Employees' Perspectives on Intermittent Work Capacity: What Can Qualitative Research Tell Us in Ontario?

Deliverable #5 – Final report

Submitted to:

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Acronyms

ACT	AIDS Committee of Toronto
AODA	Accessibility for Ontarians with Disabilities Act
ARV	Anti-retro-viral
AS	The Arthritis Society
ASO	AIDS Service Organization
ATIP	Access to Information and Privacy
BUILT	Building Up Individuals through Learning and Teamwork
CAPA	Canadian Arthritis Patient Alliance
CMHA	Canadian Mental Health Association
CPP	Canada Pension Plan
CPP-D	Canada Pension Plan Disability
CRIAW	Canadian Research Institute for the Advancement of Women
CUPE	Canadian Union of Public Employees
CWGHR	Canadian Working Group on HIV and Rehabilitation
EDN	Episodic Disabilities Network
EDEN	Episodic Disabilities Employment Network
ERDCO	Ethno-Racial Disabled Citizens of Ontario
ESUB	Employment Start-Up Benefit
ETB	Employment Transition Benefit
EHAO	Environmental Health Association of Ontario
HR	Human resources
HRSDC	Human Resources and Skills Development Canada
IFF	Inter-sectional Feminist Framework
LMAPD	Labour Market Agreement for Persons with Disabilities
MCSS	Ministry of Community and Social Services
MDSC	Mood Disorders Society of Canada
MOHLTC	Ministry of Health and Long-Term Care
MS	Multiple sclerosis
MTCU	Ministry of Training, Colleges and Universities
NNMH	National Network for Mental Health
ODSP	Ontario Disability Support Program
OECD	Organisation for Economic Co-operation and Development
OEDN	Ontario Episodic Disabilities Network
OHIP	Ontario Health Insurance Plan
OW	Ontario Works
RGI	Rent-geared-to-income
SRDC	Social Research and Demonstration Corporation

Acknowledgements

First and foremost, we would like to thank the 73 participants who shared with us their challenges and successes regarding employment and disability. We hope this report does justice to their experiences.

Our sincere thanks as well to the ten policy experts, program developers, and service providers and others who provided us with information about relevant policies and programs, and to the many organizations that publicized the project and put us in touch with the people with whom we needed to speak. A particular thanks to the staff at the Canadian Working Group on HIV and Rehabilitation (CWGHR) and to the members of the Ontario Episodic Disabilities Network (OEDN) for their full engagement and support of the project from the beginning.

We would also like to express our sincere thanks to the staff at the Office for Disability Issues (ODI) and to Human Resources and Skills Development Canada (HRSDC) for its financial support of the project.

EXECUTIVE SUMMARY

Background

People with disabilities are much more likely to be unemployed than non-disabled Canadians, for reasons directly related to their disability and beyond their control. As a result, their incomes are generally much lower, and many rely on disability benefits provided through income support programs.

Yet substantial numbers of Canadians with disabilities are willing and able to work – if not full-time, then at least on an intermittent basis. Certain conditions such as multiple sclerosis, arthritis, HIV, some mental health conditions, and others have symptoms that are considered "episodic," in which periods of good health are interrupted – often unpredictably – by periods of illness or disability that affect one's ability to work. In other cases, people with more stable symptoms may still be able to work some of the time if provided with appropriate supports.

The Government of Canada is interested in finding ways to assist people with disabilities who can work intermittently to do so. Helping more people with disabilities stay in the labour force will help Canada deal with a predicted shortage of skilled labour, and will give people with disabilities a chance to enjoy the benefits of employment such as feeling more included in society and having improved quality of life.

Purpose and scope

Human Resources and Skills Development Canada commissioned this research to better understand why some people in Ontario with disabilities who have intermittent work capacity remain working, while others with similar disabilities become discouraged and drop out of the labour force. The goal of the project was to identify the conditions, support services, and employer practices that help people with disabilities and intermittent work capacity stay employed.

The study examines the experiences of people with disabilities who are not able to work full-time and who have some employment experience. The focus of the study is on the experiences of employees in Ontario, since other research commissioned by HRSDC is looking at employees' experiences in other provinces and on employer perspectives.

Methodology

The Social Research and Demonstration Corporation (SRDC) conducted this study between August 2010 and March 2011. Research activities centered on three areas:

1. Partnerships with community-based agencies in the disability sector;
2. A multidisciplinary literature review;

3. Data collection via 10 key informant interviews with experts in policy and program delivery; 10 focus groups (held in Ottawa, Toronto, North Bay, and by teleconference); and return-to-work stories submitted electronically by people with disabilities. A total of 83 people participated – 10 as key informants, 60 in focus groups, and 13 people electronically.

Key informant interviews helped to draw the "map" of Ontario policies and programs related to employment and income supports, and focus groups explored topics such as myths and misconceptions about disability, barriers to work, disclosure of disability, accommodations in the workplace, supports to employment, and other issues.

Results

Most participants said they wanted to work and could do so, given the right supports. This includes people with episodic disabilities and more stable health conditions as well. Conditions that support employment success and longer-term attachment to the labour force include:

- A diverse, robust labour market that provides a variety of good jobs in different sectors;
- Employment that pays a decent living wage and has good health insurance and extended health benefits to cover the often high costs of treating and managing a disability;
- Fulfilling employment that doesn't exploit people with disabilities.While a few people said "survivor jobs" – low-wage, low-skilled jobs – helped them get back into the labour force, the majority saw this only as a way to find work that better matched their skills, education, and experience;
- A workplace environment that values differences and has clear, accessible policies about how to accommodate them. Workplaces that provide support through Human Resource (HR) departments and/or labour unions regarding disclosure of disability needs and that provide appropriate accommodations to employees with disabilities as their work capacity changes;
- Employers and co-workers who understand disability and intermittent work capacity and who focus on what people can do, not their limitations. Employers who provide flexibility in how the work gets done (e.g., flexible hours, telecommuting, job redesign, etc);
- Access to personal supports (friends, family, co-workers, etc.) and caring service providers/professionals;
- Access to appropriate medical and disability-related supports and services;
- Income supports that are adequate and flexible enough to allow movement in and out of employment as health permits. The majority of participants said that no matter how much they wanted to work, the unpredictability of their health meant they could not afford to risk losing the security of their income assistance benefits. Many saw current features of these programs – such as reducing benefits by 50 per cent of employment income – as further disincentives to employment. Many were also apparently misinformed about other features,

such as being able to be paid for expenses related to volunteering and to go back onto income assistance in the event of illness;

- Access to transportation that is affordable, reliable, and accessible, and to employment-related supports to cover its costs, along with the cost of clothing, equipment, and child care, such as through benefits offered by ODSP and OntarioWorks. Many participants did not appear to know about these, however, and according to key informants, they are under-utilized;
- Employment support services that do not focus only on employment outcomes but also on other related achievements, since many people with disabilities face barriers that mean they are not "job ready" without supports. Access to a range of individualized employment supports - including pre-employment counseling and post-employment job coaching - to address the many structural barriers in the labour force for people with disabilities.

Conclusions

SRDC researchers found that, to a certain extent, recent reforms to the income support system do consider the needs of people with disabilities who can work intermittently, and help them move into employment. Key features include being able to get benefits reinstated quickly after illness, and having access to certain health benefits if an employer isn`t able to offer these. However, some participants in this study were not aware of these program features, and many argued that there are still a number of built-in disincentives to employment.

In addition, some participants expressed concern about the recent shift of employment support programs in Ontario toward an outcome-based funding model, which in their opinion, has meant that many people with disabilities are not receiving the supports they need to overcome the numerous structural barriers that exist for them in the labour market. Many participants also reported that they still face stigma and discrimination in the workplace, and do not receive the accommodations they need to do their work effectively.

Based on the literature and the experiences of people involved in this study, the authors of the study's final report conclude that the likelihood of being successfully employed in the longer-term is directly related to three factors: 1) the degree of control a person has over disclosure of his or her disability, 2) whether or not s/he still has a job to return to, and 3) whether or not s/he receives appropriate accommodations in the workplace.

Key research gaps

1. **Develop more responsive research tools**: Current data is not very clear about the numbers of people with disabilities who can work intermittently in Canada, and what their employment looks like over time. Research definitions need to take the complex and dynamic nature of disability into account, and research that explores the impact of disability on employment over time is needed.

2. **Explore the experiences of specific sub-groups:** In order to develop effective solutions to systemic barriers to employment, it is important to understand their impact on specific sub-groups, and how they might be affected by proposed solutions. The current study only highlighted issues for a few sub-groups of people with disabilities and intermittent work capacity, such as women, Francophones, people from racialized communities, and people living in the North. These issues should be explored in more depth and with other groups of people such as men and Aboriginal people to develop a fuller understanding of their experiences and how they might be affected by possible interventions.

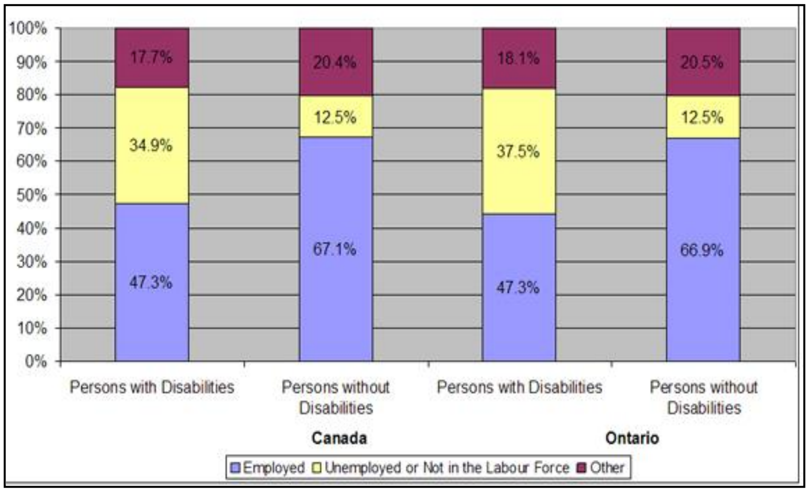
3. **Test promising practices and innovations:** Whether in the area of income or employment supports, innovations and promising practice should be appropriately evaluated to ensure long-term effectiveness in scaled-up versions. The effectiveness of work-related benefits as incentives to employment should be evaluated, and new models could be tested, such as the milestones approach to employment supports used in British Columbia.

1. INTRODUCTION

1.1 Background

The research evidence is clear that the level of participation in the labour market of persons with disabilities[1] remains low. In 2006 for example, Canadians with disabilities were twice as likely to be out of the labour force and one-third less likely to be employed (Galarneau & Radulescu, 2009). The overall picture of labour force participation among people with disabilities aged 16-64 in Ontario is no more encouraging. As Figure 1 indicates, over one third of people with disabilities in Ontario (37.5 per cent) were unemployed or not in the labour force in 2008, compared to only 12.5 per cent of Ontarians without disabilities. Furthermore, among all people with disabilities in Canada, those in Ontario were more likely to be unemployed or not in the labour force (Government of Ontario, 2010). As Galarneau and Radulescu (2009) and others note, people with disabilities are more often completely excluded from participating in the labour force for reasons directly related to their disability and beyond their control.

Figure 1 - Percentage of persons with disabilities in both Ontario and Canada who are not in the labour force



Source: Canada-Ontario Labour Market Agreement for Persons with Disabilities 2009-10 Annual Report (December 2010), using data from Statistics Canada (2008), Survey of Labour and Income Dynamics, 2008. Data re-printed as published.

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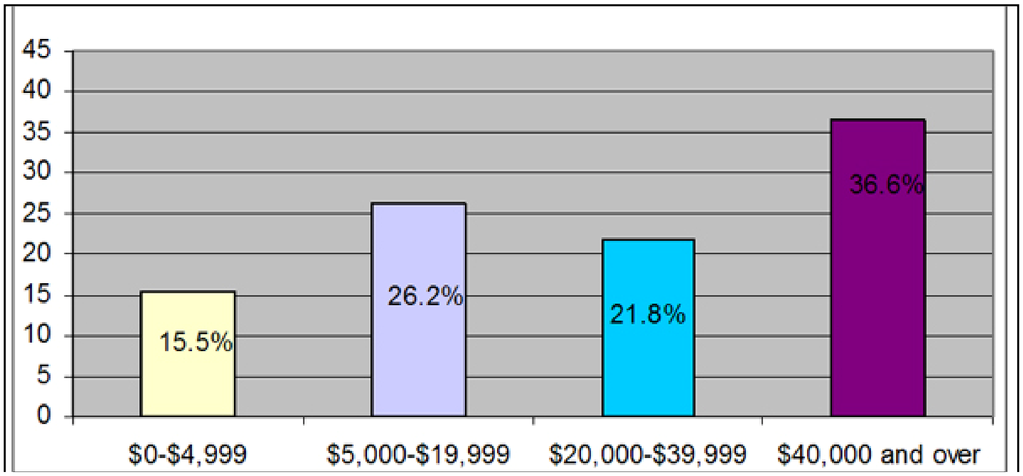
[1] Most Statistics Canada surveys, including the Participation and Activity Limitation Survey (PALS), the Canadian Community Health Survey (CCHS), and Survey of Labour and Income Dynamics (SLID) have, since 1999, used the definition of disability from the World Health Organization (WHO) in disability is “the result of complex interactions between a health problem or functional limitation and the social, political, cultural, economic, and physical environment. These, in combination with personal factors such as age, gender, and level of education, can result in a disadvantage—that is, a disability. Disability is [therefore] not defined merely as being the direct result of a health problem or any physical or mental limitation” (Human Resources and Social Development Canada 2006, as cited in Galarneau and Radulescu, 2009, p. 6).

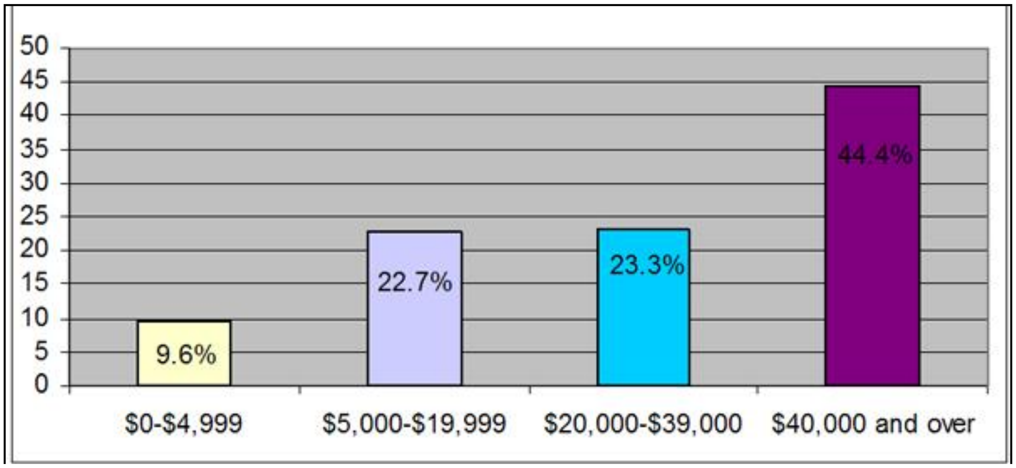
As a result, people with disabilities in Ontario – like other disabled Canadians - are much less likely to report having employment income, and among those who do, levels are substantially less: a person with a disability in Ontario earned on average $37,700 in 2008, compared with an average of $45,500 for the person without a disability (Government of Ontario, 2010).

Figure 2 – Distribution of earnings for people aged 16-64 with disabilities in Ontario



Source: *Canada-Ontario Labour Market Agreement for Persons with Disabilities 2009-10 Annual Report* (December 2010), using data from Statistics Canada (2008), Survey of Labour and Income Dynamics, 2008.

Figure 3 – Distribution of earnings for people aged 16-64 without disabilities in Ontario



Source: *Canada-Ontario Labour Market Agreement for Persons with Disabilities 2009-10 Annual Report* (December 2010), using data from Statistics Canada (2008), Survey of Labour and Income Dynamics, 2008.

Evidence also suggests that substantial numbers of Canadians with disabilities are willing and able to work. In some cases, this is due to the fact that new treatments have changed the progression of illness. Access to consistent anti-retro-viral treatments, for example, has transformed HIV into a chronic disease for many people (though not all), enabling them to live longer, with greater quality of life, and to continue activities such as employment that were once thought impossible.

In other cases, certain conditions are recognized as "episodic" disabilities. 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*" (website of the Canadian Working Group on HIV and Rehabilitation - CWGHR), though be unable to predict when these episodes will occur or how long they will last. Finally, 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.

Canada, like other OECD countries, has made reform of sickness and disability policies a priority (OECD, 2010), and there have been recent legislative changes to make eligibility criteria for disability income benefits more flexible. The impetus for this reform stems from two areas: on the one hand, a desire to promote social and economic inclusion and social justice, and on the other, to capitalize on the potential contributions of an under-utilized labour force (Statistics Canada, 2006; OECD, 2010; Williams, 2006). Reform takes place in the context of employment equity and human rights legislation that ensures access to the labour force for people with disabilities, and has increasingly emphasized the employer's duty to accommodate their needs (Shain, 2009).

Beginning in 2006, Human Resources and Skills Development Canada (HRSDC) initiated a number of studies related to intermittent work capacity. These included:

- a population-based economic analysis of episodic work benefits (CWGHR, 2006);
- a survey study of certified human resource professionals regarding episodic disabilities (CWGHR, 2006);
- a report from SRDC outlining proposed options for random assignment demonstration projects to study policy interventions that would improve the accessibility to the labour market for people with episodic disabilities (SRDC, 2007); and
- a study of the prevalence of episodic disability in Canada and the impact on employment (Furrie, 2010).

In 2010, HRSDC commissioned an additional three pieces of qualitative research meant to build on the emerging knowledge of intermittent work capacity among people with disabilities: one focusing on employer perspectives and two on employee perspectives, the latter in Ontario and British Columbia. The Social Research and Demonstration Corporation (SRDC) was commissioned to explore the experiences of people with disabilities in Ontario who have intermittent work capacity. The present report represents the *Final report* (Deliverable #5) of the research project entitled *Employees' Perspectives on Intermittent Work Capacity: What can qualitative research tell us?* Together with a PowerPoint presentation deck and dissemination plan (Deliverables #6 and #7), this report forms the final set of deliverables for the project.

1.2 Project Objectives

The purpose of this qualitative research study is to understand why some people with disabilities who have intermittent work capacity remain attached to the labour force, while others with similar disabilities become discouraged and drop out. Its goal is to identify the conditions, support services, and employer practices that enable people with disabilities and intermittent work capacity to stay attached to the labour force.

The Request for Proposals (RFP) identified the following research questions, which form the backbone of the Findings section of this report:

1. Why do some people with disabilities and intermittent work capacity remain attached to the labour force?
2. Why do some people with disabilities and intermittent work capacity become discouraged and drop out of the labour force?
3. How does the workplace environment encourage or discourage labour force attachment? What is the impact of accommodations, management, union presence, and non-wage benefits?
4. What policy and program interventions support labour force attachment for people with disabilities with intermittent work capacity?
5. How important are income supports to people with disabilities, and what are the best ways to provide these?
6. How important are local employment support programs to people with disabilities?

1.3 Project Timelines

The project and its associated research activities took place over eight months, between August 2010 and March 2011. The approximate timelines for each of the main activities are provided below:

- September to October: literature review; consultations with key disability organizations;
- October to January: key informant interviews with Canadian disability experts in advocacy, program delivery, and/or policy; focus groups with people with disabilities; solicitation and submission of return-to-work narratives; preliminary data analysis;
- February and March: in-depth analysis of the qualitative data; final project report.

2. METHODOLOGY

2.1 Overall scope, approach and framework

This research study focused on the employment experiences of people in Ontario with disabilities and intermittent work capacity, in order to develop a better understanding of the systemic and structural factors that facilitate or present barriers to participation in the labour force.

From the beginning, this study sought to explore gender differences in intermittent work capacity. However, we also recognize that like everyone, participants have multiple identities beyond that of a person with a disability, and that individually and together, these various identities can profoundly affect one's experience of employment. We were particularly interested to learn how gender, language, culture, disability, and location affect employment from participants' perspectives. Our efforts to explore the intersection of these identities were limited by the relatively small scale of the project, but were informed by the Inter-sectional Feminist Framework (IFF) developed by the Canadian Research Institute for the Advancement of Women (CRIAW). This framework is essentially a way of thinking about "interconnecting and interacting causes of marginalization, poverty and exclusion" (CRIAW, 2007, p. 1) and especially, how "different systemic conditions…work together to reproduce conditions of inequality" (p. 4). The results of this analysis are integrated into the broader findings.

Study components

The research project was comprised of three complementary components: (1) the engagement of disability community-based agencies; (2) a multidisciplinary literature review; and (3) an analysis of new primary data via key informant interviews with key experts, focus groups with people with disabilities, and return-to-work stories submitted by people with disabilities.

Terminology

In defining the scope of the project, we chose to take an inclusive, cross-disability approach that focused less on specific medical conditions than on capacity for employment among people with diverse disabilities. While some conditions have symptoms that are more variable and episodic than others, even those with more stable conditions can have symptoms that vary (e.g., pain, fatigue, side effects of medications) and thereby affect work capacity. Moreover, people with disabilities can and often do have multiple conditions – especially mental health problems - and these secondary conditions may have more effect on work capacity than the primary condition. Lastly, many people with disabilities find their work capacity depends in part on the work environment itself, such as the presence of harmful chemicals or working conditions, the degree of stress, etc.

This emphasis on the more general and shared notion of work capacity means that where possible, we used the term “intermittent work capacity.” Whereas the term “episodic disability” is occasionally used in other contexts to refer to specific medical conditions, we have chosen to interpret it in a more inclusive sense and used it interchangeably with “intermittent work capacity” or “variable work capacity” in this report.

In keeping with the language presented in the RFP, therefore, we defined intermittent work capacity as:

- not being able to work full-time hours because of a disability or health condition;
- 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.

In defining work capacity, we also focused on the experiences of people with disabilities who have had at least moderate participation in the labour force – even if they were currently unemployed or have had repeated bouts of unemployment – rather than those who have experienced chronic, long-term unemployment.

We are aware that not everyone who has an ongoing health condition or illness considers it to be disabling, and we consciously use the term “disability” to go beyond bio-medical considerations and include the broader set of social, psychological, cultural, and political meanings ascribed to the condition by others (usually as limitations or deficits), and which can affect functioning in many life domains. However, on more than one occasion, we spoke with people who did not see themselves as disabled, and we respect that the terminology used in this report may not resonate with all participants. Similarly, we understand that other terms used in this report are, at best, imperfect ways to describe the various socially-constructed identities and experiences participants may have, and hope that participants will understand our attempts to find respectful ways to describe their experiences.

Finally, while “participant” is a generic term, in this study we typically use it to describe people with disabilities who participated in the project in focus groups or interviews, or who submitted via email written stories of their return to work. We use the term “key informant” to refer to those who provided a broader perspective on employment and disability than that based on their own personal experience, and who were typically involved in policy analysis, program development, or service provision. This is not to imply the two groups are mutually exclusive, however; while key informants did not participate in focus groups, several did disclose that they too, coped with conditions that could be considered episodic or disabling.

2.2 Engagement with disability sector organizations

Throughout the research project, SRDC collaborated closely with disability sector organizations, especially the Canadian Working Group on HIV and Rehabilitation (CWGHR). CWGHR was an important partner organization even from the proposal stage, given its role as the coordinating body for several networks related to episodic disability, including the Episodic Disabilities Network (EDN), the Ontario Episodic Disabilities Network (OEDN), and the Episodic Disabilities Employment Network (EDEN). Where applicable, the member agencies and associations of these networks were invited to participate in the project, either in terms of providing assistance with recruitment of participants, identifying key informants, and/or commenting on the study's methodology and preliminary findings.

2.3 Literature review

SRDC conducted a multidisciplinary literature review of both Canadian and international research literature, focusing on academic as well as "grey" literature (i.e., policy reports and working papers not published in academic journals). In addition to recently published academic articles identified via an extensive search of scholarly databases, the review included materials provided by episodic disability experts and those identified following a scan of the reference sections from the retained source documents. Documents retained for the review were systematically searched for references as to how men and women had different experiences – either of employment, episodic disability or both. The main findings of the literature review are integrated into this report, and the full review can be found in Appendix H.

2.4 Data collection

SRDC used a purposive sampling approach to recruit people to participate in the key informant interviews and the focus groups. This approach was felt to be most appropriate in terms of locating sources that would be "information-rich" (Patton, 2002) and provide a diversity of perspectives and views.

Key informant interviews

Our focus for the key informant interviews was on people who could provide information from a broad perspective about employment and disability in terms of policy, design and delivery of programs, or on specific supports or barriers. We spoke with representatives of government agencies, service providers, community-based organizations, and advocacy groups. Some of these people were known to us previously from our disability-related work, while others were identified through the literature review, were referred by community partners, or in one case, contacted us directly. One key informant took it upon herself to canvas a few others with similar conditions about their experiences, and reported these to us in the interview. In total, SRDC conducted ten key informant interviews. A list of key informants' organizational affiliations is found in Appendix A.

The interviews were conducted over the phone, and followed a semi-structured protocol that typically lasted 45 minutes (see Appendices B and C for the informed consent (conducted orally) and interview protocols, respectively). The discussion topics included coordination of programs, eligibility and access, and effective models and mechanisms for supporting people with disabilities to overcome barriers to employment. Key informants were also asked to comment on innovative and promising practice in policy development, program design and delivery, and community engagement, and to provide suggestions for the focus groups.

Focus groups

Recruitment for the focus groups was done mainly through contact with individuals in key disability organizations and networks who promoted the study to members, clients, acquaintances, and colleagues, and assisted with outreach and recruitment. Those organizations included:

- Ontario Episodic Disability Network (OEDN)
- Episodic Disability Employment Network (EDEN), through CWGHR
- Multiple Sclerosis (MS) Society
- AIDS Committee of Toronto (ACT)
- The Arthritis Society
- Canadian Arthritis Patient Alliance (CAPA)
- Mood Disorders Society of Canada (MDSC)
- Canadian Mental Health Association (CMHA) Ontario, and Ottawa and Toronto branches
- Horizons Renaissance, Inc.
- National Network for Mental Health (NNMH)
- Ethno-Racial Disabled Citizens of Ontario (ERDCO)
- Independent Living Canada
- DAWN Ontario
- CauseWay Foundation, Ottawa
- Muscular Dystrophy Canada
- Fibromyalgia Support – Ottawa West

- Canadian Association of Professionals with Disabilities
- Migraine Association Of Canada
- Toronto Fibromyalgia Support Group
- East Ottawa Fibromyalgia and Chronic Fatigue Syndrome Support Group
- Lupus Ontario
- Native Training Centre
- North Bay Indian Friendship Centre

Recruitment for the focus groups emphasized the three following criteria for participation: having a disability, some experience in the labour force (including full- or part-time, occasional, sporadic employment as well as current, repeated or short bouts of unemployment), and a capacity to work intermittently. Depending on whether participants for a given focus group were recruited from among the clientele of a specific organization or more broadly, either SRDC or the disability organization was responsible for ensuring that participants met the recruitment criteria. For groups organized by SRDC, individuals were never asked to disclose their disability.

Ten focus groups were conducted for this study. Five of these groups had no additional criteria for recruitment beyond that used for the study in general, while five were reserved for a more specific sub-group of participants: people living with HIV/AIDS (PLWHAs), people with mental health problems, women, Francophones, and people from racialized communities. These groups were held separately to explore specific issues such as stigma or the impact of gender, language, or ethnicity on people’s experiences of disability and employment. Attempts were made to organize a focus group with Aboriginal people with disabilities and another one with people with environmental sensitivities, but the short time frame for the project did not allow time to engage sufficiently with these organizations to organize data collection in a manner that would meet their needs.

Three focus groups were held in Ottawa, three in Toronto, one in North Bay, and three by teleconference. These three particular communities were approached because of the presence of disability organizations known to be active in the area of episodic disabilities, and because they represented different geographic and employment contexts. Toronto has a diverse economy spread over a large geographic area, Ottawa’s economy is dominated by government and the high technology sector, and North Bay’s economy was considered more focused on specific sectors and perhaps less robust.

Table 1: List of focus groups, by date, location and participant group

Focus Group	Date	Location	Participant group
1	Nov 23/10	Teleconference	Members of OEDN
2	Dec 1/10	Toronto	Both genders, people living with HIV
3	Dec 2/10	Toronto	Women only; mix of disabilities
4	Dec 3/10	Toronto	Both genders, mix of disabilities
5	Dec 7/10	Ottawa	Both genders, mix of disabilities
6	Dec 9/10	Ottawa	Both genders, people with mental health issues
7	Dec 13/10	Teleconference	Members of EDEN
8	Dec 16/10	North Bay	Both genders, mix of disabilities
9	Jan 18/11	Ottawa	Both genders, Francophones with mental health issues
10	Jan 19/11	Teleconference	Members of ERDCO

The semi-structured protocol for the focus groups focused discussion on employment supports, workplace supports and accommodations; myths and misconceptions; barriers and incentives; the role of coworkers and supervisors; accessing and navigating information and support programs; and recommendations for change and promising practices (see Appendices D and E for the informed consent protocol and focus group protocol, respectively).

Focus groups lasted on average two hours. Participants were provided an honorarium of $30 and reimbursements for transportation and childcare expenses upon request. Two SRDC project team members attended each focus group. Notes were taken and all discussions were digitally recorded to ensure veracity of the notes and analysis.

In total, 60 individuals with disabilities and intermittent work capacity participated in the focus groups. Although we generally tried to over-recruit to achieve an ideal size of 8-10 participants in each group, a few groups were smaller than anticipated, due in part to winter weather and the targeted nature of some of the groups in some locations.[2] In two cases, telephone interviews were conducted with individuals who had expressed an interest in attending a focus group but were unable to do so.

We deliberately did not ask focus group participants to provide specific demographic information for several reasons. First, asking for specific information about employment and disability was seen as being too intrusive and incompatible with our stance that people should

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[2] For example, three men in Toronto expressed an interest in participating in a focus group, but none of the focus groups held there were applicable. These men were invited to submit their stories electronically.

only disclose information to the extent they felt comfortable. Secondly, asking for categorical information about employment and disability would have been inconsistent with our conceptualization of both as fluid, multi-dimensional experiences. Lastly, we felt asking people to complete such data at the start of the focus group would interfere with the process of establishing a trusting rapport, on which – given the personal nature of the discussion topic – the quality and richness of the discussions depended.

A consequence of this decision is that we are not able to provide much quantitative description of participants and their circumstances. To the best of our knowledge,[3] the 60 participants were two-thirds female (roughly 40 women, 20 men). Based on the experiences they shared, we can confidently state that participants represented a broad range of employment experiences in a variety of workplaces. Some participants had worked in professional positions, others worked in lower-skilled jobs. Many if not most had experienced unemployment, some for lengthy periods of time. Some – though a minority – were currently employed at the time we spoke to them, and a few people were self-employed. Most indicated they relied on some form of income assistance for all or part of their income.

The majority of participants also disclosed their primary condition or disability. These represented a wide range of conditions, including HIV/AIDS, mental health issues (including depression, anxiety, post-traumatic stress disorder (PTSD), seasonal affective disorder (SAD), bi-polarity, and schizophrenia), epilepsy, multiple sclerosis, arthritis, fibromyalgia, and environmental sensitivities. Given the particular sampling method we used, people living with HIV/AIDS and people with mental health problems were represented more than any other disability group. This is also because a number of people who did not attend groups specifically organized by mental health service providers indicated that they too, coped with mental health problems in addition to another disability or more. A couple of participants indicated they suffered from chronic pain, in some cases related to an accident or injury, and there were a couple of participants who indicated they had repetitive strain injuries that were work-induced. Several participants had conditions that would typically be characterized as more stable disabilities, including muscular dystrophy and cerebral palsy, as well as vision and other mobility impairments; some of these participants indicated they had symptoms that varied (e.g., fatigue, sores, pain, neurological impairment) or had a secondary condition that affected their ability to work full-time.

Return-to-work stories

In close collaboration with CWGHR, an invitation to submit return-to-work stories was sent electronically to members of the Episodic Disabilities Employment Network (EDEN; see Appendix F). The invitation requested stories on the barriers or supports that people in Ontario encountered in the decision of whether or not to return to work, or to maintain employment.

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[3] Exact numbers of women and men are not confirmable because several focus groups were conducted via teleconference. There is also the possibility that some participants were transgendered.

Individuals who had expressed interest in participating in a focus group but were unable to do so were also invited to submit a story.

The invitation included the goal of the study and identified SRDC as the organization carrying out the research and HRSDC as the project funder. The invitation requested employment stories in 400 words or less. The invitation stipulated that a $30 honorarium would be provided and that any information submitted to SRDC would be treated confidentially. An SRDC return email address created specifically for the project (workcapacity@srdc.org) was provided in the invitation. The email account, housed on SRDC's secure servers, was accessible by only one SRDC researcher.

A thank-you email was sent to those who submitted a story, stating that personal identifiers would not be used in any reports, and that copies of the final report would be sent to those who expressed interest in receiving a copy (see Appendix G). The message also encouraged participants to submit their story directly to EDEN. Lastly, these participants were asked in the email to provide their full name and mailing address so that the honorarium could be sent by mail. Two requests for additional information about privacy and confidentiality of the data were received and responded to on an individual basis by an SRDC researcher, after which both individuals chose to submit a return-to-work story.

A total of 13 return-to-work narratives were received. As with the focus group participants, we did not ask individuals to provide us with demographic information or to disclose their disability, although several did so in their narratives. To the best of our knowledge based on the stories received, there was equal representation across men and women, and a similar range of employment and disability experiences was described as those by focus group participants.

2.5 Data analysis

SRDC took an inductive and iterative approach to the analysis of the primary data for this project. Rather than approaching the analysis with a predetermined framework for coding and analysis, the decision was made to let the codes and themes emerge from the data themselves, and were developed through several reviews of the data (see below).

Analysis by theme and pattern

Both team members reviewed the extensive notes taken during the key informant interviews and the focus groups and used these to identify the key points and themes of each discussion.

Once these were outlined, key points and common themes *across* the various discussions were identified, as were patterns among various sub-groups of participants. Successive reviews of the data were conducted for all three lines of qualitative evidence in order to determine to what extent and in what patterns the themes and patterns applied.

Composite portraits

SRDC used a narrative, modified case study approach to create portraits of three fictitious individuals. These portraits are composites, each an amalgam of several stories recounted through the focus groups and return-to-work narratives, and to a lesser extent, the interviews as well. They are included here to illustrate the impact of some of the structural factors affecting employment for people with disabilities and intermittent work capacity. Of course, names are fictitious, and details related to participants' experiences have been changed to ensure no participant could be identified, as per our consent protocols.

Validity and reliability

Whereas quantitative research focuses on the validity and reliability of findings in relation to an objective, external "reality," qualitative research frameworks re-frame these concepts in ways that are more suited to the subjective nature of the phenomena being explored. Validity is more appropriately framed in terms of the credibility and transferability of research results, and reliability and objectivity as dependability and confirmability, respectively (Lincoln & Guba, 1985). Taken together, these criteria can be used to judge the overall "trustworthiness" or quality of qualitative research findings.

SRDC used several techniques known to enhance the trustworthiness of qualitative research findings (see Johnson, 1997), including successive reviews of the data during analysis, as noted above. Two SRDC team members were involved in both data collection and analysis, and we collaborated on the development of the coding structure and emerging themes to ensure accuracy and achieve consistency of interpretation. We periodically reviewed each other's coding and writing to achieve consensus. We also used verbatim quotes from participants extensively to ensure we accurately reflected participants' perspectives. In addition, we invited members of the OEDN to comment on the preliminary findings during a teleconference, and invited three key informants from disability sector organizations to provide their feedback on the final report; both sets of comments were very helpful to fine-tune our conclusions and their presentation, and enhance the trustworthiness of the study.

2.6 Study limitations

Though it may seem obvious, the qualitative nature of the methods used in this study and the fact that much of the data was derived from group discussions means that we were unable to quantify participants' experiences with any precision. As is common in qualitative research, we used words such as "a few," "several," "many," or "most" to indicate the prevalence of a given opinion or sentiment. Whereas statistics are helpful to understanding quantifiable phenomena, we felt the approach we adopted is more appropriate for exploring the nature of participants' experiences and reflecting their perspectives, and in accordance with the purpose of the study.

As with any qualitative research that uses purposive rather than random sampling to recruit participants, there is no question that those who participated in the study cannot be expected to represent the larger population of people with disabilities who can work intermittently. However, given the extensive efforts that were made to maximize diversity of perspective and the extensive description of study methods and context, it may be possible to generalize or transfer our results to other contexts or settings in specific, limited ways, keeping in mind the specific limitations that follow.

It should be remembered that in terms of scope, this research project did *not* seek to address the perspectives of employers or the experiences of people outside of Ontario, nor was it intended to provide an exhaustive overview of programs and services in Ontario. It should also be noted that the people we spoke to, whether through the focus groups, interviews or return to work narratives, do not necessarily represent the full breadth of experiences of the barriers and supports to employment one might encounter. In particular, we spoke to only a few people who were in receipt of Canada Pension Plan Disability (CPP-D) benefits, and few who had been referred to employment supports through the Ministry of Health and Long-Term Care (MOHLTC) or the Ministry of training, Colleges and Universities (MTCU) (insofar as this was even apparent to participants and ourselves), so our ability to comment on these services is limited. Similarly, only a couple of people talked about occupational injury and the role of the Workplace Safety and Insurance Board (WSIB) of Ontario, as well as the role of labour unions in addressing accommodation needs, so these too, are topics which – though highly relevant – we have not addressed to any great extent in this report. Comments on any specific programs are necessarily limited to the current time frame.

While we were able to talk to participants in several locations (and participants themselves sometimes traveled from other locations to be part of a focus group), the limited number of locations may limit the extent to which conclusions are applicable in other regions of the province. The short timeframe and broad scope of the study also meant that we were only able to explore in a limited fashion issues regarding gender, language, and culture/ethnicity; our exploration of these issues was also due to the small number of participants from each of these groups, and the fact that focus groups are best suited for providing insight into a range of experiences, rather than an in-depth, personal account. In particular, we did not have a men-only or an Aboriginal group and can therefore not speak to the nuances of their experiences. The perspectives of these groups certainly warrant further exploration.

As we discovered, there is also the potential that participants shared erroneous information during the discussions or in the return-to-work stories (e.g., on income support program rules and regulations. However, the intent of the project was not to clarify or correct participants' viewpoints, or to minimize the importance of participants' experiences in our analyses if based on erroneous information. Our focus was to reflect as accurately as possible what we heard in the discussions. We felt that the presence of misinformation, if identified as a theme, could be a finding in and of itself insofar as it impacts on the perceptions, and therefore experiences, of the participants. As such, the accuracy of every point shared during the discussions was beyond the scope of the verification process.

Lastly, the focus of the literature review was purposefully kept narrow due to time and budgetary constraints. The search parameters only briefly touched upon illness-specific resources, and as such, it is likely that a more in-depth search of these materials would reveal greater nuances about the employment and labour force experiences of people with HIV/AIDS, multiple sclerosis, migraine headaches, back pain, to name just a few of the illness and conditions known to increase the likelihood of intermittent work capacity. In addition, little information was found in terms of the unique needs and experiences of vulnerable sub-groups with episodic disabilities, such as new immigrants, Aboriginal peoples, and older workers. This is not to say that this information does not exist, but that our search did not identify these potential resources.

3. FINDINGS

3.1 The literature review

Our review of the literature[4] on employment and episodic disability revealed first and foremost that the notion that disability can be experienced as variable and intermittent - rather than as a fixed state - is still relatively new. The research literature on episodic disability is fairly sparse, definitional issues make it difficult to quantify prevalence, and there is little longitudinal data that captures the dynamic nature of disability and its impact on employment trajectories or experiences over time.

The research evidence also indicates that for people with disability and intermittent work capacity to be successfully engaged in the labour market, active implementation of workplace policies is critical. Yet a majority of workplaces do not have relevant policies or mechanisms in place to handle job assessments and workplace redesigns. This is despite the fact that after modified work hours, job redesign is the second most requested physical/structural accommodation requested by workers in Canada. The role of human resource (HR) professionals as champions appears to be a critical factor, although many of these professionals report being ill-equipped in terms of knowledge and training to manage cases of episodic disability.

Policy analyses have identified a number of other workplace barriers to employment of people with disabilities, among them, stigma, discrimination, and a lack of knowledge among employees and employers about human rights and employment legislation. Many people with disabilities do not have their accommodation needs met at work, and there is evidence that employers can negatively perceive requests for accommodations, affecting both the employee's

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[4] Key findings from the literature review are embedded in dialogue boxes throughout the Findings section. For readers who may be interested, the full literature review is included in Appendix H.

ability to perform his or her job as well as opportunities for training and promotion. A key issue regarding non-wage benefits is lack of portability of health insurance and extended health benefits, which constrains disabled workers' job mobility (known as "job-lock") because of concerns over "pre-existing condition" clauses and proof of insurability when changing employers. Similarly, gaining access to extended health and other benefits relies to a great extent on a medical model of health provision with the physician as gatekeeper, though new guidelines suggest a shift towards more holistic bio-psycho-social models of assessment for devising health and return-to-work plans.

Our review also noted several important barriers with respect to employment and income support systems: difficulty accessing clear information, which leads to existing benefits being underutilized; inflexible eligibility requirements; a jurisdictional patchwork of coverage that makes it difficult to coordinate benefits; and lengthy bureaucratic processes to get benefits reinstated, with no guarantee of approval. Innovative and promising practices include supported employment; ongoing, flexible support through the various stages of employment; greater client engagement in the formulation of individual progress plans; and efforts to engage, inform, and support employers in employing people with disabilities (see the full literature review in Appendix H).

3.2 Interviews and focus groups

As expected, our interviews with key informants were extremely useful in helping us apply the results of our literature review to the Ontario context, and to learn about the specific system of income and employment supports available to people with disabilities in the province. Some of this information was used to describe these systems in the relevant sections that follow, supplemented by additional information found on-line or in relevant documents.

When conducting the key informant interviews, one of the first things that struck us was that those who were (or had been) involved in designing and implementing income and employment support programs for people with disabilities demonstrated a good understanding of many of the barriers facing people with intermittent work capacity, and struggled themselves with the limitations of the programs they administered. Moreover, as a group, key informants appeared very knowledgeable about employers' needs as well as those of disabled workers, and most emphasized that successful accommodation arrangements depend on meeting the needs of all parties.

As such, key informants helped us deepen our understanding of the unique issues facing people with disabilities and intermittent work capacity from the perspective of service providers and policymakers in government as well as in the disability sector. This information was particularly helpful to identify the factors that encourage or discourage labour force attachment, and has been integrated with feedback from focus group participants in these sections.

Once we began speaking to participants with disabilities, we heard first-hand what impacts the above-mentioned program limitations had on their ability to cope with their disabilities and to work, as well as other systemic barriers they faced and supportive factors. We explore these in detail in subsequent sections. For the most part, subsequent sub-sections under Findings emphasize the points of view elicited through key informant interviews and focus groups; where these deviate from each other, this is noted. Contextual information discovered in the course of data collection (e.g., the Ontario landscape of employment support programs) is included in relevant sections.

First, however, we present an overview of the key, defining features of employment as experienced by people with disability and intermittent work capacity, based on what we learned and heard in the stories shared by participants.

3.3 Defining features of disability and employment

The diversity of participants' characteristics and identities, their individual circumstances, and their experiences of disability and employment obviously defy any attempt to define a universal experience of episodic disability or intermittent work. Nevertheless, we did hear certain commonalities of experience from participants time and again in terms of both disability and employment. We present our understanding of these common elements of participants' lived experience here, in order to highlight some of the ways in which employment and disability are inter-related and can affect both the success of any given employment experience, as well as longer-term attachment to the labour force.

As might be imagined, the initial experience of a disabling illness or condition – whether upon experiencing first symptoms, receiving a diagnosis, or recovering from catastrophic onset, accident, or injury - is a pivotal, critical experience at a physical, emotional, psychological, and practical level. How that initial experience of disability happens – the circumstances surrounding it – and whether subsequently, a person's condition manifests itself in public or private appears to define his or her employment experiences to a large degree.

Control over disclosure: a public/private divide

To the extent that an individual has some control over disclosure of his or her disability, attachment to the labour force seems to be easier and employment experiences more positive. Those who have little or no ability to control what information is shared, with whom, when, how, and for what purpose appear to experience far more barriers to employment and to a greater degree.

These differences in control over disclosure are partly due to the specific nature of the condition or illness someone has, but they quickly become barriers to the extent that others regard those conditions as disabilities. Many people have "invisible disabilities" that are not obvious or apparent to other people; this has the advantage of allowing control over disclosure but can also make it hard to legitimize requests for accommodations in the workplace and elsewhere. Moreover, some of these invisible disabilities (e.g., HIV and mental health problems) carry such stigma that control over disclosure is vital to avoiding potential discrimination and abuse. We heard that the most damaging experiences for people with invisible disabilities – personally and professionally – are circumstances in which others disclose information about their disability to co-workers or an employer without permission.

People with more obvious physical symptoms or conditions often find it difficult to overcome others' preconceived notions of their ability and resulting discriminatory behaviour. Visible disabilities necessarily entail a lack of control over disclosure, and according to the participants of this study and many others, this can present particular and significant barriers to obtaining employment, as well as on an ongoing basis in the workplace.

Return to work as employee vs. job seeker

Another, perhaps obvious, defining feature of the employment experience is whether someone has a job to go back to or faces unemployment after the onset of disability. Return-to-work to an existing position is a very different process than returning to the labour force after a period of unemployment, particularly if the latter is prolonged. While both situations can be challenging, the latter is undoubtedly more so owing to the social stigma of unemployment and the dampening effect it has on career development. Just as most people looking for work find they are more attractive to other potential employers if they are still employed, we learned that people with disabilities and intermittent work capacity who have the opportunity to plan their return to work to an existing position tend to have better employment outcomes (at least for short-term) compared to those – often the majority – who have to overcome the many significant barriers that exist in the labour market for unemployed people with disability.

Access to workplace accommodations

A final key feature to a successful employment experience and longer-term engagement in the labour force is the extent to which a person with a disability is able to access appropriate accommodations in the workplace. To the extent this is feasible (depending on the workplace and the job), that all parties see mutual benefit to the arrangement, that it is negotiated in good faith, that accommodations fit the needs of the employer and co-workers as well as the employee, and can be adapted over time as needs change, employment is generally more successful and durable. As outlined in subsequent sections of the report, however, this situation seldom fits with the descriptions we heard from participants of their own lived experiences in the labour force.

The following section outlines some of the conditions identified through the literature review, key informant interviews, and focus groups as supporting employment. As such, it answers the first research question, ‘Why do some people with disabilities who have the capacity to work intermittently remain attached to the labour force?’

3.4 Conditions that support labour force attachment

Financial support and security

Virtually every participant we spoke to considered work to be extremely important. Employment served a number of purposes for participants, the most practical of which is that it provided an income and a means of financial support for themselves and their families. Regardless of whether employment was a primary source of income or supplemented income assistance, work also provided participants with a measure of financial security and independence, or if they were unemployed, then at least the hope of this. Many of those who were currently receiving income assistance – either basic or disability benefits - indicated they would rather rely on employment as their main source of income.

Access to health and retirement benefits

Employment was also important to study participants because it could provide access to much-needed benefits such as health insurance (i.e., short- and long-term disability insurance), extended health benefits, and pension plans. Many participants said they had incurred expenses related to their disability - for treatments, medications, and devices – that were not covered by income assistance or OHIP, and were prohibitively high. One participant, for instance, was unable to use her electric wheelchair because she could not afford to repair it and there was no provision for this under her income assistance plan. Several participants also said they worried about what would happen when they reached retirement age, since they had little in the way of pension plans or retirement savings. Work was seen as a means of accessing benefits that would ease the financial burden related to the high costs of disability and provide some security for retirement.

Quality of life

Participants also told us that work provided structure and routine to daily life, a chance to *“keep busy.”* In this sense, work provided an alternative to tedium, but more importantly, a way to avoid sliding into depression and ennui. As one woman told us, “*I’m isolated when I stay at home, so I sleep too much and it’s hard to motivate myself to get up*.” Similarly, work provided participants with the chance to socialize with others, make friends, and “*get out of the house*,” an antidote to isolation and diminished mental health. Work was seen as a means of coping with the negative effects of one's illness or condition, and a means of recovery. As one participant noted, *"the more well I become, the more I need to work."*

Personal and professional fulfillment, identity

When asked in the focus groups what work meant to them, participants often described the emotional and intellectual satisfaction they derived from work, and the opportunity it offered for personal fulfillment. As one person said, *"you need something that's going to enrich you, that's going to spark you…"* More fundamentally, work was important to participants because, like most of us, they always expected to be part of the labour force. Many had significant work experience as well as relevant education, training, skills, and expertise, and wanted to put these to good use. During introductions, participants often described themselves in terms of previous or current positions held, and outlined in detail the kind of employment they hoped to obtain or aspire to.

This sense of identity associated with a particular job and with being an employed person is critical to quality of life, well-being, and to social and economic inclusion. To a large extent in industrialized society, what we "do" for a living defines us, and our sense of identity and citizenship is closely linked to our ability to lead productive lives. In this vein, participants in our study spoke about the importance of "*giving back*," making a contribution to society, and of doing "*something worthwhile.*"

Sense of purpose

For all these reasons, the vast majority of the participants in this study said they wanted to work. Those currently working wanted to stay in the labour force, and those currently unemployed wanted to find work. Even those few who said they weren't ready to work at this particular point in time had a good idea of what job they would like to do, and said they wanted to find some way of making a contribution. Many participants were involved in volunteer work, often as disability advocates or advisors on disability issues. In some cases, this volunteer involvement was extensive, with a few people describing themselves as "*professional volunteers.*"

In fact, participants in the study were vocal about the fact that people with disabilities have much to offer employers and the labour market in general. As mentioned earlier, many have high levels of education, skills, training, and expertise. In addition to their previous and current work experience, people with disabilities have additional expertise stemming from their experience with disability, which can have tangible benefits for organizations seeking ways to provide services in a more accessible, inclusive manner. One focus group participant regularly advised a city council committee on matters relating to wheelchair accessibility; another was a consultant who helped groups write proposals for disability-related grants. Several others who had experienced mental health problems found that this "*complex experience*" enabled them to relate well to others with similar conditions, and considered an asset in consumer-survivor or peer-led initiatives.

In summary, one of the most important reasons why some people with disabilities remain attached to the labour force is that employment meets a number of basic and more complex needs – not only for financial support and security, but also to optimize quality of life, personal and professional fulfillment, and a sense of identity and purpose.

Conditions that support labour force attachment

Feedback from participants with disabilities and from service providers and policymakers alike provided a clear outline of the conditions that make it easier for a person with a disability and intermittent work capacity to remain attached to the labour force. Some of these conditions are more related to the specific disability or individual circumstance, while others are more

Composite portrait – Yuri

We met Yuri in a focus group in Ottawa. He was in his mid-40s, and told us he was HIV+. He had moved to Ottawa because he thought it would be much more progressive than the small town where he had grown up, where he said being gay was a "no-no" and being "poz" even more so: "Everyone there knew about me." He told us he had completed a college degree "by the skin of his teeth", owing to occasional bouts of anxiety and depression that had caused him to miss classes for several weeks at a time. To succeed, he told us, he would ask his teachers to give him extra assignments so he could make up the marks "to be equal to the others."

In terms of his illness, Yuri said that he had been quite lucky, since his medication was controlling his symptoms relatively well and he felt quite healthy. Most of the time, he had been able to work in his chosen field as a rehabilitation therapist, but the last time he'd had to change his medication regime, he had to miss work for three weeks while his body adjusted. During that period, there was no way he could continue working due to nausea, fatigue, and other symptoms. When he returned to work, he was told the organization was going through downsizing and his position was being cut. Although he had never disclosed his HIV status, he suspected this was the reason for his termination; however, he didn't feel he had the evidence – or the energy - to pursue this. Yuri was accepted onto ODSP with no difficulty, although he'd had to wait until his severance pay was depleted to receive benefits. Yuri's ODSP worker referred him to an employment support program at a local ASO, where, he said, the staff was extremely supportive. In fact, it was the opposite of the stigma he'd experienced growing up.

As it happened, a position as a peer support worker at a local community health agency became open, and Yuri's counsellor encouraged him to apply. Although it was not exactly what he was looking for, the career counselling he had received had helped him broaden his initial career goal, and he applied. With his professional qualifications, good work history, and his lived experience with mental health problems viewed as assets, he was hired. Now, he said, he is starting to see himself as consumer survivor, and he's so relieved not to have to hide his status anymore: "I don't have to justify it, and there's a lot of support. No one says, 'he's just the peer worker'. It makes my job so much easier. When I go home, I'm not worrying about whether or not I'll have the job the next morning."

structural. Both are included here because of our desire to present people's experiences in a holistic fashion, and because of the way in which personal, social, organizational and systemic factors can interact.

Conditions that support labour force attachment for people with disabilities are described in more detail in subsequent sections of the report, and include the following:

- a physical disability or a condition with less stigma;
- symptoms that are more predictable or are well-controlled;
- access to personal supports (i.e., family, friends, peer networks), and caring service providers/professionals. This was important for all participants, but women especially said employment was much more feasible for them to the extent they had help with household and family responsibilities;

Gaining access to extended health and other benefits relies to a great extent on a medical model of health provision with the physician as gatekeeper, though new guidelines suggest a shift towards more holistic bio-psycho-social models of assessment for devising health and return-to-work plans.

- access to appropriate medical and disability-related supports and services (e.g., doctors and specialists who can help manage the condition and its symptoms; networks and disability support groups);
- access to appropriate formal employment supports such as pre-employment and career counselling, education, training and skills development, post-employment and job retention supports;
- access to transportation that is affordable, reliable, and accessible. This is true not only for people with mobility problems (though particularly so for them and especially in winter), but also for people with chemical and environmental sensitivities, and those coping with symptoms and/or side effects of medication – in other words, most of the people to whom we spoke;
- minimal absence from workforce, so skills are still up-to-date and relevant to the local labour market, and there are no lengthy absences to explain;
- access to a diverse and robust labour market – there have to be jobs to go to – which is much more difficult in the current economic downturn;
- self-employment for those who want it;
- being able to request and receive appropriate

"ODSP set me up with a business consultant, [who helped me set up my own business here] and the City... has a networking and facility specialist who has suggested many 'no charge' or service in lieu of payment services."

accommodations, especially job parameters that are flexible around when and how the job is done (e.g., job hours, telecommuting, part-time work), and physical adaptations (e.g., ergonomic equipment);

- a positive work climate – co-workers and management that are knowledgeable, understanding and supportive (see Workplace environment, below);
- work in disability-friendly organizations such as consumer/survivor initiatives and AIDS Service Organizations (ASO)s; work in organizations where there are clear and accessible policies promoting accommodations and against workplace discrimination, harassment, and violence; work in non-profit organizations – "*more motivating*";
- employment that is a good "fit" – matches the person's skills, education, and experience, and is fulfilling;
- employment that pays a decent living wage and has benefits that cover the disability-related costs and other health treatments, and provide security for retirement. Alternatively, income supports that do the same, and are flexible to allow movement in and out of employment.

The following section provides answers to research question #2, 'Why do some people with disabilities who have the capacity to work intermittently become discouraged and drop out?'

3.5 Conditions that discourage labour force attachment

Even among those who were unemployed at the time they participated in our project, very few participants had "dropped out" of the labour marker entirely; the vast majority were looking for a means to participate in some way, whether in occasional work, self-employment, or regular part-time or even full-time work. Many were actively engaged in their own job search, or were receiving employment supports through the Canada Pension Plan – Disability benefits (CPP-D), the Ontario Disability Support Program (ODSP), or Ontario Works. Nevertheless, participants were vocal and eloquent about how discouraging it was to try to surmount a multitude of barriers to employment, sometimes on a daily basis.

Many of these barriers are the inverse of the pre-conditions for labour force attachment described in the previous section. Some apply more particularly to those who are unemployed and looking to work (i.e., job-seekers), while others are more relevant to those in ongoing employment, or who are planning to return to work after a leave of absence.

For ease of comprehension, we have categorized these barriers as **systemic**, **social/external**, and **personal/internal,** but we recognize that they are all inter-related and interact. Discrimination, for instance, can be at once institutionalized and systemic, manifested in social interactions and internalized as values and attitudes, either consciously or not. Vick and Lightman (2010) have eloquently described how cycles of work, termination, and unemployment can leave those with episodic disabilities feeling they and their bodies are "*unreliable*", partly because this is how they have been characterized by previous employers. Furthermore, "*bureaucratic demands for job readiness [that] counteract what it means to live with shifting disabilities"* (p.76) can lead to disenchantment with employment and income support systems, and stymie people's attempts to explore options for employment.

In the same way, we heard participants in our project struggle to describe the complexity and precariousness of their health and employment, and to locate the source for their challenges and frustrations. Our schema is based primarily on participants' own perceptions of their barriers to

Composite portrait – Adele

Adele is a woman in her early 50s who has been working for over twenty years as a claims adjuster for a small insurance company, a job she loves. Five years ago, she was hospitalized and diagnosed with epilepsy, and put on anti-seizure medication.

Adele's driver's license was suspended because of the seizures, which in her words, meant "getting to work using public transit consisted of using three different transit systems…it was a long commute." Adele also experiences side effects from the medication that make her drowsy and require her to take short naps to help her function better. Her employer was willing to accommodate her condition, as she has over twenty years of service and was a valued employee. "They arranged for a friend to drive me to work and allowed me to work from home two days a week. The days that I worked from home allowed me to spread my eight hours over a longer period of time and I could take power naps to recharge myself. I found it impossible to work a full work week in the office without feeling exhausted due to the medication but could manage some days in the office."

Although she lives alone, Adele also has the support of her sister, who lives nearby, and who can help her with groceries and other errands.

Fortunately, Adele's job is such that work from home was feasible, and she can pretty much keep up with her workload. She periodically has to take a few days off because of fatigue, but otherwise has relatively few symptoms. She also has very supportive co-workers; while everyone at work has known about her illness and subsequent condition, she says she's never felt any negative reaction. If anything, she says, they have been too solicitous, always asking her how she feels and if she's going to be OK. She thinks this may be due to the fact that she's had to inform her colleagues what to do if she ever had a seizure at work – "for my own protection."

While her workplace is too small to have an HR department or a union, Adele nevertheless feels her condition has been accommodated pretty well – she attributes this to the fact that it is a small workplace (only 5 employees), with a family-like atmosphere.

employment, and differentiates among 1) those barriers that are fundamentally caused by or expressed in structural, systemic terms such as policies and programmes; 2) those that are primarily expressed in others' words or behaviours, such as stigma and discrimination; and 3) those that participants expressed as their own opinions, feelings, and behaviours.

Those barriers that are described in more detail in subsequent sections (such as features of the workplace environment, for example) are only outlined here, while others are described in more detail. Income and employment support systems were certainly also perceived by participants as barriers, but are dealt with in their own sections.

Systemic/structural barriers

Labour market conditions

The most obvious barrier to employment – and the most challenging in terms of policy or program intervention – is the state of the current labour market. The recent recession and current economic downturn in Ontario have meant that jobs are in short supply, and competition for them can be fierce. While this is true across the province and even across the country, some local labour markets have been more affected than others; we heard much more about the economy as a barrier from participants in the North Bay focus group, for example, than in Ottawa or Toronto.

One participant in North Bay recalled a recent job ad for a receptionist position that had apparently received over 200 applications from "*doctors and lawyers*" and such. Another participant from a smaller Northern community noted that much of the employment there is seasonal, which created a double-bind for her: many summer jobs are targeted at students, but even after finding and finishing one, she discovered she was ineligible for further skills development training because she had already used up her allocation of one funded intervention.

The stiff competition for jobs in a tight economy disadvantages people with disabilities; given ample choice of candidates, an employer is more likely to hire someone who does not require accommodations. Moreover, even if a disabled applicant can present a good business case for being hired, participants said, why would the employer take the risk? "*If I say there isn't much risk involved, the employer might think 'what does she know?' They might not trust me or think I'm educated enough to know the full extent of the cost, or that I'm lying in order to get the job.*"

Transportation

We heard a great deal from participants about the barriers posed by a lack of accessible, appropriate, and affordable transportation. Some participants live in small communities that have no transit system and so were reliant on friends or taxis. Others said the available transit in their community was too sporadic and irregular to rely on for employment. This was even truer for those who relied on specialized transit systems such as WheelTrans or ParaTranspo. The service standard for pick-up for these services is typically within two hours of the booking time, and return trips are not guaranteed. Moreover, bookings usually have to be made seven days in advance, so there is little flexibility in the event of changes to work schedules.

Still other participants said it was not possible for them to take public transit when they were ill with symptoms or the side effects of medications, or that it could trigger problems for those with difficulties with stress, nausea, or chemical/environmental sensitivities. Affordability was another barrier for many, particularly for those on income assistance or in low-paying jobs, and who did not have access to subsidized transit passes.

Cost of disability-related aids, treatments, and medications

The high cost of disability-related aids, treatments, and medications can also become a disincentive if they exceed an individual's ability to pay, even with a decent income and/or benefit plan. Among participants with HIV in particular, we heard several stories of staggering medication bills, since many anti-retro-viral (ARV) medications are not covered under private drug plans; one person noted that he had a debt of $40,000 as a result of his treatments. When a person's ability to pay becomes strained, they are often left with no choice but to go on social assistance, either to access those drug benefits alone or for income assistance. Yet this is not a panacea, since many participants – including those with Multiple Sclerosis, Post-Traumatic Stress Disorder, and other conditions – noted that some of their medications or treatments were not covered under either public or private plans, nor was travel to seek treatment from the few specialists who provided these treatments. One key informant who works with immigrant and refugee clients noted that some of them go without ARV treatment because of both the stigma and high cost of ARVs; to undertake treatment means they would have to reveal their HIV+ status and go on social assistance, both of which might jeopardize their applications for citizenship.

> *"My plan covered 80%, but the additional 20% still amounted to over $400 per month, which became increasingly unaffordable at my income level."*

Lack of French language services

We conducted only one focus group with Francophones. Though few in numbers, they were nevertheless vocal about how important it was for them to receive services in their own language. As one participant noted, "*C'est toute une culture, une mentalité. C'est plus qu'une langue. D'être compris – c'est l'atmosphère…" (It is all about culture, about mentality. It's more than a language. To be understood – it's the atmosphere*). This participant went on to describe how, even though he considered himself bilingual, the process of thinking and talking in a different language was disorienting, and when added to the mental health problems he experienced, not conducive to good communication. Several participants had had the experience of seeking services from agencies that were supposedly bilingual, but who could not deliver services in French: "*C'est un peu scandaleux, parce qu'ils reçoivent des fonds pour être bilingue" (It's a little scandalous, because they receive funding to be bilingual)*. Moreover, they remarked that insisting on receiving services in French could create "*l'énergie negative"*

(negative energy) in an important relationship with a service provider, one they preferred not to jeopardize. In this sense, being Francophone in Ontario further contributed to the already complicated "power politics" people with mental health problems can experience trying to establish their personal credibility in the context of accessing and receiving ongoing services.

Discrimination

> *"I am very well educated, at both the university and college level. I am very well read, and highly literate in a number of areas. I have no criminal record, and will work long hours until I get the job done well. Why can't I find a regular salaried position? Because I cannot drive due to a disability. Virtually all jobs in my region state as part of their job description, or job ads, "candidates must have a full G class license and daily access to a personal vehicle". These ads might as well say, "Whites Only" (if I was Black). Most of these jobs do not involve daily driving, and for those that involve some driving, there are ways these jobs can be restructured to accommodate non-drivers. I have yet to see a single employer do this. As a result, many otherwise qualified people are being overlooked in [the local] job market."*

A last, but certainly not least important systemic barrier to employment mentioned by participants is discrimination in all its forms – racism, sexism, ageism, class-ism, homophobia, as well as discrimination on the basis of disability. For example, several participants said that some job ads include certain requirements such as for a driver's license or ability to lift heavy objects even when these appear to have no link with the job's responsibilities, presumably as a means of discouraging people with disabilities from applying: "*it's a way to weed people with disabilities out.*"

Several participants of colour spoke of being perceived differently in person than on the phone, such as being overlooked in waiting rooms by service providers or potential employers because of their skin colour – "*they just assumed I wasn't the person they were looking for*." As is true of many people with intersecting identities that have historically been de-valued, several participants had encountered discrimination on the basis of more than one personal characteristic. The limited extent to which participants felt able to avail themselves of existing tools and supports to exercise their rights was equally troubling (see Policies and programs that support labour force attachment, below).

> *"I am a woman of colour and have several university degrees. I have an invisible disability..., mental health issues. Once I disclosed in the black community, I was isolated, patronized, ostracized by my own community. And by society at large, I was stigmatized and discriminated against. Even though I am intelligent, attractive, a hard worker, none of my accomplishments matter. As soon as they hear 'mental health issues', I become invisible."*

Others' attitudinal barriers: myths and misconceptions

Disability in general

When asked in focus groups about myths and misconceptions about people with episodic disabilities, many participants spoke movingly and at length about the stigma associated with disability in general, and with episodic disabilities in particular. The bulk of these myths and misconceptions can be summarized as follows:

- that people with disabilities are DIFFERENT;
- that people with disabilities are lazy or malingering;
- that people with disabilities are a liability;
- that people with disabilities are less smart, or that their condition is the result of a skill limitation or cognitive deficiency. One woman described other people talking to her more loudly, even though it was her vision that was impaired, not her hearing;
- that people with disabilities are too fragile/sick/incapable of employment, "*a sympathy trip*";
- that people with episodic disabilities take more sick time;
- that episodic disabilities are not real or serious, or are somehow self-induced. One woman remarked, "*This disability we have, it's treated like we've inflicted this on ourselves. If it was diabetes, it would be no fault of our own…I did not ask for this*."

While such attitudes are challenging enough when expressed by strangers or acquaintances, several participants said they found it particularly difficult when these attitudes were voiced by co-workers (see Workplace environment, below), professionals, and service providers. They found it particularly frustrating to feel that others were defining them by their disabilities – what they couldn't do - instead of by their abilities and potential. Other anecdotes of service provider attitudes were more troubling: one woman described having to endure a "*humiliating*" series of cognitive and psychiatric assessments after seeking a relatively simple accommodation for a minor musculoskeletal injury. Many participants spoke of the need for service providers, like others, to become more tolerant and accepting of differences.

Invisible disabilities

In many cases, myths and misconceptions arise from the fact that many episodic disabilities are invisible, or that their outward manifestations are so variable. One participant, for example, noted that, "*with heroic effort I can be almost athletic one day, and in a wheelchair the next as a result,*" and recognized how understandably confusing this could be for other people, especially co-workers. In addition to a general lack of acceptance of differences in our culture, participants and key informants alike bemoaned the lack of awareness and understanding of disabilities, how they manifest themselves, their trajectories, and how people coped with them. As one service provider put it, "*people need to understand that mental health is a spectrum, just as physical health is a spectrum.*"

Stigma related to HIV and mental health disorders

Participants with HIV and those with mental health disorders also described specific myths and misconceptions regarding their conditions, such as that HIV is easily transmitted (i.e., through casual contact), and that people with mental health problems are violent. As one man living with HIV remarked, "*people don't want to approach you, because of lack of knowledge around transmission.*" As expected, these participants described a whole other level of stigma associated with these conditions that in some cases could be described as nothing less than fear and outright loathing. One young man with schizophrenia told us that his friends and close family members more or less accepted his condition, but that his uncle now seemed to detest him ("*il me détestait*"). Another participant related the story of how a colleague reacted upon hearing that she had a mental illness: "*When he found out I was a consumer, his response was as if he was afraid he was going to get something on him – he was disgusted,*" and then he exclaimed, "*But you're so smart!"*

This heightened level of stigma experienced by participants with HIV and mental health disorders entailed different coping mechanisms. A hierarchy of disability became evident, wherein depression was generally more accepted than other mental health problems, and just about any other physical disability was more acceptable than being HIV positive. A few participants said they were not above using these other conditions to camouflage their own symptoms or avoid disclosure. One woman said she periodically used migraines as an excuse when her symptoms related to mental illness required her to leave work. A young man living with HIV said, "*Sometimes I lie about my illness when my landlord or others ask me about why I'm on ODSP…I say I have cancer or epilepsy*". Other participants said they were more open about their diagnosis and used it to gauge the level of acceptance among new acquaintances.

Stigma related to other identities

As mentioned earlier, stigma can be experienced on several levels. Members of one focus group talked at length about how their ethno-racial identities compounded the stigma they experienced in relation to their disabilities, as well as to their sexual orientation. Again, mental health disorders and HIV were the two conditions that seemed to elicit the greatest reactions in their respective communities. Two participants said that in their experience, other people of colour were less inclined to take these issues seriously. With regard to HIV, one person said, "*It's a Big Flaming Stigma...It goes back to religion, culture. [They say] 'You're this way because of what you did, your lifestyle'.*" Another woman said people with mental health issues were viewed harshly in her Caribbean community: "*They see it as a weakness. We're supposed to be strong, like, 'We survived slavery. You're showing us up.'"*

Personal or individual barriers

While the focus of this study is on systemic and structural barriers rather than personal ones, we include the latter here because of the way in which they interact with some of the systemic and attitudinal issues identified above. In some cases, participants described patterns of thought or behaviour that were reinforced by others' attitudes or in management/employer practices. How others respond to some of the personal barriers described below can positively or negatively affect an existing work situation and facilitate or create further barriers to employment. Personal barriers are also important because of the way in which they affect intermittent work capacity; to the extent such barriers can be controlled or reduced, work capacity improves. Participants and key informants identified the following key personal barriers for people with episodic disabilities and intermittent work capacity:

- **Severity of symptoms and side effects, especially fatigue**: These affect one's ability to commute to work, and people on certain medications or with certain conditions (e.g., epilepsy) cannot drive. Symptoms and side effects can also affect the ability to work a full day, the ability to concentrate or remember, to relate to others, and to deal with stress;

> *"I may at times experience remissions anywhere from a few days to much longer. I am never able to know how long the remission will last, and there are some jobs that actually exacerbate my symptoms and take me out of remission"; "Finding a job is not the hard part, it's asking myself whether or not my seizures will be affected, dealing with more responsibility that could be stressful."*

- **The episodic nature of symptoms** makes planning impossible; hence, the chorus of calls from participants for understanding from employers and for flexibility as a key accommodation;
- **Not seeing or framing one's condition as a disability**, despite how it may impact work and other life domains. This prevents people from accessing relevant information and resources that could be helpful. Some people (especially those struggling with trauma and/or addictions) may lack insight or knowledge into their condition and how it affects them, what their needs are, and therefore what accommodations would help. This is sometimes linked to having unrealistic work expectations;
- **Lack of information and understanding** about how to do return-to-work planning, seek accommodations, or exercise rights and responsibilities in an employment context. Likewise, a lack of understanding about how income supports work and what one is entitled to, combined with uneven access to information;
- **Lack of trust**, for example of the employer, of co-workers, of HR, of the income and employment supports bureaucracy, etc. People with disabilities may have a great deal of fear and anxiety surrounding disclosure in the workplace – often for very good reason – yet some degree of disclosure is necessary in order to justify the request for accommodations. The employee has to be willing to take a certain risk to identify his or her needs, and to accept accommodations and support. "Creative disclosure" – focusing on what one needs to do the job well rather than the diagnosis – can be helpful here;
- **Others' attitudes can be internalized**: One participant told us that many people with disabilities struggle with "*feeling unequal to the core*"; a service provider said she often encounters clients who have "*written themselves off.*" Not feeling entitled to accommodations or able to ask for them – let alone stand up against discrimination – could stem from a variety of personal situations, differences, and barriers, including those related to gender, income, educational level, culture, and language, or a combination of these;

- **Self-acceptance**: One woman with MS told us that after disclosure of her diagnosis at her workplace, "*I looked at myself differently when people knew…I was mortified.*" A related barrier is what one key informant described as "*over sensitization – a disability lens or filter*" that can sometimes lead to mistaken assumptions such as one's status or condition is obvious to others, even if it is invisible. This in turn can lead to inappropriate or unnecessary disclosure, or misinterpretations and misattributions of others' behaviours;
- **Over-compensation**: This was a common theme in participants' personal stories, "*having to prove that you can do it leads to over-doing it, which can work against you.*" Several participants – especially women – admitted they often over-worked themselves both at home and at work, in order to "*make up*" for times when they would be disabled and to feel they still had the upper hand over the disease: "*You don't want to let it beat you.*" Unfortunately, this strategy often backfired, since the additional stress could trigger an attack or worsening of symptoms. As a result, stress was often described as a trigger for decision-making around seeking treatment, disclosure, and leaving work;
- **Low motivation to look for work**: This depends in part on the cycle or stage of employment readiness e.g., not being in workforce for a long time erodes confidence. It may also be related to the specific condition e.g., people living with HIV who are younger or newly diagnosed may feel fatalistic about their mortality. Others feel they are unable to work because a doctor has told them so;
- **Feeling isolated and alone**; that no one understands. Hence the need for support, especially from peers – "*we've been there.*"

In one way or another, participants said these personal barriers contributed to them feeling isolated and discouraged; when reinforced by others' attitudes or behaviours, or through practices in the workplace or by service providers, these barriers led people with disabilities to feel dis-empowered and excluded from the labour force. Given that most of the people we spoke with hadn't dropped out of the labour force entirely, and in fact, were trying to participate in the labour force in some way, the question ought perhaps be re-worded, "why does anyone with a disability and intermittent work capacity persist in the labour market despite the tremendous obstacles against them?"

The following section outlines how the workplace environment can either encourage or discourage labour force attachment for people with disabilities and intermittent work capacity (research question #3).

3.6 The workplace environment

The impact of the workplace environment on labour force attachment for people with disabilities and intermittent work capacity cannot be overstated, whether one is trying to maintain current employment, returning to work after a leave of absence, or looking to re-join the workforce after a period of unemployment. In fact, the workplace environment is relevant at all stages of the employment process: recruitment, selection and hiring, training, ongoing work, promotion/advancement, leave, return to work, and unemployment.[5]

Workplace culture

Based on the experiences of study participants, we conclude that the precise nature of the impact at any of these stages depends on the extent to which there is a *workplace culture* that accepts, appreciates, and accommodates differences among *all* employees, not just people with disabilities. Workplaces that participants described as having tried to accommodate their needs – even if this was not always successful in the long term – generally offered flexibilities to other employees as well (such as flexible hours, telecommuting, etc.) as part of its usual way of conducting business. Unfortunately, only a minority of participants had been lucky enough to work in such environments. More often, we heard stories of inflexible, challenging, or even hostile work environments, which in turn created barriers for participants to accessing, keeping, or returning to work.

Policy analyses have identified a number of other workplace barriers to employment of people with disabilities, among them, stigma, discrimination, and a lack of knowledge among employees and employers about human rights and employment legislation.

We have grouped manifestations of culture into the following categories: **physical elements** (that is, the built environment); **formal/structural elements** (i.e., workplace policies and programs); and **informal or social elements** that are evident in the social interactions of all who work there. Again, these distinctions are somewhat arbitrary, since all these elements interact.[6] Moreover, workplace culture is influenced by everyone, including managers, union representatives, supervisors and employees, so all these elements are influenced both top-down and bottom-up.

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[5] These stages of the employment process are adapted from the work of Stensrud and Gilbride, 1999, as cited in Stensrud, 2007.

[6] One need only consider how workplace smoking policies, for example, are facilitated or undermined by building design (such as the design and location of cigarette disposal units), and how enforcement of policies (or lack thereof) can affect people's attitudes and behaviours and vice versa.

Physical elements

In terms of the built environment, workplaces encourage labour force attachment for people with disabilities and intermittent work capacity to the extent they exhibit the following characteristics:

- **All areas of the workplace are accessible and barrier-free** to people with disabilities, including – but not limited to – people who use mobility aids such as wheelchairs and scooters. There are still many buildings and workplaces that do not meet basic standards in terms of physical accessibility. As one participant told us, "*Sometimes you can tell right at the front door*" there's no point going in to apply for a job, let alone ask for accommodations. In this case, actions – and design – speak louder than words;

The research evidence indicates that for people with disability and intermittent work capacity to be successfully engaged in the labour market, active implementation of workplace policies is critical. Yet a majority of workplaces do not have relevant policies or mechanisms in place to handle job assessments and workplace redesigns. This is despite the fact that, after modified work hours, job redesign is the second most requested physical/structural accommodation requested by workers in Canada.

- **The work environment is conducive to getting the work done effectively and efficiently and without compromise to workers' health and safety.** This means proper lighting, heating, ventilation, etc. While these basic conditions affect all employees, their lack can be especially hard on people with disabilities. Some participants with HIV talked about being sensitive to temperature changes, for example, and appreciated having windows they could open or close, and a heater or fan by their workstation. For people with Environmental Sensitivities or who are prone to migraines, this also means workplaces that are free of both scents and noxious chemicals such as those in cleaning products;
- **Physical amenities are provided.** In particular, participants mentioned the need for private spaces – a safe place to go to de-stress, to rest, or to take medication, especially if they had to self-administer these by needle (e.g., insulin). Several participants with HIV said they preferred to have washrooms close by, given that they often suffered from nausea and gastro-intestinal distress as a result of side effects and/or symptoms. Other participants said they appreciated having a fridge or other place to keep medications that needed to be taken during the workday;
- **Smaller workplaces with fewer people, and more personal space.** As one participant noted, "*Sharing a workspace with too many people makes dealing with symptoms more challenging…*" Regardless of their specific condition, many participants described stress as extremely debilitating, and any arrangement that allowed them to have personal space where they could work and cope with job demands was seen as important;

The physical work environment and work tools can be adapted as necessary with aids and devices such as voice-activated computers, modified keyboards, elevated work stations (e.g., for people with back problems), magnifying devices to enhance readability, full-spectrum lighting (i.e., for people with Seasonal Affective Disorder). Very few participants mentioned having requested such devices. One woman said her employer told her, "*Whatever you need, just ask and I'll get it for you,*" but this was the exception rather than the rule.

Structural/formal elements

Given the nature of many episodic disabilities, we heard far more from participants about how policies and programs affected their ability to do their work, to stay employed, and/or to become re-employed than about the built environment. The following structural or formal aspects of the work environment encourage labour force attachment:

- **The necessary policies are in place, made accessible, and enforced.** Key informants in the disability sector and participants with disabilities alike were adamant about the need for workplace policies that recognize employees' rights to seek accommodations and that clearly outline the process for doing so. Equally important are policies that prohibit workplace discrimination, harassment, and violence – for the well-being of all employees, not just those with disabilities. A workplace environment in which these policies are valued, clearly communicated to all employees, and enforced has a culture that is evident even to outsiders – for example, in job ads that identify an "equity-employer," or in managers being able to articulate what accommodations look like in their organization, even to an applicant at the hiring stage;
- **Additional policies, programs, and benefits are in place to meet employees' needs.** Ideally, this includes workplace wellness programs that promote healthy living, including strategies for coping with job stress, which many participants said was challenging for them. More important for participants of this study, it includes adequate health insurance for short- and long-term disability leave, and extended health benefits for dental care, health treatments, and medications. The availability and adequacy of benefits to cover disability-related costs was often cited by participants as a factor in deciding where to look for a job, what job to take, and whether they could afford to keep or leave a job they currently held. Several participants reported having to leave jobs they loved because of low pay and lack of benefits. A couple of other participants said it was their spouse who experienced "job-lock," because as a family, they were now dependent on his or her benefits to cover the participant's disability-related costs;
- **Job parameters are flexible.** Flexibility from the employer was mentioned time and again as the most important factor in determining participants' ability to stay attached to the labour market. For some participants, this flexibility entailed actual job re-design to meet their particular needs (e.g., job-sharing, shifting to part-time, etc). For many, it meant doing the

same job but having the freedom to do it according to their own schedule and/or from home, if possible and at least occasionally. Many participants with a variety of conditions – including HIV, mental health problems, spinal cord injuries, and others – said the typical 9 a.m. to 5 p.m. workday was problematic for them, either because symptoms or side effects of medication made it difficult to function early in the morning, or because they needed occasional breaks to rest. Having access to flex-hours and/or telecommuting – flexibilities that are increasingly being provided to other employee groups such as working parents – had enabled several participants to remain working, and from the perspective of dozens of others, could have helped them to do the same;

The role of human resource (HR) professionals as champions appears to be a critical factor, although many of these professionals report being ill-equipped in terms of knowledge and training to manage cases of episodic disability.

- **Supports for accommodations are in place.** Participants and key informants alike pointed to the complexity and risks associated with the process of disclosure and request for accommodations. Having a knowledgeable person to provide information and guidance through this process is essential. A human resource (HR) professional – assuming the workplace is large enough to have one – is well placed to help identify when and what accommodations might be needed, to represent both the employer's and the employee's interests in developing an effective accommodation, and to make links to appropriate community resources as required. In the words of one key informant, the HR professional can play a key role in helping to "*create a positive workplace culture*" provided support is shown from senior management;

Many people with disabilities do not have their accommodation needs met at work, and there is evidence that employers can negatively perceive requests for accommodations, affecting both the employee's ability to perform his or her job as well as opportunities for training and promotion.

- **All parties work together.** In the words of one key informant, "*successful programs to maintain people in the workplace involve communication*" among all partners – the employee, management, HR, union representatives, as well as the employee's medical professional and insurance provider. Early intervention is also key to reducing the likelihood of performance issues, negative reactions from co-workers, and the need for long-term disability. In this respect, trust and good working relationships are essential ingredients to successful accommodations; to the extent they allow employees to articulate needs without fear of punitive action, employers to articulate their needs and what accommodations are feasible, and unions and HR personnel to support the process of finding reasonable solutions.

Other potential sources of support to employees in the workplace include a staff ombudsman or peer support programs, but our data collection did not reveal much information about these initiatives.

Informal/social elements of the workplace

How people interact with each other – what they say and how they behave – both express and define a workplace culture. Based on the experiences and information we heard from participants and key informants, we have identified the following informal or social elements of workplace culture as important factors to engagement for people with variable work capacity:

- **The employer becomes informed and knowledgeable about disabilities, needs, and accommodations.** Participants and key informants described attitudes of supervisors and management that echoed many of the general myths and misconceptions mentioned earlier: that it would be difficult and expensive to accommodate the needs of people with episodic disabilities; that one's illness or symptoms are self-induced or exaggerated (e.g., "*are you really* that *sick?…You were probably out way too late last night"*); and a lack of understanding that the need for flexible work hours is not a question of punctuality or motivation, but rather, a necessity to cope with side effects and symptoms. One participant pointed out that in certain workplace contexts such as healthcare, employers are particularly leery or afraid of having a person with a disability on staff because of the notion that this might lead to a mistake being made and the employer being held liable. Some of these attitudes can be attributed to a lack of awareness and knowledge; others require more sustained dialogue and negotiation about meeting both organizational and individual needs. To this end, key informants say, engagement of employers is critical to the successful attachment of people with disabilities and intermittent work capacity in the labour force;
- **The employer models acceptance**. Several participants and key informants pointed to the pivotal role of the employer and senior management in modeling acceptance of people with disabilities and accommodation of intermittent work capacity. The actions of those "at the top" were seen as setting the tone for the workplace environment. According to one participant, an ideal employer would be "*understanding…, work around my illness… [Be] willing to have discussions… about what it would take to be successful and to maximize abilities*." To the extent that employers can be "*creative, and accepting and tolerant of people being different,*" the potential for achieving an effective accommodation is increased, along with the opportunity for people with disabilities – especially those out of the workforce for a long time – to have positive employment experiences and fulfill workplace expectations;
- **Supervisors and managers actively demonstrate understanding, acceptance and support.** In working out the practical details of accommodations and implementing them on an ongoing basis, the involvement of supervisors is vital. Often the supervisor is the first to

become aware of a possible problem, and this first response – whether framed as a performance issue or as a need for support – can determine the success of subsequent dialogue about disclosure and accommodations. Moreover, supervisors can help negotiate implementation of accommodations in a way that deals effectively with workload issues, such that co-workers don't feel they are bearing the brunt of the accommodation;

- **Co-workers are supportive.** Many participants spoke about the importance of their co-workers' attitudes to having a successful employment experience, particularly, of feeling accepted and not judged. In some cases, negative judgements appeared to stem from the invisible and episodic nature of participants' disability; in others, from the fact that certain episodic illnesses such as fibromyalgia and chemical/environmental sensitivities have yet to be fully accepted as legitimate. A few people with these conditions reported that their co-workers lacked compassion, or thought they were trying to get out of performing their duties, even of being ostracized and victimized. Other participants said they were lucky to have "*good relationships with colleagues… a colleague I can talk to,*" or "*caring and supportive coworkers,*" and that this made all the difference to them.

Disability-friendly workplaces

Together, the above-mentioned physical, formal, and informal characteristics represent the ideal workplace environment for people with disabilities and intermittent work capacity. In search of this ideal, many people with disabilities and intermittent work capacity gravitate toward "disability-friendly" workplaces, especially those that serve a specialized clientele such as AIDS Service Organizations (ASOs) or in the mental health field, peer-led or consumer/survivor initiatives. Several participants said these organizations offered the positive workplace culture they were looking for, and that it was a relief to not have to worry about disclosure and acceptance: "*If I had a choice, I would never work for anyone other than an HIV-friendly company because I couldn't handle ducking questions for the rest of my life*." On the other hand, a few people said they sometimes found the atmosphere at such organizations to be too open, that co-workers could be presumptive or not respectful of personal boundaries, and they wanted to retain control over disclosure and privacy: "*I'm not comfortable talking about my HIV, even with others with HIV*."

Fighting discrimination

As mentioned earlier, however, we met very few people who had had the benefit of working in such environments; we heard more about physical barriers, non-existent policies regarding accommodations, and a lack of knowledge or support from management, supervisors, and co-workers. We heard how some employers effectively discriminated against people with disabilities by listing a requirement for a driver's license in a job ad, even when it wasn't relevant to the job duties. We even heard stories of more flagrant abuse – how in a few instances, employers had either not complied with or sabotaged accommodated work arrangements, then dismissed the disabled employee for not performing the job properly, or tried to pressure them into leaving.

"With respect to the failure to accommodate disabilities, employees can file a grievance with the Human Rights Tribunal, and those grievances will be investigated. Unfortunately, this is a slow process, and by the time it gets to this point, there is often irreparable damage in the relationship between employee and employer. Other than that, there really is little other recourse if an employer chooses not to respect a medical return to work plan, or acknowledge the disabilities of an employee."

We also heard that the very condition that makes people vulnerable to workplace abuse and discrimination also makes it difficult for them to advocate for themselves. In some cases, participants said they had had to choose between fighting for their rights and their health, because the stress of the battle would jeopardize their already-tenuous health and ability to work: "*A lot of us walk away from the fight because we are not able to deal with the disability and unfair employers [at the same time]…Even if we win, it's at the expense of our health*." In other cases, participants said they chose not to challenge discriminatory practices because the mechanisms for exercising one's rights – such as arbitration, litigation or the Ontario Human Rights tribunal – are extremely slow and only helpful for seeking redress, not to repair an already-difficult employment situation. Others put up with challenging work environments because to leave without cause or be fired would make them ineligible for employment insurance benefits.

The following section describes the policy and program interventions designed to support labour force attachment in Ontario, specifically, employment support programs (research question #4). Much of this information was sketched out for us by key informants, and then validated in relevant documents.

3.7 Employment support programs

The Ontario context

The Canada-Ontario Labour Market Agreement for Persons with Disabilities (LMAPD) signed in 2004 provides cost-shared funding for employment support programs for Ontarians with disabilities.[7] In Ontario, these programs are funded by three separate Ministries: Health and Long-Term Care (MOHLTC), Training, Colleges and Universities (MTCU), and Community and Social Services (MCSS). Approximately $194.9 was spent on LMAPD programs in 2009-10, of which $76.4 million was from the federal government as its maximum contribution. Other

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[7] There are also services provided through non-publicly funded sources, including through the work of private foundations, but these were not the focus of this project, nor were they mentioned by participants or key informants.

employment support programs and benefits for people with disabilities in Ontario are funded through HRSDC's Opportunities Fund and Trillium project funding.

Together, these funding sources support a variety of employment programs in a wide range of settings: government, community agencies, post-secondary institutions, hospitals, and both specialized and mainstream employment agencies (for-profit and non-profit). Programs that are particularly relevant for people with disabilities and intermittent work capacity are as follows:

Composite portrait – Sylvie

Sylvie was a young woman in her mid-twenties who struggled with post-traumatic stress disorder (PTSD) as a result of childhood abuse. She had not been able to finish high school, but was trying to finish her remaining courses through the local adult high school. Her work history was sporadic – a series of "survivor" jobs as a cashier, counter help at the local Tim Horton's, and similar positions that often ended badly. She told us she had trouble controlling her anger and sometimes lashed out at co-workers or employers whom she felt were making fun of her or not taking her seriously. As a result, she did not have any good employer references to help with her job search. She was hoping to work at the local call centre, in part because at $572, her income from OntarioWorks was not covering her living costs (her rent alone was $425 per month). She had applied for ODSP but her application had been denied. A guidance counsellor at her school referred her to an employment support service. Sylvie described her experience of employment supports as follows:

"When I selected an agency… they had a job for me to go to, [and] an interview immediately after I began working with their agency. I went for the interview and felt it was not a suitable job for me, for a variety of reasons. The worker I had…was very pushy and told me that I needed job history and a reference so I should accept the position. Since I respected her position I cooperated and took the job against my better judgement. Soon after I began the job I knew it was not going to be a good fit. The very reasons I thought it was not suitable began to be a problem."

Sylvie went on to say that her new employer treated her condescendingly and the equipment she was supposed to use was broken. She said she told her worker about the problem, but "…she just kept saying 'hang in there, this is not a long term job'." Sylvie told us that the situation became worse, and even after receiving assurances from the supervisor and manager that things would improve, they did not. Her worker now told her that, "…if I left before 13 weeks were up, their agency would not get paid for helping me. This made me feel obligated to stay in an unbearable job even longer and I did stay 13 weeks. This meant the agency got paid the $6000 for placing me in a very unsuitable, horrible job. I quit the job after 13 weeks because I was suffering a severe bout of depression."

Sylvie noted that after this experience, her worker became very hard to reach. When they finally did make contact, the worker suggested Sylvie go to Ontario Works (OW) employment supports to begin a new job search. Fortunately, Sylvie's new worker at OW – an employment support specialist – understood the complexity of her condition and realized she needed more intensive supports. The worker has provided some initial career exploration with Sylvie, and referred her to a local mental health agency for intensive case management services. While staff members there are not equipped to deal with all aspects of her disorder, they are able to help her with life skills, anger management, and another application to ODSP. She continues to look for work but feels she is now getting at least some of the support she needs.

MCSS programs include employment supports and work-related benefits through the Ontario Disability Support Program, as well as employment counselling through OntarioWorks; MOHLTC funds community mental health programs to provide services such as job development/job creation, skills development and training, assistance with job search, career planning, supported education, leadership training, and supports to sustaining education and employment, as well as consumer-operated alternative businesses;

- MTCU-funded programs are primarily intended to help students with disabilities in post-secondary education complete their education and enable them to move into meaningful employment. As the Ministry that sets policy regarding adult education and labour market training, MTCU also has primary responsibility for Employment Ontario, a network of employment and training services throughout the province;
- HRSDC’s Opportunities Fund is primarily intended for people not eligible for Employment Insurance. It funds wage subsidies, work experiences, enhanced employment assistance, and supports to self-employment, either directly or through businesses and organizations.

In some cases, certain services such as Employment Assistance Services (e.g., résumé writing, interview preparation) are contracted out to third party providers, while in other cases, a range of employment support services are provided under one roof. A few organizations use a peer-based model of service delivery (e.g., ASOs, consumer/survivor initiatives), and some offer supported employment in consumer-run businesses.

This variety in employment supports programming in Ontario extends also to their underlying funding and service delivery models. While all three ministries have taken steps to improve employment outcomes for people with disabilities in recent years, MOHLTC programs generally support a broader array of activities – including social recreational activities – that subscribe to a more therapeutic model, leading to a broader range of acceptable outcomes than just employment. MTCU and MCSS programs, on the other hand, focus almost exclusively on employment outcomes.

MCSS, for example, transformed its ODSP Employed Supports program in 2006 from a fee-for-service-based program to one that is outcomes-based. According to key informants, this was done in part because the vocational rehabilitation model used previously – which focused heavily on pre-employment counselling and job preparation – was not demonstrating effectiveness vis-à-vis employment outcomes. Feedback from clients was similar: that services were too drawn out and didn’t lead to jobs. Under the current model, providers of employment support services receive payment based on their success placing clients in stable employment, defined as 13 weeks’ duration. MCSS is currently planning an evaluation to assess the effectiveness of its employment support services in achieving employment outcomes for clients, the funding formula, and client satisfaction.

Since many participants said they had received services from ODSP – either income or employment supports or both – this program receives particular focus in the analysis that follows.

Effective practices

As with other areas of this study, we often heard more from participants and key informants about what is *not* working in the area of employment supports. Certainly, several key informants expressed serious concerns about the impact on clients of the ODSP's change to a performance-based funding model. Even those involved in program planning and delivery said that "*it works for people in general, but [the changes are] moving too fast*" for people facing multiple barriers and those who have been out of the labour force for several years, which was felt to describe the majority of ODSP clients. These key informants said they felt many people were being left behind, "*falling through the cracks.*"

There are two reasons for this: 1) many, if not most clients of ODSP employment supports aren't considered to be "job ready" – they face multiple barriers to stable attachment to the labour force that cannot be overcome without considerable intervention and support; and 2) the funding formula rewards employment support providers for employment outcomes, which disadvantages both clients who require more support and providers, many of whom end up providing support long after the allotted funds have been spent.

The following are some of the practices key informants and participants felt were more effective at helping people with disabilities and intermittent work capacity to become or stay attached to the labour market:

- A recovery-oriented model of service. This approach doesn't necessarily imply full recovery in a medical sense, but rather, acknowledges the extent and multiplicity of needs many clients have and accordingly, develops long-term strategies to employment and celebrates incremental successes. This recovery model is particularly prevalent in the mental health sector, but could be considered for use with other groups of people with disabilities as well (i.e., a cross-disability approach);
- Longer-term employment services that include focus on multiplicity of need, a broader range of needs, including pre-employment/employability support, skills development (essential skills, technical skills), education, and training, as well as career development, not just job placement;
- Employment services that engage employers, provide incentives to hire people with disabilities and intermittent work capacity (such as Targeted Wage Subsidies) as well as supports, such as through workforce intermediaries or job coaches who help identify needs and resolve issues;

- Post-employment supports such as job coaching, job shadowing that are substantial, active and durable (i.e., longer than 3 months);
- Supports of alternative employment arrangements such as home-based, self-employment through ODSP and the Opportunities Fund;
- More flexible, client-centred models of employment supports that measure success by more than just employment outcomes, and acknowledge the multiplicity of barriers to overcome, including limited job opportunities;

Innovative and promising practices include supported employment; ongoing, flexible support through the various stages of employment; greater client engagement in the formulation of individual progress plans; and efforts to engage, inform, and support employers in employment of people with disabilities.

- Employment supports that are empowering. Many participants spoke of their ambivalence toward "survivor jobs" – low-wage, low-skilled jobs such as working at McDonald's or as a Wal-Mart "Greeter." On the one hand, these positions could be a useful way of *"starting over*" in the labour force after a lengthy absence and were sometimes the only work participants could handle at the time. As one participant remarked, *"When I finally got out of the depression, I realized, `Wow! I'm an old man. I'm not looking at a career anymore.`"* On the other hand, many participants objected to being defined by these positions: "*I don't want people to think that just because I have a mental illness, that that's [store greeter] all I can do."* Key informants who provided employment supports recognized the need to acknowledge clients' skills, experience and potential, but faced with a competitive labour market, felt they had few options to suggest as a way of building a client's résumé and experience, and obtaining good references;
- Peer-based models of employment supports that help clients feel accepted and empowered but which nonetheless challenge clients to take risks to employment; peer support networks within disability-organizations (e.g., Epilepsy job-finding group), external peer support networks;
- Culturally appropriate services in the language of clients' choice; programs that explicitly acknowledge systemic barriers: "*The…anti-oppressive, anti-racist frameworks [at my workplace] are very helpful and empowering*";
- Practical assistance to overcome problems of access – transportation, clothing, child care;
- Education and awareness (e.g., employer champions, celebrity advocates) to increase acceptance of differences/disability and the need for integration and social inclusion. Includes training, education, and development of opportunities. Can be provided through

formal resources and services such as specific employment support programs, disability orgs (mutual support);

- Access to supports and tools for advocacy and to exercise rights to employment without discrimination e.g., human rights legislation, ATIP, arbitration, AODA. Sometimes these supports are used after-the-fact (by the time they are used the situation can't usually be salvaged) but are nevertheless important to make cultural/organizational change.

3.8 Income supports

Government policies and programs are still mostly reliant on the traditional dichotomies of disabled/able-bodied and employable/unemployable, although there have been recent changes federally and provincially to introduce more flexibility into eligibility criteria.

In answer to research question #5, 'How important are income supports?' participants and key informants alike agreed that income supports are absolutely critical to people with a disability and intermittent work capacity. While some participants in our study said they were currently working, relatively few indicated they relied on employment as their main source of income. The majority of participants indicated that they relied on income supports – particularly ODSP – either to supplement earnings from work or as their main source of income, and in some cases, had done so for many years. Only a few participants indicated they received CPP-D benefits – in a couple of cases, in conjunction with ODSP – and most of these had visible mobility impairments. Only one participant indicated she was currently receiving long-term disability benefits from private insurance.

For most participants, therefore, access to some form of income assistance and their associated health benefits was vital. Income support programs were seen as providing a basic level of financial security during periods of disability and helping to mitigate financial risk during periods when employment might be possible. In this respect, certain features were considered to be particularly important, including rapid reinstatement of ODSP, OW, and CPP-D benefits after unemployment due to recurrent disability, and the opportunity to maintain ODSP health benefits upon commencing employment without equivalent health coverage. On this front, Ontario was considered by at least one key informant to be "*quite progressive.*"

That said, many participants indicated ambivalence about receiving income supports, in that income security sometimes was achieved at the expense of personal dignity and the ability to capitalize on their capacity to work. Many participants alluded to features of program design or delivery that constituted barriers to employment and successful long-term engagement in the labour force, although it appeared at least some participants did not have up-to-date information about specific benefits. In fact, of all the topics covered in the focus groups, income supports elicited the strongest, most negative, and most vocal reactions from participants. Answering the research question, 'How should income supports be delivered?' therefore involves an implicit conversion of the comments we received. We present these at the end of this section, and incorporate those we felt to be most feasible into recommendations.

More flexible eligibility criteria

Although only a few participants said they received CPP-D benefits, several said they thought these were the hardest to obtain because of "*rigid*" eligibility criteria. Even ODSP, however – despite being a program of last resort – was considered to be unreasonably restrictive with regard to eligibility, for example, denying a participant's application even after she had already been denied CPP-D. One participant said both CPP and ODSP routinely refused first applications, and that appeals were considered the norm. According to this participant, the trouble is that this is not common knowledge and people with disabilities do not necessarily have the energy or resources to follow through with the appeal process.

People with episodic disabilities face an even greater challenge in proving their eligibility for income supports because disability is typically defined as significant impairment in employment and other life domains. To the extent one has the capacity to work – no matter how intermittent or under what circumstances – eligibility is threatened. In the case of CPP-D, for example, one participant noted that, "*if you become asymptomatic, you are no longer eligible.*" Another participant who submitted a written narrative described his situation this way:

> *I left my position in June 2010, as issues of job-related stress, depression, and medication side-effects had become too great to battle daily, at least in the position I held (and on a full-time basis). Sadly, my long-term disability insurer disallowed any benefits, as they held that my continuing to work following diagnosis showed that I was still able to work. This left me extremely frustrated, as their view was an "all-or-nothing" one – there was no middle ground.*

In this respect, ODSP can be considered innovative; a couple of key informants told us that ODSP had incorporated the notion of recurrent disability into its design from the beginning, and was examining other ways to make the program more suitable for people with disabilities and intermittent work capacity.

On the other hand, several participants felt strongly that current income support programs in general are not flexible or responsive enough for people with episodic disabilities. One participant in a mixed focus group[8] noted how most income support programs looked at "*the biography of disability*" instead of the biography of the individual client. Another participant noted, "*The instruments for support are very blunt. They aren't flexible or fine-tuned enough to match fluctuating needs.*"

Participants identified other eligibility criteria and regulations related to income supports that posed barriers for them, such as those that reduce benefits for couples (even due to pension income), and limit the amount of permitted assets such as RRSPs.[9] Many participants viewed such restrictions as punitive and unfair: "*You must become completely destitute to be eligible*"; "*you shouldn't have to give up everything you've worked for.*" Moreover, they felt these restrictions serve as a disincentive and barrier to employment because they do not allow one to "*get ahead*": "*Without being able to save, how are you supposed to save for a house, or to have any quality of life?*" Many participants saw these regulations as effectively keeping them mired in poverty, even if they weren't designed to do so.

Rapid reinstatement of benefits

As mentioned earlier, a few participants and key informants especially noted how important it was to be able to have both income and health benefits quickly reinstated in the event of unemployment due to recurring disability. Since February 2006, for example, ODSP has permitted rapid re-instatement of benefits as well as extended health coverage (called the Transitional Health Benefit) for an unlimited time if necessary, as long as recipients "meet financial and other eligibility requirements" (Income Security and Advocacy Centre, 2006).

> *Our review also noted several important barriers with respect to employment and income support systems: difficulty accessing clear information, which leads to existing benefits being underutilized; inflexible eligibility requirements; a jurisdictional patchwork of coverage that makes it difficult to coordinate benefits; and lengthy bureaucratic processes to get benefits reinstated, with no guarantee of approval.*

Unfortunately, while several participants mentioned ODSP's extended health coverage continuing after employment commences, few indicated they knew about rapid re-instatement of benefits. In fact, during one focus group, a participant revealed that he had passed his one-year anniversary of being employed and off ODSP, which elicited applause and congratulations from the group. He then described

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[8] One focus group was held with members of the OEDN and so contained a mix of people, some of whom disclosed that they had a disability, but not all.

[9] The limit for assets for OntarioWorks is $548 for a single person and $5,000 for ODSP (MCSS, n.d.). Information retrieved from MCSS website, http://www.mcss.gov.on.ca/en/mcss/programs/social/odsp/income_support/odsp_workearn.aspx February 26, 2011.

how conflicted he felt about the situation, since he was unsure if his mental health – and his employment – would continue to be stable. No one else in the group appeared to know that his benefits could be reinstated if necessary.

In the absence of correct information, concern about the stability of health and work capacity, along with the need for a stable income meant that many participants felt they could not jeopardize their income supports for employment. Nearly all participants told us that the risk of losing benefits meant that continued unemployment posed less risk for them than taking a job, no matter how appealing. Rapid reinstatement of benefits such as that provided by OW, ODSP, and CPP-D eliminates one of the most powerful disincentives to employment for people with disabilities and intermittent work capacity, but for this to be effective, recipients must know about the feature and be encouraged to avail themselves of it.

Employment earnings deductions

Another area of contention among participants was current restrictions on how much employment income they are permitted to keep before benefits are reduced, though again, this barrier was complicated by misinformation. A couple of participants told us that CPP-D permits no employment income, on the basis that recipients are supposed to be permanently unemployable. In fact, vocational rehabilitation has been a permanent feature of CPP-D since 1996, and while recipients must inform CPP-D when their employment earnings exceed $4700 per year (as of 2010), benefits are not affected until earnings reach roughly 80 per cent of the maximum monthly income.[10]

Both ODSP and OW both reduce benefits by 50 per cent of employment earnings; net positive monthly earnings of more than $100 are eligible for a $100 work-related benefit. This means that, in general, recipients can keep half of what they earn, to the maximum value of their income assistance cheque. But according to more than one participant, "*that calculation or formula doesn't work in the real world,*" particularly when wages are low.

Participants in one focus group, many of whom worked occasionally as residential cleaners for a community-based agency, described how defeated they felt trying to make the current formula work: "*If I work three hours at ten dollars an hour – and it's a hard job, let me tell you – then six dollars goes to pay my bus, and I have to give fifteen dollars back to ODSP. I'm left with twelve dollars. What's the point?"*

Despite the fact that the exemption limit for earnings used to be only 25 per cent,[11] this "*claw-back*" of 50 per cent was widely perceived among participants to be a strong disincentive to

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[10] Source 1: Staying in Touch. Newsletter #9, February 2010, HRSDC. Accessed at http://www.hesdrc.gc.ca/eng/oas-cpp/cpp_disability/newletter/stayintouch_2010.shtml , March 31, 2011.
Source 2 : Disability Vocational Rehabilitation Program, Service Canada. Accessed at http://www.servicecanada.gc.ca/eng/isp/pub/factsheets/vocrehab.sthml, March 31, 2011.

[11] prior to 2006 when it was raised to 50 per cent.

employment, especially since most felt that higher paying jobs were not a realistic option for them.

Risk to housing

Participants in another group talked about the double disincentive to employment of being on income supports and living in social housing. Rent-geared-to-income (RGI) housing is relatively scarce in most parts of the province, and therefore a valuable benefit for those living in poverty. Like ODSP, once a certain income threshold is reached, the rent subsidy is withdrawn and the market rent applies.

Unlike ODSP, however, there is no rapid reinstatement; once lost, the subsidy is given to another occupant. One can re-apply, but since the number of subsidies in any given building is limited, there is a waiting list and it can take a long time before re-obtaining one, regardless of eligibility. Some housing providers even require tenants to move units, depending on which rent level applies. One participant told us that she had received a couple of offers of employment, but had to refuse them since they were contract jobs with no benefits; even if the contracts had been extended, she would have risked losing her rent subsidy and her unit after 12 months. Trading a secure income for employment is doubly risky when it also means potentially losing one's housing.

Adequate levels of income support

A recent OECD report found benefit levels in Canada to be "relatively low by international standards, and often not enough to secure an adequate standard of living" (OECD, 2010, p. 52). One might speculate that low levels of income support are designed to be an incentive to employment. However, this simplistic notion does not account for the complexity of barriers many people face to employment – including the availability of suitable employment – especially those with disabilities.

Despite recognizing their critical importance to their financial security, many participants nonetheless felt stigmatized by current levels of income supports. These were generally considered to be grossly inadequate. As one woman noted, "*I couldn't live on CPP alone if I wasn't married*"; another thought her insurance benefits were low until she heard what others in the group received from CPP-D or ODSP, and said there was no way she could exist on such an income. As mentioned earlier, many participants also incurred costs related to their disability – for medications, treatments, devices and repairs – which sometimes surpassed the level of support they received. Two women on CPP-D were particularly frustrated at the lack of extended health benefits under that program.

Several other participants agreed that current levels of support do not provide "*an overall decent income to pay bills, rent, [or] an appropriate cost of living in general.*" A persistent theme we heard was that, at current levels, "*it's not enough to get ourselves out of poverty.* As a result, many people reported being heavily in debt, struggling to make ends meet, and/or being reliant on spousal or family income.

Participants in one focus group were particularly vocal about their deep resentment with the disconnection between their reality and the income support system: "*Times are tougher now than they have been, and they raise the benefits one per cent?!... When you see that, the heartlessness of that. The whole system was set up not to be that way.*" Another person said, *"One per cent doesn't pay for anything. I'm living in a room with no kitchen or cooking facilities. I didn't get sick to put up with all this. It's not my fault I got sick, but I have to take responsibility. I'm doing that, and I'm not getting support.*" A third participant remarked – without irony – that social assistance reform was now imminent because "*middleclass families are running out of their savings... Suddenly the other part of the world we're not a part of, they're discovering these people aren't able to work their way out... It must be horrible for them. It's bad enough for us, but we've been struggling with it for years…"*

Stigma

Many of the people we talked to were ambivalent about income supports. They were seen as both a safety net and an entitlement, yet many people were reluctant to avail themselves of them in large part because of the social stigma associated with income assistance. CPP-D appeared to be more acceptable to participants than ODSP or especially, OntarioWorks, presumably because of the fact that it is a contributory program, rather than social welfare. Several participants, in fact, said they wished there was a way to disassociate the two provincial programs because of the particular stigma attached to social assistance – "*don't lump us all together.*"

Some participants told us that being on ODSP was at least as stigmatizing as being disabled, if not more so. There were many comments about the general attitudes held of people on social assistance that echoed the myths and misconceptions about people with disabilities: "*If you're on social assistance, you're perceived as lazy, not ill"; "if you're on ODSP, the cards are really stacked against you.*" As a result, some participants felt they had to hide their receipt of income assistance from others such as landlords and employers. One of the reasons work in an ASO was valued by some people living with HIV was that "*my work doesn't question about why I'm faxing stuff to ODSP, but it wouldn't be the same at another organization."*

Reporting requirements

Several participants noted how the stigma inherent in income support programs was expressed in their delivery. In this respect, requirements to report changes to income were viewed as onerous, punitive, and de-motivating. For those with intermittent work and fluctuating incomes, the burden of reporting was perceived to be even more onerous - depending on how quickly ODSP or OW could respond to the change, it was difficult for recipients to predict the amount of their monthly assistance income: "*From the 1st to the 19th, I don't know how much money I'm going to* *get. I don't want to need them [ODSP] – it would be easier if I didn't have to fill out all the paperwork - but I need it. I couldn't work full-time – I would burn out.*"

A couple of participants also remarked that ODSP and OW were quick to reduce benefits in the event of an increase in income, but slow to adjust upwards when required. Similarly, they noted that any errors filling out forms or missing documentation could result in immediate cessation of benefits; one participant described waiting several months for her previous employer to provide documentation that would allow her benefits to be re-calculated.

The reporting requirements for income supports were regarded by many participants as confusing and excessive, particularly by those with mental health conditions, which several said affected their ability to concentrate on paperwork and to keep it organized. "*Someone with mental illness may have difficulty getting their papers in order. But ODSP expects that will just disappear*." Two groups talked about the particular stress and burden of ODSP's "snap audits," which, according to those participants, require recipients to assemble bank statements, income and expense receipts within 48 hours. One woman asked, "*How many people in the general public could pull all that together in 48 hours?*" Another dryly remarked, "*I have a trauma-based illness – you want to make me sick, that will do it!"*

Irregularities in service delivery

As alluded to above, irregularities in service delivery were also a great source of frustration for many participants who received income supports, and sometimes led to negative consequences. Several participants in focus groups or who submitted narratives cited examples of frequent turnover of case workers ("*In one day I had three [different] workers!*"), instances of lost documentation, and the like. According to these participants, such events caused them undue stress, particularly when they were held responsible for any errors that occurred, and when benefit payments were delayed as a result.

Several participants in the North Bay focus group also expressed frustration at the fact that benefit levels there were perceived to be lower than in other regions of the province, even though their costs were not appreciably different. This was tied to general dissatisfaction about a lack of services there (e.g., doctors and specialists) and the level of financial support provided by ODSP in relation to the real cost of living. Several participants echoed the view of one woman, who said, "*Programs are designed in Toronto and work great in Toronto. But things don't always translate when you leave an urban centre. Politicians forget about the North and focus on major centres such as Toronto, London, and Hamilton. I had benefits there that I don't get here…but my obligations haven't changed."*

In summary, while recent reforms to CPP-D and particularly to ODSP have helped introduce some flexibility into the design of income support programs, there are still many features that people with disabilities perceive to be disincentives to employment, regardless of their own capacity to work. This is due to the inherent risk to financial security associated with intermittent work capacity. In addition, there may be misperceptions and misinformation that nevertheless function as disincentives because of gaps in program delivery. Recognition and reduction of continued barriers and disincentives – as well as enhanced flexibility – would make engagement in the labour market more feasible for people with disabilities and intermittent work capacity.

The following are ways in which the design and delivery of income supports could be improved, as suggested by our consultations and documentary review. Most of these are not new to this study, having been the focus of calls for social assistance reform for many years:

- Coordinate federal and provincial income support programs to eliminate duplication and provide more comprehensive supports to address gaps in coverage (e.g., benefit "stacking" so that recipients of CPP-D might have access to health and dental benefits);
- Provide support to individuals to navigate the existing complex system of income supports, including proactively and systematically providing up-to-date information on program rules and regulations, and support for self-advocacy and appeals;
- Provide a guaranteed annual income to people with disabilities, adequate to maintain a decent standard of living and to cover disability-related costs. In the absence of this, provide monthly supports at a more stable level to allow recipients some ability to plan and forecast their monthly income and expenses;
- Provide training for income assistance service providers on the needs of people with disabilities (episodic and otherwise) and how best to provide appropriate support.

3.9 Other employment-related support programs

This section describes other employment-related support programs, in response to research question #6: How important are local employment supports? These benefits concern transportation, clothing and equipment, childcare and other such costs. They are referred to here as employment-*related* supports to distinguish them from employment support services, described above.

ODSP and OW provide additional work related benefits to recipients of their respective income support programs. Recipients who report earnings from employment or training program are entitled to a payment of $100 per month to cover transportation and other employment-related costs. This Work-Related Benefit is "*automatic and not pro-rated with level of income or related to actual costs*" (Income Security and Advocacy Centre, 2006).[12]

Transportation

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[12] All specific information regarding additional employment-related benefits provided by OW and ODSP is from this source.

Some of the participants in our study mentioned that they had a bus pass provided for through ODSP, while others did not. It was not clear if every participant who was eligible for this benefit received it, or if it was restricted to those with stable – not occasional – employment. Certainly, several participants said they had difficulty covering the cost of transportation to attend occasional employment, and some said they relied on (and were grateful for) transit tickets/tokens occasionally distributed through community agencies.

Start-up benefits

Another important benefit provided to both OW and ODSP recipients is a $500 Employment Start-Up Benefit (ESUB), formerly set at $253. The ESUB benefit is intended to cover costs such as clothing, tools and equipment, licensing fees, grooming costs, etc. that are required either for employment or for volunteer work that could lead to employment. As of 2006, it can also be applied toward costs related to a job search, job preparation, or volunteer positions that will lead to employment. This benefit is limited to actual costs, and is permitted once in any 12-month period.

There is a similar benefit of $500 in any 12-month period for recipients who leave ODSP for employment, or if a recipient’s spouse begins to earn a sufficient amount to render the family ineligible for ODSP. Unlike the ESUB, this Employment Transition benefit (ETB) is a flat rate and not related to actual costs, and is payable even if the ESUB has been provided in the previous 12 months. However, it is available only for those who leave ODSP entirely; that is, one cannot be in receipt of either income supports or transitional health benefits in order to receive the Employment Transition Benefit.

Other work expenses

In addition, ODSP provides a deduction for disability-related work expenses that are required for employment and not covered by any other program (e.g., full-spectrum lighting for people with Seasonal Affective Disorder, dentures, etc.). This means the recipient is allowed to keep a greater portion of his or her earnings – in this case, $300 – before the 50 per cent reduction is applied. A similar deduction of $600 from employment earnings is provided to ODSP and OW recipients for childcare costs, along with a payment of $600 per month to cover the upfront costs of informal childcare (as opposed to licensed daycare) prior to beginning employment or related activities.

We did not find much information about these additional employment-related benefits in our review of the literature, nor did we discover any other programs that provided similar benefits in a systematic manner through our consultations. Participants did not talk about having used the childcare benefits or the Employment Transition Benefit. We did, however, hear several comments from participants about coverage of work-related costs, though it was not clear if participants were speaking about the Work-Related Benefit or the Employment Start-Up Benefit, or indeed, if they knew themselves. In fact, it often happened that one person would start talking about coverage for work-related costs and others would express surprise, saying they had never heard about this before. According to one key informant involved with the delivery of ODSP, these benefits were generally quite under-utilized.

Accessibility of information

It became clear to us that accessibility of information about employment-related supports and even the level of benefits themselves varied from one region to another. One woman said she heard about the possibility of having transportation costs covered for volunteer activities from a friend in another region, but when she approached her own worker about it, she was told the benefit was a different amount. More frustrating was the way in which it was to be administered: "*I was told, 'you go to the meeting and have the taxi invoice us.'…I have to be "outed" [as a person on ODSP]…That's an invasion of privacy and a breach of confidentiality, and that's not acceptable. Why are they allowed to do that to us just because we have a disability? It's not right."*

Another woman was similarly frustrated with the fact that her clothing allowance apparently could only be paid out once she had actually started work, which meant she had no appropriate clothing to wear the first few weeks until her cheque arrived: "*It's an awful feeling to have to go to the boss and say, 'I only have [these clothes to wear].'"*

Unfortunately, these experiences did nothing to lessen many participants' impressions that they had to fight for every benefit that was due them, and that the process of asking and receiving such benefits robbed them of their dignity.

4. CONCLUSIONS

In 1970, Brown wrote that people with disabilities were frustrated and disappointed with the state of income security for disabled people in Canada (as cited in Prince, 2004). Forty years later, we would suggest that frustration has developed into a sense of betrayal and anger. Participants in this study told us they felt "*punished*" by an income support system that does not meet even basic needs and is delivered in a manner as to make them feel like second-class citizens, despite recent changes. Moreover, the unfairness of this treatment was hard to comprehend since disability was not something they chose, but a personal tragedy with which they were still trying to cope. Considering the myriad challenges of daily living associated with these conditions – whether due to side effects of treatment, symptoms, or mobility challenges – being forced to live in poverty and without dignity was felt to be, quite literally, insult added to injury.

Participants' responses about employment supports were more measured and varied. Many had had the experience of receiving appropriate services delivered by caring and helpful providers. Whether or not they had yet succeeded in finding work, many of these participants said the employment supports they had received had been very affirming and beneficial, especially those that had been delivered in an explicitly client-centred, recovery-oriented manner. Other participants had not been so lucky, and their experiences point to inherent assumptions in the program and funding models for employment supports in Ontario that do not fit the needs of people with disabilities and intermittent work capacity, or for that matter, providers of these services, many of whom commit far more resources to helping clients than for which they are reimbursed.

The reality is that many people are not "job-ready" on their own – they face a multitude of personal, attitudinal, and systemic barriers that require more comprehensive and intensive supports of longer duration. Discrimination is a particularly challenging barrier to overcome without supports, especially for those who experience this on multiple levels, such as by being francophone or from racialized communities, living in the North, receiving social assistance, or being gay, lesbian, or transgendered. It is clear from our discussions with participants and key informants that just as disability can be a multi-faceted and variable state of being, so too can employment. People with intermittent work capacity have much more fluid attachment to the labour market, working occasionally, part-time, full-time, in professional positions as well as "survivor jobs" and as volunteers to the extent both their health and external conditions allow. Performance-based measurement frameworks need to allow for a broader range of employment experiences as indicators of success.

As participants told us time and again, the key to employment for people with disabilities and intermittent work capacity is flexibility. For employers, this doesn't have to mean lowering expectations, but rather, being flexible about *how* the work is done, and developing accommodation arrangements that can adapt as needs change. For policymakers, it means developing means of support that allow more fluid movement in and out of the work force as health permits. For all of us, it means greater flexibility of thinking – of discarding binary thinking that categorizes people into one of only two groups, such as able or disabled, employable or unemployable. It is also incumbent upon all of us to discard outmoded ideas about differences being limitations and to be open to the abilities and potential people with disabilities have to offer. It means according people with disabilities their full rights as citizens and participants in society.

5. RECOMMENDATIONS

These recommendations continue the study's emphasis on the perspective of people with disabilities and intermittent work capacity. That is to say, they are based primarily on the feedback we received from participants and key informants, rather than the perspective of SRDC. They are presented more or less in the same order as the previous sections of the report, not in order of priority.

5.1 Medical supports

1. **Improve access to medical supports:** For people with health conditions, appropriate medical supports are an important way to stay well and reduce the likelihood of significant illness and/or disability. For people on disability-related leave, they can help to reduce the length of time away from work or the labour force, and ensure the success of accommodations. In the workplace, HR and labour unions should work proactively to ensure referrals are made for medical supports and to community-based disability organizations. Staff of employment and income support programs should also ensure this is part of each client's case management plan.
2. **Provide education and training to medical personnel re: disability:** Physicians who provide documentation on a person's disability have a great deal of influence on critical decisions related to both disability income supports and workplace accommodations. The federal and provincial governments should take a lead role with health service organizations and medical professional associations in promoting training on the episodic nature of some disabilities and their impact on employment, as well as on effective workplace accommodation and income assistance eligibility criteria.

5.2 Income supports

1. **Improve access and coverage**: The federal and provincial governments should continue to make eligibility rules for income support programs less restrictive and more flexible to reflect the fact that many people experience disability and work capacity as variable, episodic, and intermittent. The focus should be on what the individual can do rather than on his or her limitations, since these can fluctuate. Adopting a client-oriented, case management approach would help people with disabilities and intermittent work capacity navigate the complex income support system, understand precisely to which supports they are entitled, and receive this in a timely, coordinated fashion.

2. **Provide adequate levels of income support:** The federal and provincial governments should establish benefits at levels that adequately reflect the real costs of living (e.g., shelter, food, utilities, etc.) as well as of treating/managing disabilities.
3. **Remove disincentives to employment:** The federal and provincial governments should eliminate restrictions against employment, and increase employment earnings deductions. As one participant recommended, establish "*a guaranteed income support [at] a liveable amount.*" Doing this in consultation with stakeholders (i.e., disability sector groups, service providers, citizen advocacy groups) will help determine how best to provide incentives to employment that do not threaten income security, and that recognize the advantages of fluid movement in and out of the labour force.

5.3 Employment supports

1. **Modify the outcome-based funding model:** The provincial government should undertake consultations to determine how to make this model more appropriate and effective for people with disabilities and intermittent work capacity, as well as for service providers. Potential modifications should recognize the multiplicity of clients' needs and indicators of success. The recovery-oriented model used in the mental health services sector could be adapted for use with other disability groups.
2. **Broaden the range of services provided:** Employment support programs should provide a broader range and more intensive supports to employment, including pre-employment and career development counselling, job search assistance and preparation, job coaching, and longer-term follow-up, along with other wrap-around supports to meet psycho-social needs.
3. **Provide more support for education and training:** including employability skills, literacy and essential skills, as well as technical and vocational skills training, to ensure people with disabilities and intermittent work capacity remain competitive in the labour force.

5.4 Non-wage benefits

1. **Equalize access to extended health benefits:** The federal government should explore ways to permit recipients of CPP-D to access extended health benefits (e.g., through ODSP). The Ontario government should be applauded for extending health benefits to people with disabilities in employment but information about this benefit needs to be systematically provided to all recipients to eliminate perceived disincentives to employment resulting from misinformation.

2. **Continue to provide non-wage supports to employment:** Providers of all income support programs should provide consistent information and access to work-related benefits such as those offered through OW and ODSP to cover the costs of transportation, clothing, equipment, and child care. This should help people with disabilities and intermittent work capacity overcome structural barriers such as access to affordable transportation.

5.5 Workplace supports

1. **Inform employers:** Governments and disability-sector organizations should continue to work with employers to enhance awareness about their obligations under human rights, employment standards, and other relevant legislation to accommodating the needs of people with disabilities. HR professionals, labour unions, and management are important target audiences for this initiative, but consideration should also be given to connecting with smaller businesses that may not have such resources.
2. **Provide incentives to employers:** Governments should provide specific incentives for employers to hire and accommodate people with disabilities and intermittent work capacity, such as through greater use of targeted wage subsidies, job coaching, and follow-up support. The emphasis should be on the business case – what people have to offer rather than their disability – or as one participant said, *"market the idea that disabled people have skills."*
3. **Provide more support to employers for accommodations:** The federal and provincial governments should enhance financial supports for employers to provide accommodations for employees with disabilities, especially for small businesses. As suggested for income assistance recipients, a system navigator or intermediary could work with specific industry sectors to ensure employers are informed about their responsibilities and obligations with respect to accommodating employees with disabilities and intermittent work capacity, promising practices in terms of workplace policies and approaches, and the supports for which their business might be eligible.
4. **Engage employer champions:** Through employment support programs, engage employers willing to hire people with disabilities and intermittent work capacity and provide leadership to other employers within specific sectors and industries.

5.6 Education and training

1. **Raise awareness, knowledge, and skills for service providers:** Provide information and training for those providing direct services within the employment and income support systems to enhance their knowledge about disabilities and how they affect work capacity, as well as about other client needs and barriers they experience, and how to address these within the scope of their roles and organizations.
2. **Public education:** Educating the general public on disability issues and the importance of inclusion continues to be needed to address issues of stigma and discrimination.

Through this study, SRDC has identified several research gaps, which the following recommendations would address:

5.7 Research

1. **Develop more responsive research tools**: Current data present a very imperfect understanding of current labour force participation of people with disabilities and intermittent work capacity in Canada. Researchers should consider definitions of disability that take the complex and dynamic nature of disability into account; longitudinal research that explores the impact of disability on employment trajectories over time is also needed.
2. **Explore the experiences of specific sub-groups:** The current study only highlighted systemic barriers and supports to employment for a few sub-groups of people with disabilities and intermittent work capacity (i.e., women, Francophones, people from racialized communities, and people living in Northern Ontario). The federal government should undertake research to explore these issues in more depth and for other groups such as men, Aboriginal peoples, and immigrants, as well as people working in specific industries (e.g., health care) to develop a fuller understanding with which to design possible interventions and predict how these groups might particularly benefit.
3. **Test promising practices and innovations:** The federal government should take a lead role in sharing best practices and promising policy developments in how best to facilitate labour force attachment among people with disabilities and intermittent work capacity. The effectiveness of specific approaches to workplace accommodations should be evaluated, and particularly, the effectiveness of work-related benefits as incentives to employment. New models of employment supports could be tested, such as the milestones approach used in British Columbia, and other approaches used internationally.

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Appendix A – List of Organizational affiliations of Key Informants

Key informants were interviewed from the following organizations:

- Canadian Working Group and HIV and Rehabilitation (CWGHR)
- National Network for Mental Health (NNMH)
- Building Up Individuals Through Meeting and Teamwork (BUILT) Network Customer Service Representative Program, National Network for Mental Health
- Employment and Income Support Unit, Ontario Disability Support Program Branch, Ministry of Community and Social Services
- Employment Supports Program, Ontario Disability Support Program (ODSP) – Ottawa
- Ontario Works (OW) – Ottawa
- AIDS Committee of Toronto (ACT)
- Canadian Mental Health Association (CMHA), Ottawa branch
- Canadian Mental Health Association (CMHA), Ontario division
- Person with environmental sensitivities and board member, Environmental Health Association of Ontario (EHAO)
- Equality Branch, Canadian Union of Public Employees (CUPE)

Appendix B – Informed Consent Protocol for Key Informant Interviews

1. GREETING
Good morning/afternoon. This is [name of researcher] calling from the Social Research and Demonstration Corporation. May I please speak with [name of person]?

2. INTRODUCTION AND CONSENT
First of all, I want to thank you for agreeing to speak with me today.

As I mentioned before, SRDC is conducting a qualitative study on the experiences and needs of people with disabilities who have intermittent work capacity. We are seeking to identify and better understand the conditions, support services, and employer practices that enable people with disabilities to stay attached to the labour force. The project is being funded by HRSDC and SRDC has been contracted to carry out the research. In addition to providing important insights, these expert interviews will help inform the questions we will be asking during our focus groups with people in Ontario who have experienced intermittent work capacity.

This interview will last about 30 minutes and I will be taking notes of our conversation for the analysis. Since this is a qualitative study, we will be using quotes from the interviews in our final report. The quotes will be reported anonymously; however, given that the number of key informant interviews is small, and that potential key informants have been previously identified, there is always the possibility that someone reading the report may be able to identify the information source. Therefore, please consider this interview as "on the record."

Of course, as with any interview, if there is any question you do not want to answer, please feel free to pass on it.

Do you have any questions before we begin? **(YES/NO)**

Can we go ahead with the interview? **(YES/NO)**

Appendix C – Interview Protocol for Key Informant Interviews

1. Client characteristics, needs, and barriers

- In your estimation, what proportion of your clientele has disabilities that would allow them to work on an intermittent basis?
- In general terms, what are the characteristics of these clients (i.e., gender, age, type of disability, type of employment experience)?
- What are some of the specific barriers or challenges to employment faced by your clients living with episodic disabilities?

2. Program Design and Delivery

- Tell me how your organization/program serves people with episodic disabilities. What kinds of employment-related supports, services or programs does your organization provide?
- Are there specific programs or services that are more suited to people with episodic disabilities? Who uses what kinds of employment support services, and why?
- What are some of the key features of these programs?

3. Challenges and Promising Practices

- To what extent do clients with episodic disabilities receive adequate supports to address their needs and barriers, and to benefit fully from employment supports (e.g., counseling or training)? What client needs are hardest to address? What else do clients need?
- In your opinion, what strategies or programs are most effective at helping people with disabilities to overcome employment and workplace barriers (either specific to your organization or more broadly)? What features make these programs/services more effective?
- What are examples of innovation and promising practice in income and employment support programs for people with episodic disabilities?
- At a systems level, what are the gaps in terms of service delivery? What change would make the most difference?
- Many recipients, support providers, and employers are not aware of the existence or to access the full range of supports and programs available to people with episodic disabilities who wish to work. How do you think this should be addressed?
- In your opinion, what are some of the most important factors affecting why some people with episodic disabilities are able to stay attached to the labour force whereas others with similar disabilities do not?

- What is the single most important change that needs to be made at a systems level, and what next steps would be required to achieve this?

4. Focus Group Suggestions

- Whose voices are missing from the debate on employment and disability, or need to be amplified? In your capacity as a service provider, who would you like to hear more from?
- If you had one question or topic you would like discussed with clients with episodic disabilities, what would it be? What would you want to ask?
- Is there anything in particular you would recommend we keep in mind when conducting our focus groups?

Appendix D – Informed Consent Protocol for Focus Groups

You are invited to participate in a focus group as part of a small research study. The goal of the study is to understand the work experiences of people who have disabilities leading to unpredictable or irregular periods of employment. The study is being funded by Human Resources and Social Development Canada (HRSDC). Our organization, the Social Research and Demonstration Corporation (SRDC), is carrying out the research.

The focus group will be a group-based discussion with a maximum of 10 participants with disabilities. The focus group will take about two (2) hours. We will be asking questions about the barriers and supports you have encountered or are encountering in trying to find, keep or return to a job. You may also be asked to participate in an activity to help us better understand what has influenced your employment decisions.

Your participation is completely voluntary and you may withdraw from the study at any time without penalty. You can also choose not to answer any of the focus group questions.

Two (2) members of the research team are present today. One will act as the focus group facilitator and the other will take detailed notes of the discussions. We will be recording the discussions. Your individual responses, including personal information, are being collected solely for SRDC's use for research and the information will not, at any time, be made available to HRSDC or the Government of Canada. Due to the nature of group discussions, it's impossible for us to promise strict confidentiality of the information you share during the focus group. However, we ask that focus group participants refrain from sharing what is said during the group discussions with others outside of the group.

Also, all reasonable precautions will be taken to protect the confidentiality and privacy of the information you may provide us with today. All notes and recordings will be transported in a locked briefcase from the focus group site to SRDC's research office under the direct supervision of one the members of the research team, after which materials will be stored in a locked office within SRDC's secure building. The recordings and notes from the focus groups will be transferred to password protected computer files and will be stored on SRDC's secure servers. Only authorized members of the research team and SRDC will have access to the focus group data. SRDC will not release any information that contains your name or any information that could identify you to anyone without your permission, unless otherwise required by law. The report to be submitted to the project funder will only present group results. No information that could identify you will be included in the report.

The recorded files will be destroyed at the end of the research project in April 2011.

Benefits to participating in this focus group include having the chance to share your experiences and to hear about other people's work and employment experiences. You will also be contributing to research that may help better inform policies and programs.

If you would like to receive a copy of the final report, please let one of the research team members know and they will gladly provide you with a copy at the end of the project.

You can contact a member of the project team if you have any questions or concerns after participation:

Heather Smith Fowler
Project Leader and Senior Research Associate
Social Research and Demonstration Corporation
Tel: 613-237-7444 or toll-free 1-866-896-7732, ext. 2231
E-mail/Courriel: hsmithfowler@srdc.org
www.srdc.org

Dominique Leonard
Researcher
Social Research and Demonstration Corporation
Tel: 613-789-1364 or toll-free 1-866-896-7732, ext. 2235
E-mail/Courriel: dleonard@srdc.org
www.srdc.org

By signing this consent form, you are indicating that you fully understand the above information and agree to participate in this study.

Participant's name: ____

Participant's signature: ____

Date: ____

Researcher's signature: ____

Date: ____

Location: ____

Appendix E – Discussion Protocol for Focus Groups

1. What is your idea of the perfect job for you right now? What kind of organization would it be with, and what would you need to get that job and do it well?

2. Using just a couple of words, what does work mean to you?

3. What are some of the most prevalent myths/misconceptions held about people with disabilities and their ability to work?

4. What has been the greatest barrier or obstacle you've encountered in your work life, or in trying to find work?

5. Have there been times when you continued to work despite poor health? Or have there been occasions when you felt well enough to work but were prevented from doing so? Why?

6. Everyone has different stages in their employment – these typically include hiring, orientation and training, ongoing performance and accommodation, promotion and advancement, and return to work. In your opinion, what stage of employment presents the greatest barriers for people who can work intermittently? Why do you think this is true?

7. What kinds of accommodations would make it easier for you to work, or to do your current job better/more effectively? What would make it easier for people with disabilities to request accommodations to meet their needs?

8. What are some of the most helpful programs, services, or supports to employment you've received? What made them helpful?

9. How did you find out about the various programs and supports available to you?

10. What policy or program would you most like to see changed, and how?

Appendix F – Invitation for Return To Work Narratives

Share your employment story!

Are you someone with an episodic disability or illness (including HIV, arthritis, diabetes, some forms of mental illness, cancer, etc.)? Do you live in **Ontario**? Do you have a story to share about employment?

The Social Research and Demonstration Corporation (SRDC) wants to hear about what makes it easier or more difficult for you to return to work or to consider doing so, or to maintain employment.

If you live in a rural area, how does this affect the employment and support options available to you?

Please send your story of 300- 400 words to workcapacity@srdc.org **before January 15, 2011**. The first 25 people to submit their employment story will receive $30 as a thank you. Only one entry per person will be accepted. SRDC will contact the 25 people to make arrangements for payment.

Any information you provide will be treated confidentially.

SRDC is a non-profit organization that conducts research for governments, foundations, and other non-profits on social policy issues. Visit our website at www.srdc.org.

This study is funded by Human Resources and Skills Development Canada (HRSDC).

Appendix G – Template Response for Return To Work Narratives

Hello [NAME]. Thank you so much for taking the time to share some of your experiences with work. We very much appreciate your willingness to share some of the challenges and supports to employment you've encountered. Stories such as yours are invaluable to our understanding of the support services and employer practices that enable people with disabilities in Ontario to find, keep or return to a job.

The research was commissioned by Human Resources and Social Development Canada (HRSDC) and the non-profit organization I work for – the Social Research and Demonstration Corporation (SRDC; www.srdc.org) - has been engaged to undertake the study. SRDC will take every reasonable precaution to protect your privacy and to ensure the anonymity of the information you provide as a participant in this research. You will not see your name in any of the reports we prepare, and if we use a quote from your story, you will not be identified as the person who wrote it. If you would like to receive a copy of the final report, please let me know and I will gladly provide you with a copy at the end of the project in April 2011.

I would also like to encourage you to share the story you submitted to us with the Episodic Disabilities Employment Network (EDEN), a group with which you may already be familiar. The EDEN works to share information on enabling people living with various forms of episodic disabilities to connect and communicate with each other. By sharing your story with EDEN, your experiences could help others who are living through similar circumstances. As a research organization, SRDC cannot share your story with any person or external group. However, we have worked closely with EDEN as part of this project and would encourage you to share your story by sending a version to post on the EDEN website to eden@hivandrehab.ca.

As promised, I would like to make the arrangements to send you a cheque for $30 as a token of thanks for your submission. Please send me your **full name and complete mailing address** and I will send you the cheque in the mail, with the cheque arriving within 4-6 weeks.

Thank you again, [NAME], for your story.

Regards,

Appendix H – Literature Review

2 LITERATURE REVIEW[13]

2.1 Purpose and Scope

The goal of the literature review is to develop a broad understanding of the research and policy development to date related to the intermittent work capacity of people with disabilities. More specifically, the review seeks to:

1. Summarize work to date identifying the extent and nature of labour force attachment by people with disabilities who have intermittent or variable work capacity;
2. Identify systemic and structural factors that facilitate or inhibit labour force attachment for this group;
3. Identify innovative or promising practices in terms of policy or programmatic interventions.

This review is not a comprehensive review of all the literature related to disability and employment, nor an overview of the policy and program landscape in these areas. Given the emphasis on intermittent work capacity, we have focused on literature in the area of *episodic disability*, which is terminology increasingly used by people to describe their own experience of disability, as well as by practitioners and researchers in the field. Episodic disabilities are defined as conditions in which periods of good health are interrupted by periods of illness or disability (CWGHR, 2006a). Often-cited examples include HIV, multiple sclerosis, arthritis and some forms of mental illness. However, our review is defined less by specific illness or conditions than by the employment *experience* of people with disabilities who have intermittent work capacity.

This literature review is divided into two main sections: methodology and findings. As per the goals identified above, the section on findings is further divided into 1) an introduction, which deals with how disability – in particular, episodic disability - has been defined in the literature; 2) the extent and nature of labour force attachment by people with disabilities; 3) systemic and structural factors that affect the experience of employment among people with disabilities, especially those with variable work capacity; and 4) innovations and promising practice. The implications of the literature review for the current research project are dealt with in the body of the methodology report.

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[13] The literature review is reproduced from the Methodology Report. Sections headings and numbers are maintained from the original report for consistency. References for the literature review have been incorporated into the main Reference section for the Final Report, since many are cited in the body of this report.

2.2 Methodology

SRDC conducted a multidisciplinary literature review of both Canadian and international research literature, focusing on academic as well as “grey” literature (i.e., reports and working papers not published in academic journals). In addition to recently published academic articles identified via an extensive search of scholarly databases, our review includes materials provided by episodic disability experts and those identified following a scan of the reference sections from the retained source documents.

The database search was conducted for articles published after 1995 via a search of the following eight (8) databases: ABI/INFORM Global , CSA Sociological Abstracts , E-Journals @ Scholars Portal, EconLit, Education Abstracts @ Scholars Portal, ERIC, FRANCIS, and PsycARTICLES. Search parameters were limited to articles containing the keywords “episodic” or “intermittent” and “disabilit*”, resulting in the preliminary identification of 194 articles. All titles and abstracts were scanned, resulting in the exclusion of all but 14 articles on the basis of the following exclusion criteria: duplicate articles, Masters or PhD dissertations, and articles without a clear focus on the current research project’s topic (e.g., disability-specific without mention of episodic, articles focusing on a specific medical condition without reference to impact on employment, treatment studies for chronic or intermittent medical conditions, psychometric validation studies for assessment tools for chronic or episodic illnesses). A Google Scholar search using the search terms *episodic disabilities research* identified a further three (3) relevant articles.

The paucity of academic literature located in the database search would seem to indicate that the study of episodic disability in relation to employment and labour force attachment is still relatively emergent. However, the “grey” literature appears to be more developed, with a good mixture of empirical and policy studies exploring employee and employer perspectives, and a number of Canadian and international reviews of income and employment support policies for people with intermittent work capacity.

In applying a gender lens to the literature review, resources did not permit us to venture into the large and rich literature on gender and disability. Once sources relevant for this project were identified, however, we systematically searched this material for references as to how men and women had different experiences - either of employment, episodic disability or both - and highlighted these where appropriate.

2.3 Findings from the literature review

2.3.1 Definitions and prevalence of episodic disability

Disability groups and increasingly, research studies assert that people with a wide range of disabilities experience these as fluctuating over time, rather than as a static condition. Longitudinal studies in the medical and rehabilitation literature find that, “*while disability in one* *[study] period is associated with a higher risk of disability in later periods, there is by no means a universal or uniform decline from first onset"* (Burchardt, 2000, p. 648). In fact, improvements in functional status over time were often noted, especially among younger people (e.g., Boaz, 1994; Lagergren, 1994; Maddox, Clark & Steinhauser, 1994; cited in Burchardt, 2000).

Perhaps not surprisingly, this more dynamic understanding of disability has led to some challenges in terms of terminology and definition. Using data from the British Household Panel Study (1991-1997), Burchardt (2000) differentiated among the following disability "trajectories":

- "one-off" (disability[14] reported in one year only;
- short repeated (disability reported in two or three years but not consecutively);
- short continuous (disabled in two or three years consecutively);
- long repeated (disabled in four, five or six years, but not consecutively);
- long continuous (disabled in four, five, or six years consecutively); and
- always (disabled in seven years consecutively).

Burchardt found that while 27% of working-age respondents reported some disability during the seven years of the panel study, those who reported disability in every period ("always") were only a small proportion; the largest group reporting a disability were those who experienced it as a "one-off" episode (just over 10%), and between 3 and four per cent reported each of the other trajectory types. More women than men experienced a disability at some point in the study (31 versus 23 per cent), and were more prominent in all trajectories except among those who experienced disability throughout the study (always disabled) or as a long continuous spell (rates in these two trajectories were equal). The author contends that longitudinal research is more effective than cross-sectional analysis at correctly identifying those with intermittent or fluctuating disabilities.

Similarly, Burkhauser and colleagues in the US have found that the proportion of people reporting a disability decreases if the definition requires positive responses in two consecutive years or study periods (Burkhauser & Wittenberg, 1996; Burkhauser & Daly, 1996, 1998; cited in Burchardt, 2000). As a result, they distinguish among the "disabled" (reports of disability in two years), the "short-term disabled" (report of disability in only one year), and the "non-disabled" (no reports of disability). Among the first group, they also identify the "newly-disabled," who did not report a disability prior to the study period, and who report better health

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[14] Burchardt uses two definitions of disability in her research: 1) limitation or restriction in activities of daily living (ADL), and 2) two or more positive responses to the General Health Questions (GHQ), which are usually taken as an indicator of mental health status. While we respect the more comprehensive picture these additional data provide, we report here only on the findings related to ADL, since that is more comparable to definitions used in legislation and survey methodology in Canada, the US, and the UK.

and functioning than their disabled peers, but worse than those in the short-term disabled or non-disabled categories (Burkhauser & Daly, 1996; cited in Burchardt, 2000).

Broader definitions of disability – including either episodic or "recurring" disability - have also recently been incorporated into disability legislation, notably in the 2008 amendment to the Americans with Disabilities Act (ADAAA), and in the consultation document regarding amendments to the Disability Discrimination Act in the UK. While no similar legislative change has been made in Canada, there is increasing recognition by the federal government of this more dynamic nature of disability. There are no statistics on the exact number of people living with lifelong episodic conditions, but the Government of Canada's 2003 report, *Listening to Canadians: A first view of the future of the Canada Pension Plan Disability Program*, suggested that recurrent and episodic disabilities are becoming more prevalent in Canadian society (Government of Canada, 2003).

Research by Furrie (2010) attempted to estimate the number of Canadians with episodic disabilities, using data from the 2006 Census and 2006 PALS. These surveys indicate that 11.7 per cent of the population of working-aged adults (2,457,900 individuals aged 16-64 years) reported a disability that year. Of these, 46.4 per cent (1,140,500 people) reported having one of 27 conditions identified in the research literature as episodic in nature, and only half of these indicated they were "often" or "sometimes" limited their activities at work or school. However, an additional 704,800 people who also reported being often or sometimes limited at work or school reported health conditions other than the 27 identified as episodic, implying that the "underlying health condition" approach may not be the most effective means of defining episodic disability. Moreover, when used with cross-sectional data such as the PALS, the "impact on employment" approach does not differentiate episodic and chronic disabilities, only the degree of limitation experienced. Longitudinal analyses are required to fully assess patterns of disability.

Fortunately, the Survey of Labour and Income Dynamics provides this opportunity, though it is less rich in terms information on the nature of disability and the degree of limitation experienced. Similar to Burchardt (2000), Galarneau and Radelescu (2009) found that while 41 per cent of individuals aged 20 to 59 years reported having a disability at some point between1999-2004, only 15 per cent did so during a single year, and only 5 per cent reported a disability during all six years.[15] They also found that differences between those reporting a disability and those who reported none became more apparent the longer the disability persisted. In particular, those disabled for all six years of the study were more likely to be female, older, and single, have lower levels of education, and be in poorer health (for employment characteristics, see *Labour force experience of people with disability*, below).

Despite the emerging research on the dynamic nature of disability, policy and programs in Canada, as in the US and the UK, are still largely based on static definitions that view disabled

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[15] The remaining 21 per cent reported between two and five years of disability.

and non-disabled people as separate sub-groups. In the same way that static definitions of disability do not fit the experience of many people with disabilities, people with episodic disabilities in particular have more varied and complex experiences of employment. They do not "fit" into the traditional categories for recipients of current disability benefits programs, which were designed as an "all or nothing" or "employable vs. unemployable" dichotomy of ability to work. For people with episodic disabilities, work trajectories are more unpredictable; they are typified by movement into and out of the labour force over time in what may be called intermittent or variable work capacity. The following section articulates the labour force experience of people with episodic and other disabilities, and how this is affected by such definitions.

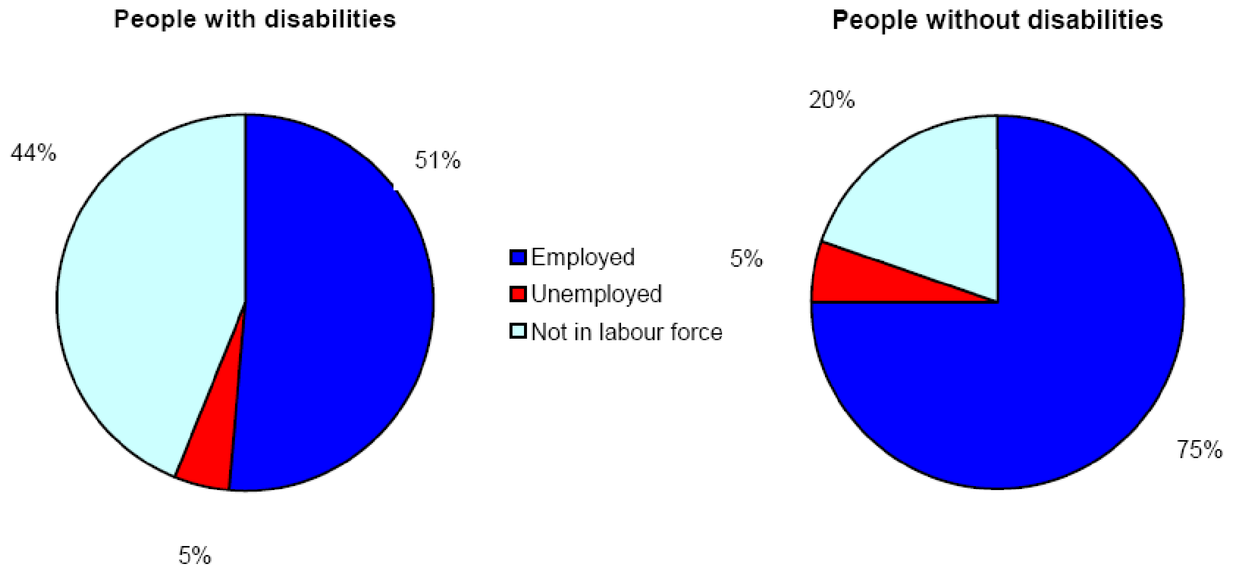
2.3.2 Labour force experience of people with disability

The recently released OECD report, *Sickness, Disability and Work: Breaking the Barriers – Canada: Opportunities for Collaboration* (2010) states that "*sickness and disability policy reform has been a priority for OECD countries wanting to improve employment and social outcomes in this domain*" (p. 3). The impetus for this reform stems from two areas: on the one hand, a desire to promote social and economic inclusion and social justice, and on the other, to capitalize on the potential contributions of an under-utilized labour force (Statistics Canada, 2006). In Canada, this reform takes place in the context of employment equity and human rights legislation that ensures access to the labour force for people with disabilities, and has increasingly emphasized the employer's duty to accommodate their needs (Shain, 2009). There has also been increasing recognition of the benefits of employment to the individual in terms of enhanced self-esteem and quality of life, even in public policy (e.g., Government of Canada, *In Unison 2000*). Interest in maximizing the labour force participation of people with disabilities also stems from concerns about potential labour shortages as a result of an ageing population and the recent downturn in the global economy (OECD, 2010; Williams, 2006).

However, participating in the labour market can pose numerous challenges for people with disabilities, both in terms of managing their disability and overcoming systemic and structural barriers to employment. As discussed later in this report, these challenges are faced at all stages of employment, whether securing or retaining employment or returning to work after illness, onset, or episode of disability. Yet despite a patchwork of employment and support programs delivered by governments, community agencies, and the private sector, there is a large and persistent gap in labour market participation between Canadians with and without disabilities.

Chart 1 shows the differential employment of people with and without disabilities in 2006, taken from Statistics Canada's Participation and Activity Limitation Survey (PALS).

Chart 1: Labour Force Status for People with and Without Disabilities, Canada, 2006

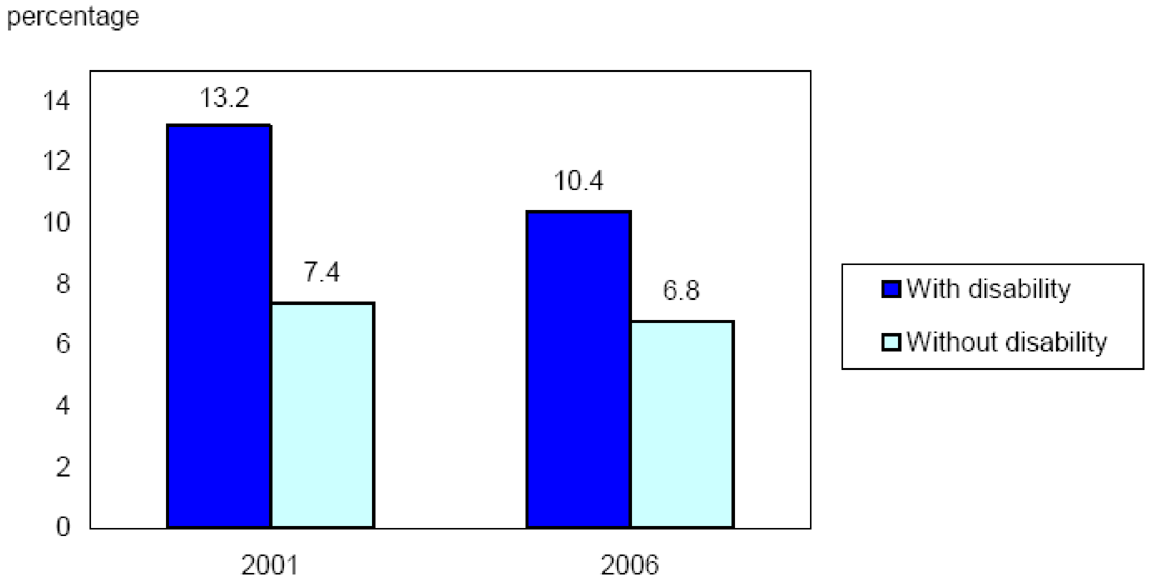


Source: Statistics Canada. (2008). “Participation and Activity Limitation Survey 2006: Labour Force Experience of People with Disabilities in Canada.” Ottawa.

In 2006, people with disabilities were twice as likely to be out of the labour force and one-third less likely to be employed. In fact, forty-two per cent of disabled people of working age reported being unable to work. The differential labour force participation rates indicate that while being out of the labour force can often be due to choice or temporary life circumstance for people without a disability (e.g., for retirement, educational pursuits, or family responsibilities), people with disabilities are more often completely excluded from participating in the labour force for reasons directly related tot heir disability and beyond their control. When compared to women who reported no disability, women with a disability were somewhat more likely to be the main income earner for their family (Galarneau & Radulescu, 2009).

While the PALS data indicates persistently lower rates of labour force participation and employment for people with disabilities, the two most recent surveys in 2001 and 2006 suggest that labour market outcomes for this group have improved with the strengthening of the economy in the past decade. Chart 2 shows the unemployment rate for people with and without disabilities in the two survey years, indicating that while the employment improved for all Canadians of the five-year period, people with disabilities made proportionally larger gains, with their unemployment rate dropping from 13.2 per cent in 2001 to 10.4 per cent in 2006, closing the gap between the two groups considerably.

Chart 2: Unemployment Rate of People With and Without Disabilities in Canada, 2001 and 2006



Source: Statistics Canada. (2008). "Participation and Activity Limitation Survey 2006: Labour Force Experience of People with Disabilities in Canada." Ottawa.

These gains were in large part due to higher rates of employment among people with disabilities over the period – nearly double their population growth – rather than people leaving the labour force. Employment gains were experienced across all age groups, with the largest gains among women, resulting in more women with disabilities being employed than men in 2006 (Statistics Canada, 2008).

The authors of the PALS study (Statistics Canada, 2008) suggest that improvements and greater accessibility of technology has played a major role in improving the employment situation of people with disabilities, particularly for people with learning limitations. However, they go on to say there continue to be many systemic and practical barriers which prevent people with disabilities from participating in the labour force in a meaningful way, many of which are compounded for people whose disabilities are episodic in nature.

Further analysis of the 2006 PALS survey by Furrie (2010) reveals that 43.2 per cent of Canadians with disabilities were active in the labour force at the time of the interview. Almost twenty (19.4) per cent of these people had experienced intermittent periods of unemployment in the previous 12 months, particularly for males who had often experienced limitations. Among those who said they were often limited at work or school, almost 60 percent (59.1) said this caused them to work part-time.

Analysis of SLID by Galarneau and Radelescu (2009) provides a more nuanced picture of the how the experience of employment varies with different patterns of disability.[16] The characteristics described earlier that are associated with longer periods of disability – being female, older, living alone, and having less education and poorer health – are all associated with lower participation in the labour force. Yet even when demographic characteristics were taken into account, people with disability worked fewer hours than those without a disability, by as much as 1.6 years. In addition, participation rates and hours worked remained lower for people with disabilities - even in the years when disability was not reported - and there was a significant earnings gap between the disabled and non-disabled by as much as 20 per cent as years of disability progressed: for men, this started at two to three years of disability, and for women, starting at four to five years. Work interruption rates (e.g., layoffs, etc.) were more or less equal to those of non-disabled workers, although people with disabilities were more likely to stop work for health reasons.

As a result of all these difference, it is not surprising that people with disabilities are at greater risk of having low incomes, especially for men, whose risk is two times that of non-disabled peers when disability is reported for four to five years, and increases to eight times at six years of disability. Women disabled six years are four times more likely to have low incomes than non-disabled women, but this study found little difference for shorter periods of disability. The following section attempts to articulate some of the barriers to labour force participation, some of which may be targets for intervention to improve this economic outlook.

2.3.3 Systemic and structural barriers to employment

Based on the literature, we have grouped the systemic and structural factors related to employment supports for people with disabilities with intermittent work capacity into six (6) categories:

- Workplace supports – including management practices and other human supports;
- Accommodations– including structural/physical accommodations, and work arrangements and schedules;
- Non-wage benefits – e.g., employer-provided health care and dental plan and extended health benefits (sick leave, short and long-term disability);
- Local employment support – e.g., transportation, clothing, equipment, caregiving arrangements, attendant care;
- Government income support programs – e.g., CPPD;
- Government employment support programs – e.g., vocational rehabilitation program, job-readiness training, often delivered in junction with income support measures.

While the focus of this review (and the project as a whole) is on systemic rather than personal barriers to employment for people with disabilities, it is important to recognize that these are somewhat arbitrary distinctions. The ways in which systemic barriers are perceived and experienced by people with disabilities is informed, shaped by, and inter-connected with personal experiences, characteristics, and situations. According to Vick and Lightman (2010), *"the precariousness of complex episodic disabilities as physically and emotionally 'lived in' raises unique obstacles to securing and retaining employment in a global economy"* (p.76). These authors describe how people can come to perceive their bodies as untrustworthy and - through cycles of unemployment - themselves as unreliable workers, with obvious consequences to self-confidence and self-esteem. Furthermore. "*bureaucratic demands for job readiness [that] counteract what it means to live with shifting disabilities"*(p.76) can lead to disenchantment with employment and income support systems, and stymie people's attempts to explore options for employment.

In the same way, our six categories of structural or systemic factors are somewhat arbitrary, but nevertheless useful in terms of being areas of policy or program activity. We recognize that for people with disabilities, their experience of these factors is likely more defined by the chronological sequence of the employment process, that is, recruitment, selection/hiring, training, accommodation, and promotion/advancement (Stensrud and Gilbride, 1999, as cited in Stensrud, 2007). For people with episodic disabilities, a sixth stage is likely relevant, that of leaving work and re-employment, which can happen at any time in the employment process. This conceptualization aligns closely with that used in other studies exploring barriers to employment for people with HIV/AIDS (O'Brien, Bayoumi, Strike, Young and Davis, 2008; ICAD, 2005).

2.3.3.1 Workplace supports

Management practices and human supports

When reviewing the literature on various supports provided to people with disabilities in the workplace, we determined that the presence of disability policies - beyond that required by human rights and employment equity legislation – is critical, and that such policies be available, understandable, and actively supported by both the employer and employees (ICAD, 2005). This active implementation of workplace policies governing employment and retention of workers with episodic disabilities signals a corporate awareness of disability issues, provides access to information, outlines mechanisms for action, and when supported by employers and employees, signals an organizational culture of openness and acceptance. However, according to a policy review by CWGHR (2006a), few workplaces have formal polices for disability and return-to-work. Moreover, a survey of Canadian HIV/AIDS service organizations – which might be presumed to be at the forefront of this issue - found that nearly 60 percent did not have an HIV/AIDS workplace policy, and 69 percent reported not having a life threatening, chronic or episodic illness policy (ICAD, 2005). Some of the barriers cited to policy development and implementation included a lack of human and financial resources and a lack of knowledge of employment and human rights legislation with respect to disability.

This same survey found that unionized workplaces were more likely to have disability policies in place, but even more important was the presence of a Human Resource (HR) department or staff member (ICAD 2005). This is not surprising, since HR professionals are expected to be familiar with workplace accommodation strategies, workplace culture, rehabilitation resources, and to act as the interface among the various income support systems (CWGHR, 2006b, p. 3). Contrary to this expectation, however, a survey of HR professionals found that over 60% felt they had little to no knowledge on approaches to managing cases of episodic disability and needed more training; and 69 per cent were unable to statistically identify cases of episodic disability on their caseloads (CWGHR, 2006b). In terms of hiring and supporting people with disabilities, one study (Stensrud, 2007) acknowledged that the role of the HR personnel could sometimes be somewhat at odds with the priorities of direct supervisors and management, particularly in terms of diversity and equity goals competing with concerns about performance and other business needs.

The presence of an HR professional has also been linked to positive employment outcomes for people with disabilities. According to the Canadian Council on Social Development (CCSD, 2004), people with disabilities employed with core firms (i.e., companies with >75 employees, revenue per employee in the top quartile, multiple locations, or having a dedicated human resource unit) had better wage profiles, more training opportunities, and increased promotion rates compared to workers with disabilities employed in non-core firms. Specifically, far fewer workers with disabilities employed in non-core firms had wages in the lowest quartile (15.4% compared to 36.5% of workers with disabilities in core firms) and much more likely to be in the top wage quartile (34.2% compared with 18.8%). Workers with disabilities in core firms were more likely to receive in-class training (21.7% compared to 17.6%) and less likely to report receiving no training (52.2% versus 58%) than their non-core firm counterparts. And finally, with respect to promotion rates, workers with and without disabilities in core firms reported nearly equal promotion rates (35% and 35.5% respectively), whereas 30% of workers with disabilities in non-core firms reported receiving a promotion.

In terms of management practice, it is clear that the employment experience of people with disabilities can be significantly influenced by the knowledge, attitudes, and behaviours of those with whom the individual works, particularly direct supervisors and management. These employer attitudes and behaviours can be either barriers or facilitators to employment at all stages of the process, from recruitment and hiring to retention, leaving, and re-employment. Research with employers in Canada and the US outlined specific concerns around finding suitably qualified candidates with disabilities (Dixon, Cruse & van Horne, 2003), early disclosure of disability (Stensrud, 2007), performance (Stensrud, 2007), costs associated with accommodations (CWGHR, 2007; ICAD 2005; Dixon, Cruse & van Horne, 2003). Likewise, various policy analyses have identified poorly informed employers (CWGHR, 2006a), as well as stigma and discrimination as important barriers to employment of people with disabilities (Canadian HIV/AIDS Legal Network, 2003-2005).

From the perspective of an employee (or potential employee), the decision to disclose one's disability status, whether at the selection stage or at a later stage during employment, is seen as a key issue, particularly for employees with HIV/AIDS (ICAD, 2005) and those with mental health issues. Specifically, self-disclosure is closely linked to the perceived level of trust and support in the workplace, but this can be difficult to gauge prior to being hired or after a prolonged absence.

Fears of hiring discrimination following disclosure are not unfounded. Roessler, Neath, McMahon & Rumrill (2007) conducted a study of the prevalence and type of perceived workplace discrimination among workers with multiple sclerosis. Along with unjustified discharge, failure to provide reasonable accommodation, failure to meet terms and conditions of employment, and harassment, hiring discrimination was one of five most common allegations of workplace discrimination. Using a database of over 3,000 resolved allegations made by adults with multiple sclerosis (MS) to the Equal Employment Opportunities Commission (EEOC) between 1992 and 2003, the authors found that 27.7% of claims of hiring discrimination resulted in *merit* closures (i.e., sufficient evidence presented to the EEOC in support of the allegation of discrimination). Evidence of a relationship between company size and likelihood of merit closures for hiring discrimination was also found, with workers from smaller companies (15-100 employees) more likely to receive merit closures than workers from large (>500 employees) companies (Roessler et al., 2007).

The findings of this study echo earlier results from a national survey of adults with MS in which the majority of respondents had reported experiencing hiring discrimination, in addition to discrimination from supervisors, provision of reasonable accommodations, and equitable pay and benefits (Roessler et al., 2003, as cited in Roessler et al., 2007).

2.3.3.2 Accommodations

Many of the issues influencing the employee experience of requesting and receiving workplace accommodations are influenced by awareness and enactment of accommodation rights. Specifically, there is a shared lack of knowledge among employees and employers about human rights legislation protecting the rights of disabled workers to request and receive reasonable[17] accommodations from employers (CWGHR, 2006a; ICAD, 2005; Canadian HIV/AIDS Legal

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[17] Reasonable accommodation is defined as one that does not cause undue hardship on the organization, whereby undue is defined as "the point of accommodation, where if provided, would threaten the sustained operation of the organization.

Network, 2003-2005). Coupled with an absence in many workplaces of policies specifically to address the accommodation needs of workers with episodic disabilities and the acknowledgment that, even for those workplaces that have implemented policies, they are inadequate and in need of review, it is little surprise that employees report significant challenges in finding the information on what accommodations are available, navigating the request process (ICAD, 2005), and fear of stigma (Canadian HIV/AIDS Legal Network, 2003-2005). Requests for accommodation from employees have been characterized by some employers as a source of distrust in the employee-employer relationship, linked to unreasonable requests and diminishment of work effort (Stensrud, 2007).

Structural/physical accommodations

In Canada, it is estimated that over 20% of employed people with disabilities have a need for workplace physical/structural accommodation need to successfully fulfill their job functions (HRSDC, 2009). However, important gaps exist in meeting the physical accommodation needs of people with disabilities in the workplace, with only close to half (49.1%) of employed people with disabilities in Canada reporting that their physical/structural accommodation needs at work have been met (HRSDC, 2009), with men being less likely to report than women that these needs have been met.

The prevalence of accommodation needs reported by workers is not necessarily reflected in surveys with employers, indicating a potential and important gap in employer knowledge and responsiveness around accommodations. Close to three quarters (73%) of employers in the U.S. reported that no accommodations were needed for their employees with disabilities (Dixon et al., 2003), although requests for structural/physical workplace accommodations are the most prevalent accommodation type.

Failure to acknowledge the accommodation needs of employees may be rooted in concerns of the perceived costs associated with meeting those needs. Dixon et al. (2003) found that 40% of employers saw workplace accommodations as difficult and costly, a finding mirrored by Canadian employers (ICAD, 2005), with smaller employers (25 employees or less) being even more likely to perceive accommodations as difficult and costly (Dixon et al., 2003).

Failure to provide necessary structural/physical accommodations also appears to have an impact on the provision of worker training and promotion opportunities. Among the 10.5% of employees with disabilities in Canada who wanted to take workplace training but were prevented from doing so, 13.4% were unable to partake in training due to physical accessibility issues, 4.6% cited a lack of course adaptation to meet condition needs, and a further 4.3% cited transportation barriers (HRSDC, 2009). Stensrud (2007) found evidence that career promotions to workers with disabilities who are receiving workplace accommodations could be seen negatively by other workers (i.e., preferential treatment) and that extending accommodations to the new position would entail additional cost considerations.

Work arrangements and schedules
Slightly fewer employed people with disabilities in Canada report needing this category of workplace accommodation compared with physical/structural accommodations (16.6% versus 21.7%) (HRSDC, 2009). The most common accommodations in this category required by workers with disabilities in Canada are job redesign and modified work hours (17% and 19%, respectively) (CCSD, 2005). 70.2% of workers reported that their workplace accommodation needs in this category were met, a marked improvement over the rate of met needs reported in the first category of workplace accommodations (HRSDC, 2009).

However, with only 20% of HR professionals reporting that their organization had mechanisms to handle requests for job assessment and workplace redesign (CWGHR, 2006b), there is reason to suggest that significantly more workers may have needs that are not reported because their workplace does not have the system to record these types of accommodation needs. Other data point to important differences in work arrangement accommodations provided to workers with and without disabilities. Workers with disabilities were less likely to work flexible hours than those without disabilities (29.5% vs. 35.5%), and were less likely to work from home (15.9% vs. 23.6%). This finding is of particular concern if we consider that workers with disabilities may particularly benefit from these work arrangements (CCSD, 2005).

2.3.3.3 Non-wage benefits

Limited research was found describing the employee perspective of non-wage benefit impacts on employment, although a number of policy analyses and recommendations point to the importance of these types of benefits on people's disability and employment experience.

The lack of portability of employer health benefits was noted as a defining factor in what has been termed "job-lock" (CWGHR, 2007; Canadian HIV/AIDS Legal Network, 2003-2005). There are concerns that proof of insurability and pre-existing condition clauses common in private insurance plans provided by employers would come into effect if an employee with disabilities were to change employers, leading some employees to stay "locked" in their current jobs.

Challenges associated with the "coordination of benefits" clauses in private insurance policies often entail the obligation to seek out all possible benefits provided under provincial/territorial social assistance programs, often resulting in few additional benefits but requiring significant resources in time to complete forms and to undergo the necessary assessments for each benefit program (Canadian HIV/AIDS Legal Network, 2003-2005).

Gaining access to non-wage benefits, and especially extended health benefits, relies on a medical model whereby the physician acts as gatekeeper (Canadian HIV/AIDS Legal Network, 2003-2005), with the worker-physician interaction most often involving requests for sick notes, medical certification for work disability, and clearance for return-to-work (Costa-Black, Loisel, Anema et al., 2010). Further complicating the worker-physician interaction, especially as it relates to the physician as one of the main sources of eligibility determination assessments, are reports that some physicians feel ill-prepared to deal with specific workplace contextual factors, including patient beliefs about work, social support/dysfunction in the workplace and job satisfaction, that are critical factors to consider when assessing ability/readiness to work/work disability (Costa-Black et al., 2010; Pransky, Shaw, Franche & Clarke, 2004)).

For those individuals not in receipt of workplace extended health benefits, level of access to these across provinces, and in some cases are limited to those who are on social assistance (Canadian HIV/AIDS Legal Network, 2003-2005). The result is a disincentive to work as the likelihood for loss of benefits increases with income.

Other barriers associated with non-wage benefits in the form of private disability insurance provided through the workplace include the psychological impact of declaring total disability, difficulty in accessing the relevant information on coverage levels and eligibility requirements, and lack of fixed timelines for adjudication (Canadian HIV/AIDS Legal Network, 2003-2005).

2.3.3.4 Local employment support

Our search identified research or policy-relevant literature in the area of local employment supports. This may be a reflection of the nature of the programs providing this type of support, in that they are more regional in nature and would require a much more targeted search to locate. The interviews with experts will undoubtedly shed some light on the barriers to local employment supports provided to people with disabilities.

2.3.3.5 Government income support programs

Text box 1 below presents the main government income support programs available to people with disabilities.

Text Box 1: Brief Description of Selected Income Programs for People With Disabilities

FEDERAL

HRSDC

- Canada Pension Plan Disability Program (CPPD)
- Employment Insurance Sickness Benefits

Veterans Affairs Canada

- Veterans Disability Pension
- Rehabilitation and Vocational Assistance Services

Canada Revenue Agency

- Several personal income tax measures relevant to disability issues, including the disability tax credit, disability tax credit for children, medical expense tax credit, caregiver credit, infirm dependant credit, refundable medical expense tax credit, and disability supports deduction.
- Registered Disability Savings Plan, Working Income Tax Benefit exemption of training from the goods and services tax / harmonized sales tax (GST/HST) and the expansion of the list of GST/HST-free medical and assistive devices

PROVINCIAL

- Disability benefits or social assistance for persons with disabilities (ODSP)

WORKERS' COMPENSATION

- Publicly-administered insurance fund paid into by employers for employees injured on the job or who contract an occupational disease from work. Is comprised of a cash component and a medical or vocational component.

PRIVATE SOURCES

- Long-term disability or private insurance plans (mostly sponsored by employers, professional associations and administered by private insurance companies)

A number of the policy documents we reviewed noted that the eligibility criteria for many government income support programs were too narrow and resulted in a strict dichotomy between individuals who are fully able to work and those fully unable to work. As was indicated in numerous reports, this strict able/unable distinction fails to meet the needs of people with intermittent work capacity (Stapleton & Tweddle, 2008) and ultimately serves as a work disincentive since the return to work is accompanied by a withdrawal or significant reduction in income support (ICAD, 2005). Employees with disabilities or those wishing to re-enter the labour force after a period of illness have described this in terms of a fear of loss of benefits (Canadian HIV/AIDS Legal Network, 2003-2005).

There is a consistent theme in the literature reviewed regarding the lack of inter-jurisdictional coordination and inconsistencies across income support programs and jurisdictions in the definitions and assessment methods used (Stapleton & Tweddle, 2008). The result is a patchwork of programs that are exceedingly challenging to navigate, and can lead to underutilization of benefits and supports (ICAD, 2005). This inter-jurisdictional coordination also touches on the coordination of benefits. Whereas we spoke of the challenges of coordination of benefit clauses in private insurance plans, the coordination of benefits among the various publically funded income support programs have been seen as not necessarily serving the best interests of people in need of these supports (Canadian HIV/AIDS Legal Network 2003-2005), mainly for reasons of overly-cumbersome administrative processes, income from one program being clawed back when claimants access other government income programs without always being aware in advance of the financial repercussions (Canadian HIV/AIDS Legal Network, 2003-2005). As one study noted, the patchwork of income supports offered are done without an overarching strategy to ensure that all the needs of people with disabilities are met (Stapleton & Tweddle, 2008).

Psychological factors associated with declaring for benefits were also identified as potential barrier to accessing the full range of supports available to a person with intermittent work capacity. In particular, the Canadian HIV/AIDS Legal Network (2003-2005) noted that claiming full work incapacity in order to qualify for a benefit (e.g., CPP/QPP disability benefit) runs counter to the belief by many with episodic disabilities that they are able to work but under modified circumstances. Accepting the label of fully unable to work presents significant impacts to an individual’s self-esteem and self-concept as a productive member of society. Focus groups with adults living with HIV/AIDS raised concerns over the psychological impact of not returning to work, despite desire to do so, because of structural disincentives such as fear of losing benefits and the re-application process, resulting in further negative impacts on psychological wellbeing and health (ICAD, 2005; Canadian HIV/AIDS Legal Network, 2003-2005).

2.3.3.6 Government employment support programs

Text box 2 provides an overview of some of the federal and provincial (Ontario only) level employment support programs available to people with disabilities (Stapleton & Tweddle, 2008):

Text Box 2: Brief Description of Selected Employment Programs for People With Disabilities

FEDERAL
HRSDC

- Labour Market Agreements for Persons with Disabilities (LMAPD)
- The Opportunities Fund for Persons with Disabilities

PROVINCIAL (ONTARIO)
Ministry of Community and Social Services

- Ontario Disability Support Program (ODSP) - Employment Supports

Ministry of Training Colleges and Universities

- JobConnect Program

Ministry of Health and Long-Term Care

- Community Mental Health Employment Programs

The following section describes some of the barriers to employment people with disabilities in their interactions with government employment support programs, although we recognize that many support programs provide both income and employment assistance to people with disabilities and that barriers cited in this section share a great deal of overlap with those presented in the income supports section.

In their international policy review of employment support programs, CWGHR (2006a) identifies five (5) main sets of issues, many of which resemble those highlighted in the section on income support programs: inadequate funding; eligibility criteria; unclear jurisdictions; uneven implementation and coordination, and lack of integration. CWGHR (2006a) notes that "responsibility for the social integration of people with disabilities, especially in employment, is highly fragmented among national and provincial/territorial levels, divided between departments and agencies and across policies, laws, regulations and programs" (p. 58).

The study by Corden and Thornton (2002) consists of an international review of program evaluations of employment support programs with disability components in the UK, US, Canada, Australia, and Austria, done as part of the development of the *New Deal for Disabled People* in the UK. Evaluation designs used across the six (6) program evaluations included one randomized field experiment, quasi-experimental with matched or unmatched comparison groups, among several other less rigorous evaluation designs (not identified). Among the most common type of service offered through the evaluated programs were: general support, advocacy and counselling, work guidance, education and training, financial advice, direct financial support, work tasters, physiotherapy, and provision of aids and equipment (n.p.).

Corden and Thornton (2002) found general support for the case management approach among program clients, but that certain factors associated with this approach could act as barriers to clients. Communication delays and poor communication with the case manager was found to lead to poor client satisfaction. The quality of the relationship with the case manager was identified as a key component to achieving high levels of satisfaction, although no evidence was presented regarding impacts of this relationship on employment outcomes. Intensive and time-consuming assessment methods in programs which took a systematic and highly procedural approach were found to be overly cumbersome for both the clients and the case managers.

Results from the program evaluation review from Corden and Thornton (2002) indicate that benefits to employees of employment supports programs tend to diminish within one year. However, the provision of in-work supports may help offset these diminishing impacts. The authors note that many of the programs reviewed focused almost exclusively on pre-employment support, leaving a gap in helping workers successfully transition to sustained employment.

2.3.4 Innovative and promising practices

Our review of the literature yield very little in the way of robust evidence or evaluations of employment and income support programs for people with disabilities, let alone any indication of what kinds of programs and services work best for specific client groups. The exception to this is the review referred to earlier by Cordon and Thornton (2002) that reviewed six employment support program evaluations. Specific findings from this study have already been noted in the previous section, but in general, they note the effectiveness of job search assistance, supported employment approaches (versus traditional vocational rehabilitation), and ongoing support through the various stages of employment. They also highlight the need for greater client engagement in the formulation of individual progress plans and in on-going service delivery, and for employer awareness of program options and resources to support disabled workers.

Similarly, in their review of nine employability assistance programs for people with disabilities (EAPD), HRSDC (2002) identified high level of client focus and a holistic approach to assessing client needs as best practices for these programs. In addition, they emphasize the importance of creating supportive but challenging interactions with clients, establishing partnerships with employers and three-way communication among program staff, employers and clients. The Canadian Medical Association (as cited in Costa-Black et al., 2010) goes even further in its guidelines for medical practitioners, suggesting that assessment of the need for employability supports take into account not just the medical needs of the client but also the psychosocial characteristics of the workplace context. Such characteristics include quality of relationship with supervisors and colleagues and job satisfaction).

An international review of policies and programs to facilitate labour force participation for people with episodic disabilities (CWGHR, 2006a) identified the following priority recommendations:

- *increased flexibility* by providing more inclusive access for people with episodic disabilities to benefits by restricting the use of ‘severe’ and ‘prolonged’ in eligibility criteria, and permitting part-time or periodic work without penalty or loss of benefits;

- *clearer jurisdictional responsibility* to reduce the complexity, facilitate access, and eliminate gaps in support programs amid the myriad of public and private coverages;

- *holistic case management* that addresses all underlying barriers to employment using a biopsychosocial approach to defining health and functioning;

- *resources and supports to employers* in the form of financial incentives and information and technical supports to develop and implement effective workplace policies that support disabled workers;

- *guaranteed and immediate reinstatement of benefits* in the event of employment interruption due illness recurrence.

Subsequent to its 2006 report, CWGHR, on behalf of the Episodic Disability Network, called on the federal government to host a national policy dialogue on the following three (3) topics:

1. financial implications of increasing coordination among existing disability support programs;
2. developing a program that provides partial disability income support to complement earned income;
3. changing disability income support programs to allow people to work part-time while still receiving partial sickness benefits.

2.3.5 Summary of key findings

This literature review included numerous research and policy reports believed to cover the main literatures available on the labour force experience of people with intermittent work capacity due to episodic disability. However, we acknowledge that our search parameters only briefly touched upon illness-specific resources, and as such, it is likely that a more in-depth search of these materials would reveal greater nuances about the employment and labour force experiences of people with HIV/AIDS, multiple sclerosis, migraine headaches, back pain, to name just a few of the illness and conditions known to increase the likelihood of intermittent work capacity. In addition, little information was found in terms of the unique needs and experiences of vulnerable sub-groups with episodic disabilities, such as new immigrants, Aboriginals, and older workers. This is not to say that this information does not exist, but that our search did not identify these potential resources.

The main findings of this literature review point to persisting issues related to defining episodic disability, an issue which has made it difficult to quantify the prevalence of episodic disability in Canada and has contributed to the creation of systemic barriers to support systems for individuals with episodic disabilities. Government policies and programs are still mostly reliant on the traditional dichotomies of disabled or not, and able/unable to work, although efforts from the episodic disability community to bring about changes in eligibility criteria signal a shift towards greater flexibility.

The data currently available in Canada on disabilities generally and episodic disabilities specifically is in large part cross-sectional in nature. Numerous calls have been made for the importance of longitudinal research to capture the dynamic nature of episodic disability and its impact on employment trajectories.

Active implementation of workplace policies governing employment and retention of workers with episodic disabilities is critical but evidence suggests that a majority of workplaces do not have policies relevant to episodic disabilities. Moreover, few organizations appear to have the mechanisms in place to handle job assessments and workplace redesigns, despite the fact that job redesign is the second most requested physical/structural accommodation requests by workers in Canada, behind modified work hours. The role of human resource (HR) professionals in acting as champions for developing and implementing workplace policies appears to be a critical factor, although many of these professionals report being ill-equipped in terms of knowledge and training to manage cases of episodic disability.

Concerns from employers regarding the hiring and retention of employees with episodic disabilities include finding suitably qualified candidates, the importance of early disclosure of disability, and costs associated with accommodations. A number of policy analyses have identified poorly informed employers, and fear of stigma and discrimination as important barriers to employment of people with disabilities. There also appears to be a shared lack of knowledge among employees and employers about human rights and employment legislation protecting the rights of disabled workers to request and receive reasonable accommodations from employers. In addition to significant gaps meeting the accommodation needs of people with disabilities in the workplace, we found some evidence showing that requests for accommodations could sometime be perceived negatively on the part of employers. It would also appear that accommodation needs appear to impact not only the employee’s ability to fulfill the functions of their jobs but also have a bearing on the training and promotion opportunities afforded to them.

Key issues related to non-wage benefits include lack of portability of health insurance and extended health benefit coverage across jobs and provincial/jurisdictions. This lack of portability is associated with employee “job-lock” whereby job mobility is significantly constrained because of employee concerns over pre-existing condition clauses and proof of insurability requirements that may come into effect when changing employers. Similarly, gaining access to extended health benefits and other non-wage benefits relies to a great extent on a medical model of health provision whereby the physician acts as gatekeeper, with new guidelines from Canadian medical organizations moving physicians towards greater biopsychosocial models of employee and workplace assessments in devising health and return to work plans.

With respect to employment and income support systems, our literature review identified several important barriers faced by people with episodic disabilities: difficulty in accessing and understanding relevant information, which at times leads to underutilization of supports and benefits; inflexible eligibility requirements that do not reflect the reality of episodic disabilities; a patchwork of coverage across the various jurisdictions, each with different eligibility criteria and assessments leading to challenges in benefit coordination; and time consuming processes involved in re-applying for benefit reinstatement along with non-guarantee of approval.

Innovative and promising practices center around the use of job search assistance, supported employment approaches, ongoing support through the various stages of employment, greater client engagement in the formulation of individual progress plans, employer awareness, importance of creating supportive but challenging interactions with clients, establishing partnerships with employers, and three-way communication among program staff, employers and clients. We anticipate that interviews with key informants and focus groups with people who have episodic disabilities and intermittent work experience will help develop a greater and more in-depth understanding of these issues and ways to address them.