



Episodic Disabilities in Canada

*People with episodic
disabilities in Canada: Who are
they and what supports do they
need to obtain and retain
employment?*

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Abstract

Background: Many people who have certain types of health conditions (e.g. multiple sclerosis, bi-polar disorder, HIV or arthritis) have unpredictable episodes of illness followed by periods of wellness. The episodes of illness often result in intermittent work capacity (IWC). Our research is one step in the gathering of information to gain a better understanding of the employment issues faced by this segment of Canada's population with disabilities. **Methods:** We conducted a literature review and developed a statistical profile of people with episodic disabilities derived from the 2012 Canadian Survey on Disability. **Results:** Many people with episodic disabilities have sought, obtained and retained employment. Many have found employers who have worked with them to accommodate their fluctuating work disability. However, there are many who are still struggling. **Conclusions:** The findings of this report advance the emerging literature on episodic disability and employment. It highlights the need to better understand the employment trajectories of persons with episodic disabilities, as well as their interactions with various income support programs over time. There is also a need to explore successful cases of retention in order to understand the strategies that these employers had implemented.

1. Overview, Objectives and Scope of the Research

Many people who have certain types of health conditions (e.g. multiple sclerosis, bi-polar disorder, HIV or arthritis) have unpredictable episodes of illness followed by periods of wellness. The episodes of illness often result in intermittent work capacity (IWC). From an employer's perspective, IWC is expressed as instability in an employee's attendance and productivity that results in the employer trying to balance her/his business objectives while still being able to maintain an inclusive workforce with appropriate accommodation for the employee during an illness episode (Lysaght *et al.*, (2011). Some employers have been able to achieve that balance, and, in these instances, employees with a chronic or episodic health condition that results in IWC are able to obtain and retain employment. Others with IWC are left without employment and, because of the intermittent nature of their disability, cannot access income support programs that, for the most part, define disability as severe and prolonged.

According to the Episodic Disabilities Network, there are 21 health conditions that can result in an episodic disability, which, in turn, can result in IWC.¹ What are the demographic, socio-economic and disability characteristics of the population of Canadians with episodic disabilities and what is the impact on their education, labour force participation and income? What is their labour market experience? How well does the Canadian disability policy system serve their needs? Answering these questions is a

¹ A list of these conditions is included as Annex A.

step in the gathering of information to gain a better understanding of the employment issues faced by this segment of Canada's population with disabilities.

This research is part of a three-phase project that has as its focus the hiring, retention and progression in employment of people with episodic disabilities. The three phases of the project include Information Gathering (Phase 1), Enhancement of the Job Accommodation System (JAS[®]) and the Development of Resource Materials (Phase 2), and Dissemination to Effect Change (Phase 3).

Phase 1 includes five activities:

1. a statistical profile of people with episodic disabilities derived from the 2012 Canadian Survey on Disability (CSD), including a literature review;
2. the development of a questionnaire to be completed by individuals who have health conditions that result in unpredictable episodes of illness and wellness;
3. a survey of individuals with episodic disabilities and the dissemination of the findings;
4. an environmental scan of employers' policies and programs to accommodate employees with fluctuating health status; and
5. a review of JAS[®] to determine its' current capacity with respect to accommodating the needs of people with episodic disabilities.

Phase 2 (Development of Resource Materials) involves the development of the resource materials and Phase 3 (Dissemination to Effect Change) includes the development of a media plan and webinars for employers, service providers and people with episodic disabilities and their supports, as well as the development and conduct of an evaluation survey to measure the impact that the resource materials have had to effect change.

This report covers the first activity in Phase 1.

2. Literature Review

2.1 Introduction and methodology

Work related to episodic disability in the context of employment has emerged as a critical area of work disability policy over the last decade. There is a growing understanding that many people with disabilities experience an episodic course that impacts their work capacity in unpredictable ways (Furrie, 2010). Approximately six years ago, work began to emerge that specifically addressed episodic disability in the context of employment, beginning with the publication of two seminal literature reviews exploring episodic disability and employment. Lysaght *et al.* (2011) conducted a literature review on IWC resulting from episodic disability that focused on the challenges related to the worker (person with a disability), the employer and employment context, and the larger social environment. They found that the impact of episodic disability on work capacity and employment was influenced by a multitude of

factors that varied across individuals and circumstances, including: the clinical course of the condition; the individual and their ability to manage their condition; the nature of the work and characteristics of the workplace, including the capacity to implement appropriate accommodations and employers' attitudes towards disability; and the larger labour market and economic conditions. Simultaneously, Smith Fowler (2011) conducted a literature review exploring how episodic disability has been defined in the literature, the extent and nature of labour force attachment by people with IWC, systemic and structural factors that impact the experience of employment of people with disabilities who have IWC, and innovative and promising practices.

These reviews noted that although much is known about episodic disability and employment, the term episodic disability was only beginning to infiltrate the literature. More recently, Furrie (2013) explored definitions of episodic disability in the context of employment, and highlighted the many ways it has been defined, as well as the similarities and differences across definitions. Common across definitions are notions of reoccurring and unpredictable changes in health status that impact employment.

The purpose of the current review is to provide an update and take stock of the current literature on episodic disability and IWC related to:

1. the experiences of people with episodic disability, employers and other stakeholders; and
2. strategies and practices that can improve employment opportunities and income security among people who experience episodic disability.

In order to summarize the current literature on employment and episodic disability, eight electronic databases were searched for papers published between 2010 and 2015: PubMed, ASSIA, Sociological Abstracts, Cochrane, Psych Info, Embase, Medline and Google Scholar. The keyword *work disability* was combined with *intermittent work capacity*, *short-term disability*, *episodic disability*, *employee absenteeism*, *sickness benefit* and *hiring*. Grey literature related to episodic disability and employment was also identified through a search of key organizations that have written about episodic disability and employment, including the Canadian Working Group on HIV and Rehabilitation, Public Health Agency of Canada, Interagency Coalition on AIDS and Development, and the Institute for Research on Public Policy. Titles and abstracts were excluded if they did not address work disability and episodic disability or if they were published before 2010. From these searches we identified 51 documents for full-text review. The findings from 36 papers matched our criteria and informed our summary of the literature.

2.2 Findings

Our review of the literature has highlighted that the terminology associated with episodic disability remains elusive and inconsistent across researchers. There remain few studies that have used episodic disability as a key term. Rather, most of the

literature concerning episodic disability continues to be related to conditions with episodic trajectories. However, searching by condition is also challenging, as many studies related to episodic conditions do not address the effects of the episodic course or intermittent work capacity. In recent years authors such as Furrie (2013), Vick (2012; 2014), and Antao *et al.* (2013) have specifically examined episodic disability in the context of employment. Vick (2012) highlighted the fluctuation and unpredictability associated with episodic disability and how this plays out in the context of employment in ways that conflict with existing categories of illness and wellness. Furthermore, the invisibility of many episodic disabilities can further obscure understanding, inviting a sense of disbelief and suspicion (Vick, 2012), which can take a toll on workplace relationships (Lysaght *et al.*, 2011).

Through our review of the literature, we extracted findings that highlight: 1) the challenges and consequences of episodic disability and employment; and 2) strategies and promising directions to improve employment opportunities and income security for people with episodic disabilities.

2.2.1 Challenges and Consequences

The literature highlights ongoing challenges faced by individuals with episodic disabilities as they relate to finding and keeping jobs. Vick (2014) relates these challenges to the uncertain and unpredictable trajectory of the disability. Another factor is the ever-present fear that relapse might occur, which poses a major barrier to negotiating employment relationships (Vick & Lightman, 2010). The most common challenge highlighted in the literature remains the inability to fit those who experience episodic disability resulting in IWC into existing categories of disability benefits (Antao *et al.*, 2013; O'Brien *et al.*, 2014; Vick, 2014; Vick & Lightman, 2010). Therefore, those on benefits fear losing their benefits and those not on benefits fear being disqualified in the future (Antao *et al.*, 2013). Such circumstances threaten income security and stability, and can prevent people from pursuing employment despite a desire to work and the presence of employment opportunities and work capacity. Furthermore, precarious employment and work insecurity can result in added stress that can exacerbate existing conditions (Vick & Lightman, 2010).

The consequences of the current circumstances were most prominently highlighted by Vick and Lightman (2010) in their qualitative study of women with complex episodic disabilities who identified as welfare recipients. The women's experiences over the five years that they were followed highlight how the significant strain associated with precarious employment exacerbates existing vulnerabilities. Many chose to remain on social assistance rather than pursue employment that might ultimately threaten their income security in the event of a relapse. Vick (2014) expanded on these findings and reported that many individuals who experience episodic disability maintain their status on social assistance in order to maintain their health and manage their conditions.

2.2.2 Strategies

Strategies put forth in the literature focused on three areas: 1) steps taken by individuals living with episodic disabilities; 2) efforts by employers/workplace to improve inclusion and flexibility; and 3) efforts at the level of social policy to improve flexibility in the system.

At the level of the individual, Antao *et al.* (2013) noted that there is a need for individuals to become proficient at navigating the system. Specifically, individuals need to be able to utilize self-management strategies (Antao *et al.*, 2013; Tveito *et al.*, 2010) and communicate appropriately in the workplace in order to negotiate accommodations (Tveito *et al.*, 2010; Varekamp *et al.*, 2013). These findings are consistent with those of Lysaght *et al.* (2011), who highlighted the need to build predictability within the unpredictable by anticipating needs and establishing contingency plans.

At the level of the workplace, accommodations and communications were most commonly noted. Job flexibility and appropriate job accommodations that could evolve and fluctuate over time were described as essential for job maintenance and security (Mehnert *et al.*, 2013; Shaw *et al.*, 2013). Flexibility in terms of the work arrangement was also noted. Specifically, the ability to work part-time might be important in order to allow individuals with episodic disability time to recover and attend to their health-related needs (Palstam *et al.*, 2013).

Effective communication between other workplace stakeholders was helpful to meet ongoing needs (Yarker *et al.*, 2010). Not sufficiently addressed in the literature was the perspective of the other stakeholders, including employers and coworkers (Mehnert *et al.*, 2013). However, the literature is quite clear that an organizations' reputation for inclusion and its capacity to address the needs of its workers are seen as important factors that lead to an improvement in the employment opportunities of those with episodic disabilities (Lysaght *et al.*, 2011; Smith Fowler, 2011; Tveito *et al.*, 2010; Vick, 2014; Vick & Lightman, 2010).

Several authors describe the need for improved disability benefits and an income security system that could provide greater flexibility for individuals with episodic disabilities. Antao *et al.* (2013) and Smith Fowler (2011) recommended that policies could be structured to allow for trial periods and increased flexibility to move on and off benefits as needs fluctuate over time. Furthermore, the part-time work arrangements recommended by Palstam *et al.* (2103) would require flexibility in the disability benefit system. Categorization for eligibility would also need to evolve to account for the fluidity of disablement experienced by many with episodic conditions.

2.2.3 Summary

Although we examined short-term disability, we found those studies to be less relevant as they tended to focus on time off work rather than the experience or impact. However, generally, those with mental health or behavioural disorders were significantly more likely to experience a second episode of disability sooner than those with other types of conditions (Dewa *et al.*, 2014). Furthermore, the category of episodic disability becomes challenged due to complex comorbidities such as mental illness (Hakola *et al.*, 2011), which can also be episodic in nature.

Despite additional studies conducted in the last five years, the findings from this review are consistent with those reported by Lysaght *et al.* (2011) and Smith Fowler (2011). The number of studies focused specifically on episodic disabilities has increased; however, it remains a relatively limited area of focus. As reported in past studies, issues related to income insecurity remain prominent. Engaging with stakeholders within business and government to improve employment opportunity and access to disability benefits through flexible structures for workplace accommodations and income replacement benefits remain paramount. There is a need for more research directed at identifying the number of people with disabilities who experience IWC, examining the experiences of specific sub-groups and exploring promising practices.

3. Methodology

3.1 Data source: The 2012 Canadian Survey on Disability (2012 CSD)

The 2012 CSD provides a snapshot of the population with disabilities aged 15 years and older. This recent survey used the 2011 National Household Survey (NHS) for its sampling frame. The sample for the CSD was selected from respondents who answered positively to the disability questions and who were residing in private households in the ten provinces and three territories (excluding people residing on Indian reserves). The CSD data includes disability-specific data, as well as selected data from the 2011 NHS. The CSD data base also includes a sample of persons who answered negatively to the NHS disability questions. This provides the opportunity to analyze the common NHS variables such as age, gender, Aboriginal status, ethnic origin, level of education, occupation, industry, employment income and income sources for both the population with disabilities and the population without disabilities,. The disability-specific data include information about the underlying health condition(s) that result in an episodic disability coded using the International Classification of Diseases – 10th Revision (ICD-10) (Statistics Canada, 2014).

The focus for the 2012 CSD was employment and, as such, there is rich information on work experience, the use of and need for workplace accommodation, workplace training, and discrimination in the workplace. There are also additional income data related to sources specific to disability. The CSD also includes information on the nature

and extent of care received with activities of daily living such as preparing meals, doing housework, running errands, etc.

The response rate to the survey was 74.6%. The sample size of people aged 15 years and older who responded positively the NHS disability questions is 33,900 persons; for persons aged 15 to 64 years, the sample size is 14,075. The sample of people without disabilities aged 15 years and older is 124,000; for persons aged 15 to 64 years, the sample size is 96,941.

3.2 Defining the research population using the 2012 CSD

For our research, we first had to answer the question “Who is a person with an episodic health condition that impacts on her/his ability within the workplace?” We needed to define our population for this and subsequent phases of our research if we want our research to inform the discussion on improving the work situation for these individuals, as well as to inform the discussion around income security for these individuals.

The use of the social model of disability was a given since this was the lens used by the 2012 CSD to identify the population with disabilities. For a more complete description as to how the social model was operationalized in the 2012 CSD, readers are encouraged to access the *Concepts and Methods Guide - Catalogue no. 89-654-X — No. 2014001*.

Within the population with disabilities as defined by the 2012 CSD, we agreed on the following:

- We needed to dichotomize the population with disabilities: those who experience unpredictable and fluctuating periods of wellness and illness and those who do not. For this, we used underlying health condition as reported by the individual who had been classified as having a disability and the list of the health conditions that had been identified by Canadian experts as possibly resulting in an episodic disability. A list of those conditions is attached as Annex A. To this, we added individuals who indicated that they had:
 - a mental health condition that limited their activities “sometimes” or “often”, and/or
 - pain that limited their activities “sometimes” or “often”.
- We needed a measure of IWC. Given that the 2012 CSD did not specifically address IWC, we used “limitation in the workplace” as a proxy for IWC and included people who reported that they were “sometimes” or “often” limited at work (work disability or WD). We excluded people who reported that they were “always” limited at work. The questions used are provided in Annex B.

The following table provides the results of the application of the episodic condition and WD as defined within the 2012 CSD.

| Table 1. 2012 CSD population with disabilities aged 18 to 64 years | | | |
|---|------------|------------------|---------------------------------|
| | Acronym | Estimate | Description |
| Episodic with work disability | EPI/WD | 607,870 | Research population |
| Episodic but no work disability | EPI/No WD | 522,440 | Comparator population 1 |
| Episodic and completely prevented from working | | 498,030 | <i>Not included in research</i> |
| Episodic and permanently retired | | 254,150 | <i>Not included in research</i> |
| No episodic with work disability | Not EPI/WD | 117,280 | Comparator population 2 |
| No episodic and no work disability | | 133,690 | <i>Not included in research</i> |
| No episodic and completely prevented from working | | 90,700 | <i>Not included in research</i> |
| No episodic and permanently retired | | 59,090 | <i>Not included in research</i> |
| Total | | 2,283,250 | |

Source: Unpublished data, 2012 Canadian Survey on Disability

Applying our definition resulted in 1,882,490 individuals, or 82.4% of the adult population aged 18 to 64 years with disabilities, being classified as having an episodic disability. Reporting an episodic health condition increased as age increased. Among persons aged 18 to 29 years inclusive, 77.4% reported an episodic health condition. This increased to 81.4% among adults aged 30 to 44 years, 83.5% among persons aged 45 to 54 years and 83.7% among persons aged 55 to 64 years.

Included in our research are 1,247,590 individuals who were active labour force participants or who indicated that they were or would be available for employment in the future.

Excluded from our research are 498,030 individuals (26.5% of the episodic disability population) who, at the time of the survey interview, reported that they are completely prevented from working. Some of their characteristics are as follows:

- 62.5% were aged 45 years or older;
- 44.3% had some post-secondary education;
- 60.9% reported a disability as a result of a mental health condition and 85.2% reported pain;
- 76.6% were classified as having a severe or very severe level of disability; and
- 91.8% (457,290) reported previous work experience and were receiving benefits from disability income support programs in 2010, including:
 - 42.9% - CPP-D/QPP-D,
 - 19.6% - long-term disability,
 - 3.7% - EI Sickness Benefits,
 - 7% - Workers' Compensation, and
 - 25.7% - social assistance.

Also excluded from our research are 254,150 (13.5% of the episodic disability population) who state that they are permanently retired. Some of their characteristics are as follows:

- 69.3% were aged 45 years or older;
- 39.4% had some post-secondary education;
- 39.9% reported a disability as a result of a mental health condition and 87.8% reported pain;
- 65.7% were classified as having a severe or very severe level of disability; and
- 99.7% reported previous work experience and were receiving benefits from disability income support programs in 2010, including:
 - 42.4% - CPP-D/QPP-D,
 - 13.2% - long-term disability,
 - 8.9% - Workers' Compensation, and
 - 18.1% - Social Assistance.

“EPI/WD” represents those individuals who meet both research criteria: reports at least one of the episodic health conditions and indicates having limitation in the workplace. For the remainder of the report, this population will be referred to by the acronym “EPI/WD” or “the research population.” According to the 2012 CSD, there were an estimated 607,870 adults with disabilities aged 18 to 64 years who met the two criteria, representing 26.6% of the population with disabilities aged 18 to 64.

“EPI/No WD” represents those individuals who report at least one of the episodic health conditions and who indicate through their responses to selected employment questions that they do not have limitations in the workplace. For the remainder of the report, this population will be referred to by the acronym “EPI/No WD” or “the first comparator population.” According to the 2012 CSD, there were an estimated 522,440 adults with disabilities aged 18 to 64 years in this group, representing 22.9% of the population with disabilities aged 18 to 64.

“No EPI/WD” represents those individuals who do not report any of the episodic health conditions but who indicate that they have a work disability. For the remainder of the report, this population will be referred to by the acronym “No EPI/WD” or “the second comparator population.” According to the 2012 CSD, there were an estimated 117,280 adults with disabilities aged 18 to 64 years in this group, representing 5.1% of the population with disabilities aged 18 to 64.

The remaining adults with disabilities aged 18 to 64 meet neither of the research criteria. We acknowledge that some individuals who are permanently retired or who report that they are completely unable to work may, in fact, have a work disability. However, for the purpose of the research, we decided to exclude them from our analyses and have as our focus the populations who are currently in the labour force and those who are potential workers.

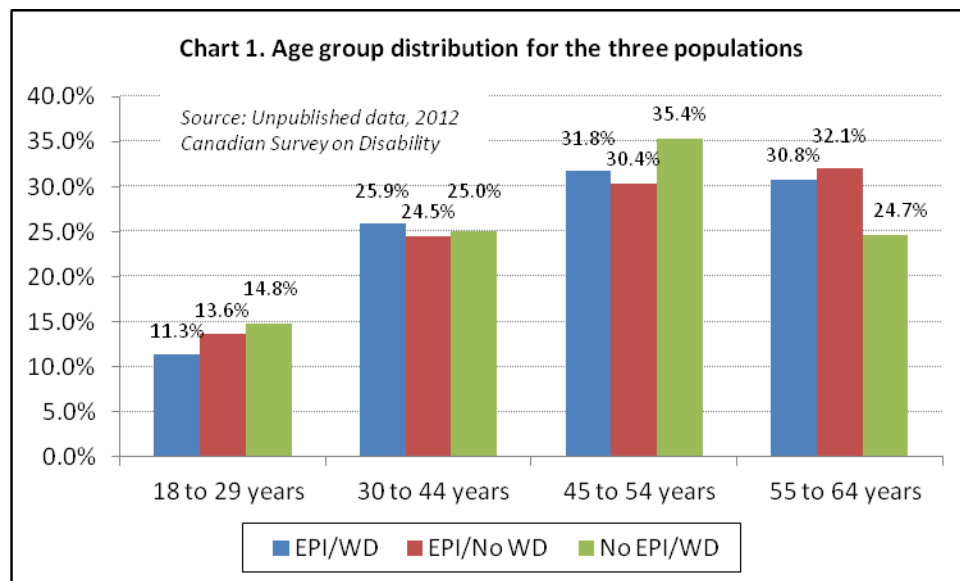
You will note that the age range for our research is 18 to 64 years inclusive. We made the decision to exclude the 54,980 young adults with disabilities aged 15 to 17 years. The majority (80.1%) of these young adults are full-time students at elementary, junior high or secondary schools, and the majority had limited work experience. We understand that gaining work experience while in school is an important contributor to a successful transition from school to work and, as such, their specific needs should be explored. CRWDP has funded another Seed Grant to undertake this research.

4. The research questions

4.1 *What are the demographic, socio-economic and disability characteristics of the research population and what is their impact on education, labour force participation and income?*

Our research population (EPI/WD) included 607,870 adults aged 18 to 64 inclusive who report having an episodic health condition that results a work disability. To put the characteristics of these individuals into a context, we have included two additional populations: 522,440 individuals in the same age group who report having an episodic health condition that results in some limitation in activity but does not include any limitation in the workplace (EPI/No WD) and 117,280 individuals in the same age group who report a health condition that is not episodic but that results in a work disability (No EPI/WD).

Annex Table C1 provides selected demographic characteristics for the three populations. Consistent with the literature, both EPI populations include more females than males: 54.3% (EPI/WD) and 62.3% (EPI/No WD) versus 42.4% (No EPI/WD).

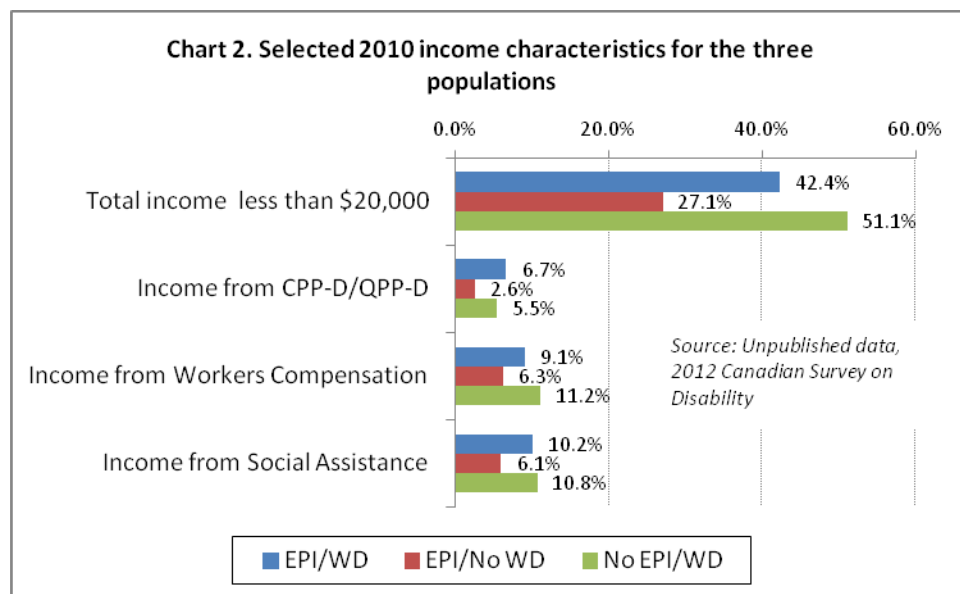


The major difference among the three populations is the proportion of young adults. Only 11.3% of the EPI/WD population are young adults aged 18 to 29 years inclusive, compared to 13.6% among EPI/No WD and 14.8% among No EPI/WD.

The EPI/WD population is more like to be single and living alone than the two comparator populations. Also, compared to the other two populations, they are more likely to identify as one of Canada's three Indigenous peoples, but less likely to be a member of a visible minority group or an immigrant.

Annex Table C2 provides two selected education characteristics. When compared to EPI/No WD, the EPI/WD population is less likely to have post-secondary education: 54.6% versus 60.1%, with the difference being among those obtaining a university degree. Just over half (51%) of the No EPI/WD population have post-secondary education. Approximately 23% of both EPI populations report that they had their condition prior to completing their education; among the No EPI/WD population the figure is 19%.

Annex Table C3 includes income data for 2010, and these data begin to show a pattern related to the three populations. Firstly, in terms of total income in 2010, the EPI/No WD population report more income than the EPI/WD population, who themselves report more income than the No EPI/WD population. Almost three-quarters of the EPI/NoWD (73%) reported total income of \$20,000 or more, compared to 57.6% among EPI/WD and 48.9% among No EPI/WD. As a result, the EPI/No WD population has less reliance on income support programs such as CPP-D/QPP-D, Workers' Compensation and Social Assistance. Both the reference population and comparator population 2 (No EPI/WD) have more reliance on social programs and total lower income, which point to the possibility that it is WD not EPI that is the issue.

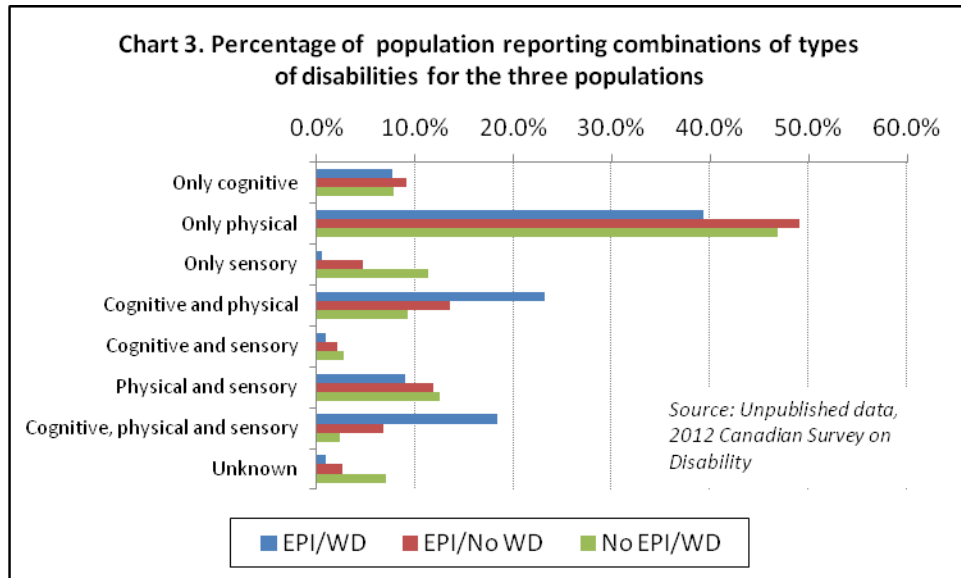


The 2012 CSD asked questions to classify limitation in activity (disability) in 11 types of disabilities, including seeing and hearing (sensory), mobility, dexterity, flexibility and pain (physical), memory, mental health, developmental and learning (cognitive), and unspecified limitation (unknown). Based on the responses to these questions, which included a measure of frequency and intensity, Statistics Canada created a four-level severity index: mild, moderate, severe and very severe (Statistics Canada, 2014).

When comparing the disability characteristics of our research population to the EPI/No WD, our research population is

- more likely to report cognitive disabilities: 50.2% versus 31.6%, with much higher rates in mental health, learning and memory;
- similar in terms of physical disabilities: 89.8% versus 81.5% with much higher rates in all four types (mobility, dexterity, flexibility and pain);
- much more severely disabled: 51.1% classified as severe and very severe versus 18.9%; this difference is reflected in the number of disabilities, where 41.6% of our research population reports four or more types of disabilities versus 13.6%; and
- similar in terms of onset of disability.

People reporting an episodic health condition and IWC (EPI/WD) are far more likely to have sensory, physical and cognitive disabilities than either of the two comparator populations. Almost two in 10 (18.3%) report limitations that are classified as sensory, physical and cognitive compared to 6.8% among people in the EPI/ No WD population and only 2.4% among people in the No EPI/WD population. A similar difference is noted among those individuals who report both cognitive and physical disabilities, but no sensory disability: 23.2% within the EPI/WD population, 13.6% within the EPI/No WD and dropping to 9.2% within the No EPI/WD population.

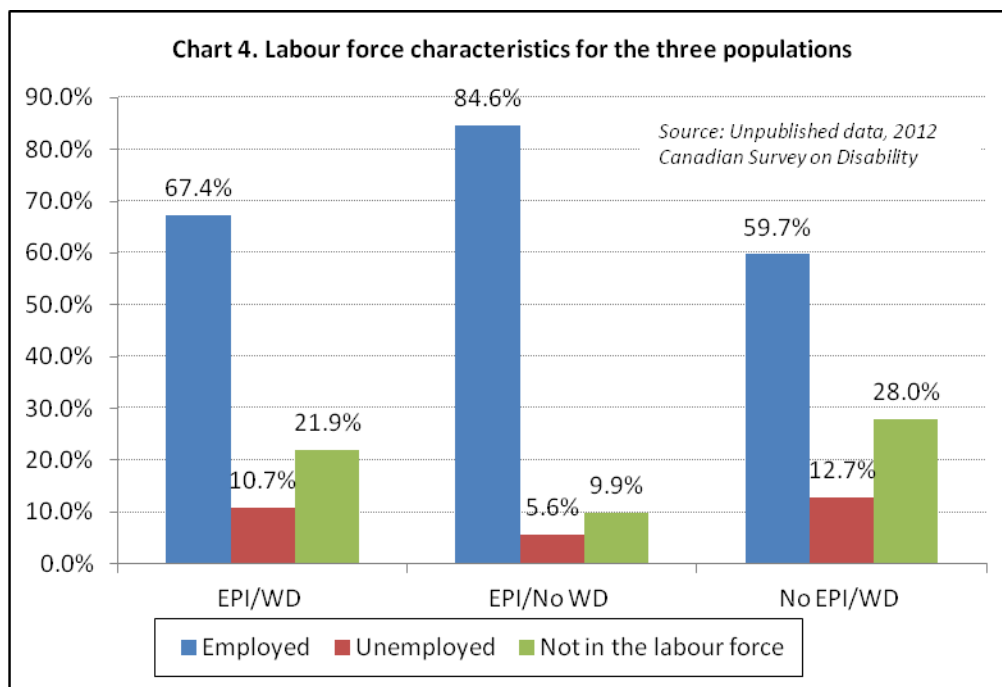


By far, the majority of people in the EPI/WD and EPI/No WD populations reported that pain was the condition that limited their daily activities. Among people in the EPI/WD group, three out of four reported experiencing pain that sometimes or often limited what they were able to do in a day. For people in the EPI/No WD, this dropped to almost two out of three people.

The second most reported health condition that resulted in limitation in activities was a mental health condition such as depression or anxiety. These conditions were reported by just over one in three people among the EPI/WD population and just over one in five in the EPI/No WD population.

Annex Table C4 provides additional disability details for the three populations.

Not taking into account any other characteristics of the three populations, it appears that it is work disability, not episodic condition, that results in a barrier to obtaining employment. The proportion of unemployed in the EPI/WD population is 10.7%, almost double that of the EPI/No WD (5.6%). This difference is even more marked for the No EPI/WD population (12.7%). The similar difference holds for those individuals who are not in the labour force.



The unemployment rate varies significantly among the three populations. The EPI/No WD has the lowest unemployment rate of 6.2%, followed by EPI/WD at 13.7% and 17.6% experienced by people in the No EPI/WD population.

The participation rate follows the same pattern: 90.1% in the EPI/No IWD, 78.1% in the EPI/WD and down to 72.4% in the No EPI/WD population.

4.2 Does their labour market experience differ?

Because different questions on employment barriers were asked depending on the respondent's employment status at the time of the 2012 CSD interview, the analysis that follows is organized by employment status.

4.2.1 The employed

| | | | | | |
|--------|---------|-----------|---------|-----------|--------|
| EPI/WD | 409,450 | EPI No WD | 441,825 | No EPI/WD | 70,040 |
|--------|---------|-----------|---------|-----------|--------|

Using 30 hours or less to define part-time work, the data show that people who indicate having a limitation at work (our research and comparator 2 populations) are more likely to report that they are working part-time: 30.1% of the EPI/WD and 21.6% of the No EPI/WD, compared to 13.4% of the EPI/No WD.

When asked why they were working part-time, 52.7% of the 123,140 people in the EPI/WD population who were working part-time said that it was their disability /health condition that prevented them from working more hours; this proportion dropped to

45% among the 70,040 people in the No EPI/WD population who were working part-time and dropped further to 15.4% among people who were working part-time in the EPI/No WD population.

People reporting a limitation in the workplace were more likely to be self-employed than those who did not. Almost one in four (23.1%) people in the EPI/WD population and more than one in four (28.1%) in the No EPI/WD population reported being self-employed, compared to 12.7% among the EPI/No WD population.

Among those individuals who were not self-employed, nine out of ten in all three populations were in a permanent job. When asked if they believe that their health condition(s) makes it difficult for them to change jobs or advance in their present job, more than two thirds in each of the WD populations said it would be difficult or very difficult: 68.4% of EPI/WD and 71.7% of No EPI/WD. Among the EPI/No WD population, only 29% reported difficult or very difficult.

| Table 2. Impact on employment for persons who were employed at the time of the interview for the three populations | | | |
|---|---------------|------------------|------------------|
| | EPI/WD | EPI/No WD | No EPI/WD |
| Number of employed | 409,450 | 441,825 | 70,040 |
| Number reporting "No" to all four scenarios | 98,420 | 288,420 | 22,220 |
| Number reporting "Yes" to at least one scenario | 311,030 | 153,400 | 47,820 |
| ... changed kind of work | 63.4% | 55.8% | 52.3% |
| ... changed amount of work | 77.7% | 57.4% | 79.9% |
| ... changed jobs | 46.4% | 49.3% | 34.2% |
| ... began telework or working from home | 19.3% | 14.2% | 8.6% |

Source: Unpublished data, 2012 Canadian Survey on Disability

Survey respondents were given four scenarios to provide an insight into the impact that their health condition(s) had on their labour force participation. As would be expected, a greater proportion in both of the WD populations answered "Yes" to one or more of the scenarios. Among

those individuals in the EPI/No WD, almost two out of three (65.3%) answered "No" to all four scenarios. Among the EPI/WD population, only 24% answered "No" to all four questions, and among the No EPI/WD the figure was 31.7%. Changing the amount of work evoked the largest number of positive responses by all three populations, ranking second for all three. It is interesting to note that almost half of each of the two EPI populations reported that they had changed jobs because of their health condition.

Table 3. Perceived discrimination for the three populations who were employed at the time of the survey interview

| | EPI/WD | EPI/No WD | No EPI/WD |
|--|---------|-----------|-----------|
| Number of employed | 409,450 | 441,825 | 70,040 |
| Perceived discrimination because of health condition | | | |
| refused a job interview | 9.3% | 3.5% | 11.0% |
| refused a job | 14.3% | 6.9% | 18.5% |
| refused a promotion | 12.7% | 5.0% | 10.1% |

Source: Unpublished data, 2012 Canadian Survey on Disability

All employed people in the three populations were asked about their experience with discrimination in the workplace. Again, both WD populations' perception of discrimination in the workplace is greater than the EPI/No WD

population. This holds for the three situations explored: being refused a job interview, a job and a promotion.

The two WD populations were asked if they were employed by their present employer when they first experienced a workplace limitation. Among the 370,690 individuals in the EPI/WD population who were working when they first experienced a work limitation, more than half (55.4%) reported that they were with their present employer. Among the 60,760 individuals in the No EPI/WD population who were working when they first experienced a work limitation, only 39.8% reported that they were with their present employer.

When these two populations were asked if they are doing the same kind of work now that they were doing when they first experienced a work limitation, 50.6% in the EPI/WD population and 55.5% in the No EPI/WD population said they were. Among those individuals who said "No" to that question, three out of four in both populations said that it was their health condition(s) that made them change the kind of work they did.

Not all employed people in the three populations need workplace accommodations, and not all who required an accommodation got any or all of what they needed.

Among the 409,450 employed adults with disabilities in the EPI/WD population, 60.9% required at least one workplace accommodation. Of the 249,440 who did require at least one workplace accommodation,

- 53.9% had all of their needs met,
- 25.6% had some of their needs met, and
- 20.5% had none of their needs met.

Among the 441,825 employed adults with disabilities in the EPI/No WD population, 26.1% required at least one workplace accommodation. Of the 115,360 who did require at least one workplace accommodation,

- 70.7% had all of their needs met,

- 7.3% had some of their needs met, and
- 22% had none of their needs met.

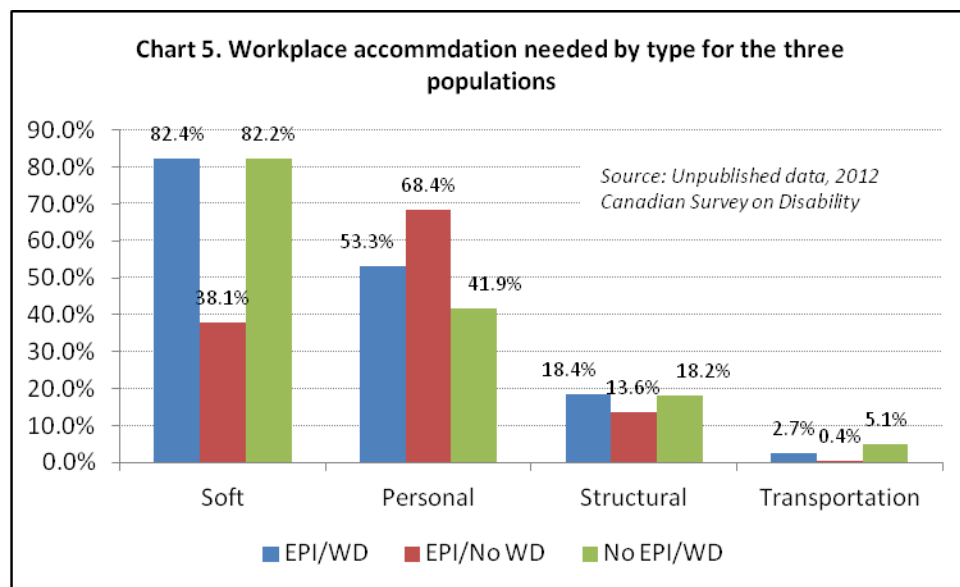
Among the 70,040 employed adults with disabilities in the No EPI/WD population, 66.1% required at least one workplace accommodation. Of the 46,440 who did require at least one workplace accommodation,

- 63.5% had all of their needs met,
- 20.6% had some of their needs met, and
- 15.9% had none of their needs met.

Workplace accommodations can be grouped into four categories:

- **soft** (job redesign (modified or different duties), telework, modified hours or days or reduced work hours),
- **personal** (human support (reader, Sign language interpreter, job coach, personal assistant, etc.), technical aids (voice synthesizer, TTY, an infrared system, portable notetaker, etc.), computer or laptop with specialized software or other adaptations (such as Braille, screen magnification software, scanner), communication aids (Braille, large print materials, recording equipment, etc.), a modified or ergonomic workstation, a special chair/back support),
- **structural** (Handrails, ramps, widened doorways or hallways, adapted or accessible parking, an accessible elevator, adapted washrooms), and
- **transportation** (specialized transportation).

Respondents to the 2012 CSD were provided with the detailed list, and we have grouped them into these four categories for ease of presentation in this report.



Among the 60.9% (249,440 persons) in the EPI/WD population who reported that they needed a workplace accommodation,

- the majority (82.4%) needed a “soft” accommodation and, within that group, 170,560 needed modified hours or days or reduced work hours.
- 53.3% required a “personal” accommodation and, within that group, 95,310 needed a special chair or back support and 73,220 needed a modified or ergonomic workstation.

Individuals who needed workplace accommodation in the No EPI/WD population followed a similar pattern. Among the 66.1% (46,440 persons),

- 82.2% needed a “soft” accommodation and, within that group, 30,870 needed modified hours or days or reduced work hours.
- 41.9% required a “personal” accommodation and, within that group, 12,110 needed a special chair or back support and 8,000 needed a modified or ergonomic workstation.

Only 38.1% of the EPI/No WD required a “soft” accommodation. It is important to remember that only 26.1% in this population required any accommodation.

4.2.2 The unemployed

| | | |
|---------------|------------------|------------------|
| EPI/WD 65,230 | EPI No WD 29,040 | No EPI/WD 14,910 |
|---------------|------------------|------------------|

| Table 4. Unemployed by when last worked for the three populations | | | |
|---|--------|-----------|-----------|
| Last worked in | EPI/WD | EPI/No WD | No EPI/WD |
| Total | 65,230 | 29,040 | 14,910 |
| 2012 | 58.4% | 43.3% | 36.7% |
| 2011 | 8.3% | 18.6% | 14.1% |
| 2010 | 11.4% | 29.4% | 3.2% |
| Before 2010 | 17.2% | 6.1% | 37.2% |
| Never worked | 2.1% | 2.4% | 4.9% |
| DK/Ref | 2.6% | 0.2% | 4.1% |

Source: Unpublished data, 2012 Canadian Survey on Disability

The unemployed comprise 10.7% of the EPI/WD population, 5.6% of the EPI/No WD population and 12.7% of the No EPI/WD population.

While the majority in the three populations had worked at some point between 2010 and 2012, there are some unique differences among the three

populations. Only 78.1% of the EPI/WD unemployed population had recent work experience (between 2010 and 2012) compared to 91.3% among the EPI/No WD population and only 54% among the No EPI/WD population.

Reliance on social assistance benefits in 2010 was reported by almost one in four (22.3%) people in the EPI/WD population and almost half (49%) of the EPI/No WD population.

When asked if their health condition affected their ability to look for work, 69.6% of the EPI/WD and 74% of the No EPI/WD populations said that it did. Among the EPI/No WD population, only 21.6% responded positively to the question.

Almost four out of 10 (39.3%) of the unemployed in the EPI/WD population said that they were able to work at either a part-time or full-time job. Among the EPI/No WD population who were unemployed, just over six out of 10 (60.6%) said they could do either part-time or full-time work. Among the unemployed in the No EPI/WD population, this dropped to just over three out of 10 (31.3%).

When asked of those who had previous employment if their employer was aware of their health condition, 55.3% of the EPI/WD and 59.5% of the EPI/No WD unemployed answered “Yes”, compared to 71.8% among the No EPI/WD unemployed.

All unemployed people in the three populations who had some employment in 2007 and onward were asked about their experience with discrimination in the workplace. Again, both WD populations’ perception of discrimination in the workplace is greater than the EPI/No WD population. This holds for the three situations explored: being refused a job interview, a job and a promotion.

| Table 5. Perceived discrimination for the three populations who were unemployed at the time of the survey interview but who had worked at some point between 2007 and 2012 | | | |
|---|---------------|------------------|------------------|
| | EPI/WD | EPI/No WD | No EPI/WD |
| Number of unemployed | 56,910 | 27,960 | 9,000 |
| Perceived discrimination because of health condition | | | |
| refused a job | 21.5% | 9.7% | 32.7% |
| refused a job interview | 31.0% | 4.4% | 40.7% |
| refused a promotion | 16.3% | 5.0% | 18.4% |
| <i>Source: Unpublished data, 2012 Canadian Survey on Disability</i> | | | |

Not all unemployed people in the three populations need workplace accommodations. Seven out of 10 (69.5%) unemployed people in the EPI/WD required at least one workplace accommodation. A larger percentage (88.2%) of unemployed people in the No EPI/WD, and only 15.3% of EPI/No WD, required a workplace accommodation.

Among the 69.5% (45,320 persons) in the EPI/WD population who reported that they needed a workplace accommodation,

- the majority (60.5%) needed a “soft” accommodation and, within that group, 28,830 needed modified hours or days or reduced work hours.
- 45.5% required a “personal” accommodation and, within that group, 34,600 needed a special chair or back support and 35,940 needed a modified or ergonomic workstation.

Estimates for specific types of accommodations for the two other populations — EPI/No WD and No EPI/WD — were too small to be reliable and are therefore not included.

4.2.3 People not in the labour force

| | | |
|----------------|------------------|------------------|
| EPI/WD 133,200 | EPI No WD 51,580 | No EPI/WD 32,790 |
|----------------|------------------|------------------|

| Table 6. Not in the labour force by when last worked for the three populations | | | |
|---|---------------|------------------|------------------|
| Last worked in | EPI/WD | EPI/No WD | No EPI/WD |
| Total | 133,200 | 51,580 | 32,790 |
| 2012 | 26.7% | 28.8% | 22.7% |
| 2011 | 10.9% | 8.9% | 15.6% |
| 2010 | 13.5% | 14.7% | 6.2% |
| 2007 to 2009 | 19.5% | 21.1% | 15.3% |
| Before 2007 | 16.9% | 11.4% | 27.0% |
| Never worked | 10.2% | 11.4% | 11.8% |
| DK/Ref | 2.3% | 3.7% | 1.4% |
| <i>Source: Unpublished data, 2012 Canadian Survey on Disability</i> | | | |

Recall that the individuals included in this section of the report are individuals who are not retired and who are not completely prevented from working. Also, these individuals are neither employed nor actively seeking employment.

In terms of recent employment (worked at some point in 2011 or 2012), there is little

difference among the three populations. Approximately four out of ten in each population fall into this category. The major difference among the three populations is the proportion whose last employment was before 2007. Within the EPI/WD, 16.9% fall into this category, 27% in the No EPI/WD and 11.4% in the EPI/No WD.

Reliance on social assistance benefits in 2010 was reported by almost one in five (19.3%) people in the EPI/WD population and 13.7% of the EPI/No WD population.

Those individuals who had some work experience were asked if they had looked for work in the past two years. Among the EPI/WD population, 34.3% answered “Yes”. Among the EPI/No WD, this dropped to 22.6% and, among No EPI/WD, the percentage was down to only 17.6%.

| Table 7. Barriers to finding employment for people not in the labour force in the three populations | | | |
|--|----------------|------------------|------------------|
| Barriers encountered that have discouraged looking for work | EPI/WD | EPI/No WD | No EPI/WD |
| Total who experienced barriers | 107,080 | 36,920 | 25,770 |
| Expected income would be less than current income | 16.3% | 18.1% | 5.7% |
| Loss of additional supports such as drug plan or housing | 18.4% | 8.8% | 7.7% |
| Lack of specialized transportation | 12.4% | 8.7% | 7.7% |
| Family responsibilities | 17.6% | 25.5% | 15.9% |
| Past attempts to find work unsuccessful | 26.3% | 20.4% | 17.4% |
| Family/friends discourage working | 5.4% | 12.3% | 1.9% |
| Experienced discrimination | 17.1% | 6.4% | 10.4% |
| Training or experience not adequate for current job market | 32.3% | 21.4% | 17.2% |
| Few jobs available in local area | 33.6% | 23.0% | 21.6% |
| Experienced accessibility issues when applying for work | 12.0% | 15.7% | 4.7% |
| Other barrier | 22.5% | 9.8% | 18.5% |

Source: Unpublished data, 2012 Canadian Survey on Disability

Gaining an understanding of the barriers that exist that discourage people with disabilities from looking for work has been an integral part of Statistics Canada's disability data program since its inception in 1983. The list of barriers has evolved over time based on consultation with the disability community. The 2012 CSD asked respondents to consider 10 specific barriers and asked if each barrier was applicable to their situation. Respondents were also given the opportunity to report other barriers.

Of the 133,200 people who were not in the labour force in the EPI/WD population, 19.6% reported that they had encountered no barriers. This percentage increased to 28.4% among people in the EPI/No WD and to 21.4% among people in the No EPI/WD population.

Among the 107,080 people in the EPI/WD population who experienced at least one barrier,

- one in three (33.6%) said that there were few jobs available in the local area and the same percentage (32.3%) reported that their training or experience was not adequate for the current job market.
- 26.3% said that past attempts to find work had been unsuccessful.
- 18.4% were concerned about losing their supports, such as their drug plan or housing, and 16.3% said that their expected income would be less than their current income.

- 17.1% reported that they had experienced discrimination and 12.4% responded that they had experienced accessibility issues when applying for work.
- 22.5% reported another barrier, but the nature of the barrier was not identified.

Among the 36,920 people in the EPI/No WD population who experienced at least one barrier,

- 25.5% said family responsibilities, 23% said that there were few jobs available in the local area and 21.4% reported that their training or experience was not adequate for the current job market.
- 20.4% said that past attempts to find work had been unsuccessful.
- 18.1% said that their expected income would be less than their current income.

Among the 25,770 people in the No EPI/WD population who experienced at least one barrier,

- 21.6% said that there were few jobs available in the local area and 17.2% reported that their training or experience was not adequate for the current job market.
- 17.4% said that past attempts to find work had been unsuccessful.
- 18.5% reported another barrier but the nature of the barrier was not identified.

Table 8. Perceived discrimination for the three populations who were not in the labour force at the time of the survey interview but who had worked at some point between 2007 and 2012

| | EPI/WD | EPI/No WD | No EPI/WD |
|---|--------|-----------|-----------|
| Number not in the labour force | 91,730 | 36,760 | 19,500 |
| Perceived discrimination because of health condition | | | |
| refused a job | 1.2% | 3.0% | 5.4% |
| refused a job interview | 17.0% | 3.8% | 16.7% |
| refused a promotion | 9.7% | 0.6% | 3.4% |
| <i>Source: Unpublished data, 2012 Canadian Survey on Disability</i> | | | |

People in the three populations who had worked during the period 2007 and 2012 were asked about their experience with discrimination in the workplace setting.

Almost two in 10 people in the two WD

populations perceived that it was their health condition that resulted in their being refused a job interview.

Not all people who are not in the labour force need workplace accommodations. Just over half (50.8%) of people who are not in the labour force who are in the EPI/WD population required at least one workplace accommodation. Slightly fewer (49.3%) of those not in the labour force in the No EPI/WD and only 14.6% of the EPI/No WD required a workplace accommodation.

Among the 50.8% (67,730 persons) in the EPI/WD population who reported that they needed a workplace accommodation,

- the majority (71.5%) needed a “soft” accommodation and, within that group, 39,010 needed modified hours or days or reduced work hours.
- 58.8% required a “personal” accommodation and, within that group, 28,090 needed a special chair or back support and 20,580 needed a modified or ergonomic workstation.

Among the 49.3% (16,160 persons) in the EPI/WD population who reported that they needed a workplace accommodation,

- the majority (76.9%) needed a “soft” accommodation and, within that group, 8,410 needed modified hours or days or reduced work hours.
- 69.9% required a “personal” accommodation and, within that group, 5,090 needed a special chair or back support and 3,480 needed a modified or ergonomic workstation.

Estimates for specific types of accommodations for the EPI/No WD population were too small to be reliable and are therefore not included.

4.3 How well does Canada’s work disability income support system serve the needs of Canadians with episodic disabilities?

Canada’s work disability support system is a complex mosaic of income security programs that are designed for adults who, because of a chronic health condition, are completely unable to work or who require financial support when unable to work. This patchwork of seven separate programs provided \$25.7 billion in benefits or tax credits to people with disabilities in fiscal year 2008/09. These programs are offered by different providers (federal, provincial/territorial and private), and each has different eligibility criteria. These seven programs are as follows:

1. The Canada Pension Plan Disability (CPP-D)/Quebec Pension Plan Disability (QPP-D) – This program accounted for almost 16% of the \$25.7 billion in disability benefit expenditures in 2008/09. These are compulsory contributory social insurance programs where eligibility is based on minimum contribution requirements, as well as a definition of disability that is both “severe” and “prolonged”, resulting in the individual being completely unable to work at any job on a regular basis. *By definition, many people with episodic disabilities are excluded because of the “prolonged” criterion and also because many have precarious employment that fails to meet the minimum contribution requirement.*
2. Employment Insurance (EI) Sickness Benefit – This benefit accounted for 3.8% of disability benefit expenditures in fiscal year 2008/09. It is a compulsory contributory social insurance program where eligibility is subject to minimum contribution requirements and requires that the individual is unemployed and, except for sickness/injury/quarantine, would otherwise be available to work. *By definition, many people with episodic disabilities are excluded because many have precarious employment that fails to meet the minimum contribution requirement.*
3. Employment-based long-term disability plans – These plans accounted for 18% of disability benefit expenditures in fiscal year 2008/09. These plans require medical evidence of a

permanent or long-duration impairment that prevents the individual from working. Typically, the benefits cover a two-year period for pre-disability occupation and extend beyond the two years if the individual is unable to work at any occupation. These plans cover about 55% of Canadian workers and are typically offered to full-time employees. *By definition, many people with episodic disabilities are excluded as many have precarious employment that excludes them from coverage.*

4. Worker's Compensation benefit – This benefit accounted for 21% of disability benefit expenditures in fiscal year 2008/09. This income security benefit is available to workers who experience wage loss as a result of a disease or injury that can be attributed to the work environment. *By definition, only some of the health conditions considered episodic could be attributed to the work environment.*
5. Veterans' benefits – These benefits accounted for 7.7% of disability benefit expenditures in fiscal year 2008/09. These benefits are available only to Canadians who are veterans or members of the Canadian Armed Forces whose disability can be attributed to exposures arising from service. In addition, that disability must be severe. *By definition, only some of the health conditions considered episodic could be attributed to exposures arising from service.*
6. Tax measures – These measures accounted for just over one per cent of disability benefit expenditures in fiscal year 2008/09. These tax measures include the Disability Tax Credit, which also includes the Working Income Tax Benefit - Disability and the Registered Disability Savings Plan. To qualify for these measures, one has to have taxable income and must meet the definition of disability that is used for CPP-D. *Because many people with episodic disabilities do not meet the CPP-D definition of disability, many do not have access to these tax measures.*
7. Provincial/territorial social assistance programs – These programs accounted for 31% of disability benefit expenditures in fiscal year 2008/09. These programs, commonly referred to as “welfare”, function as Canada's social safety net of last resort. They provide financial assistance and in-kind goods and services to individuals whose income from employment or other sources is not sufficient to meet their needs and who have exhausted other avenues of support. For non-senior adults, the definition of disability for program eligibility purposes varies by jurisdiction and, sometimes, by program. The expected minimum period of impairment varies from 90 days (e.g. Manitoba) to a year (e.g., Ontario, Saskatchewan, Alberta) to two years (some elements of the British Columbia program).

For example, Ontario uses a wide-reaching definition of disability: “A person with a disability is defined as a person who has a substantial physical or mental impairment which results in a substantial restriction in one or more activities of daily living (ability to attend to personal care, function in the community or function in a workplace).” All provinces have a specific reference to the ability to work or “earn a living,” and most refer to “attend to personal care.”

Eligibility for social assistance is first determined on the basis of categorical definitions outlined in provincial regulations. In the case of persons with disabilities, most provinces require that applicants have a physical or mental disability that severely impedes their ability to engage actively in paid employment in the labour market. Medical certification of disability is typically required. Once applicants qualify on the basis of a categorical definition, they must then qualify on the basis of their liquid and fixed assets. That is, they

cannot have cash, bonds, stocks, other securities or immovable objects whose value exceeds certain amounts set out in the provincial rules. An assessment is then conducted to determine the resources available to applicants to meet their basic needs. Income from sources, such as government allowances, public and private pensions, and paid employment is taken into account.

In fairness to all who are providing disability income support programs, disability is an evolving concept, and there must be mechanisms within the existing programs to accommodate those changes. And, in fairness, many of the seven programs are attempting to do just that. However, the bureaucratic wheels move slowly, and for Canadians with disabilities, just as for Canadians without disabilities, their ability to have the resources to live today and in the short term is what is important. At this point in time, the existing work disability income support programs are not designed to support the fluctuating levels of disability experienced by many Canadians living with episodic health conditions.

5. Summary of Findings

Many people with episodic disabilities have sought, obtained and retained employment. Many have found employers who have worked with them to accommodate their fluctuating work disability. However, there are many who are still struggling. From our research, we learned the following:

- Four out of five Canadians with disabilities aged 18 to 64 years report an episodic health condition as either their primary or secondary condition.
- The majority of people with episodic disabilities who are working and need an accommodation are receiving at least some of the accommodations they need.
- People with episodic disabilities tend to be isolated, yet resourceful and resilient. We see this through higher rates of living alone but also high rates of self-employment.
- Work disability may have a bigger impact on employment than simply having an episodic health condition.

With respect to work, we see that people with episodic disabilities who experience work disability

- are more likely to have worked recently than people with other disabilities;
- are more likely to report that they have been discriminated against at work or have been refused a promotion because of their health condition;
- benefit from “soft” accommodation strategies with flexible work, including modified hours or days or reduced work hours, as the most needed. Some individuals reported needing a “personal” accommodation such as a special chair or back support or a modified or ergonomic workstation: and are more likely to have changed their type of work and/or be engaged in teleworking or flexible work or be self-employed.

With respect to life circumstances, we see that

- people with episodic disabilities are more likely to live alone, than with a spouse and/or children;
- if they are not currently employed, they are more likely than others to have been connected to disability income support programs; and
- people with episodic disabilities, in particular, experience significant concerns associated with rejoining the workforce that include worries about losing their access to drugs plans and subsidized housing.

While this report provides a better understanding of the life circumstances experienced by people with episodic health conditions, it identifies a number of other important factors related to this population.

Significantly, *for employers*, this report indicates that, across all three of the populations considered in this research, the majority of people surveyed are receiving at least some of the accommodations they need at work in order to stay engaged in the workforce. This means that some employers, working with their employees with episodic disabilities, have found what it takes to successfully navigate the complexities of IWC and/or working with an episodic health condition. Better understanding the successful accommodation practices of employers and more broadly disseminating their knowledge are important next steps. Recent research conducted by CCRW² provided an inventory of disability awareness tools that had been developed by Canadian employers, many of which dealt with hiring and retention practices. While none specifically address episodic disabilities, this inventory provides further insights into the nature and extent to which employers are addressing the needs of individuals with IWC.

There is also, however, a small but significant group of people surveyed who have reported that they have had none of their accommodation needs met. Unfortunately, the data tell us very little about the employers themselves or reasons why they may or may not be successful at accommodating people with episodic disabilities. Could these disparities be related to the types of employers for whom the research populations work? Are there industries where soft accommodations, like flexible hours, are not easily implemented? Does the size of the employer have an impact on their effectiveness in accommodating workers? What is the role of other intangible factors, like the value attributed to the individual or the importance of the job they do, on the likelihood that a person is accommodated? These are questions that require further examination.

² CCRW, through contract with Adele Furrie, developed an inventory of awareness tools, including supporting documentation for the Community Business Development Restigouche.

Significantly, **for the disability support system**, the data tell us very little about the length, duration and frequency of health episodes experienced by individuals living with episodic health conditions. We can see that many in the three populations with disabilities included in our research rely on the disability income support programs, but we cannot know for how long and if they have had returns to work throughout. Many individuals who experience limitations at work do so intermittently but can work continuously if provided with the appropriate accommodations. However, at times, flexibility in public benefits is needed to ensure they can work when they are able to without risk of income insecurity when they are unable to work.

6. Conclusions

The findings of this report advance the emerging literature on episodic disability and employment summarized in section 2. Specifically, the findings tell us more about people with episodic disabilities and highlight key issues for future study in order to make recommendations for policy and practice. Building on the seminal work of Antae *et al.* (2013), Lysaght *et al.* (2011), Smith Fowler *et al.* (2011) and Vick (2012, 2014), this work provides a snapshot into the characteristics of people with episodic disabilities and their experience related to employment. It highlights the need to better understand their employment trajectories and their interactions with various income support programs over time. Furthermore, the findings reported here highlight that some employers are doing a good job of meeting the needs of their employees with episodic disabilities by providing accommodations. There is a need to explore successful cases of retention in order to better understand strategies that employers might be able to implement.

Glossary of terms

Episodic Disability – are long-term conditions that are characterized by periods of good health interrupted by periods of illness or **disability**. These periods may vary in severity, length and predictability from one person to another. (Episodic Disability Employment Network (EDEN))

Work Disability – indicates having limitation in the workplace

Intermittent Work Capacity – is expressed as disturbances in attendance and productivity that impact the work organization both with respect to meeting its business objectives and maintaining good social relations. (Lysaght et al., (2011)

JAS® – Canadian Council on Rehabilitation and Work (CCRW) Job Accommodation Service

EPI/WD – (Episodic Disability and Work Disability) – individuals who report at least one of the episodic health conditions and indicates having limitation in the workplace

EPI/ No WD – (Episodic Disability and No Work Disability) – individuals who report at least one of the episodic health conditions and do not have limitation in the workplace

No EPI/WD – (No Episodic Disability and No Work Disability) – individuals who do not report any of the episodic health conditions but indicate they do have limitation in the workplace

Annex A List of “episodic” conditions

1. Anxiety
2. Arthritis
3. Asthma
4. Bi-polar disorder
5. Cancer
6. Chronic Obstructive Pulmonary Disease (including chronic bronchitis and emphysema)
7. Chronic Pain
8. Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
9. Crohn’s disease & Ulcerative Colitis
10. Depression
11. Diabetes
12. Epilepsy
13. Hepatitis C
14. HIV/AIDS
15. Lupus
16. Meniere’s Disease
17. Multiple Sclerosis
18. Migraines
19. Parkinson’s Disease
20. Post-traumatic stress disorder
21. Substance abuse disorder

Annex B Algorithm to identify work disability

A person was considered to have a work disability if she/he responded “yes” to Question EDE_15 (employed) or UDE_12 (unemployed) or NDE_13 (not in the labour force) or RET_05 (retired). All four questions were the same but asked of different populations. The question was “Does your condition limit the amount or kind of work you can do?”.

A person was considered not to have a work disability if she/he responded “no” to Question EDE_15 or UDE_12 or NDE_13 or RET_05. All four questions were the same but asked of different populations. The question was “Does your condition limit the amount or kind of work you can do?”.

A person was considered to be completely prevented from working if she/he responded “yes” to NDE_11 or RET_04. The two questions were the same but asked of different populations. The question was “Does your condition completely prevent you from working at a job or business?”.

A person was considered to be permanently retired if she/he did not fit into one of the three preceding categories.

People with episodic disabilities: Who are they and what supports do they need to obtain and retain employment?

Annex C Supplementary Tables

| Annex Table C1. Selected demographic characteristics for the three populations | | | |
|---|----------------|------------------|------------------|
| | EPI/WD | EPI/No WD | No EPI/WD |
| Total | 607,870 | 522,440 | 117,280 |
| Age group | | | |
| 18 to 29 years | 11.3% | 13.6% | 14.8% |
| 30 to 44 years | 25.9% | 24.5% | 25.0% |
| 45 to 54 years | 31.8% | 30.4% | 35.4% |
| 55 to 64 years | 30.8% | 32.1% | 24.7% |
| Sex | | | |
| Male | 45.7% | 42.1% | 57.6% |
| Female | 54.3% | 62.3% | 42.4% |
| Marital Status | | | |
| Single and not living common law | 28.0% | 21.5% | 25.3% |
| Married or living common law | 55.1% | 62.8% | 65.8% |
| Separated, divorced, widowed and not living common law | 16.9% | 15.7% | 8.9% |
| Living arrangements | | | |
| Spouse/partner without children | 27.3% | 28.9% | 32.9% |
| Spouse/partner with children | 27.5% | 33.4% | 32.5% |
| Lone parent | 8.0% | 9.6% | 5.8% |
| Child | 10.0% | 9.4% | 13.8% |
| Person living alone | 20.9% | 14.9% | 8.2% |
| Aboriginal identity - Yes | 6.1% | 3.6% | 2.1% |
| Visible minority - Yes | 11.8% | 18.2% | 20.0% |
| Immigrant - Yes | 15.6% | 22.4% | 22.9% |

Source: Unpublished data, 2012 Canadian Survey on Disability

| Annex Table C2. Selected education characteristics for the three populations | | | |
|---|----------------|------------------|------------------|
| Highest level of education | EPI/WD | EPI/No WD | No EPI/WD |
| Total | 607,870 | 522,440 | 117,280 |
| Less than a high school diploma | 16.1% | 12.6% | 18.6% |
| High school diploma | 29.0% | 27.2% | 29.7% |
| Diploma/certificate - non-university | 35.5% | 36.1% | 32.5% |
| University degree | 19.1% | 24.0% | 18.4% |
| Not provided | 0.3% | 0.2% | 0.9% |
| | | | |
| Condition present while attending school | 22.8% | 22.7% | 18.7% |

Source: Unpublished data, 2012 Canadian Survey on Disability

| Annex Table C3. Selected education characteristics for the three populations | | | |
|---|----------------|------------------|------------------|
| | EPI/WD | EPI/No WD | No EPI/WD |
| Total | 607,870 | 522,440 | 117,280 |
| Total income in 2010 | | | |
| No income or negative income | 2.6% | 3.4% | 3.9% |
| Under \$20,000 | 39.7% | 23.7% | 47.2% |
| \$20,000 - \$49,999 | 36.2% | 44.8% | 32.9% |
| \$50,000 or more | 21.4% | 28.2% | 16.0% |
| Major source of income in 2010 | | | |
| Wages and salaries | 59.6% | 79.6% | 58.1% |
| Self-employment | 21.2% | 16.9% | 15.4% |
| Workers' Compensation | 9.1% | 6.3% | 11.2% |
| CPP-D/QPP-D | 6.7% | 2.6% | 5.5% |
| CPP/QPP (not disability) | 8.9% | 8.3% | 7.0% |
| Long-term disability (private plan) | 7.8% | 3.7% | 4.0% |
| Motor Vehicle Accident insurance | 1.6% | 1.0% | 4.6% |
| Veterans Affairs disability pension | 1.0% | 1.0% | 0.5% |
| Social Assistance | 10.2% | 6.1% | 10.8% |
| Employment Insurance (including Quebec Parental Insurance Plan) | 11.9% | 11.6% | 9.0% |
| Living below the LICO (after tax) | 13.2% | 10.3% | 17.1% |

Source: Unpublished data, 2012 Canadian Survey on Disability

| Annex Table C4. Selected disability characteristics for the three populations | | | | |
|--|---------------------------|----------------|------------------|------------------|
| Characteristic | Category | EPI/WD | EPI/No WD | No EPI/WD |
| Total | | 607,870 | 522,440 | 117,280 |
| Type of disability | Cognitive | | | |
| | Mental health | 42.4% | 25.5% | 5.4% |
| | Developmental | 4.7% | 3.0% | 6.9% |
| | Learning | 21.0% | 9.0% | 11.5% |
| | Memory | 18.4% | 6.7% | 9.9% |
| | Physical | | | |
| | Mobility | 42.9% | 26.8% | 45.4% |
| | Dexterity | 25.9% | 9.4% | 14.5% |
| | Flexibility | 54.9% | 35.3% | 50.8% |
| | Pain | 86.5% | 72.3% | 38.8% |
| | Sensory | | | |
| | Hearing | 16.4% | 15.5% | 17.4% |
| | Seeing | 18.3% | 13.8% | 17.0% |
| | Type unknown | 0.9% | 2.6% | 7.1% |
| Severity of disability | Mild | 26.5% | 57.5% | 33.5% |
| | Moderate | 22.4% | 23.7% | 18.9% |
| | Severe | 28.2% | 14.7% | 28.5% |
| | Very severe | 22.9% | 4.1% | 19.2% |
| Age of onset | Before school (0-4) | 6.7% | 4.7% | 13.3% |
| | 5-18 (school years) | 17.3% | 18.2% | 10.7% |
| | 19-29 (transition years) | 16.2% | 16.3% | 14.6% |
| | 30-44 (early work years) | 28.1% | 28.1% | 36.3% |
| | 45-54 (middle work years) | 20.7% | 21.6% | 14.3% |
| | 55-64 (later work years) | 9.8% | 10.4% | 10.0% |
| | Onset unknown | 1.3% | 0.7% | 0.9% |
| Number of disabilities | 1 | 16.5% | 40.3% | 40.0% |
| | 2 | 22.9% | 27.7% | 23.5% |
| | 3 | 19.1% | 18.4% | 20.0% |
| | 4 or more | 41.6% | 13.6% | 16.5% |

| Annex Table C4. Selected disability characteristics for the three populations (concluded) | | | | |
|--|--|----------------|----------------|----------------|
| Characteristic | Category | EPI/WD | EPI/No WD | No EPI/WD |
| Total | | 607,870 | 522,440 | 117,280 |
| Selected episodic health conditions³ | Pain | 74.6% | 64.5% | |
| | Mental health conditions | 33.7% | 21.5% | |
| | Arthritis | 26.6% | 34.1% | |
| | COPD | 2.4% | 3.2% | |
| | Asthma | 1.8% | 2.8% | |
| | Diabetes | 1.7% | 3.5% | |
| | Multiple sclerosis | 1.3% | 1.1% | |
| | Migraines | 1.1% | 1.5% | |
| | Crohn's Disease and Ulcerative Colitis | 0.9% | 1.8% | |

Source: Unpublished data, 2012 Canadian Survey on Disability

³ Only nine of the episodic conditions had estimates that were releasable from Statistics Canada.

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