

Advancing Inclusion: How Our Understanding of the Dynamic Nature of Disability Is Informing Interventions That Support Employment

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Abstract

Over the past three years, the policy division in the Office for Disability Issues in the Ministry of Human Resources and Skills Development of the Government of Canada has been involved in a research initiative to better understand the dynamic nature of disability and its impact on employment and inclusion. The initiative uses both quantitative and qualitative research methods to better understand how disability is experienced over time. It also involves reviewing data from recent program interventions that view disability as a dynamic process. The final phase of the initiative will be a roundtable of researchers and community stakeholders. The roundtable will serve as forum where the research is presented and an action plan for future research and policy development will be discussed.

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Executive Summary

Over the past three years, the policy division in the Office for Disability Issues in the Ministry of Human Resources and Skills Development of the Government of Canada has been involved in a research initiative to better understand the dynamic nature of disability and its impact on employment and inclusion. The research encompasses five phases and includes:

1. Analysis of cross sectional data from the 2006 Participation and Activity Limitation Survey;
2. A review of data from two recent federal program interventions that view disability as a dynamic process;
3. Analysis of available longitudinal survey data that captures disability and labour force participation over time,
4. Qualitative research that explores the perspectives of both people with disabilities and employers on intermittent work capacity, and
5. A roundtable meeting of researchers and stakeholders to discuss research findings and plan future activities.

Results from phase one indicate that the prevalence of people with disabilities who are sometimes or often limited at work is over 50%. Data indicate that work activity patterns for people with disabilities who report being sometimes or never limited at work mirror the population of people without disabilities.

People with disabilities who report that they are often limited at work are far less likely to work full time, full year and yet they are no more likely to work part time or part year. Rather, they are more likely to not be working at all. Also of interest, are the differences in unemployment spells between the “often”, “sometimes” and “never” populations. People with disabilities in the “often” group are significantly more likely to report three or more periods of unemployment during a twelve month period than individuals in the “sometimes” or “never” groups.

Phase two of the initiative presents an interesting overview of two recent interventions at Canada Pension Plan Disability and Veterans Affairs Canada. Both recent interventions view disability as a dynamic process. Phases three and four involve further quantitative analysis on longitudinal data, as well as, an in-depth qualitative research component. The qualitative research seeks to capture the perspectives of both employees and employers on intermittent work capacity. The research initiative will culminate in a roundtable which brings together researchers and stakeholders.

In seeking to better understand and describe disability as a dynamic process, this initiative has helped to underscore the complexity of disability as it is experienced by an increasingly larger numbers of Canadians. It has also suggested a way to

frame important issues facing policy makers. From this initiative important questions are emerging namely:

1. How can government support individuals with intermittent work capacity?
2. How can government support employers to hire, retain and accommodate people with disabilities who have intermittent work capacity?

Introduction

In recent years, social policy researchers and Canadian disability organizations have begun to explore different approaches to better understand and document the dynamic nature of disability.

Some of the impetus has come from the disability community which has encouraged government policy makers to better address the needs of people with “episodic” disabilities. The growing body of literature on episodic disability defines it as lifelong and chronic conditions such as arthritis, HIV and multiple sclerosis etc. People living with episodic disabilities may experience periods of good health that may be unpredictably interrupted by periods of illness or disability¹. Additional “episodic” disabilities identified in the literature include underlying conditions such as those associated with musculoskeletal and neurological disorders and severe migraines. Individuals who experience disability as episodic can alternate between periods in which they are able to work full-time and periods in which they need to work part-time or not at all.

Another impetus to better understand the dynamic nature of disability has come from the social policy research community. Using longitudinal data, social policy researchers have challenged the traditional understanding of disability as a static or continuous state. Researchers have challenged policy makers to leverage existing longitudinal data as well as develop new survey instruments that capture the experiences of people with disabilities over time.

This paper provides an overview of a research initiative undertaken by the policy division in the Office for Disability Issues of the Canadian government, to better understand the dynamic nature of disability and its impact on employment.

The research encompasses five phases and includes:

1. Analysis of cross sectional data from the 2006 Participation and Activity Limitation Survey;
2. A review of data from two recent federal program interventions that view disability as a dynamic process;
3. Analysis of available longitudinal survey data that captures disability and labour force participation over time,

¹ Statement of the Common Agenda on Disability: full participation in employment and work, 2005. Co-Authored by ARCH: A Legal Resource Centre for Persons with Disabilities, Canadian Association of Nurses in AIDS Care, Canadian Association of Physical Medicine and Rehabilitation, Canadian AIDS Society, Canadian Breast Cancer Network, Canadian Cancer Society Ontario, Canadian HIV/AIDS Legal Network, Canadian Working Group on HIV and Rehabilitation (CWGHR), COCQ-sida, Lupus Canada, Multiple Sclerosis Society of Canada, Muscular Dystrophy Canada, Ontario Breast Cancer Research Initiative

4. Qualitative research that explores the perspectives of both people with disabilities and employers on intermittent work capacity, and
5. A roundtable meeting of researchers and stakeholders to discuss research findings and plan future activities.

1. Analyzing cross-sectional survey data

1.1 *Capturing the dynamic nature of disability using cross-sectional survey data*

The 2006 Participation and Activity Limitation Survey (PALS) is a cross-sectional post-censal survey and is the fifth in a series of disability-specific surveys designed to provide information about the barriers that prevent full economic and social inclusion for people with disabilities. It also contains important data on the nature and severity of disability and underlying health problem or condition. Establishing the research population in PALS was possible using two lenses – as defined in the literature using specific underlying health problems or conditions or as defined by barriers experienced when interacting with the labour market. Both approaches were pursued.

The literature review conducted as part of the research identified 27 underlying conditions that are considered to be “episodic”.² These conditions included: chronic conditions such as multiple sclerosis, HIV/AIDS, lupus, Hepatitis C, some forms of mental illness, cancer, arthritis, musculoskeletal disorders, migraine, and neurological disorders. Using this approach, it was determined that 46.4% of the 2.5 million working age population (aged 15-64) with disabilities reported having one of the 27 conditions associated with episodic disability.

A further examination of the descriptions provided by the respondent of his/her underlying health problem/condition showed that slightly less than half of the remaining 48% of the working age population with disabilities did not provide a health problem/condition but gave instead a symptom such as sore back, bad knees, problem learning, bad memory, etc. The PALS data also include 5.6% of the population with disabilities who did not provide any information on their underlying health problems/conditions.

Using the responses to the 2006 Census disability questions that were repeated on the PALS questionnaire, it was possible divide the population of people with disabilities into four groups: those who indicated that they are “often” limited at work or school, “sometimes” limited, “never” limited and those who neither work nor attend school.³ Among the 2.5 million working age adults with disabilities, 51.8% indicated that they were “often” or “sometimes” limited in the workplace, 19.6% stated that they were “never” limited in the workplace and 28.6% reported

² “Towards a better understanding of the dynamics of disability and its impact on employment”, Adele Furrrie Consulting Inc, 2010.

³ Hereafter referred to as “often”, “sometimes” and “never”.

that the concept of limitation at work or at school did not apply since they neither attended school nor worked.

Table 1 below shows that individuals who report being “often” or “sometimes” limited in the workplace are more likely to fall into the group that does not report at least one of the “episodic” health problems/conditions. Given the issue with the self reporting of the underlying health problem/condition in PALS, it was decided that for this first foray into survey data to look at disability as a dynamic state, research would focus upon the population that report work limitations.

It is acknowledged that this approach can only be considered a crude proxy for episodic disability but given the data available, it was an approach which could contribute to our understanding of disability as a dynamic state.

Table 1 Work classification by health problem/condition classification

Table 1: Work classification by health problem/condition classification					
Underlying health problem/condition as defined in the literature	Work limitation				
	Often	Sometimes	Never	Concept not applicable	Total
At least one of the 27 “episodic” health problems/conditions as defined in the literature	200,500	368,700	189,800	382,600	1,140,500
None of the 27 “episodic health problems/conditions	253,400	381,400	248,800	296,200	1,179,800
Underlying health problem/condition not provided	30,500	39,500	42,300	24,600	137,600
Total	484,400	789,600	480,900	703,400	2,457,900

Source: Towards a better understanding of the dynamics of disability and its impact on employment, Adele Furrie Consulting Inc, 2010

1.2 Understanding different “age” distributions

Table 2 below shows the breakdowns of “often”, “sometimes”, “never” populations by age and sex. Age is always a factor to consider when comparing the population of people with disabilities to the population without disabilities. Because disability is correlated with aging, the population of people with disabilities is on average older than the population of people without disabilities.

Interestingly, the age distributions for “often”, “sometimes”, “never” populations are different. The “never” groups’ age distribution more closely resembles the population of people with disabilities as whole. The “often”, “sometimes” populations tend to be younger than the population of people with disabilities as a whole. And yet, these “often” and “sometimes” groups are still significantly older than the population of people without disabilities.

Table 2 Populations by age group and sex

Data for Table 2 Populations by age group and sex for persons with disabilities by Census classification of “work limitation” and for persons without disabilities

Sex	Age groups	Census classification of "work limitation" - persons with disabilities reporting limitation at work/school					Persons without disabilities
		Often	Sometimes	Never	Concept not applicable	Total	
Females	15 – 24	12.6%	10.1%	7.6%	1.4%	7.2%	20.4%
	25 – 34	11.9%	13.5%	9.1%	6.1%	10.0%	19.8%
	35 – 44	21.7%	21.9%	21.7%	11.1%	18.3%	22.9%
	45 – 54	32.2%	33.9%	28.6%	28.6%	30.9%	22.1%
	55 – 64	21.5%	20.6%	33.0%	52.8%	33.5%	14.6%
	15 – 64	228,600	407,500	247,100	423,200	1,306,400	9,521,100
Males	15 – 24	14.6%	10.2%	7.3%	2.7%	8.8%	21.4%
	25 – 34	10.6%	11.9%	9.7%	5.0%	9.5%	19.3%
	35 – 44	20.9%	22.4%	20.9%	10.5%	18.9%	22.4%
	45 – 54	28.4%	32.0%	28.0%	27.6%	29.3%	22.0%
	55 – 64	25.4%	23.6%	34.1%	54.2%	33.6%	14.8%
	15 – 64	255,900	382,100	233,300	280,200	1,151,500	9,394,100
Both sexes	15 – 24	13.7%	10.1%	7.5%	1.9%	8.0%	20.9%
	25 – 34	11.2%	12.7%	9.4%	5.6%	9.7%	19.6%
	35 – 44	21.3%	22.1%	21.3%	10.9%	18.6%	22.7%
	45 – 54	30.2%	33.0%	28.3%	28.2%	30.1%	22.1%
	55 – 64	23.6%	22.1%	33.5%	53.4%	33.6%	14.8%
	15 – 64	484,500	789,600	480,400	703,400	2,457,900	18,915,200

Source: 2006 PALS

With respect to gender, the composition of people with disabilities in the “often” group is different from the populations in the “sometimes” and “never” groups. Women are less likely to report being “often” limited and more likely to report being “sometimes” or “never” limited at work.

1.3 The characteristics of the “sometimes”, “often” populations

Of the estimated 2.5 million people with disabilities aged 15 to 64 years, 51.8% or 1.3 million indicated that they were “often” or “sometimes” limited in the workplace.

The research report on which this part of the paper is based included data covering the disability characteristics of the populations, their demographic characteristics, their work-related data and their socio-economic characteristics. We have limited our discussion in this paper to selected work-related characteristics but encourage the readers to access the full report that is available through the consulting firm.⁴

⁴ Adele Furrie Consulting Inc., Ottawa, Canada adfurrie@rogers.com

We begin with work activity patterns⁵ and note that only 23.3% of people with disabilities who report being “often” limited at work worked full-time, full year in 2005. Contrast this to persons who report being “sometimes” limited and “never” limited where these two percentages are much larger and very similar to the population without disabilities – 42.1%, 42.6% and 45.8% respectively. There is little difference noted among the four groups for those individuals who worked full time but for only part of 2005. People with disabilities who report being “sometimes” limited are slightly more likely to report working part-time (21%) compared to 16.9% (“often” limited), 18% (“never” limited) and 17.5% (persons without disabilities).

Table 3: Work limitation by work activity

Table 3: Work limitation by work activity						
Work activity	Work limitation					Persons without disabilities
	Often	Sometimes	Never	Concept not applicable	Total	
Worked full time, full year in 2005	23.3%	42.1%	42.6%	6.2%	28.2%	45.8%
Worked full time, part year in 2005	18.0%	19.4%	18.3%	6.3%	15.2%	19.7%
Worked part time, full year in 2005	6.5%	8.1%	6.7%	2.0%	5.8%	6.4%
Worked part time, part year in 2005	10.4%	12.9%	11.3%	6.0%	10.1%	11.1%
Did not work in 2005 but worked in 2006	4.0%	2.4%	2.2%	1.7%	2.5%	2.4%
Did not work in 2005, worked before 2005 or never worked	37.8%	15.0%	19.0%	77.8%	38.2%	14.6%
Total	484,400	789,600	480,400	703,400	2,457,900	18,915,200

Source: 2006 PALS – Towards a better understanding of the dynamics of disability and its impact on employment, Adele Furrie Consulting Inc, 2010.

Among the 1.1 people with disabilities who were employed at the time of the PALS interview, an estimated 205,000 or 19.3% had some periods of unemployment during the 12 months preceding the survey interview. Again, the more limitation reported in the workplace, the more likely there were periods of unemployment. Within this 205,000 group of employed individuals with disabilities:

- 16.4% report three or more periods of unemployment
- among those who report being “often” limited at work, this percentage increases to 25.5%
- among those who report a “sometimes” limitation, only 13% report three or more periods of unemployment.

⁵ The number of weeks in which a person worked for pay or in self-employment in 2005 at all jobs held, even if only for a few hours, and whether these weeks were mostly full time (30 hours or more per week) or mostly part time (1 to 29 hours per week).

Proportionately, more people with disabilities who report that they are “often” or “sometimes” limited at work indicate having to change the kind of job that they do, the amount of work they can do or the nature of job because of their disability.

When asked if:

- they changed the kind of work that they did because of their disability, 33.7% in the “often” group and 33.1% in the “sometimes” group answered “Yes” - compared to 27.9% among all adults with disabilities who were employed at the time of the PALS interview.
- they changed the amount of work that they did because of their disability, 37.2% in the “often” group and 39.6% in the “sometimes” group answered “Yes” - compared to 32.4% among all adults with disabilities who were employed at the time of the PALS interview.
- they had to change jobs because of their disability, 25.4% in the “often” group and 25.6% in the “sometimes” group answered “Yes” - compared to 22% among all adults with disabilities who were employed at the time of the PALS interview.

2. Recent program interventions

2.1 *New Veterans’ Charter*

With the New Veterans Charter (2006), the Government of Canada makes a major commitment to provide both veterans and their families with the support needed to make the transition from the military to the civilian workforce. This suite of modernized programs provide needs based support to support Canadian Forces members, Veterans and their families as they transition from military to civilian life.

One of the goals of the New Veterans Charter is to provide releasing military personnel employment in the civilian sector that requires at least the same level of education and training and provides equivalent compensation.⁶

⁶ This discussion of the New Veterans Charter will only focus narrowly on employment objectives and supports. However, it is important to note that the New Veterans Charter is much broader in scope. The desired outcomes of the Charter are that Canadian Forces Members, Veterans and their families:

- experience improved health status and functional capacity as a result of access to treatment benefits and rehabilitation services;
- actively participate in the civilian workforce (unless totally disabled or retired) as a result of access to employment-related supports in the form of vocational assistance, training and job placement assistance;
- have a level of income adequate to meet basic needs as a result of enhanced employment opportunities provided by job placement assistance, and access to employment enhancement supports such as re-training opportunities as part of vocational rehabilitation;
- actively participate in and integrate into their communities; and

The Charter outlines three broad areas of support available to veterans with disabilities:

1. Rehabilitation including: medical, psycho social and vocational
2. Financial Benefits: including earning loss during rehabilitation and broader income support
3. Health Benefits: access to the public service health care program

The suite of services and benefits available under the Charter includes a lump-sum disability award, rehabilitation, financial benefits, health benefits, and career transition assistance

Research has identified the need for programs to focus on rehabilitation and reintegration to civilian life, with the aim of helping veterans regain employment and attain their fullest potential. Moreover, to achieve these outcomes, the New Veterans Charter is aligned with the best practices of modern disability management.

The Charter takes a holistic approach to disability management and seeks to return clients to work to their fullest capacity. The Charter also recognizes that some veterans may need continuing support to maintain attachment to the workforce.

The Canadian Forces Income Support benefit is designed to provide a soft landing for Veterans that have successfully completed the rehabilitation program, and are capable of returning to 'suitable gainful employment' but have not been successful in obtaining such employment.

Temporary Earnings Loss provides transitional income after a client finishes intense rehabilitation programs. Extended Earnings Loss will continue to top up wages up to the 75% pre-release level to support veterans who are in work but at a lower earnings level. While these broader income support benefits are reviewed on an ongoing basis, they can continue up until the veteran is eligible for a retirement pension. Thus, the program continues to support workforce attachment even if capacity remains intermittent or limited.⁷

The Health Benefits program supports workforce attachment for veterans. Veterans are able to buy into the plan regardless of employer or employment status. Thus, veterans have affordable access to often necessary drugs, aids,

-
- feel recognized for their contribution.

⁷ Canadian Forces Income Support is only for clients who have completed rehab and capable of "suitable" gainful employment and provided while looking for employment. If they end up working part-time (at their choice) there is no additional support provided.

devices and therapies. This supports veterans to explore self employment as well as work in enterprises that may not offer supplemental health insurance as a non-wage benefit.

In many respects the New Veterans Charter addresses the concerns that workers and policy makers have with the emergence of non-standard work. Non-standard work is work that is less than full time, full year. The emergence of non-standard work has traditionally been seen as a concern of policy makers and workers, as it is often characterized by low wages, less job security and few if any non-wage benefits. Yet, the Charter recognizes that for some veterans, non-standard work may be an important pathway to maintain workforce attachment.

2.2 *Canada Pension Plan Disability (CPPD) Return to Work Supports*

CPPD is Canada's largest long-term disability insurance program. It is a contributory program that provides basic income replacement to working age Canadians with severe and prolonged disabilities who are unable to work regularly at any job.

The CPPD program pays benefits to approximately 300,000 persons (about 2% of the working age population). Approximately half of all CPPD beneficiaries either have a mental illness or a musculoskeletal condition.

Since the mid-90's, CPPD has included a suite of program policies designed to proactively support community participation and workplace reintegration; including a small, targeted vocational rehabilitation program. Building on this foundation, and to address the concerns of those who feared loss of benefits if they were unable to remain in the workforce, automatic reinstatement of disability benefits was introduced as a legislated entitlement in 2005. This represents a key work incentive and support.

About 10% of CPPD recipients have low levels of employment earnings each year (mean earnings \$2000 - \$3000). Of those who leave the benefit for work, approximately 15% experience a recurrence of their medical condition and return to benefits using Automatic Reinstatement.

While the number of beneficiaries working regularly enough to leave the benefit has doubled in seven years, it remains just below 1% of the caseload. This reflects the severe nature of disabilities found in the CPPD eligible population.

These results, combined with client feedback, suggest that Automatic Reinstatement, combined with other supports for returning to work is targeting at-risk clients with episodic or terminal conditions, including mental illness and cancer.

3. Analyzing longitudinal survey data

3.1 *Some background*

In 2000, Tania Burchardt published her ground breaking research “The Dynamics of Being Disabled” in the Journal of Social Policy.⁸ Professor Burchardt used longitudinal data from the British Household Panel Survey (BHPS) to demonstrate that only a “small proportion of working-age people who experience disability are long-term disabled (Burchardt, 2000).” Challenging the prevailing understanding among social policy makers that disability is a static state, she introduced the concept of ‘disability trajectories’ that map the variations in how individuals experience disability over time.

By analyzing the BHPS data over a seven year period, she was able to identify six distinct trajectories of disability: “one off” (disability reported only in one year, “short repetitive” (disability in two or three non- consecutive years), “short continuous” (disability in two or three consecutive years), “long repetitive” (disability in four, five or six years non-consecutive years), “long continuous” (disability in four, five or six consecutive years), and “always” (continuous state of disability in all seven years).

Some shortcomings to the approach include:

- Since the data records observations at one point in time during each year, duration of spells associated with intermittent disability (“short repetitive”, “long repetitive” trajectories) cannot be precisely measured.
- Observations at yearly intervals may also fail to capture individuals with intermittent disability who fall outside the identified “short repetitive”, “long repetitive” trajectories.
- Individuals may report disability in alternating years but as the result of very different underlying conditions (i.e. year 1 = 1 because of an automobile accident injury, year 3 = 1 because of a fall leading to broken leg, year 5 = 1 because of cancer diagnosis).

Burchardt’s work highlights that the available longitudinal survey instruments, while better at capturing the dynamic nature of disability, are still problematic.

3.2 *Analysis of Canadian longitudinal survey data*

There are two Canadian surveys that afford the opportunity to apply the Burchardt disability trajectory methodology – the Survey of Labour and Income Dynamic (SLID) and the National Population Health Survey (NPHS). Both these surveys include a set of questions to identify the population with disabilities. While they lack much of disability specific information contained in PALS (notably information on severity, type of disability and barriers to participation), they allow researchers to look at the labour force status of people with disabilities over time.

⁸ This article was published in the Journal of Social Policy, 29, 4, 645-668: 2000.

Current research underway is using available longitudinal data to map different disability trajectories and generate estimates of prevalence for each trajectory group. Differences in labour force outcomes and income levels of the different trajectory groups will be explored. While this research is still in the preliminary phase, it is anticipated that it will provide more insights into the impact over time on the employment of people with disabilities.

It is important to note, however, that this research is encountering many of the same limitations that Prof. Burchardt encountered using BHPS data. Yearly observation points mean that there will be both false negatives and false positives in attempting to capture the population of people who experience disability episodically, or who may have intermittent work capacity.

SLID panels are also shorter than the BHPS and contain fewer observation points. The NPHS is continuous survey but over time individuals dropout and the sample is not refreshed. Additionally, neither SLID nor NPHS contain specific questions on how the presence of a disability affects work capacity. This stage of the research is anticipated for completion in early 2011.

4. Increasing our understanding through qualitative research

In designing the research initiative to gain better understanding of the dynamic nature of disability and its potential impact on employment, it was determined that a qualitative component was needed. The qualitative component recognizes that present quantitative instruments may not be adequate to capture the dynamic nature of disability. It also recognizes that qualitative research can provide rich data on how disability is experienced in workplace.

Presently this research is exploring in detail how people with disabilities who have intermittent or limited capacity have been able to successfully maintain attachment to the labour force, while others become discouraged and drop out.

For this research, a person with intermittent work capacity is defined someone with a disability or health condition who:

1. needs to be absent from the workplace more frequently or for extended periods of time because of his/her disability or health condition or
2. who is not able to work predictable full-time hours because of his/her disability or health condition or
3. whose productivity is unexpectedly and periodically diminished because of his/her disability or health condition.

The research is designed to capture perspectives from employees and employers and actively involves the participation of the disability community. While it builds on the findings of the previous quantitative work, this work focuses less on specific medical conditions and more on systemic and structural barriers that keep people out of the labour force. It is also attempts, with greater precision, to understand the conditions and supports that make it possible for

people to stay in the labour force. There are currently three qualitative projects underway and they are expected to be completed in early 2011.

5. Roundtable bringing together researchers and stakeholders to discuss findings

Scheduled for the spring of 2011, the Office of Disability Issues will host a roundtable forum to bring researchers and stakeholders together to discuss research findings. Research findings from the initiative will be presented and a structured discussion will take place. The goal of the roundtable will be to produce a discussion paper which outlines how our emerging understanding of the dynamic nature of disability can inform research, program and policy interventions in the future.

Conclusion

In seeking to better understand and describe disability as a dynamic process, this initiative has helped to underscore the complexity of disability as it is experienced by an increasingly larger number of Canadians.

It has also suggested a way to frame important issues facing policy makers. From this initiative important questions are emerging namely:

1. How can government support individuals with intermittent work capacity?
2. How can government support employers to hire, retain and accommodate people with disabilities who have intermittent work capacity?

Further, it is hoped that the data, analysis and resulting roundtable discussion will be the foundation of a process which seeks to answer these questions and to develop effective interventions that advance economic and social inclusion for all Canadians.