the authors examine factors associated with movement into and out of the workforce resulting from episodic disability using the term intermittent work capacity. Interviews were conducted with 10 key informants in policy and program delivery, 10 focus groups were conducted with people living with disabilities and return-to-work stories were compiled from people living with disabilities. Important factors in employment engagement were noted in a variety of domains, including personal, employer policy, workplace culture, access to medical and community supports, and the general labour market.

29. Stapleton, J. & Tweedle, A. (2008). Navigating the maze: Improving coordination and integration of disability income and employment policies and programs for people living with HIV/AIDS – A discussion paper.

    This discussion paper provides an in-depth discussion of the barriers to employment faced by people living with HIV and other episodic disabilities in Canada that result from the lack of coordination between the various income support programs and health benefits providers across geographic jurisdictions. When stable income and extended drug and health benefits cannot be accessed through a workplace, Canadians may need to remain external to the workplace to ensure continued access to benefits in the long-term. The paper also examines the adequacy of benefits, workplace barriers, mechanisms to improve dialogue on these issues and ways to examine improved coherence among income support policy programs. The paper also provides a review of disability income support programs across Canada.

30. Vick, A. (2012). Theorizing Episodic Disabilities: The Case for an Embodied Politics. *Canadian Social Work Review*, 29(1).

    The daily lived experience of people with episodic disabilities often does not fit many of the current systemic definitions of disability that classify someone as either able or disabled. For those living with episodic disabilities, the experience of disability varies over time and is classified by the author as living "in-between" states of wellness and illness that are highly variable in nature. Written from a theoretical perspective, this paper explores how to fit this lived experience of intermittent disability into current definitions disability. A fixed or static definition of disability fails to take into account individual differences. By their very nature, variation in the severity of individual health and wellness and the resultant changes in ability to perform daily life activities, including employment, validate some forms of disability that are more easily categorized as "severe" and "prolonged" as "credible" forms of disability. The author favours the use of broader definitions of disability, including "intermittently disabled," "partially disabled," "partially employable," and "partially employable if and when able."

31. Vick, A., & Lightman, E. (2010). Barriers to employment among women with complex episodic disabilities. *Journal of Disability Policy Studies*, 21(2), 70-80. doi: http://dx.doi.org/10.1177/1044207309358588

    The expansion of the global economy, characterized by shifts in the organization of labour markets, has increased demands for flexible employment. Changes from standard, permanent employment relationships to non-standard or "precarious" work arrangements have become the norm in many work settings. Although a significant amount of scholarship explores precarious employment among the non-disabled, little work examines precarious work among persons with disabilities, particularly women. Drawing on a secondary analysis of a series of longitudinal, semi-structured interviews, this article explores the personal and structural barriers to employment identified by five women with complex episodic

disabilities. The implications for practice relationships and policy that considers an alternative understanding of (dis)ability and employability as a contingent, fluid embodiment are considered.

32. World Health Organization. (2002). Towards a common language for functioning, disability and health. http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf
    This paper discusses the international classification of functioning, disability and health (ICF) and outlines the differences between disability and functioning. Disability is always an interaction between features of the person and features of the overall context in which the person lives; however, some aspects of disability are almost entirely internal to the person, while other aspects are almost entirely external. In other words, both medical and social responses are appropriate to the issues associated with disability. The World Health Organization describes disability as resulting from impairments to body functions and/or structures, activity limitations, and/or participation restrictions. The purpose of the article is to put forward the rationale for the use of a common system of language in discussing disability and functionality within the health communities. The paper further addresses how the ICF can be used for policy and decision-making purposes.

3.5 Other Findings

Other terms were identified during the literature review that overlaps with the five key terms and their interaction with employment. The following section presents a brief discussion of these terms for future consideration.

Chronic Illness

1. Beatty, J.E. & Joffe, R. (2006). An Overlooked Dimension Of Diversity: The Career Effects of Chronic Illness. Organizational Dynamics, 35(2). http://cicoach.com/pdf/org-dyn_FINAL.pdf
   Beatty and Joffe (2006) describe a chronic illness as an illness that lasts longer than one year, causes some limitations to what a person can do and requires ongoing medical care. This type of illness can occur at any age, and symptoms vary in their severity from mild to seriously debilitating. Further, these illnesses do not follow an expected pattern. Some people experience “flares” or peaks of symptoms, followed by remission periods, while others might live with constant symptoms. There might also be an impact on the workplace, Since the symptoms of a chronic illness are often invisible, organizations may be unaware of the presence of people with chronic illness in the workplace. This definition is quite similar to that of episodic disability as defined above, with the “flares” being similar to the “episodes”. The term “chronic illness” is commonly used to mean a long-term or permanent illness that has some ongoing limitations. Chronic illness definitions are also primarily medical in nature, focusing on medical diagnostic criteria as determinants of inclusion. One important difference is the possibility that symptoms might be continuous or occasional. Hence this definition has partial overlap with the definition of episodic disability.

2. Walker, C. (2010). Ruptured Identities: Leaving Work Because of Chronic Illness. International Journal Of Health Services, 40(4), 629-643.

   Walker (2010) also notes an overlap between chronic illness and episodic disability and work. She states that "nearly all people whose work lives are affected by any serious illness, whether chronic, acute, or terminal, face these issues: the centrality of work in their lives; the uncertainty of how illness will affect their future and how to negotiate the necessary steps, which involve disclosing their illness; and deciding whether to stay on at work or to leave, and the impact of the decision on employers, fellow workers, and the broader community. Chronic illnesses, by their very nature, may be episodic – have acute phases, be degenerative, or have remissions – thus intensifying the uncertainty experienced by people who have them. When the trajectory of the illness is uncertain, making a decision about employment is problematic, since only time will tell whether the decision was a correct one."

Invisible Impairments

3. Lingsoma, S. (2008). Invisible Impairments: Dilemmas of Concealment and Disclosure. Scandinavian Journal of Disability Research, 10(1).

   Lingsoma (2008) writes that people with invisible impairments have the choice of whether or not to reveal or conceal their impairments in their social interactions. They may pass for "normal" if they silence impairment and disability experiences. Social conventions support silence. The disclosure of an impairment may occur in many ways, for many reasons and may have many ramifications. People with invisible impairments and the dilemmas they face have received little attention in the disability research. This article discusses concealment and disclosure of invisible impairments as ongoing processes, with an emphasis on performance, motivation and context.

4. New Brunswick Human Rights Commission. (2004). Guideline on Accommodating Physical and Mental Disability and Work.

   http://www.gnb.ca/hrc-cdp/e/g/Guideline-Accommodating-Disability-at-Work-New-Brunswick.pdf

   "The nature or degree of certain disabilities can render them "non-evident" to others. Chronic fatigue syndrome and back pain, for example, are not apparent conditions. Other disabilities might remain hidden because they are episodic. Epilepsy is one example. Similarly, environmental sensitivities can flare up from one day to the next, resulting in significant impairment to a person's health and capacity to function, while at other times, this disability may be entirely non-evident."

Work-limited Disability

5. Munir, F., Jones, D., Leka, S., & Griffiths, A. (2005). Work limitations and employer adjustments for employees with chronic illness. International Journal Of Rehabilitation Research, 28(2), 111-117.
   Munir et al. define work-limited disabled as "a long-term health problem that limits the type or amount of work." In contrast, a non-work-limited disabled person may experience a "long-term health condition that does not limit either the type or the amount of work" that can be done.

4. Disability Organizations and Disability Researchers

4.1 Description of Methodology

The list of disability organizations and disability researchers was compiled based on the author's knowledge of the community, and it was reviewed and augmented by members of the PwDAC Working Group.
The content of the email was reviewed and revised by members of the PwDAC Working Group. The revised text was translated, and a copy of the English and French version is attached as Annex A.
The email was sent to 27 organizations and 19 academic researchers. The response rate from the organizations to date is 59%. Only five of the 19 academic researchers have provided input; five declined to participate.

4.2 Summary

A consistent comment from the majority of the respondents was that the three disability-related terms were looking at different characteristics of a person with a disability. "Episodic" deals with the stability of the impairment. Some impairments are stable and/or predictable. Some impairments are stable for a period of time and then there is a progression of the disease/condition with the result being a different level of impairment. Still other health conditions result in impairments that fluctuate between being stable and worsening with those fluctuations/episodes being unpredictable both in terms of severity and duration. Still others may be as a result of an injury (such as a broken leg or arm) or a health condition (such as gestational diabetes) that is expected to resolve itself within a short period of time.

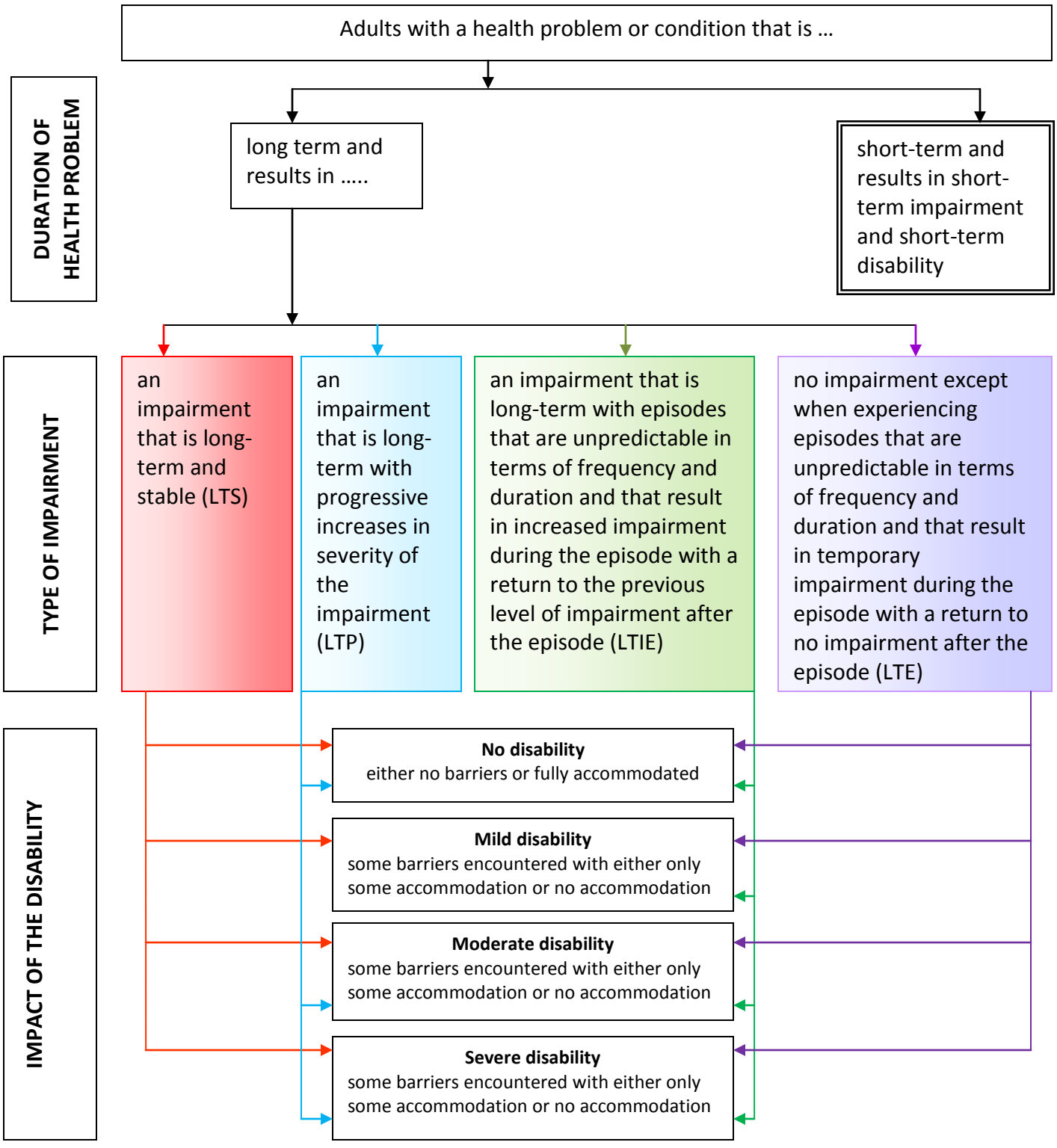
"Short-term" is a measurement of duration and, in the trajectory of health conditions/injuries, can be present in all types. From the community's perspective, short-term disabilities that are a result of an injury or a health condition that resolves itself with no residual limitation in activities are not typically included when speaking about the population with disabilities. Respondents pointed out that Statistics Canada surveys use the phrase "lasted or is expected to last six months or more."

The general consensus for "moderate" disabilities is that this term identifies the severity of the impact in various contexts — work, school, leisure and home — that one experiences when living with an impairment.

The two employment-related terms each have an impact component associated with them. "Intermittent work capacity" is the phrase used by many of the respondents to describe the individual who moves in and out of employment because of the impact of living with an impairment, while "intermittent employment" deals with attachment to the labour force. Longer-term sustained employment is described by some as stable employment that offers economic security for the individuals and their families.
One researcher proposed that if the focus for future research is on employment, then one should also consider "precarious employment" where the individual finds him/herself in short-term jobs that have low wages, few benefits and with virtually no long-term security.

It is clear from the comments received from the disability community and researchers that they were made in the context of the social model of disability. In this model, the individual has a health problem or condition that can be long term or short term (duration). This health problem results in an impairment (i.e., a loss of function). When the person with the impairment undertakes an activity, that individual may experience a barrier that prevents or impedes him/her from fully participating in that activity (impact). The impact on the individual can be measured by a severity scale such as mild, moderate or severe.

It should be noted that the consensus was that while one could look at an overall measure of disability, it would make more sense to look at disability in the context of different life activities (work, leisure, within the home, etc). One could then develop a severity of disability for each type of activity. Within each type, one could look at both physical and attitudinal barriers.
The following diagram is an attempt to capture the collective opinions of the respondents concerning the relationships between a health problem and different types of impairments and, within each type of impairment, the severity of the disability.


Adults with a health problem or condition that is …
DURATION OF HEALTH PROBLEM
long term and results in …..
short-term and results in short-term impairment and short-term disability
TYPE OF IMPAIRMENT
an impairment that is long-term and stable (LTS)
an impairment that is long-term with progressive increases in severity of the impairment (LTP)
an impairment that is long-term with episodes that are unpredictable in terms of frequency and duration and that result in increased impairment during the episode with a return to the previous level of impairment after the episode (LTIE)
no impairment except when experiencing episodes that are unpredictable in terms of frequency and duration and that result in temporary impairment during the episode with a return to no impairment after the episode (LTE)
IMPACT OF THE DISABILITY
No disability
either no barriers or fully accommodated
Mild disability
some barriers encountered with either only some accommodation or no accommodation
Moderate disability
some barriers encountered with either only some accommodation or no accommodation
Severe disability
some barriers encountered with either only some accommodation or no accommodation

The significance of this approach to understanding the impact that a disability has on the life of an individual with a disability is the nature of the impairment and the individual's experience when interacting with his/her environment. The individual with an impairment can move from one level of disability to another depending on this interaction, thus having an episodic disability (as cited often in the literature review).

- Example 1 – A person with a stable impairment changes employer. His first employer provided all of the accommodation that he needed and thus he experienced no limitation in the workplace. At his new employment, he experiences attitudinal barriers that result in him experiencing some limitations in the workplace. In terms of level of disability encountered in the workplace, this individual would indicate some level of disability.
- Example 2 – A person has lupus that, to date, has not resulted in any impairment and she has been under contract with the same small employer for many years. She now experiences flare-ups that are occurring with increasing frequency and intensity and that result in extreme fatigue. This results in frequent absences from work. Although her employer understands the situation, he finds that it is affecting productivity both because she is absent and because other employees resent having to take on additional duties. He makes the decision not to renew her contract. She would now indicate a limitation in her activities with respect to employment.

4.3 Validation of Key Words

The following is a summary of the comments received from both the representatives from the community and researchers. There were no differences of opinions put forward for the five key words; rather, the same comment was made using different words. These comments are offered below.

4.3.1 Episodic

Episodic disabilities:

- are unexpected and/or periodic diminished capacity relative to one's usual functioning and/or capacity to fulfill customary self-care, leisure and/or work roles.
- have symptoms that recur and then remit. When the symptoms recur, they can cause increasing limitation in activities. When the symptoms remit, the individual can return to his/her normal activity but perhaps at a reduced pace for a period of time.
- connotes an impairment of sensorial, communicative, physical or emotional functioning that "comes and goes" such as an emotional disorder where depression is aggravated by lack of sleep, stress, poor diet and social isolation.
- are long-term conditions that are characterized by periods of good health interrupted by periods of illness. These periods may vary in length, severity and predictability from one person to another with the same condition. They are often more difficult to manage with regard to employment. These episodes can force a person out of the labour force without

warning and for indeterminate periods of time. This can have significant impact on both health and income stability.
- can result in serious barriers to accessing and/or maintaining employment. From the individual's perspective, the barriers include lack of understanding and awareness among employers. From the small business perspective, accommodating a person with an episodic disability can be a considerable challenge.
- can be associated with a progressive disorder such as diabetic retinopathy where vision can fluctuate substantially.

4.3.2 Short-term disabilities

Short-term disabilities:
- is a condition that is expected to last for a limited period of time and the prognosis for the individual is that he/she will regain full functioning or function again at a level that he/she considers normal.
- is a disability that can individual will "recover" from (e.g., a broken leg).
- is a change in functional performance for a limited period of time. Typically, this is thought to be one month or less by the disability researchers who have work as their focus.

4.3.3 Moderate disabilities

Moderate disabilities depend on the context within which the degree of disability is being measured. Statistics Canada developed a severity scale that measures the extent of limitation that an individual encounters when performing a specific set of activities. The response from the community is that moderate disability should refer to a scale that measures a mid-point in the limitation of and the nature and extent of the barriers encountered when the individual undertakes an activity. The extent of the limitation can be type specific, such as work, or cumulative (i.e., across all activities).

4.3.4 Intermittent Employment/Work Capacity

Intermittent employment is attachment to the labour force that fluctuates between periods of employment and unemployment with one or more employers with most periods of employment lasting 6 months or less (or even 12 months or less if there is a recurrent pattern of unemployment).

Intermittent work capacity refers to an individual with unexpected and/or periodically diminished capacity relative to his/her usual or expected workload because of his/her chronic health problem(s) or who is absent from the workplace frequently or for extended periods of time because of his/her chronic health problem.

4.3.5 Longer-term Sustained Employment

Longer-term sustained employment

- carries on for several years.
- provides sufficient employment income to sustain an individual and her/his family.
- is stable and offers a paycheque for a number of years.

5. Income Support Programs

5.1 Methodology

Face-to-face meetings were held with representatives from CPP-D, WSIB, Ontario Works and ODSP. These meetings provided an initial overview of the program and were followed by emails for clarification. Provincial representatives on the Working Group were contacted via e-mail. Electronic contact was made with Employment Insurance – Sickness Benefits. All participants were asked the following questions.

1) How is disability defined in your program?
2) What information do you maintain on the nature of the disability? Are conditions coded to a classification system such as the ICD09?
3) Is there a way of identifying the severity of the disability that could be used to identify sub-sets of the population such as:
   a) Episodic;
   b) Moderate;
   c) Short-term?
4) Are any of the three terms used in your program and, if so, what is your definition of those terms?
5) What type of employment data are collected at the time of application for your program?
6) What data are collected on an ongoing basis for persons who meet the program criteria?
7) Do you have statistics on the number of persons who meet the program criteria and those who do not? Is there a variable on the file to indicate why the person did not meet the criteria?
8) Do you have information on the number of persons who appeal and are successful/unsuccessful and their characteristics with respect to age, gender and nature of disability?
9) What data do you have for persons who do not meet the program criteria? Would those data be available for future research?
10) What type of employment-related services is offered to clients? Do these services differ by type of disability?
11) If future research is undertaken, would you share your best practices?

5.2 Summary

Administrative data are maintained by the various ministries, and those data could be used for future research on the employment patterns for persons with episodic, short-term and/or moderate disabilities. However, it is important to note that these data only cover specific segments of the adult population with disabilities. There are many adults with disabilities who would not be covered by these administrative databases. Prince (2008)[2] provides the following table that demonstrates the estimated coverage of adults with disabilities by selected income support programs. It should be noted here that an individual can be in receipt of income from more than one income support program and, as such, the percentages are not additive.

Chart 3
Adults with disabilities who are recipients of income support programs (percentage of 3.42 million)

Program	%
Canada/Quebec Pension Plan	10.0
Social assistance	9.9
Veterans' benefits and other assistance	6.4
Private disability insurance plans	6.2
Workers' compensation	5.1
EI sickness benefits	4.3

Source: Participation and Activity Limitation Survey (PALS) 2001.

Nonetheless, the data maintained by these programs have the potential of offering new insights into the issues facing some adults with disabilities and, therefore, could be considered as possible data sources for future research. However, gaining access to these data was not part of this project. Clearly, this would require further negotiations between members of the PwDAC and the appropriate ministry.

[2] Prince, Michael J. (2008). Canadians Need a Medium-Term Sickness/Disability Income Benefit. Retrieved from http://www.caledoninst.org/publications/pdf/670eng.pdf, February 28, 2013.

CPP-D provides income support for those persons who meet the medical criterion and who have had recent attachment to the labour market. The database of CPP-D recipients includes variables that could be used to identify persons with episodic disabilities as defined by the underlying health condition. CPP-D also maintains another database that includes information on individuals who do not meet the medical criterion and thus have had their application rejected. These data could also be explored by underlying health condition. Both databases include information on occupation, industry and level of education.

In addition to similar data maintained on CPP-D recipients, WSIB also includes information on length of claim; these data could be used to measure duration of disability.

The Canadian Health and Life Insurance Association (CHLIA) conducts an annual survey of disability benefits paid to beneficiaries by member companies. These data are dichotomized by duration of claim: short-term and long-term. Data maintained by the member companies would provide some better insights into the nature and extent of the populations with both short- and long-term disabilities. Initial contact was established between HRSDC and one company; however, time and resources did not permit a detailed discussion.

ODSP, and their counterparts in Alberta and British Columbia, provide income support for persons with disabilities who meet both the financial and medical criteria of the program. The underlying health problems that result in the individual experiencing a disability is recorded; however, only the primary and, in some programs, the secondary health problem is part of the electronic database. All three provinces record electronically the employment and education characteristics of applicants.

5.3 Canada Pension Plan – Disability (CPP-D)

5.3.1 Background

The Canada Pension Plan - Disability (CPP-D) is a program of the Government of Canada that is designed to provide some protection to working Canadians, including the self-employed, against the loss of earnings due to a long-term disability from any cause. Quebec manages and administers its own plan, the QPP, and participates in decision making for the CPP. Benefits from either plan are based on pension credits accumulated under both.

Benefits under the CPP-D are available to people between the ages of 18 and 64 who are not in receipt of retirement benefits, and who have a disability that is “severe” and “prolonged” making them unable to do work that is regular and substantially gainful. “Severe” means the disability prevents the applicant from working at any job on a regular basis. “Prolonged” means the severe disability will prevent the individual from going back to work in the next 12 months or is likely to result in death. Recipients must have made the required minimum amount of contributions to the CPP. During the period 2001 to 2006, the average approval rate for Canada was 56%, with the highest rates observed in PEI (66%), Newfoundland (65%), and New

Brunswick (63%), and the lowest observed in the Prairies provinces (ranging from 45% to 51%). Between 2001 and 2006, the average approval rate at the initial stage of the application was 45%. Within the denied group, more than 80% were rejected because they did not meet the medical criteria. Of the denied group of applicants at the first round (55%), approximately 35% reapplied and, of these, 40% finally succeeded. A limited number of cases went to the pension appeals board, which isthe last stage of the appeals process.[3]

Disability benefits represented about 13% of the total benefits paid out by the CPP in 2010–11. The CPP-D caseload has grown by an average of two percent per year over the last five years. Since 2005–06, "mental disorders" have surpassed "diseases of the musculoskeletal system and connective tissue" as the most prevalent medical condition category for all CPP-D beneficiaries. As of December 2012, there were 326,505 CPP-D beneficiaries and, of those, 98,254 (or 30.1%) had been classified as having a "mental disorder."[4]

Since the mid-90s, CPP-D has included a suite of programs designed to proactively support community participation and workplace reintegration, including a vocational rehabilitation program. Building on this foundation, and to address the concerns of those who feared the loss of their benefits if they were unable to remain in the workforce, automatic reinstatement of disability benefits was introduced as a legislated entitlement in 2005.[5]

5.3.2 A Possible Data Source

To be eligible for CPP-D benefits, you must:

- be between the ages of 18 and 64,
- have a "severe" disability (i.e., prevented from working at any job on a regular basis),
- have a "prolonged" disability (i.e., prevented from going back to work in the next 12 months or is likely to result in death), and
- have made sufficient CPP contributions to during four of the past six years.

The applicant completes a comprehensive form that includes Social Insurance Number as well as information on education, work history, type of benefits currently being received, and medical information, including nature and severity of difficulties/functional limitations with a

[3] Human Resources and Skills Development Canada (2011). Summative Evaluation of the Canada Pension Plan Disability Program. Retrieved from http://www.hrsdc.gc.ca/eng/publications_resources/evaluation/2011/sp_983_02_11-eng/sp-983-02-11-eng.pdf on February 7, 2013.

[4] Retrieved from http://www.servicecanada.gc.ca/eng/isp/statistics/statmain.shtml on February 7, 2013.

[5] Furrie, Adele and E. Cahill (2010). Advancing Inclusion: How Our Understanding of the Dynamic Nature of Disability Is Informing Interventions That Support Employment

series of daily activities, information about current and past physicians, number and nature of hospitalizations over the past two years, medications, treatments, and uptake of vocational rehabilitation. A health professional completes a detailed form that includes much of the same medical and functional limitation information included in the self-report.

The Master Benefit File (MBF) contains all administrative data related to CPP benefits and clients from 1966 to May 2009 and is derived from the Legacy system. Information includes personal data (gender, age, address/region, marital status, medical condition) and payment data (benefit amount and status).

The New Application Status Record (NASR) contains administrative data related to all CPP Disability applications from December 2000 to May 2009. Information includes personal data (gender, age, address/region, main medical condition, marital status, broad education and occupational categories) and application/appeal status (granted, denied, reasons for denial). NASR also contains primary and secondary (if applicable) health conditions (coded using the International Classification of Diseases (ICD)). Based on the medical information provided by the applicant and supporting medical information submitted, the adjudicators decide on the most appropriate ICD code(s) for each case.

The MBF and NASR databases were replaced with the Enterprise Reporting System (ERS) in June 2009. The ERS includes information on both granted and denied applicants. The content of the ERS is similar to NASR and the MBF but not identical. Further detailed examination of the similarities and differences would be required if the proposed research includes a times series analysis.

These three data bases provide an opportunity to explore the characteristics of persons who were granted “beneficiary” status and those who were denied. If “episodic” disability is defined as having one of a list of health conditions, then one could explore the extent to which persons with an “episodic” disability are disproportionately represented in the “denied” population. The duration criterion (prolonged) most likely excludes persons with a disability of short duration. One could develop a severity of disability indicator based on the responses to the “activities of daily living” questions to identify the characteristics of persons with a “moderate” disability as defined by cumulated difficulties and limitations in activities.

NOTE: HRSDC and CPP do not allow access to administrative micro data by external researchers.

5.4 Provincial/Territorial Income Support Programs for Persons with Disabilities

Provincial/territorial governments provide financial support to individuals who require assistance, because circumstances render them incapable of maintaining employment or whose employment or other means of support does not provide sufficient income to meet their needs. The income support programs in every jurisdiction are governed by complex rules that regulate all aspects of the system, including eligibility for assistance, rates of assistance, other assets that income recipients are allowed to keep and the appeals procedures.

Eligibility for income support is determined on the basis of categorical definitions outlined in provincial/territorial regulations. In the case of persons with disabilities, most provinces/territories require that applicants have a physical or mental disability that severely impedes their ability to engage actively in paid employment in the labour market. Medical certification of disability is required.

Eligible employable persons, including people with disabilities, are actively encouraged to pursue, accept and retain any reasonable offer of employment or retraining as an initial and continuing condition of eligibility for social assistance. Thus, many jurisdictions offer employment services and training opportunities in combination with financial assistance.

Assistance consists of a basic allowance and a shelter allowance. The basic allowance covers the cost of food, clothing, utilities, and personal and household items. Basic assistance may be supplemented by provisions for in-kind supports (e.g., covering costs of supportive devices or local transit). Benefit and non-monetary assistance levels vary based on numerous criteria. However, all programs consider the number of family maintainers, the number and age of children, the capacity of family members to take on work (“employability”), and disability.

All programs have design features to assist persons with disabilities, including higher exemption levels on assets and income, higher basic assistance levels, special disability-related allowances, and supplementary health and medical benefits. An applicant with a disability may also meet the criteria of an individual with multiple barriers to employment that include substance abuse, child-care or transportation issues, a history of long-term unemployment, and low basic skills. Such individuals may require interventions to address personal circumstances in order to be able to find and maintain employment and, as such, may have higher benefit levels and exemptions to reflect their longer-term reliance on social assistance.

The following indicates the variations across the country in the ways disability status affects the levels of monetary benefits, employment assistance and other types of in-kind assistance.

- Persons with disabilities can be part of a social assistance program that includes all persons seeking social assistance. In these jurisdictions, people with disabilities are assessed to have higher "basic assistance levels" and they receive higher incomes (Nova Scotia, Quebec).
- Persons with disabilities can be provided with benefits that include assessments at higher "basic assistance levels" and, in addition, are provided supplements to address disability-related expenses (Alberta, Manitoba, Newfoundland and Labrador, Prince Edward Island, Saskatchewan) unless the "handicap" is severe (British Columbia, Yukon Territory, Northwest Territories, Nunavut).
- Persons with disabilities may be administered under a separate program with separate determinations of basic needs and separate employment and in-kind assistance provisions (New Brunswick Extended Benefits Program, Ontario Disabilities Supports Program (ODSP) and for persons with "severe handicaps" in the Alberta Assured Income for the Severely Handicapped Program (AISH)).

Several provinces/territories provide incentives to work that are tailored to beneficiaries with disabilities. British Columbia, Manitoba, Ontario, Saskatchewan and the Yukon Territory allow people with disabilities to retain benefits while receiving higher levels of employment earnings than other social assistance beneficiaries. Alberta, Manitoba and Ontario provide enhanced support benefits (e.g., work clothing, transport allowances). Finally, Prince Edward Island extends work-related and other benefits to all persons with low and moderate income irrespective of their status as social assistance beneficiaries. These incentives are designed to ensure that those who successfully leave social assistance for employment are not left worse off by accepting employment.

5.4.1 An Example of a Provincial/Territorial Income Support Program

The Ontario Disability Support Program (ODSP) is a social assistance program targeted to Ontarians who have a disability, are in significant financial need, and who do not have access to other benefits that are available to persons with disabilities from both private and public sources, including private disability insurance, CPP-D, EI and compensation from the Ontario Workplace Safety and Insurance Board (WSIB). This situation arises often when a disability exists from an early age that prevents participation in work, or where other factors have led to non-paid, part-time or precarious employment.

Ontario divides income support between the general welfare program (Ontario Works) and an income support program for people with disabilities (ODSP). A person may apply for ODSP one of two ways: they may apply directly for ODSP or, if they are in immediate financial need, they may apply for Ontario Works; staff at Ontario Works will then refer them to ODSP. An applicant must qualify financially to be eligible for ODSP. A person's income, assets and expenses from all sources are taken into account to determine whether a person qualifies and how much income support he/she can receive. In general, a person does not qualify for ODSP if his/her total

income from all sources is higher than the amount he/she would otherwise get from ODSP or if his/her assets are higher than the asset limit.

Once an applicant qualifies financially, a disability determination package (DDP) is provided to applicants who need to go through the disability determination process. Under the *Ontario Disability Support Program Act*, a "person with a disability" is a person with a substantial physical or mental impairment that is continuous or recurrent and is expected to last a year or more. In addition, the physical or mental impairment must directly result in a substantial restriction in the person's ability to:

- work,
- take care of him or herself, or
- take part in community life.

The impairment(s), its duration and the restriction(s) must also be verified by an approved health care professional. ODSP does not have a specific list of medical conditions that qualify for income support.

Part of the determination package is completed by a physician or other health care practitioner, while the "self-report" is completed by the applicant. This process focuses on determining whether the individual meets the definition of a "person with a disability" under the *ODSP Act*. The self-report includes questions on education and special assessments (vocational, educational, psychological), work history (including the need for supports), activities of daily living (including questions on pain), use of other agencies and services, and a commentary on how the disability affects the ability to work, participate in the community and care for him/herself. A health care professional completes a medical report that includes much of the same medical and functional limitation information as is included in the self-report.

The application is reviewed by the centralized Disability Adjudication Unit (DAU). The DAU is responsible for determining if an applicant is a "person with a disability" under the *ODSP Act.* The DAU consists of a multi-disciplinary team of adjudicators, including nurses, physicians, occupational therapists and rehabilitation counselors.

In determining whether or not an applicant meets the definition of a "person with a disability," the adjudicators consider the information provided in the DDP, as well as any other information submitted by the applicant, using his/her knowledge of the *ODSP Act,* case law and health sciences, along with his/her training and clinical experience.

If the DAU decides that an applicant is not a person with a disability, the applicant may request an internal review within 30 days of the notice of decision. Internal reviews are intended to provide a timely review of the original decision.

If a negative decision is made at this level, the applicant has the opportunity to have the decision considered by the Social Benefits Tribunal (SBT). The SBT can confirm, set aside or amend the decision of the DAU.

In 2012, there were 41,177 new applicants for ODSP and 12,785 that were carried over from the previous year. Of the 53,962 applicants awaiting a decision, 241 withdrew the application. Decisions were reached on 41,926 and, of those, 46.1% (or 19,320) were successful applicants.

In December 2012, ODSP served 305,053 cases (a case refers to a single individual or a family unit) or 422,832 beneficiaries — an increase of 4% from December, 2011. Persons with mental disabilities (psychoses or neuroses) accounted for the majority of the increase.

Of the 305,053 cases (individuals or family unit), 31,592 (or 10%) had earnings, with average net earnings of $862. There were 40,772 of the 305,053 cases that were also in receipt of Canada Pension Plan (30,929 receiving CPP-D and 9,841 receivng CPP Survivor/Retired benefits). There were also 3,364 cases that were receiving income from WSIB.

ODSP Employment Supports

Participation in the ODSP employment supports program is voluntary. It provides employment assistance to help people with disabilities prepare for, find and keep a job. Employment supports can include services such as employment counselling and assessment, employment planning, pre-employment training, post-secondary education, skills training, technical aids, and other supports to assist individuals in obtaining access to job opportunities and training.

A person can receive this help even if they do not qualify for ODSP income support. To be eligible for ODSP employment supports, a person must live in Ontario, be 16 years of age or older, be legally allowed to work in Canada, and EITHER be receiving ODSP income support OR have a physical or mental disability that is expected to last a year or more and, as a result, makes it hard for him/her to find or keep a job. An ODSP employment supports applicant may have to verify his/her disability if he/she is not receiving ODSP income support. This involves asking the applicant's doctor to fill out the Verification of Disability/Impairment form, which is found in the employment supports application package.

Employment services are provided through a network of community-based service providers who connect with employers in the community. Service providers work closely with clients to determine the kinds of supports they need, and they are responsible for placing and retaining employment supports clients in employment and helping those clients increase their level of

earnings through career advancement. Clients can choose the provider that they want to work with from the list of approved providers in their area. Clients work with only one employment supports provider, but a provider may refer the client to other agencies for specialized services.

Employment supports clients who also receive ODSP income support may be eligible for help with work-related costs, such as the cost of transportation, tools and equipment, and special clothing.

The ODSP – employment supports application includes the ODSP income support Member ID so it would be possible to link the income support record for an individual with his/her employment support record for those who receive both income support and employment supports.

5.4.2 A Possible Data Source

According to Prince (see Table on Page 52 of this report), social assistance is reported as one source of income for approximately 10% of the adult population with disabilities. Therefore, any use of the data captured from the administrative database for these programs must be qualified to ensure that the findings do not get extrapolated to the total adult population with disabilities.

Given the short time frame for the project, details about the availability of data were obtained from interviews with officials from ODSP program areas as well as written responses from British Columbia and Alberta. There is the potential to pursue the administrative files of all three programs as possible data sources. What follows is an overview of the data that could be available using ODSP as the example.

ODSP Database

It is unclear from the discussions with officials from the ODSP program as to the extent of the data that are captured from the initial application. The majority of questions on both the medical report and the self-report are open-ended. These data are used by the DAU, the internal reviewers (when requested) and the SBT (when requested) to decide on the status of the applicant.

The adjudicator determines which underlying health problem is the main condition (and in some instances the secondary condition), and that information is captured in the database along with other identifying information.

The amount of information available for all applicants from both the medical report and the self-report is extremely rich and could inform future research concerning persons with an episodic impairment and a moderate level of disability. What makes this data source invaluable is that the information is available from two perspectives: the individual and the health professional. Added to that is the deliberation of the adjudicator.

We recommend a four-stage process to evaluate the potential of the income support database as a source for future research on these topics. We use Ontario as the example, but the project could be undertaken in another jurisdiction or in more than one jurisdiction.

- The first stage is a correspondence activity that compares the record layout to the Disability Determination forms and the employment supports application. From that activity, one would be able to determine what data are available in the database and what data are not.
- If most of the open-ended data have not been put into the database, then I would recommend getting some basic statistics from the database (age, gender, underlying health problem (based on broad categories) and status (recipient of OSDP, terminated, denied, undecided).
- I would then select a sample with the same characteristics and do a "file crawl." One would need access to both the DAU and employment supports paper files. The information derived from the second stage could be treated as a qualitative sample (if the "file crawl" is limited) or as quantitative data (if the sample was large enough). I would start with a small sample to develop a detailed coding structure. To minimize bias, I would have each file reviewed and a summary prepared by two people independently and then have the summaries compared and evaluated by a third person.
- The fourth stage would be an analysis of the summaries.

We propose that this could be a project for two summer students or a university co-op project. Clearly, the independent reviewer would have to be someone knowledgeable from the ODSP staff member.

5.5 Workers' Compensation

Workers' compensation provides no-fault compensation to most Canadian workers who experience a job-related injury or illness. Each province and territory in Canada has workers' compensation legislation that created and empowered its own workers' compensation board and commission.[6] Federal government employees, including employees of Crown corporations and agencies, are covered under the *Government Employees' Compensation Act*.

All claims are made in writing by the injured/ill employee after the employer has been notified of the accident/condition.[7] The time frame for submitting a claim varies among the jurisdictions as

[6] Northwest Territories and Nunavut legislation empower a shared board.

[7] In many jurisdictions, the employer and/or a medical practitioner is empowered to help an injured/ill worker to prepare a claim. However the workers' compensation board can waive the requirement for a *written* claim under special circumstances (e.g., where the worker is illiterate or the industrial (occupational) disease requires isolation or quarantine).

does the nature and extent of the supporting documentation required. In most jurisdictions, entitlement to workers' compensation benefits depends primarily on the definitions of "accident," "injury" in the workplace, and "occupational disease," rather than on the definition of "disability". Benefits are paid when the results of an accident, injury or illness lead to the employee being off work past the day of accident/notification of illness, when there is a loss of earnings, or when a permanent impairment (loss of physical or mental function) occurs.

While there are slight differences among the provinces/territories, all decisions are initially reviewed using a two-step process. The first step involves a discussion between the person who made the decision and either the employee or the employer where all considerations that went into making the decision are provided and additional information (if available) is accepted for consideration. The second step is initiated if concerns remain. It involves a request for review that must be submitted within one year following an original decision and it is undertaken by internal reviewers at the workers' compensation board. If resolution is still not achieved, the case is forwarded to an internal appeal body and, if necessary, to an external review body for final resolution.

In most provinces/territories, the right to benefits begins at the moment following injury or onset of illness.[8] Benefits provided by workers' compensation can be grouped under five categories: health care, rehabilitation, temporary financial support, permanent function loss and survivor.

Workers' compensation boards across the country offer similar services in the areas of vocational rehabilitation and supports in assuring re-employment and in other areas of daily life.

5.5.1 An Example of a Provincial/Territorial Worker's Compensation Program

The Workplace Safety and Insurance Board (WSIB) provides a no-fault workplace insurance system for Ontario workplaces. The insurance system includes wage loss benefits, medical coverage and help getting back to work for workers injured on the job or who contract occupational diseases within the workplace. For employers, WSIB provides no-fault collective liability insurance and access to industry-specific health and safety information. WSIB is legislated by the provincial government of Ontario and is responsible for administering the *Workplace Safety and Insurance Act*. Funding comes from employer premiums and from income earned from investments. WSIB is governed by an independent Board of Directors made up of representatives from employers, workers and others.

WSIB maintains an extensive statistical program that offers detailed information on workplace fatalities, injuries and illnesses in Ontario. Beginning with the 2011 statistics, WSIB added

[8] Three provinces (New Brunswick, Nova Scotia, and Prince Edward Island) have a waiting period before time-loss benefits are paid: three, two and three days, respectively.

additional information, interpretation and discussion to improve the understanding of what was happening in Ontario workplaces. Their *By the Numbers* publication provides 10 years of data for 2 types of employers: Schedule 1 employers and Schedule 2 employers.[9]

In addition to variables such as age, gender, industry and occupation, duration of claim, and type of benefits received, there are four pieces of information that relates to the health specifics of the claim (nature, event, source and part of body). Since 1996, all injuries, diseases and fatalities have been coded using the CSA Z795 coding structure; prior to 1996, the International Classification of Diseases (Version 9) was used.

In 2011, the majority of the 56,672 allowed lost time claims (70.3%) were for injuries, with the majority being sprains and strains, bruises and contusions, fractures and cuts, lacerations, and punctures.[10]

5.5.2 Possible Data Sources

WSIB is open for further discussions on the use of their databases for future analyses. However, according to the 2006 Participation and Activity Limitation Survey, workers' compensation was reported as a source of income for only 5.5% of the population with disabilities.[11] That said, the duration variable could be used to assess workers who have short-term disabilities. Also, with the ever-increasing number of persons with disabilities as a result of a mental health condition, this might be a good source to explore trends in terms of the number of persons with claims because of mental health conditions and the duration of those claims.

Another possible source that merits some exploration is the Association of Workers' Compensation Boards of Canada (AWCBC) and their National Work Injuries Statistics Program (NWISP). The publicly available portion of this database includes a number of indicators related to the characteristics of claimants. There is a portion of the database that is only available to members of workers' compensation boards. It is suggested that a further conversation be held with WSIB officials to determine if this database holds the majority of the variables that are included in the WSIB database. If it does and if access could be obtained, then this might prove to be an excellent starting point for future analyses on the effect of short-term impairment and disabilities and perhaps disabilities as a result of a mental health condition.

[9] For definitions see WSIB 2012. By the Numbers: 2011 WSIB Statistical Report. Retrieved from www.wsibstatistics.ca on March 6, 2013.
[10] Ibid.
[11] Retrieved from the 2006 PALS Public Use Microdata File.

5.6 Private Disability Insurance Providers

5.6.1 Background

Private disability insurance companies could be an excellent source for persons with short-term disability. Initial discussions were held between one company and a representative from HRSDC. The limited time available for this contract prevented further discussions from taking place. However, an email to the Executive Assistant of the Chairman of the Board of Directors for the Canadian Life and Health Insurance Association (CLHIA) resulted in the following information.

CLHIA, established in 1894, is a voluntary association with member companies that account for 99% of Canada's life and health insurance business.

The best source of disability income data available from CLHIA is their proprietary survey of health insurance benefits in Canada. This survey looks at health insurance benefits at the national and provincial/territorial levels (smallest geographical area available) by type of plan (individual and group insured plans, as well as uninsured/administrative services only (ASO), contracts for which life insurers do not guarantee benefit but provide administrative services only for a fee). Data includes coverage information (i.e., number of plans/contracts and number of individuals/certificate holders) at the end of the year and the amount of claims and premiums (where available) paid during the survey year. Although claim payments are tracked, the actual number of active claims is beyond the scope of the survey.

Although CLHIA surveys are considered to be proprietary for the use by CLHIA and their members in support of the industry, the following material from the survey was provided for 2011 (latest available) and 2001, for comparison. Three tables (see Annex C) were provided for each of 2001 and 2011, as follows:

1. Disability Insurance (or Loss of Income) data under Group Insured plans (Table 4) including short-term and long-term arrangements shown separately.
2. Disability Insurance (or Loss of Income) data under Individual Insured plans (Table 5). This table includes a note that these would be considered long-term arrangements primarily for self-employed Canadians.
3. Disability Insurance (or Loss of Income) data under Uninsured/Administrative Services Only plans (Table 7), including short-term and long-term arrangements shown separately. Premium equivalents under these contracts are estimated as Benefits payments plus administrative fees. These contracts may be administered by the group sponsor, an insurer or other organization, and this table includes only those contracts administered by life insurance companies. The coverage information (i.e., number of plans/contracts and number of individuals/certificate holders) under short-term and long-term plans should not be combined as that would result in extensive double counting as most of the people with short-term disability income (insured or

uninsured) would probably also be counted in a long-term disability income plan (insured or uninsured).

Loss of income (short term) is defined as weekly or monthly income benefits with a maximum payment period of one year or less. Loss of income (long term) is defined as weekly or monthly income benefits with a maximum payment period of longer than one year.

5.6.2 A Possible Data Source

CHLIA data provides an overview of the population covered by short-term and long-term disability insurance. The rich data concerning the characteristics of these populations is retained by the companies that administer the plans. The discussion that was held between one insurance company and an HRSDC official should be continued.

Meanwhile, in their 2003 brief to the House of Commons Sub-Committee on the Status of Persons with Disabilities,[12] CHLIA speaks to the increase in the population covered by short-term and long-term disability insurance and how this coverage interacts with CPP-D coverage. In 2001, there were approximately 250,000 Canadians in receipt of income from long-term disability insurance; the corresponding number for CPP-D was 284,000.[13] The brief addresses the issue of overlap between the two programs, where a recipient of disability insurance also receives CPP-D. While the figures in the brief are dated, it does provide an opportunity to examine the type of data maintained by the insurance companies.

5.7 EI Sickness Benefits

5.7.1 Background

The Unemployment Insurance program was first implemented in 1940. In 1996, the name of the program was changed from "Unemployment Insurance" to "Employment Insurance" to better reflect the program's primary objective of promoting employment. On December 15, 2009, the *Fairness for the Self-Employed Act* was passed to extend special benefits to self-employed Canadians.

Part I of the EI program provides temporary financial assistance to workers who have lost their job through no fault of their own while they look for work or upgrade their skills. EI Part I also provides assistance to workers who are sick, pregnant, or caring for a newborn or adopted

[12] CHLIA (2003). The Role of Disability Income Insurance Plans in Canada's Disability Income System. Retrieved from http://www.parl.gc.ca/Content/HOC/Committee/372/SPER/WebDoc/WD2029620/SPER372_CPPD_Briefs/Canadian%20Life%20and%20Health%20Insurance_EN.pdf on February 28, 2013.

[13] Ibid., Page 11.

child, as well as those caring for a family member who is gravely ill with a significant risk of death.

EI Sickness benefits are available to individuals who are unable to work because of sickness, injury or quarantine. There are two criteria used to assess eligibility for sickness benefits: individuals must obtain a medical certificate signed by their medical doctor or approved medical practitioner and must have paid EI premiums.

EI Sickness benefits are paid for up to a maximum of 15 weeks depending on the length of time that the individual is unable to work. As of March 24, 2013, parents who fall ill or become injured while receiving parental benefits may also be eligible for EI sickness benefits as a result of the new provisions under the *Employment Insurance Act*.

In 2010–11, the number of new sickness claims was 321,100. Of these, 58.5% were made by women, which is similar to the proportion in previous years. The number of sickness claims decreased from the previous year for both men (-2.3%) and women (-2.0%). The 55 and older group was the only age group to show an increase in sickness claims from the previous year (+1.2%). Claims from those aged 25 to 44 (-3.1%) and those aged 45 to 54 (-3.1%) showed a decrease from 2009–10.

5.7.2 A Possible Data Source

EI maintains no information on the nature of the illness/sickness of the EI claimants as they do not have to provide their medical certificate when they apply for EI Sickness benefits. They have the requirement to keep a medical certificate but are not requested to provide it when they apply. Therefore, EI data have no way of identifying the severity of the disability, which could then be used to identify sub-sets of the population such as episodic, moderate or short-term.

EI does not maintain an historical database on the use of EI Sickness benefits. According to a senior bureaucrat at HRSDC, depending on future priorities, such information could be made available.

Some information on EI Sickness benefits is readily available in the Monitoring and Assessment Report (M&A). [14] This report includes data by gender, age, average duration, breakdown of duration used and benefit rate. In addition to the M&A Report, other information on occupation, type of employment (self-employed or not), availability of sub-plan, number of insurable hours and reception of family supplement could also be made available through further discussion with HRSDC.

[14] 2011 Monitoring and Assessment Report: Employment Insurance. Canada Employment Insurance Commission (CEIC).

5.8 Other Possible Data Sources

5.8.1 Persons with Disabilities in Revenue Canada T1 Files

Revenue Canada T1 Files include a wealth of information on individuals with disabilities. A brief description of the various tax credits, deductions and benefits is provided below.

Disability Tax Credit

The Disability Tax Credit (DTC) is an important federal disability-related tax measures. It is also an eligibility criterion — or "gate" — for several other disability-related tax credits, deductions and benefits. Individuals of any age may qualify for the DTC (also called the "disability amount") if they are blind, or have an impairment in physical or mental functioning that is severe and prolonged and if the impairment results in a marked restriction in activities of daily living. A prolonged impairment is one that lasts, or is expected to last, at least 12 months. Activities of daily living include speaking, hearing, walking, elimination (bowel or bladder functions), feeding, dressing and performing mental functions necessary for everyday life. People who are significantly restricted (but not severely restricted) in more than one activity of daily living (including vision) also qualify for the DTC. Finally, individuals qualify for the DTC if they receive life-sustaining therapy at least three times per week, for a total of at least 14 hours. Families caring for children under 18 who are eligible for the DTC may receive further tax relief through the DTC supplement for children633.

Medical Expenses Tax Credit and Refundable Medical Expense Supplement

A taxpayer may claim medical expenses using the Medical Expenses Tax Credit (METC) for her/himself, a spouse or partner and dependent children under 18. Subject to certain restrictions, claims may also be made for medical expenses incurred on behalf of other dependent relatives.

The Refundable Medical Expenses Supplement (RMES) is based on the same list of allowable expenses as the METC, but it provides a refundable credit to working individuals and families with relatively low incomes and high medical expenses.

Other Disability-Related Tax Credits, Deductions and Benefits

A number of tax measures contain special provisions that offer enhanced tax relief to individuals eligible for the DTC or their families. Other measures simply require that the individual have an "impairment" or be "infirm", without requiring DTC eligibility. [15]

[15] Labour Market and Income Support Programs in Canada for Persons with Disabilities: 2nd Edition. Adele Furrie Consulting Inc. (2011)

5.8.2 Information Platform – New HRSDC Disability Data Strategy

In April 2010, the Minister responsible for HRSDC announced a new strategy for the collection and dissemination of data concerning people with disabilities. This new data strategy brings the situation of people with disabilities into the mainstream as the department undertakes an initiative to modernize the socio-economic data system for all Canadians.

Updated more often, from different sources and more easily usable, the information will enable policy makers and researchers to be more responsive when addressing targeted disability issues in terms of education, income, labour market participation and health. Canadians will have access to the information through a citizen-centered portal. The "People with Disabilities" portal will structure the information through analytical tools and products, such as reports and indicators, synthesis, micro-simulation models, analyses, report cards, dynamic data charts, and discussion forums. It is anticipated that the implementation of the "People with Disabilities" portal will also include provincial and community-based information systems.

The new strategy is composed of three components (pillars): data from surveys, data derived from administrative files and an integrated information platform.

1. The first pillar consists of obtaining information using existing surveys and, when necessary, supplements to existing surveys. In the past, Pillar 1 included data derived primarily from the disability-specific surveys: the 1983/84 Canadian Health and Disability Survey (CHDS), the 1986 and 1991 Health and Activity Limitation Surveys (HALS), and the 2001 and 2006 Participation and Activity Limitation Surveys (PALS). This new approach maximizes the use of information in existing surveys by including a standard set of questions to identify people with disabilities that will be used in all surveys. This will enable the analysis and dissemination of the information in existing surveys for persons with disabilities and persons without disabilities (subject, of course, to sufficient sample size and other methodological considerations). Supplements to existing surveys may be required to quantify specific issues concerning people with disabilities, such as supports needed to fully participate in chosen daily activities, barriers encountered that prevent or impede full participation, etc. When fully implemented, this strategy is anticipated to provide more timely information on labour market, health, education and social outcomes for people with disabilities.
2. The second pillar is aimed at making better use of program and tax data to collect information on persons with disabilities who are eligible for programs. Two sources are currently being explored: federal tax data (disability tax credit) and the Canada Pension Plan's Disability benefits. This pillar will provide useful complementary data for enhancing the understanding of programs' beneficiaries and their characteristics.

3. The new "People with Disabilities" information Portal (Pillar 3) is part of a larger social, learning and labour market information system that HRSDC is developing. The "People with Disabilities" Portal will provide accessible, flexible, easily updateable and user-friendly information on a web platform for better knowledge sharing, communication and exchange to continuously meet the evolving information needs of people with disabilities.

HRSDC has developed three data cubes that will be released in 2014 as part of their integrated data platform including:

1. The DTC self-claimant cube that contains disability-related and demographic characteristics for 1970 to 2011.
2. The CPP-D cube that contains disability-related and demographic characteristics for 1987 to 2010.
3. The CPP-D integrated cube that provides information from the program combined with data from the tax records for 1987 to 2010.

It is recommended that discussions be held with senior officials responsible for the integrated data platform to obtain a better understanding of the data that are available in these cubes.

6. International Scan

6.1 Ireland

6.1.1 Background

The *National Disability Authority Act* was proclaimed in 1999 to secure the rights of people with disabilities by influencing public policy and legislation by working to ensure that services are of the highest quality. The *Disability Act* 2005 — a key element of Ireland's National Disability Strategy — was designed to advance and underpin the participation of people with disabilities in society by supporting the provision of disability-specific services and improving access to mainstream public services. The Act defines disability as follows:

> Disability, in relation to a person, means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of enduring physical, sensory, mental health or intellectual impairments.[16]

[16] http://www.welfare.ie/en/Pages/Illness-Disability-and-Caring.aspx

6.1.2 Administrative Data

Income Support Programs

Ireland's Department of Social Protection provides a number of income supports to persons with disabilities that are similar in scope to the programs offered to persons with disabilities in Canada.[17] One of these supports —the Partial Capacity Benefit — allows individuals currently in receipt of either the Illness Benefit (for a minimum of six months) or the Invalidity Pension with a reduced capacity to work to return to work if they wish to do so. An individual can quality for the Partial Capacity Benefit if his/her restriction on capacity to work is assessed as moderate, severe or profound. This assessment is done by a medical assessor from the Department of Social Protection who reviews the medical evidence provided with the individual's application.

National Intellectual Disability Database

Established in 1995, the National Intellectual Disability Database (NIDD) is a set of data that outlines the specialized health services currently used or needed by persons with intellectual disabilities. The database informs the regional and national planning of these services by providing information on trends in demographics, current service use and future service need. The database is maintained by the Health Research Board on behalf of the Department of Health and Children. The NIDD collects information on the degree of the individual's intellectual disability. It uses a six-point scale, as follows: 0=not verified; 1=average; 2=borderline; 3=mild; 4=moderate; 5=severe; and 6=profound.

National Physical and Sensory Disability Database

Established in 2002, the National Physical and Sensory Disability Database (NPSDD) is a set of data that outlines the specialized health services currently used or needed by persons with physical and/or sensory disabilities. Like the NIDD, this database is maintained by the Health Research Board on behalf of the Department of Health and Children to inform service planning. The NPSDD collects information on the extent that the individual's participation has been restricted as a result of his/her physical and/or sensory disability. A variety of categories of activities are listed, including "employment or job seeking." The question uses a five-point scale as follows: mildly, moderately, severely, completely and not at all.

The NPSDD also asks about the degree of difficulty experienced doing a variety of different activities, including "your day-to-day work/school." The question uses a five-point scale, as follows: none, mild, moderate, severe and extreme/cannot do. The questionnaire then goes on to ask the following: "Overall, how much did these difficulties interfere with your life?" The respondent can choose from a five-point scale, as follows: not at all, mildly, moderately, extremely and severely.

6.1.3 Survey Data

Censuses of Population

Ireland has collected data about persons with disabilities on the 2002, 2006 and 2011 Censuses of Population. The most recent Census of Population in 2011 included one impairment/disability-related question that affords the opportunity to identify the nature of the impairment and/or the disability.

> Q16. Do you have any of the following long-lasting conditions or difficulties?
> a) Blindness or a serious vision impairment
> b) Deafness or a serious hearing impairment
> c) A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
> d) An intellectual disability
> e) A difficulty with learning, remembering or concentrating
> f) A psychological or emotional condition
> g) A difficulty with pain, breathing, or any other chronic illness or condition

The 2006 National Disability Survey (NDS)

The NDS identified nine specific disability types (similar to the 2006 PALS in Canada). For each disability type, the respondent was asked to assess the extent of the difficulty encountered in doing his/her life activities. Responses were coded on a five-point scale, where 1 = no difficulty and 5 = cannot do at all. For seven of the nine disability types, persons were coded as having that particular disability if they responded 3 (moderate) or higher to the relevant filter question. For the other two disability types (intellectual and learning and emotional, psychological and mental health), respondents who answered 2 (just a little) or higher were coded as having that disability.

To obtain a severity score for each disability type, persons were coded to the highest level of difficulty recorded in the filter questions relating to that disability. To obtain an overall severity score, the disability that had the highest score would be assigned (e.g., if a respondent had a severity of 5 (cannot do at all) for mobility and dexterity, but 4 (a lot of difficulty) for other types of disabilities, his/her overall severity score would be 5 (cannot do at all)).

The Irish Longitudinal Study on Ageing

Funded in part by the Department of Health and Children and harmonized with other research being conducted in various other parts of the European Union, the Irish Longitudinal Study on Ageing (TILDA) is a study of a representative cohort of over 8,500 people resident in Ireland aged 55 and over. The study charts their health, social and economic circumstances over a 10-year period. The first wave of TILDA was collected from late 2009 to early 2011.

The study asks two questions to determine whether or not the respondent has a disability, as follows:

> PH003: Some people suffer from chronic or long-term health problems. By long-term we mean it has troubled you for over a period of time or is likely to affect you over a period of time. Do you have any long-term health problems, illness, disability or infirmity? Yes/No
> PH004: Does this illness or disability limit your activities in any way? Yes/No

Respondents are asked to assess the severity of the limitation using a three-point scale: severely limited; limited, but not severely; and not limited. If respondents indicate that their limitation in activity is expected to last less than three months, they are not considered to have a disability. In their surveys, Canada uses a six-month cut-off.

This survey also asks a number of questions related to health status and ability to work, such as "Do you have any health problem or disability that limits the kind or amount of paid work you could do, should you want to?" and "What is your main reason for working less than 30/hours per week?" with one possible response of "personal illness or disability."

6.1.4 Other Findings of Interest

National Portal for MetaData from Surveys and Administrative Records

StatCentral is the portal to Ireland's Official Statistics.[18] It provides information about statistics produced by government departments and state organizations. The "Social Conditions" section of the database provides information on the various income support programs. The site is maintained by the Central Statistics Office (CSO).

The objective of StatCentral is to strengthen and coordinate statistics across the public service. To achieve this, the portal provides standard documentation on recurring official statistics and links to where they can be found. The portal supports the National Statistics Board's (NSB's) strategy of developing a whole-system approach for the Irish statistical system, involving all areas of the public sector where official statistics are produced. StatCentral was launched in 2008 with a range of official statistics from the CSO and other departments and agencies. The NSB has recommended that CSO consider the possibility of extending the StatCentral portal to include links to data held by regional bodies and local authorities.

6.2 Australia

6.2.1 Background

Australia's *Disability Discrimination Act 1992* (DDA) defines disability as any limitation, restriction or impairment which restricts everyday activities and has lasted or is expected to last for at least six months. The 2011 *National Disability Strategy 2010-2020* sets out a 10-year

[18] http://www.statcentral.ie/

national policy framework for improving with lives of Australians with disabilities and their carers. The Strategy outlines six priority areas for action; one of those priority areas is "economic security." Related to this priority area, the Strategy states the following: "The Strategy will help ensure that policy settings, including health, education, and employment and income support systems and infrastructure are properly designed to help meet the aspirations of people with disabilities, and to maximize productivity across all sectors of the population whenever possible."

6.2.2 Administrative Data

JobAccess

JobAccess offers help and workplace solutions for the employment of people with disabilities. The Supported Wage System is part of the range of programs offered. It is a process that enables employers to pay productivity-based wages to people whose work productivity is significantly reduced as a result of the effects of their disability. It provides access to a reliable process of productivity-based wage assessment to determine fair pay for fair work.

The Australian Government engages a National Panel of Assessors that provides free workplace assessments. An approved assessor will identify a work productivity rate in the form of a percentage of the acceptable standard for that work classification. Then the employer may apply the agreed-upon percentage to the award or agreement wage for that classification.

People employed under the Supported Wage System provisions are required to have their work productivity reviewed each 12 months or earlier if the person's work productivity significantly increases or decreases. An employer may employ eligible people with disability for a trial period, usually lasting up to 12 weeks. The purpose of the trial period is to ensure the employee has every opportunity to learn the tasks of the job, to provide time for them to become familiar with the work environment and to develop their confidence.

If a person with disability is starting work in a new job, the employer may also be eligible to receive a one-off payment to help offset the initial cost of employing and training that person.

Disability Support Pension

The Department of Families, Housing, Community Services and Indigenous Affairs provides a number of income supports for persons with disabilities, including the Disability Support Pension, the Sickness Allowance and the Mobility Allowance.

The Disability Support Pension is in place for Australians between 16 and 65 years of age who are permanently blind or who have been assessed by a physician or specialist as having a physical, intellectual or psychiatric impairment and who are either

- participating in the Supported Wage System;

- unable to work or to be retrained to work, 15 hours or more per week at or above the relevant minimum wage within the next two years due to impairment; and
- have been assessed as having a severe impairment or as having actively participated in a program of support.

6.2.3 Survey Data

Census of Population

Four questions related to disability were included on both the 2006 and 2011 Censuses of Population and Housing. While these questions are based on the criteria used in the Survey of Disability, Ageing and Carers (SDAC), the population measured is different as a result of the collapsed question format and different collection methodology. Because of this, the Australian Bureau of Statistics (ABS) recommends that data generated from these questions be taken as an indication of the characteristics of people who report a need for assistance due to disability, long-term health condition or old age, not as the total population prevalence of people with a "profound or severe core activity limitation," as represented in the survey data.

Disability-specific Surveys

The most detailed and comprehensive source of disability data in Australia is the Survey of Disability, Ageing and Carers (SDAC). This survey was first introduced in 1981 as the Survey of Handicapped Persons. It has been conducted five times since then and was renamed in 1993. SDAC was last conducted in 2009 and it is expected that it will be conducted again in 2015. The main objective of the SDAC is to collect extensive national and state-level data on disability. It is the only source recommended by the ABS to provide prevalence rates of disability for all ages, including persons living in non-private dwellings and health establishments.

SDAC provides information about the presence of long-term health conditions leading to impairment, limitation or restriction in the context of the person's environment. It uses, as its conceptual base, the social model of disability and incorporates the definition of disability used by the World Health Organization (WHO) in its International Classification of Functioning, Disability and Health 2001 (ICF). The 2009 questionnaire includes 75 questions that are designed to identify the population with disabilities and the underlying conditions causing the disability.

For those identified as having a disability, the survey measures the need for assistance and the severity of specific limitations or restrictions. Four levels of severity (profound, severe, moderate and mild) are determined for each of the three core activity limitations: self-care, mobility and communication. The highest level of severity in any one of the areas of self-care, mobility or communication determines the individual's level of severity of total limitation.

People with schooling or employment restrictions may also have a core limitation; however, the level of severity is not determined on the SDAC.

Disability Module

SDAC uses 75 questions to establish both disability and severity of core activity limitation. As a result, the time available to ask respondents additional questions about their social and economic status is limited. Since this is an area of particular interest to most users of data concerning persons with disabilities, it was determined that a less time-consuming approach was needed.

To meet this need, ABS developed a 10-question Disability Module (DM) that can be used in household surveys to investigate disability in relation to the social and economic circumstances of persons with disabilities vis-à-vis persons with disabilities. This module has been used in various surveys from 1992 onwards. The module was first used, in its current form, in the 2002 General Social Survey. Most recently, it was used in the 2006 General Social Survey and the 2011-2013 Australian Health Survey.

The DM applies the same criteria as the SDAC to identify people with a disability and to determine their severity of restriction. However, instead of the 75 questions of the SDAC, the DM uses only 10 questions and a series of prompt cards. These 10 questions are based directly on the questions used in the SDAC, as follows:

Questions 1-4: determines the presence or absence of various health conditions, impairments, limitations or restrictions Questions 5-8: determine whether the person has a core activity limitation (the activities of self-care, mobility and communication), as well as the severity of that limitation; questions 5-7 are on the person's need for assistance and question 8 is about the person's possible use of aids Questions 9-10: determine whether the person has an education or employment restriction and are only asked of people aged less than 65

6.2.4 Other Findings of Interest

Planning is currently underway for the 2016 Census of Population and Housing. Part of this planning is to put forward topic recommendations for the 2016 Census. In May 2012, ABS released a public consultation paper related to the development of essential statistical assets (ESAs) along with a preliminary list of ESAs. These ESAs are organized around three pillars: economic development, environmental sustainability and societal progress. Disability-related statistics is included under the third pillar (societal progress) under the category "possibly in." The finalization of these ESAs will inform content for the 2016 Census.

6.3 New Zealand

6.3.1 Background

In order to change New Zealand from a disabling to an inclusive society, the 2001 New Zealand Disability Strategy identified the need to "collect and use relevant information about disabled people and disability issues." Statistics New Zealand contributes to the fulfilment of this objective by conducting disability-specific post-censal surveys (1996, 2001, 2006 and planned for July through October 2013).

The New Zealand Disability Strategy defines disability as follows:

> Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments... Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have.

Statistics Zealand defines disability as follows:

> Any self-perceived limitation in activity resulting from a long-term condition or health problem; lasting longer or expected to last longer than six months or more and not completely eliminated by an assistive device.

Statistics New Zealand also draws on the World Health Organization's function definition of disability of "... any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being."

6.3.2 Administrative Data

New Zealand's Ministry of Work and Income administers income support programs for persons with disabilities in New Zealand, including the Disability Allowance and the Invalid's Benefit. To be eligible for the former, an individual must have a disability that is likely to last at least six months; for the latter, the individual must be permanently or severely limited in his/her ability to work because of sickness, injury or disability or be totally blind.

The Ministry of Work and Income does use information from a Designated Doctor Report to determine the most appropriate income support or services for the individual. One question on this report is as follows: "Is the impact of the condition on the person's capacity for work likely to fluctuate or be intermittent?" thus providing a source for the generation of statistics for persons with an episodic disability.

6.3.3 Survey Data

Post-Censal Disability Surveys

New Zealand has conducted three post-censal disability surveys (1996, 2001 and 2006). The post-censal survey planned for 2011 was cancelled following the earthquake. The next survey will be conducted between July and October 2013.

Statistics New Zealand uses a three-level definition of severity of disability.

- Severe – People with severe disabilities received or needed daily help with activities such as preparing meals, shopping, everyday housework, bathing or dressing.
- Moderate – People with moderate disabilities used or needed "some type of assistive device, aid or equipment" and/or help with certain heavier or more difficult household tasks.
- Mild – People with mild disabilities had some kind of disability, but did not require regular help from other people or technical aids.

6.3.4 Other Findings of Interest

The Social Statistics Programme for New Zealand, which was approved in 2003 and implemented beginning in the 2005/06 financial year, tasked Statistics New Zealand with leading the development of a coordinated program of official social statistics across central government. It was thought that this 10-year whole-of-government program would consolidate existing surveys into a managed program; introduce new surveys to fill information gaps; exploit other sources of data such as administrative databases; and improve analytical capability, dissemination of information and access to data.

The most recent progress report on the implementation of the 2001 Disability Strategy, *Achieving a fully inclusive society 2012*, reinforced that disability statistics is a significant area that affects the inclusiveness of New Zealand's public services and wider society. However, the report went on to state the following: "Currently, there is a paucity of available disability data, with post Census Disability Survey data being the only comprehensive source of national disability statistics...In addition, government agencies generally do not record or collate disability-related data for their mainstream services, both in terms of access to these services and in terms of particular support and assistance that may be provided to access their services. Only those agencies providing specifically funded disability support services collect their own reporting data on provision of those specific services."

In September 2012, in response to an updated governmental Disability Action Plan (first published in 2007 and updated in May 2012), the Ministerial Committee agreed to seven new initiatives under the Shared Outcomes Work Programme. One of these new initiatives was to improve existing employment support for employers and persons with disabilities.

6.4 United States of America

6.4.1 Background

The *Americans with Disabilities Act* of 1990 (ADA) and the *ADA Amendments Act* of 2008 that became effective on 1 January 2009 defines disability with respect to an individual to mean (A) a physical or mental impairment that substantially limits one or more major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.[19] Further clarification is provided for "substantially limits" and "major life activities." Duration is clarified to mean six months or more. An impairment includes one that is ***episodic*** or in remission, but it is a disability if it would substantially limit a "major life activity" when active.

6.4.2 Administrative Data

Administrative data collected and maintained by administrative agencies and commercial entities for the purpose of administering programs and providing services are accessible to the U.S. Census Bureau through the guiding statute, Title 13 U.S.C., Section 6. This statute directs the agency to use data from administrative records as extensively as possible in lieu of conducting direct inquiries of the public. Several National Academy of Science panels have encouraged the expansion of administrative records to support and enhance statistical programs. Furthermore, the Census Bureau's strategic plan emphasizes the use of administrative records data to produce new information using existing data sources to meet emerging customer product needs, minimize cost to taxpayers and alleviate respondent burden.

Extensive use has been made of data from the Social Security Administration (SSA) files, including Old-Age, Survivors, and Disability Insurance (OASDI) — commonly referred to as Social Security — and Supplemental Security Income (SSI), a needs-based program that provides financial support for aged, blind, and disabled adults and children with limited income and resources.

The Office of Management and Budget, which oversees policies and procedures for all U.S. statistical programs, includes one component of SSA under its statistical purview: the Office of Research, Evaluation, and Statistics (ORES) within the Office of Retirement and Disability Policy

[19] http://www.ada.gov/pubs/adastatute08.htm#12102

(ORDP). ORES uses the Agency's administrative data to produce a wide range of research and statistical publications, as well as other products that inform the public about the beneficiary population and the operation of Social Security programs. ORDP develops and maintains a series of detailed statistical databases for research, evaluation and analysis.

SSA has been linking its administrative data with survey results for over 40 years. SSA's biggest data-linkage partner is the U. S. Census Bureau. Linkages have been done with the Current Population Survey (CPS), American Community Survey (ACS) and the Survey of Income and Program Participation (SIPP).

6.4.3 Survey Data

Census of Population

The U.S. eliminated the long-form Census beginning with the 2010 Census of Population. The ACS is now the source for the detailed socio-economic data.

U.S. Census Bureau

The U.S. Census Bureau provides a listing of surveys conducted by the Bureau and other agencies and organizations that include questions to identify the population with disabilities.[20] This link provides linkages to the other active and inactive surveys. For the purpose of this report, only the two main surveys conducted by the Bureau at this point in time — the ACS and the CPS — are reviewed.

American Community Survey (ACS)

The ACS is a continuous data collection that is used to produce annual estimates at the national, state and local levels on the characteristics of the U.S. population. It replaces the decennial Census long form. The ACS collects information on an annual basis from approximately 3 million addresses in the U.S., 2.5% of the population living in group quarters and 36,000 addresses in Puerto Rico.

The ACS now includes six questions that are used to identify the population with disabilities and, through these questions, identifies six types of "difficulties". This set of disability questions was implemented in the 2008 ACS following the content test that determined the content for the 2008 cycle of the ACS.[21] These questions continue to be used in the cycles following the 2008 cycle.

Hearing (asked of all ages): Is this person deaf or does he/she have serious difficulty hearing?
Visual (asked of all ages): Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
Cognitive (asked of persons ages 5 or older): Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
Ambulatory (asked of persons ages 5 or older): Does this person have serious difficulty walking or climbing stairs?
Self-Care (asked of persons ages 5 or older): Does this person have difficulty dressing or bathing?
Independent Living (asked of persons ages 15 or older): Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

Current Population Survey

The CPS is a monthly labour force survey conducted jointly by the Census Bureau and the Bureau of Labor Statistics (BLS). In 2008, the BLS added the set of six disability questions from the ACS so that they could report employment statistics for the population of people with disabilities. The disability questions are asked in February, March and April of each year and additional questions are also asked to determine if the individual has a "work disability." The algorithm[22] used to establish work disability status includes:

1. Individuals who have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do
2. Individuals who ever retired or left a job for health reasons
3. Individuals who are not in the labor force because of a disability
4. Individuals who did not work at all in the previous year because of illness or disability
5. Individuals under 65 years old who were covered by Medicare
6. Individuals under 65 years old who received Supplemental Security Income (SSI) in previous year
7. Individuals who received VA disability income in previous year

Individuals who meet one of criteria three to six are considered to have a severe work disability.

6.4.4 Other Findings of Interest

Both the Census Bureau and the Bureau of Labor Statistics offer users an online retrieval program that allows the development and generation of tables from the ACS and the CPS at no cost.

6.5 Countries of the European Union

Eurostat is the statistical office of the European Union. It is tasked with providing the European Union with statistics at the European level that enable comparisons between countries and regions. Eurostat plays an integral role in ensuring that consistent statistics for people with disabilities are available across Member States. Consistent statistics are a necessary component to monitor and evaluate the European Disability Strategy 2010-2020 — launched in November 2010 — as well as the UN Convention. To that end, Eurostat has, and is, developing a comprehensive and coordinated set of surveys under the umbrella name of "European Core Health Interview Survey" (ECHIS). These surveys are, and will be, performed within the European Statistical System.

ECHIS includes three pillars: The European Health Interview Survey (EHIS), Community Statistics on Income and Living Conditions (EU-SILC), and new modules on disability that include the 2011

[22] http://www.census.gov/people/disability/methodology/cps.html

labour force status module on the employment of disabled persons and the European Disability and Social Integration Module (EDSIM).

The EHIS, managed by Eurostat under the Community Statistical Programme, is planned to be held every five years, with the first round having taken place between 2007 and 2009. It will include the Mini European Health Module that is also included in the second pillar (i.e., EU-SILC).

Minimum European Health Module
1. How is your health in general? *Very good / good / fair/ bad / very bad.*
2. Do you suffer from (have) any chronic (long-standing) illness or condition (health problem)? *Yes/ No.*
3. For the past 6 months or more have you been limited in activities people usually do because of a health problem? *Yes, strongly limited / Yes, limited / No, not limited*.

The third pillar of the ECHIS is comprised of two initiatives: the 2011 LFS module on the employment of disabled persons and the EDSIM. The 2011 LFS module includes 30 questions and is asked of persons aged 15 to 64 years inclusive.

The EDSIM was originally planned to be a module in the EHIS. The module has been tested, with the latest revision completed in October 2010. In a presentation made to the Washington Group's meeting in Luxembourg in 2010, the EDSIM was described as having 12 sections based on the ICF with the questionnaire focusing on barriers to participation. To that end, the questionnaire begins with questions on participation and limitation in activities in areas such as learning opportunities, work, social activities, transport, mobility and accessibility to buildings. For those individuals who are not participating or with limited participation, the questions would then address personal barriers (health conditions and impairments) and environmental barriers (finances, lack of assistive devices, personal help).[23] The EDSIM evolved into a disability-specific survey – the European Survey on Disability and Social Integration. Contracts for the conduct of this survey in 16 member states were let on 22 January 2013.

6.6 International Bodies

6.6.1 International Labour Organization (ILO)

The ILO's work on disability dates back to 1925. Since then, concerns about workers with disabilities has been an integral part of all ILO Conventions and Recommendations, with all International Labour Standards implicitly applying to them and with some protecting their rights specifically.

The ILO has recently developed a network of representatives from multinational enterprises, employers' organizations and business networks, and selected non-governmental and disabled

[23] http://www.cdc.gov/nchs/ppt/citygroup/meeting10/WG10_Session1_3_Agafitei.pdf

peoples' organizations to share knowledge and take part in joint activities that will improve and facilitate the inclusion of persons with disabilities in the workplace. The ILO Global Business and Disability Network[24] is committed to

- sharing knowledge and identifying good practices,
- developing products and services to facilitate the hiring and retention of persons with disabilities,
- improving access to small and medium companies to build the understanding and expertise in working effectively with persons with disabilities, and
- linking companies to other related ILO activities.

Disability in the Workplace: Company Practices is a compilation of 25 company profiles that describes their hiring and retention practices, products and services, and corporate social responsibility (CSR) from the perspective of disability.

6.6.2 Organization for Economic Co-operation and Development (OECD)

The Organisation for European Economic Cooperation (OEEC) was established in 1947 and, encouraged by its success and the prospect of carrying its work forward on a global stage, Canada and the US joined OEEC members in signing the new OECD Convention on 14 December 1960.[25] The Organization for Economic Co-operation and Development (OECD) was created in September 1961. Today, there are 34 OECD member countries worldwide who work together to identify problems and promote policies to solve them.

Disability has been on OECD's agenda since the mid-70s, Canada's disability data benefited from the OECD's work when one of its Working Groups designed the first set of activity of daily living questions for use in surveys.

Published in 2010, *Sickness, Disability and Work: Breaking the Barriers - Canada: Opportunities for Collaboration*, explores some of the reasons behind the employment support programs in Canada that involve many public and private players, as well as different levels of government, to lower inactivity and increase participation. The report includes a range of policy recommendations to address evident and foreseeable gaps. The report includes a number of tables generated from the CPP-D adminstrative databases.

[24] http://www.businessanddisability.org/
[25] http://www.oecd.org/

7. Statistical Surveys

7.1 Background

Statistics Canada has been collecting information concerning the issues facing Canadians with disabilities since the early 1980s and the nature and extent of the information collected varies based on the survey's focus.

The Census of Population included disability questions on the long questionnaire in 1986, 1991, 1996, 2001 and 2006. The purpose for these questions was to provide a sampling frame for the follow-up post-censal surveys. Data derived from the Census questions were not disseminated as part of the Census dissemination program, but were available through a special request.

Post-censal surveys were conducted in 1986 (Health and Activity Limitation Survey), 1991 (Health and Activity Limitation Survey), 2001 (Participation and Activity Limitation Survey) and 2006 (Participation and Activity Limitation Survey). These four surveys provided in-depth information on the nature and severity of disability for all ages, along with the nature and extent of barriers encountered and accommodations received in various life activities. The database for each of the surveys also included selected Census variables for each selected respondent derived from their Census responses. The database also included these Census variables for a sample of non-disabled persons.

The Census disability questions have been included in a number of surveys to enable the identification of the population with disabilities. These surveys include the following:

- Survey of Household Spending
- Canadian Community Health Survey
- National Population Health Survey
- Various cycles of the General Social Survey
- Survey of Labour and Income Dynamics (SLID)

In 2012, the Canadian Survey on Disability was conducted using as its sampling frame the 2011 National Household Survey (Statistics Canada's replacement for the Census long form).

In 2014, the Longitudinal International Survey of Adults (LISA) will include the newly developed questions to identify the population with disabilities (part of HRSDC's new disability data strategy).

The following sub-sections provide more detailed information on the 2006 Participation and Activity Limitation Survey, analysis completed by HRSDC using the longitudinal data derived from SLID, the 2012 Canadian Survey on Disability, and the 2014 LISA.

7.2 2006 Participation and Activity Limitation Survey (2006 PALS)

7.2.1 Background

The 2006 PALS is a survey of adults and children whose everyday activities are limited because of a condition or health problem that has lasted or is expected to last for six months or longer.

A sample of those persons who answered "Yes" to the 2006 Census disability filter questions was chosen to participate in the 2006 PALS. The total sample size was 47,793: 8,954 children (persons under 15 years of age) and 38,839 adults (15 years of age and over). This sample size allows for an in-depth analysis of issues facing children and adults with disabilities for each of the territories and all provinces. It includes a sample of persons living in private dwellings in 10 ten provinces and 3 territories. The population living on First Nations reserves is excluded, as are people living in collective dwellings.

The 2006 PALS uses the World Health Organization's (WHO's) framework of disability provided by the International Classification of Functioning (ICF). This framework defines disability as the relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors.

The 2006 PALS provides data on the relationship between functional status, daily living activities and social participation through questions that focus on the nature and severity of the activity limitations, the use of and unmet need for assistive technology, social support, and accommodation in various activities of daily living, including education, employment, transportation and all aspects of community living.

7.2.2 A Possible Data Source

Numerous reports and a Public Use Microdata File have been released by Statistics Canada. The data from the 2006 PALS has been used extensively by researchers who have accessed the microdata through the Statistics Canada Research Data Centre Program.

Of particular interest to this research is work that my company completed in 2010 concerning episodic disabilities using these data. It is included in the annotated bibliography. I also co-authored a paper titled "Advancing Inclusion: How Our Understanding of the Dynamic Nature of Disability Is Informing Interventions That Support Employment." Also included in the definitions table of this report is a description of how the term "moderate" was used in the 2006 PALS.

By virtue of its operationalization of the concept of disability, persons with a short-term disability (defined as being six months or less) are excluded from the database.

The database includes an extensive set of information concerning the impact that disability has on employment.

Until the 2012 Canadian Survey on Disability data are released, the 2006 PALS provides the most comprehensive source for data on the impact of living with a disability in Canada.

7.3 The Canadian Survey on Disability (CSD)

7.3.1 Background

The Canadian Survey on Disability (CSD) is a survey of Canadians whose daily activities are limited because of a condition or health-related problem. It will provide data that will be used to evaluate and develop policies and programs designed for people with disabilities throughout Canada. It will also be used to provide the data inputs to measure Canada's progress with respect to its various commitments internationally, including the United Nations Convention on the Rights of Persons with Disabilities.

The population covered by the CSD includes all adults aged 15 and older (as of Census day) who answered "yes" to either of the activity limitation questions on the National Household Survey (NHS), and who were living in Canada at the time of the NHS. This includes persons living in private dwellings in the 10 provinces and 3 territories. The population living on First Nations reserves is excluded, as are people living in collective dwellings.

It is a cross-sectional survey, and the sample is a two-phase stratified design based on the 2011 NHS. The strata are defined so as to guarantee large enough samples for all of the provinces/territories and specific age groups. The total sample size for the CSD is approximately 45,500 individuals.

The survey collects information on type and severity of disability, use of and need for aids and assistive devices, help received or required to perform selected activities of daily living, educational attainment, including experiences and accommodations, labour force participation, including the use of and need for accommodation, and community involvement.

As with the previous post-censal surveys, Statistics Canada will combine information collected in the 2011 NHS to the information included on the CSD. Information from other surveys or administrative data sources may also be included, such as income from tax records.

The data are scheduled to be released in December 2013.

7.3.2 A Possible Data Source

This will be, by far, the largest and most comprehensive survey on disability conducted by Statistics Canada. The very large sample size will afford the possibility of much more in-depth analyses of the relationship between types of disabilities and employment. The only population of interest to this research that is excluded from the database is "short-term" if the accepted definition of short-term is less than six months.

The content of the survey is similar to the content in 2006 PALS; this will allow for comparisons of the employment characteristics for persons with disabilities for the pre- and post-recession periods.

7.4 Longitudinal International Survey of Adults (LISA)- Phase II

7.4.1 Background

The LISA is designed to improve understanding of what is happening in the lives of Canadians in relation to education and training, family, health, income, and employment. As well, some respondents will be asked questions related to activities such as reading, finding information, and using computers and technology. These questions are part of an international study that looks at a wide range of skills among the adult populations of countries around the world, including Canada. Data from LISA will be linked to the T1 Personal Master File, T4 Summary and Supplementary Files, and the T1 Family File. Linkages will be done using the survey respondent's personal identifiers and marital status to locate his/her Social Insurance Number, which will then be used to link to the external data sources.

7.4.2 A Possible Data Source

LISA will incorporate the newly design disability screening questions, which provide improved coverage of all adults with disabilities, including those individuals with disabilities as a result of a mental health condition or health problem.

Because LISA is a longitudinal survey, it affords the opportunity for analyses over time related to the economic and social impact of living with an “episodic” disability.

7.5 Survey of Labour and Income Dynamics (SLID)

7.5.1 Background

The longitudinal component of SLID provides an in-depth understanding of the economic well-being of Canadians by providing data on the economic shifts that individuals and families live through and how it varies with changes in their paid work, family make-up, receipt of government transfers or other factors. The survey's longitudinal dimension makes this type of analysis possible. Unfortunately, 2011 marked the end of these longitudinal data. Nonetheless, the type of analyses that could be done using this database up to and including 2011 (well into the recovery from the latest recession) is particularly pertinent to persons with episodic disabilities because one is able to assess impact of disability over a six-year period that includes the recession. Burchardt[26] developed a methodology for analyzing the impact of episodic disability on employment over time. Cahill and Spector adapted her methodology and, in their presentation to the Policy Forum on Episodic Disabilities and Employment: Challenges and

[26] Burchardt, Tania (2000) *The dynamics of being disabled.* CASEpaper, 36. Centre for Analysis of Social Exclusion, London School of Economics and Political Science, London, UK. Retrieved from http://eprints.lse.ac.uk/6468/ March 22, 2013.

Solutions in 2011, reported that people who report disability episodically over a six-year period have better labour market outcomes and income levels than the population who report continuous disability but have poorer labour market outcomes and lower income levels than the population who reports no disability. Since that Forum, both Cahill and Spector have continued to refine their analytical approach; however, these later analyses have not been made available.

7.5.2 A Possible Data Source

The longitudinal component of SLID affords an excellent vehicle to pursue the Burchardt trajectory analytical approach. It would be informative, if the source is pursued, to gain access to the work done by Spector and Cahill during 2012 before proceeding with additional analyses.

8. Consolidation of Findings

This section of the report provides a summary of the findings and is structured according to the four activities listed in Section 1 of the report. These four activities were outlined in the RFS for this research.

8.1 Validation of the Five Key Words

This sub-section of the report is structured in two parts:

1. a summary of the model developed in Section 4.2 of this report that describes the relationship among the three disability-related terms; and
2. for each of the five key words, a summary of the information collected in the literature review, the interviews with members of the disability community and disability researchers, and the international scan, as well as a discussion of the issue of the operationalization of the definition when using either survey or administrative data.

8.1.1 The Model

The model offered in Section 4.2 of this report is our attempt to capture the comments made by the "informed respondents." It describes three attributes of the health problem: its duration, the nature of the impairment that results from the health problem and the impact that the impairment has on the individual's chosen life activities when he/she interacts with the environment. This model is consistent with the model on which the ICF is based, but offers a more detailed description of the types of impairments that an individual can experience.

The focus on impairment is important as it captures the dynamic nature of some long-term health problems. Episodes can result in increased problems with a particular body function for a period of time. The impact is an increase in the level of limitation in activity (disability) requires some modification to the activity. In the example of work, the individual may require a leave of

absence, modified hours or another type of accommodation. If the employer is able to accommodate the fluctuation in level of activity, then there is no increase in the level of disability related to work. Where the employer is unable or only partially able to accommodate, the individual would experience an increased level of disability related to work.

8.1.2 Episodic

Summary

According to the literature review, use of the term "episodic" is becoming increasingly prevalent in Canada. Of note is the increase in the federal and provincial governments' acknowledgement of the term "episodic disability" in recent years,; however, these bodies do not define the term. The U.S. government uses the word "episodic" in relation to impairment and includes these individuals in their clarification of the words "major life activity" in the definition of disability in the *Americans with Disabilities Amendments Act* of 2008. Use of or reference to "episodic" is noticeably absent in other countries' disability legislation.

Common across the literature and from the "key informants" are the following characteristics of "episodic": unexpected and/or periodic diminished capacity; symptoms that recur and remit; periods of good health that are interrupted by ill-health; can be associated with a progressive disorder; results in impact on life activities; and related to specific health problems or disorders.

Operationalization of "episodic" in future research

There are three characteristics that need to be addressed in the definition: periodicity of flare-ups, relationship to particular diseases and impact on work. These characteristics are not mutually exclusive. Before proceeding with other research related to "episodic", one should further define each characteristic and then look at the various permutations that the three can take. These permutations would then have to be "mapped" against existing data sources to establish the "best fit."

8.1.3 Moderate

Summary

Consistent in all of the reviewed material is the use of "moderate disability" within a scale of severity of disability that could be measured by type of life activity, with perhaps an overall global measure across life activities. Australia looks at core activity limitation (self-care, mobility and communication) with need for assistance (personal or assistive devices). New Zealand developed a three-point severity of disability scale by looking at all life activities. Canada, with the PALS surveys, developed a four-point scale using difficulty to perform specific activities. The CPS in the U.S. has developed a two-point scale to measure work disability (severe and not-severe) for the data that it produces.

Operationalization of "moderate" in future research

This concept is fairly straightforward and requires a way of establishing the extent to which an impairment has an impact on the level of activity. Before proceeding with other research, a decision would have to be taken as to how — and in which life activities —this could be measured. It is important to keep in mind that limitation in the workplace can be ameliorated through accommodations; therefore, it will be important to be able to measure the nature and extent of accommodations received to be able to get a good measure of work disability and its level of severity.

8.1.4 Short-term

Summary

Short-term disability is most commonly used within the insurance sector, referring to an income replacement benefit period for an individual who is unable to perform his/her job requirements due to illness or disability. The period of benefits commonly runs between 15 and 26 weeks. The definitions vary somewhat from plan to plan; however, each plan refers to a time-limited temporary income replacement.

This is consistent with the opinions expressed by the "key informants." These types of short-term disabilities are temporary and there is no lasting impairment and no lasting decrease in ability to perform life activities.

Operationalization of "short-term" in future research

It is unclear how this part of the population with a health problem/injury fits into the overall objective of the three-phased research that is being proposed. This population needs temporary support for a limited period of time and WC, EI Sickness benefits and private disability insurance are in place to cover the income replacement during the short period in question.

8.1.5 Intermittent employment/Intermittent work capacity

Summary

A person with a disability experiences intermittent employment for a number of reasons, as follows:

- The individual is going to school full-time and chooses to work on an intermittent basis.
- The individual is unable to find long-term employment and so takes short-term assignments (precarious employment).

- The individual has a long-term health problem that has episodes that result in him/her being completely unable to work for a period of time (intermittent work capacity) and his/her employer is unable to accommodate the absence.
- The individual has a long-term health problem that has episodes that result in him/her having reduced capacity to perform duties (presenteeism).

Operationalization of "intermittent employment/intermittent work capacity" in future research

It is important for future research to identify which of these two populations would be the focus. Is it those individuals experiencing intermittent employment or intermittent work capacity? Is a sub-population within the intermittent employment group people who are in ongoing precarious employment? Is "presenteeism" along with employers' interventions something that could be explored when looking at best practices?

8.1.6 Longer-term sustained employment

Summary

According to the "key informants," longer-term sustained employment carries on for several years and provides sufficient employment to sustain an individual and her/his family.

Operationalization of "longer-term sustained employment" in future research

It is unclear how this population fits into the overall research plan except as a comparison population for the populations with other types of employment. If one could map out an employment path with longer-term sustained employment at one end, one could use survey data to show the impact of other types of employment in terms of income and, if available, other aspects of living such as decent housing, general health status, mental health status, etc.

8.2 Potential Sources for Data

The following table provides a summary of the reviewed sources of data against the five key words.

Type of data	Data Source	Key Words				
		Episodic	Moderate	Short-term	Intermittent employment	Longer-term sustained employment
Surveys	2006 PALS	Yes	Yes	No	Yes	Yes
	2012 CSD	Yes	Yes	No	Yes	Yes
	LISA	Yes	Yes	No	Yes	Yes
	SLID	Yes	No	Yes	Yes	Yes
Admin. data	CPP-D	Yes	No	No	No	No
	P/T Income Support	Maybe	Maybe	No	No	No
	EI Sickness	No	No	Yes	No	No
	WC	Maybe	No	Yes	No	No
	Private Disability	Don't know	Don't know	Yes	Don't know	Don't know

"Yes" means that the review indicates that there is a way of using existing variables on the file or of creating a derived variable from existing variables.

"Maybe" means that additional discussion is required before determining a "Yes" or No".

- In the case of P/T Income Support/Episodic, the proposed "file crawl" would have to be completed to determine if the underlying health condition variable was robust enough to adequately identify persons with an "episodic" health problem.
- In the case of P/T Income Support/Moderate, one would have to establish the extent to which the self-report has been completed and, if coverage is deemed sufficient, then one would have to create a derived severity of disability variable.
- In the case of WC/Episodic, one would have to establish the ability to identify "episodic" health conditions within the CSA Z795 coding structure.

"Don't know" means that such data might be available in the administrative data files maintained by the individual companies but that further investigation is required.

8.3 Validation of the Research Questions

Based on information provided by the client, it is our understanding that the principal objective of the three-phased research project is to determine what services and supports are effective in supporting people with episodic, short-term and moderate disabilities in or into employment. The research will identify key characteristics of populations with episodic, moderate and short-term disabilities, as well as the nature of their respective attachments to the labour market. This will be done by reviewing the available data and literature on the topic, including prevalence rates for these types of disabilities, both in the broader population and in social assistance caseloads. The project will also identify current barriers and challenges faced by people with episodic, moderate and short-term disabilities, and will review and identify existing national and international best practices for accommodation and supported employment.

The client provided four research questions. One of the requirements of Phase 1 of the research project was to validate these four questions.

8.3.1 Research Question #1

This is a valid research question for the three populations that could be addressed through access to a number of the potential data sources that have been described in Sections 5 and 7 of this report.

> ***Research Question #1 -*** What are the key demographic characteristics of people with episodic, moderate and short-term disabilities, and the nature of their respective attachments to the labour market (e.g. patterns of employment, seasonal vs. full-time)?

Episodic

For persons with an episodic disability, the currently available sources for the ***total*** adult population are the 2006 PALS and the longitudinal component of SLID (up to and including 2009).

1. The 2006 PALS offers detailed data on barriers and accommodations in the workplace, occupation and industry, nature of employment, level of education, details about nature and severity of disability, age, gender, marital status, and ethnic origin. Comparative data for persons without disabilities with respect to demographic, education and employment is available on the database. Furrie (see annotated bibliography) defined episodic disability as "sometimes" being limited in the workplace. These data are quite old and have been used in the Furrie analysis. That said, it might be an opportunity to do a multi-regression analysis by dividing the working-age population (18 to 64 years) with disabilities into two groups (episodic/non-episodic) using the Furrie definition of episodic and to then explore the nature and extent of barriers experienced first in employment and then in others life activities. This analysis would be a useful exercise to obtain a picture pre-recession. A similar analysis could then be done with the new CSD data when it becomes available to obtain a post-recession picture.
2. The longitudinal component of SLID offers employment data over time and affords the opportunity to apply the Burchardt trajectory methodology to the employment/disability data. SLID offers

detailed data on occupation and industry, nature of employment, level of education, age, gender, marital status, and ethnic origin. Comparative data for persons without disabilities with respect to demographic, education and employment is available on the database. The questions used to identify the population with disabilities are limited and do not reflect "the current state of the art." However, the availability of these data over time provides a unique opportunity to explore the impact on employment over time of having a disability. It would be important to determine what work has already been done on this dataset by Cahill and Spector before initiating any additional research.

3. In late 2013, the new Canadian Survey on Disability (CSD) will be released and the microdata will be available in the Statistics Canada Research Data Centres. These data include content that is similar to the 2006 PALS, thus enabling the construction of a similar definition of episodic disability. The importance of this database is that it is post-recession. As described above, a multi-regression analysis may provide some insights into the nature and extent of the barriers encountered by persons with an episodic disability.

In 2015, LISA (Phase II) will be released and the microdata will be available in the Statistics Canada Research Data Centres. The survey content covers education and training, family, health, income, and employment. As well, some respondents will have been asked questions related to activities such as reading, finding information, and using computers and technology. This database is important for two reasons: 1) it is post-recession and 2) the coverage of persons with disabilities as a result of a mental health condition or problem will be significantly improved. The questions used in the 2006 PALS to identify persons with disabilities are not included on the LISA questionnaire. If this source is pursued, it will be important to work with the researcher to develop an approach to identify persons with an episodic disability. In completing the first quantitative research on episodic disability, Furrie worked closely with HRSDC officials and developed a number of scenarios before the "sometimes" limited at work approach was accepted.

One could consider the various administrative databases that are described in Section 5 of this report, but they do not cover the entire adult population. However, analysis of these databases would provide some new insights. Of particular interest would be the CPP-D database. It includes underlying health condition, which could be used to identify the population with disabilities. The list of "episodic" health conditions developed by Furrie and the Episodic Disabilities Network (see Annex D of this report) would have to be updated before moving forward with the data source. Another possibility would be the WC databases. Given the increasing number of claims associated with mental health (including stress), the WC databases may provide some insights with respect to occupation and industry.

Moderate

The surveys described above for episodic could also be used for persons with a moderate disability. There does not appear to be an administrative database that covers this population.

Short-term
None of the surveys cover the population with short-term disabilities since the time criterion for the surveys is six months or longer. There are two administrative databases that might prove useful: the EI Sickness benefits and private disability insurance. At this point in time, EI does not maintain a historical database and there have been no detailed discussions with any of the private insurance companies.

8.3.2 Research Question #2

Based on the material covered in this primer research, this would be a valid research question for both episodic and moderate.

> ***Research Question #2***
> What are the unique employment barriers and challenges faced by people with each of the three types of disabilities?

Episodic
For persons with an episodic disability, the only current available source of data for the ***total*** adult population is the 2006 PALS. It offers detailed data on barriers and accommodations in the workplace, occupation and industry, nature of employment, level of education, details about nature and severity of disability, age, gender, marital status, and ethnic origin. Comparative data for persons without disabilities with respect to demographic, education and employment is available on the database. Furrie (see annotated bibliography) defined episodic disability as "sometimes" being limited in the workplace. These data are quite old and capture the pre-recession period.

In late 2013, the new Canadian Survey on Disability (CSD) will be released and the microdata will be available in the Statistics Canada Research Data Centres. These data include content that is similar to the 2006 PALS, thus enabling the construction of a similar definition of episodic disability. The importance of this database is that it is post-recession.

Moderate
The same databases as described above for episodic could be used to analyze the issues for persons with a moderate disability.

Short-term
None of the surveys or administrative databases is suitable.

8.3.3 Research Question #3

Based on the material covered in this primer research, this may be a valid research question for persons with an episodic disability but further work would have to be undertaken to determine if the employment support programs offered by the provinces and territories can effectively identify persons with an episodic disability.

> ***Research Question #3***
> How can people with episodic, short-term and moderate disabilities be effectively supported in or into employment, and what are some demonstrated best practices across Canada and internationally?

Episodic

The employment support programs that are offered by the provinces and territories appear to be the best source of data to demonstrate programs that are effective for getting persons with disabilities into employment or supported while employed. The three provinces that provided information during this primer research indicated that they would be willing to share best practices. However, it is still not clear if one would be able to identify persons with an episodic disability. It is recommended that, before proceeding with this research question, it would be prudent to undertake the "file crawl" project described in Section 5.4.2 of this report.

Moderate

There does not appear to be a data source to answer the research question for persons with moderate disabilities.

Short-term

There does not appear to be a data source to answer the research question for persons with short-term disabilities.

8.3.4 Research Question #4

Before being able to identify whether or not there are existing data sources that could be used to answer this question, one would have to conduct some in-depth interviews to gain an understanding of the needs for each of the three populations. Once the needs are identified, one could then assess whether or not those needs are addressed in either PALS or CSD.

> ***Research Question #4***
> How may the needs of the three populations be met through income and employment support programs?

8.4 Identification of Data Gaps

Administrative data, by its very nature, provides information for that segment of the population that the program is designed to support. These data can be used to provide profiles and, indeed, they have done so in the various program reports that have been produced. To that end, one could produce profiles for persons with short-term disabilities from the EI Sickness benefits file and the WC files, along with some basic numbers from the survey conducted by CHLIA.

As described in Section 8.2 of this report, with further exploration, one might be able to produce some data on "episodic" from CPP-D, P/T Income Support programs and WC by looking at underlying health problem.

It is recommended that further discussions take place with at least one of the private disability insurance providers to determine if this could be a viable source for data.

8.5 Other Pertinent Findings

In the course of this research, we identified willingness on the part of the officials that participated in the "administrative data" search to share their "best practices". In addition, the ILO has developed a "best practices" publication.

Annex A Content for E-mail for Private Sector Key Informant Interviews

Annex A.1 English Text

Subject Line: Seeking your input into government-funded research into episodic disabilities

As some receiving this email may already know, I am an Ottawa-based researcher who specializes in researching information related to the issues facing people with disabilities.

My current project—funded by the Ontario Ministry of Community and Social Services (MCSS) in their role with the Federal/Provincial/Territorial Persons with Disabilities Advisory Committee (PwDAC)—will build on previous PwDAC research and examine the labour force participation of, and the effects of income support programs on, persons with episodic, moderate or short-term disabilities. The objective of this research is to validate working definitions of key terms, explore the availability of survey and administrative data that cover these populations and issues and to validate proposed research questions for future studies.

To validate the working definitions of the key terms, we will be conducting a literature review, a scan of disability data strategies in other countries and most important, asking for input from Canadian community-based organizations and university-based researchers concerning their perceptions of these terms. To that end, I am seeking your perspective on any or all of the following terms:

- Episodic disabilities;
- Moderate disabilities;
- Short-term disabilities;
- Longer-term sustained employment; and
- Intermittent employment.

To help formulate your response, you might want to ask yourself the following questions:

- How would you and/or your organization define these terms?
- Does your organization use these terms and if so, in what context?
- How do the various disability terms relate to each other? Are they mutually exclusive or is there overlap between them? For example, can a moderate disability be either long-term or short term? Can episodic disabilities be severe, or medium-term? Is any one term a sub-set of the others?
- Do the terms describe different aspects of disability – for example, does “moderate” describe the severity of a disability or can it also refer to continuousness or duration of a disability?

As well, I would be most appreciative if you could provide me with references to any research articles that you think could further inform my research.

I will review all of the responses that I receive, and a summary will be included in the report that I will deliver to PwDAC. With your permission, I will include your name and/or your organization in an Annex to the report.

Given the tight timelines for this project, I would very much appreciate your response before February 22, 2013. I look forward to receiving your response and please do not hesitate to contact me if you have any questions or require any clarification.

Annex A.2 French Text

Objet : Votre avis sur la recherche financée par le gouvernement sur les incapacités épisodiques

Comme certains destinataires de ce courriel le savent déjà, je suis recherchiste, installée à Ottawa et spécialisée dans la recherche d'information sur les problèmes auxquels font face les personnes handicapées.

Mon projet actuel – financé par le ministère des Services communautaires et sociaux de l'Ontario dans le cadre de son travail avec le Comité consultatif sur les personnes handicapées (CCPH) , un comité fédéral/provincial/territorial – s'appuiera sur les recherches antérieures du CCPH pour étudier la participation au marché du travail des personnes affectées par des incapacités épisodiques, modérées ou de courte durée et les effets des programmes de soutien de revenu sur ces personnes. L'objectif de ces recherches est de valider les définitions *ad hoc* des termes clés, de voir ce qui est disponible comme données administratives et données d'enquêtes sur ces populations et questions et de valider les questions de recherche proposées pour de futures études.

Afin de valider les définitions *ad hoc* des termes clés, nous procéderons à un examen de la documentation, un survol des stratégies en matière de données sur les handicaps dans d'autres pays et, le plus important, nous demanderons l'avis d'organisations communautaires canadiennes et de chercheurs universitaires sur ces termes tels qu'ils les perçoivent. Pour cela, j'aimerais avoir votre point de vue sur certains des termes suivants, ou sur tous :

- Incapacités épisodiques;
- Incapacités modérées;
- Incapacités de courte durée;
- Emploi durable à plus long terme;
- Emploi intermittent.

Pour vous aider à formuler votre réponse, vous pouvez vous poser les questions suivantes :

- Comment vous et/ou votre organisation définiriez ces termes?
- Votre organisation utilise-t-elle ces termes et, si oui, dans quel contexte?
- Quels sont les rapports entre ces différents termes en rapport avec les incapacités? Sont-ils mutuellement exclusifs ou se recoupent-ils? Par exemple, une incapacité modérée peut-elle être de longue durée ou de courte durée? Les incapacités épisodiques peuvent-elles être graves ou de moyenne durée? Un des termes désigne-t-il une sous-catégorie des autres?
- Les termes décrivent-ils des aspects différents de l'incapacité – « modérée », par exemple, décrit-il la gravité d'une incapacité ou peut-il aussi indiquer son aspect continu ou sa durée?

J'apprécierais aussi beaucoup si vous pouviez me fournir des références à des articles de recherche susceptibles d'être informatifs pour ma recherche.

J'étudierai toutes les réponses que je recevrai et les résumerai dans le rapport que je remettrai au CCPH. Avec votre permission, je mentionnerai votre nom et/ou votre organisation dans un appendice.

Étant donné les délais serrés pour ce projet, je vous serai très reconnaissante de bien vouloir me répondre avant le 22 février 2013. J'attends votre réponse avec impatience et vous invite à me contacter si vous avez des questions ou souhaitez des précisions.

Annex B. List of Disability Organizations that Participated in Consultation

1. Alberta Committee of Citizens with Disabilities (ACCD)
2. Alliance for Equality of Blind Canadians - AEBC
3. British Columbia Coalition of People with Disabilities (BCCPD)
4. Canadian Association for Community Living
5. Canadian Association of the Deaf (CAD)
6. Canadian Hard of Hearing Association
7. Canadian National Institute for the Blind (CNIB)
8. Centre for Addiction and Mental Health
9. Citizens With Disabilities-Ontario
10. Coalition of Persons with Disabilities – Nfld. and Labrador (COD)
11. Confédération des organismes de personnes handicapées du Québec
12. Council of Canadians with Disabilities
13. DAWN-RAFH Canada
14. Episodic Disabilities Network
15. Institute for Research and Development on Inclusion and Society
16. Learning Disabilities Association of Ontario
17. Manitoba League of Persons with Disabilities Inc. (MLPD)
18. N.W.T Disabilities Council
19. National Educational Association of Disabled Students (NEADS)
20. National Network for Mental Health (NNMH)
21. Neil Squire Society
22. Nova Scotia League for Equal Opportunities (LEO)
23. PEI Council of People with Disabilities
24. People First Canada
25. Saskatchewan Voice of People with Disabilities (SVOPD)
26. Spinal Cord Injury Canada
27. Thalidomide Victims Association of Canada

Annex C. Tables from the CHLIA Proprietary Survey of Health Insurance Benefits in Canada, 2001 and 2011

HEALTH INSURANCE BENEFITS IN CANADA – 2001

TABLE NO. 4: Income Replacement (Group)

PROVINCE	PLANS IN FORCE		NUMBER OF PERSONS INSURED		DIRECT PREMIUMS WRITTEN ($000)		DIRECT CLAIMS PAID ($000)	
	Short Term	Long Term	Short Term	Long Term	Short Term	Long Term	Short Term	Long Term
Newfoundland	335	1,132	15,176	80,210	$ 6,028	$ 32,118	$ 4,591	$ 30,762
Prince Edward Island	87	312	3,063	16,636	803	10,107	520	9,669
Nova Scotia	481	2,118	24,489	138,604	7,665	65,499	6,012	58,408
New Brunswick	539	1,743	20,734	110,702	6,524	45,313	4,533	43,880
Quebec	14,698	29,742	646,917	1,753,137	215,452	596,992	187,945	476,306
Ontario	10,145	35,077	563,252	2,950,834	178,486	1,286,804	139,620	1,007,243
Manitoba	2,287	3,718	74,674	238,027	15,164	76,554	11,972	53,913
Saskatchewan	1,948	2,449	73,105	154,687	11,363	55,649	9,762	39,024
Alberta	5,050	8,440	213,982	751,964	44,919	278,214	32,689	190,342
British Columbia	4,123	8,843	186,389	586,810	56,707	257,126	47,766	219,104
Territories	102	185	4,230	21,043	778	10,616	517	5,956
CANADA TOTALS	39,795	93,759	1,826,011	6,802,654	$ 543,889	$ 2,714,992	$ 445,927	$ 2,134,607

HEALTH INSURANCE BENEFITS IN CANADA – 2001

TABLE NO. 17: Loss of Income (Uninsured or Administrative Services Only Contracts)

PROVINCE	SHORT TERM			LONG TERM			TOTAL LOSS OF INCOME BENEFITS ($000)
	CONTRACTS* IN FORCE	NUMBER OF PERSONS COVERED*	BENEFIT PAYMENTS ($000)	CONTRACTS* IN FORCE	NUMBER OF PERSONS COVERED*	BENEFIT PAYMENTS ($000)	
Newfoundland	13	5,054	$ 1,080	7	3,495	$ 1,368	$ 2,448
Prince Edward Island	9	762	241	4	1,217	516	757
Nova Scotia	45	8,973	3,740	23	25,154	13,071	16,811
New Brunswick	41	8,941	4,888	19	5,824	2,978	7,866
Quebec	238	229,157	87,603	60	53,427	52,824	140,427
Ontario	553	595,468	191,851	199	288,679	171,623	363,474
Manitoba	70	37,075	8,977	24	51,711	17,367	26,344
Saskatchewan	32	10,124	3,006	11	16,573	8,865	11,871
Alberta	119	106,889	19,652	34	69,787	37,610	57,262
British Columbia	190	168,014	67,624	72	196,553	188,914	256,538
Territories	3	1,091	303	1	189	112	415
CANADA TOTALS	958	1,171,548	$ 388,962	329	712,609	$ 495,249	$ 884,211

Notes: 1. "Uninsured Contracts" are arrangements whereby an employer undertakes to provide health benefits to employees outside of an insurance contract. The plan may be administered by the employer or by a third party administrator such as an insurance company or other independent organization. A third party administrator will, for a fee, administer a health benefit plan and settle claims but not guarantee payments because the plan is uninsured. Included above are uninsured plans for which life insurers provide administrative services only.

2. A few companies did not report the number of persons covered. The totals shown contain an estimate for those companies based on the volume of benefit payments.

3. Some national contracts may be counted in more than one province wherever employees are located. Consequently, the number of contracts included under "CANADA TOTALS" does not equal the sum of the number of contracts reported in each province.

* Business in force as at year-end.

HEALTH INSURANCE BENEFITS IN CANADA – 2011

TABLE NO. 4: Income Replacement (Group)

PROVINCE and TERRITORY	PLANS IN FORCE		NUMBER OF PERSONS INSURED		DIRECT PREMIUMS WRITTEN ($000)		DIRECT CLAIMS PAID ($000)	
	Short Term	Long Term	Short Term	Long Term	Short Term	Long Term	Short Term	Long Term
Newfoundland and Labrador	229	1,106	18,892	119,335	$ 6,566	$ 70,898	$ 5,994	$ 52,872
Prince Edward Island	89	385	3,307	41,984	1,353	19,659	709	14,232
Nova Scotia	492	2,589	31,383	193,064	9,821	113,946	8,587	87,017
New Brunswick	354	1,944	27,172	168,609	7,517	81,257	5,455	62,885
Quebec	10,791	23,519	792,038	2,093,771	305,264	1,122,359	251,812	803,149
Ontario	11,325	40,707	659,954	4,227,586	196,871	2,196,482	167,530	1,681,691
Manitoba	2,148	3,973	103,090	324,466	20,206	137,911	13,378	80,584
Saskatchewan	2,658	3,288	102,780	270,333	21,640	128,236	14,585	63,907
Alberta	6,495	11,890	301,344	1,286,038	87,150	630,784	62,647	364,222
British Columbia	4,139	11,196	200,164	914,650	65,999	497,670	47,416	366,916
Territories	87	234	5,408	47,576	1,739	23,723	1,115	15,701
CANADA TOTALS	38,807	100,831	2,245,532	9,687,412	$ 724,126	$ 5,022,925	$ 579,228	$ 3,593,176

HEALTH INSURANCE BENEFITS IN CANADA – 2011

TABLE NO. 5: Income Replacement (Individual)

PROVINCE and TERRITORY	NUMBER OF PERSONS INSURED	DIRECT PREMIUMS WRITTEN ($000)	DIRECT CLAIMS PAID ($000)
Newfoundland and Labrador	12,004	$ 9,684	$ 3,570
Prince Edward Island	1,844	3,054	2,169
Nova Scotia	22,595	19,394	10,251
New Brunswick	14,835	16,085	8,920
Quebec	265,871	265,326	113,597
Ontario	346,523	343,895	168,091
Manitoba	25,908	25,843	10,799
Saskatchewan	30,064	24,438	8,208
Alberta	96,481	96,433	43,065
British Columbia	96,079	95,037	60,836
Territories	1,325	1,889	727
CANADA TOTALS	913,529	$ 901,078	$ 430,233

HEALTH INSURANCE BENEFITS IN CANADA – 2011

TABLE NO. 18: Loss of Income (Uninsured or Administrative Services Only Contracts)

PROVINCE and TERRITORY	SHORT TERM				LONG TERM				TOTAL LOSS OF INCOME BENEFITS ($000)	TOTAL PREMIUM EQUIVALENT S ($000)
	CONTRACTS* IN FORCE	NUMBER OF PERSONS COVERED*	BENEFIT PAYMENTS ($000)	PREMIUM EQUIVALENTS ($000)	CONTRACTS* IN FORCE	NUMBER OF PERSONS COVERED*	BENEFIT PAYMENTS ($000)	PREMIUM EQUIVALENTS ($000)		
Newfoundland and Labrador	22	13,702	$ 3,189	$ 3,455	12	12,188	$ 2,858	$ 3,102	$ 6,047	$ 6,557
Prince Edward Island	10	2,348	661	704	5	2,644	731	793	1,392	1,497
Nova Scotia	59	75,191	14,544	15,669	19	20,619	7,966	8,656	22,510	24,325
New Brunswick	47	48,696	14,237	15,419	36	30,784	16,806	18,937	31,043	34,356
Quebec	202	248,881	66,257	71,862	43	130,555	53,703	57,077	119,960	128,939
Ontario	620	1,236,812	313,511	337,857	144	481,757	209,209	226,015	522,720	563,872
Manitoba	102	58,832	14,958	16,335	22	53,933	18,502	20,126	33,460	36,461
Saskatchewan	58	35,661	9,891	10,717	18	44,768	19,060	20,145	28,951	30,862
Alberta	192	291,325	70,352	76,106	30	137,068	70,105	75,719	140,457	151,825
British Columbia	220	248,671	79,498	85,387	47	250,563	278,420	299,170	357,918	384,557
Territories	14	2,080	758	807	9	2,918	1,570	1,678	2,328	2,485
CANADA TOTALS	1,037	2,262,199	$ 587,856	$ 634,318	274	1,167,797	$ 678,930	$ 731,418	$ 1,266,786	$ 1,365,736

Notes: 1. "Uninsured Contracts" are arrangements whereby an employer undertakes to provide health benefits to employees outside of an insurance contract. The plan may be administered by the employer or by a third party administrator such as an insurance company or other independent organization. A third party administrator will, for a fee, administer a health benefit plan and settle claims but not guarantee payments because the plan is uninsured. Included above are uninsured plans for which life insurers provide administrative services only.
2. A few companies did not report the number of persons covered. The totals shown contain an estimate for those companies based on the volume of benefit payments.
3. Some national contracts may be counted in more than one province wherever employees are located. Consequently, the number of contracts included under "CANADA TOTALS" does not equal the sum of the number of contracts reported in each province.
* Business in force as at year-end.

Annex D. List of Episodic Illnesses

1	ALS (Amyotrophic Lateral Sclerosis)
2	Arthritis
3	Asthma
4	Cancer
5	Chronic bronchitis
6	Chronic fatigue syndrome
7	Diabetes
8	Emphysema
9	Epilepsy
10	Fibromyalgia
11	Guillain-Barre Syndrome
12	Hepatitis B
13	Hepatitis C
14	HIV/AIDS
15	Long-term pain
16	Lupus
17	Major depression
18	Menieres disease
19	Mood disorders
20	Multiple sclerosis
21	Muscular dystrophy
22	Parkinsons
23	Personality disorders
24	Repetitive strain injury
25	Schizophrenia
26	Severe migraines
27	Tuberculosis

Source: Furrie, A. (2010). Towards a better understanding of the dynamics of disability and its impact on employment. Adele Furrie Consulting Inc. http://www.adelefurrie.ca/PDF/Dynamics_of_disability.pdf