



# Independent Living Resource Centre

## *Why Don't Those People Work?*

*A report of the findings and recommendations of a consumer focus group on  
Disincentives to Employment for people with disabilities.*

*May 2009*



## Why Don't Those People Work? - 2009

The **Independent Living Resource Centre** or ILRC is a resource centre designed by and for people with disabilities.

We are...

- Located in St. John's, Newfoundland & Labrador, Canada
- A not-for-profit community based organization
- Managed by a consumer controlled volunteer board of directors
- Open to people who have any type(s) of disability
- A member of Independent Living Canada (ILC) (previously the Canadian Association of Independent Living Centres, CAILC.)

As well, we offer a wide range of disability related information, services and resources. Our goal is to support people in making informed decisions about their lives.

Independent Living is about:

- Having choices
- Making informed decisions
- Finding solutions that work for you
- Choosing where and how you want to live
- Taking risks
- Taking responsibility
- Managing your resources
- Controlling your own supports
- Learning from each other

A consumer is a person with a disability. Instead of being "patients" or "clients" we see ourselves as active and informed consumers of products, programs and services.

Thank you to all who contributed in any way to the production of this report. A special thank you to **Michelle Murdoch** who took the time to review all of the notes from the focus group sessions and compiled this report for the Independent Living Resource Centre.

**Why Don't Those People Work?  
Disincentives to Employment  
as reported by Consumers with Disabilities**

**ILRC Focus Group -2009**

**INTRODUCTION**

During a tour of the Independent Living Resource Centre (ILRC) in St John's, a visitor asks why the organization needs an employment program specific to persons with disabilities. The coordinator replies that it is very difficult for people with disabilities to find sustainable employment. He explains the issues are very complex and involve a variety of factors, most of which persons with disabilities cannot control.

We realize many people have little understanding about the many layers of disability, particularly in regards to employment. We are often hear questions such as, "why don't those people work"?

We decided to ask. We organized a focus group of consumers and asked what disincentives happen in your life that makes employment difficult or impossible.

This is a report that looks at the disability employment issue from a different perspective. We know barriers exist, but we are trying to identify more subtle realities that significantly impact persons with disabilities. In this report we speak to how disability is (or is not) defined, participant thoughts and experiences, and while some of the issues are summarized we also include direct participant quotes and some solutions. There is no quick fix for most of the issues discussed but we do feel it is essential that we both ask consumers their thoughts and pass these thoughts on to those who directly influence change through policy.

**WHAT IS DISABILITY?**

Within the province of Newfoundland and Labrador there are almost infinite ways to create the concept of disability. What this means is that from different

perspectives we define what a disability is or is not. There is no one universally recognized determination of disability.

Within the medical system we have genetics, obstetrics, children and adult rehabilitation, psychiatric, medical and surgical services that, both together and independently, determine their understanding a normal body/mind and an abnormal body/mind. This medical model of disability influences others within society about what a disability is or is not.

Provincial government departments provide social safety nets, pharmaceutical coverage, and determine suitability of services such as home support or other disability accommodations through protocols that determine eligibility. Governments, while using validation through the medical model, have its own limits of how to define disability and who fits or does not fit the criteria for various social support systems.

Other agencies also have their own determination of disability. This may include; Workers Health, Safety and Compensation Commission (WHSCC), insurance agencies, providers of long and short-term disability plans, sick leave employment insurance, and providers of health plans. In these systems consumers must qualify via organizational standards to receive services and/or supports.

Sometimes employers feel they must have a definition of disability and use this as a tool to include and exclude. Pre-employment medicals, for many positions, can be used as filter to eliminate women, men and youth with disabilities from employment in various workplaces.

Newfoundlanders and Labradoreans elect public officials, who are, in turn highly influenced by civic opinion. Opinions of the general public have evolved over time to become more aware of disability issues. But overall, it is impossible to adequately convey to our fellow citizens what it is like to have a disability and the number of barriers that we, as persons with disabilities, face while attempting to enter (or sustain employment within) the labour market.

Even various NL community organizations serving persons with disabilities represent concepts of disability in a number of ways. Some support and work within a medical model and yet others deconstruct the medical model and have attempted to define disability from other perspectives.

The United Nations (UN) Charter and Universal Declaration for Human Rights have endorsed a concept of disability, purposively leaving the concept broad so that it can be interpreted from a number of perspectives. Interestingly, the UN also leaves room for growth, acknowledging the ever evolving nature of disability.

All of these influences and endless others, not named here, impact the manner in which women and men with disabilities are portrayed as they attempt to enter the labour market. It is difficult to accurately say how engrained and intertwined these influences are and how both those born with disabilities and those who acquire disabilities have to navigate a system with obvious and hidden obstacles.

Such obstacles range from not owning a phone or reliable source of communication, lack of suitable clothing to wear to work, unwillingness of individuals to provide references because of disability, lack of availability to disability accommodation, lack of transportation and perhaps most universal, fear.

Fear is universal within disability conversations. Fear impacts both those seeking employment and those who are employed.

## **THE PARTICIPANTS**

23 people attended this focus group organized with the purpose of discussing disincentives to employment. Two people responded to the questions by email.

Focus group participants were represented from all working age groups, both genders, some had university degrees, post graduate degrees, or other types of post secondary education and others had no post secondary training. Some have held jobs in the past, some are employed now, and others have never been employed.

While everyone had experiences about having been employed or having not been employed, some comments came with a great deal of impact. One of these comments describes a woman who travels a total of three (3) hours a day by bus to get to and from her three (3) hour a day minimum wage job. She also has to arrange childcare for this period.

Generally participants did not illustrate a sense of belonging to the wider Newfoundland and Labrador (NL) community. Most spoke of alienation and feeling others view them as less than. This is a serious problem and one that will take innovative thinking, to address.

**DISINCENTIVE** A disincentive to employment is something that tends to discourage, deter, or prevent a person from seeking, finding or keeping employment.

### **WE HEARD...**

All participants agreed that they experience many disincentives in regards to labour market entry and if they had the chance to be employed within NL it would be for the minimum wage. The group consensus was that “doesn’t everyone here start at minimum wage?” There was no overall sense that education and/or experience should impact a wage one might expect to earn and that any job is a good job.

One person commented, “We are damaged goods that no one really wants.”

Participants did not envision employment as a means to gain a sustainable income. When disability-related supports, accessible and affordable transportation, and medication costs are all considered most stated they would work for reasons other than economic independence.

When asked why people in the group wished to work, participants responded:

- emotional attachment to work
- place to have an identity
- become part of a community
- learning opportunities
- better opportunities in general (no elaboration given)

Participants were asked to identify luxuries. “What would you buy as a luxury, if you had saved up some money?” This question was followed by a lot of laughter, eventually there was the following responses.

- “Tim’s’ coffee”
- “Hair cut”
- “Walk through the mall, not to buy, just to look!!!”

The facilitator, trying to get a sense of more substantial luxuries asked if people would get a massage. No one responded because this group of consumers does not have access to ‘extra’ money. One individual who was working expressed a fear of spending anything over and above necessity because of the constant fear of getting sick and losing his job.

Throughout the two-hour conversation there was a sense that persons with disabilities are still poorly understood within government systems and as well within the greater society.

Participants made very profound (and disturbing) statements, including:

- “I’m treated like a crook.”
- “I feel people just wish we would all die.”
- “We are definitely second class citizens.”
- “We are society’s garbage.”
- “We are damaged goods that no one really wants.”

## **POINTS MADE...**

Four primary focus areas emerged and as well as a number of important but unrelated points.

1. Participants express substantial fear, dealing with government systems and others that influence their ability to access various disability-related services and supports

The problem is that when utilizing financial or disability-related supports from government support systems people lose their sense of power. Rules are not readily apparent, transferable, or understandable. A benefit within one system can be clawed back within another.

2. Participants express substantial fear of the unknown; sustained poverty is more secure than the risk of losing the little people presently receive.

Issues include loss of income and/or the loss of security, not knowing how to pay for medications, when to apply for what program, or if the cost of medication would be negated by a low hourly wage. Participants reported going without drug coverage (and therefore medications) during the transition between no job and gaining any form of employment.

There is a great unknown in regards to employer health plans. Some health plans refuse to cover any pre-existing conditions, which precludes coverage for many persons with disabilities.

3. Impossibility obtaining reliable, affordable, and accessible transportation. Accessible transportation is a relentless conversation within the disability community in general and an enormous problem in and of itself which will necessitate government leadership to solve.

There is no readily accessible transportation within NL outside of the greater St. John's area. This is particularly restrictive within rural and remote communities.

4. Not a lot of people within our society would look for employment if they thought they would be worse off as a result. Yet, persons requiring disability-related supports are habitually worse off financially when working. Participants report that the jobs they receive are generally at minimum wage level, temporary, or part time and find they are unable to support added costs such as medications, home support and equipment.
5. Those sustained within insurance plans, Canadian Pension, Disability, or WHSCC systems report a lack of transparency. People do not know and generally cannot find out what happens to their supports (such as medications, services, or equipment) should they return to work or find another source of employment. There is a fear seeking answers from these systems because inquiries often result in further investigation of their individual case or reduction in services.

It is not that people do not want employment but rather that the difficulty seeing through and within these systems tends to best serve the system rather than the individual with the disability.

## **PARTICIPANTS ELABORATED....**

### **A. They experience FEAR on a regular basis.**

This includes fear of government systems, fear of losing support if you speak out, fear of bringing attention to oneself, and fear of losing the little support people already have.

- People choose sustained poverty over the fear of losing what supports they do have.
- Participants report a fear of “ending up worse off”.
- Systems are not transparent so people do not know what is or is not expected from them. For example, it is almost impossible to get information about how persons on income support or WHSCC are impacted by return to work. Participants did not feel safe exploring such options.
- Even those presently working say they do not spend their earnings on ‘extras’ because they are aware at any time they may become ill and need money.
- Participants fear criticizing any government program. They say when programs/services are compared to another program or service what usually happens is the client favourable aspects of one program are removed rather than added to the deficient program/service. This paternalistic approach is similar to a parent who removes everything from the complaining child rather than figuring out what is at the core of the issue.
- There is a general agreement that systems are set up to defeat people because everyone is presumed to be “a crook” or “a scam” to begin with.
- One participant said she feels like “society’s garbage”. She spoke of an event whereby service providers argued about which department ‘had’ to handle her case because the issues she was bringing forward were overlapping and not clearly one department or another.

- There was some discussion about whether or not persons supported by government systems are permitted to save money. Some spoke of their need to have a safety net but others voiced no understanding of safety nets because there simply was not enough cash flow to manage day to day in the first place. Some spoke of wanting to keep tax rebates whereas others laughed, saying saving money is not the reality of their lives. A few others said they did have the option to have a savings of three thousand dollars. Many were unaware of any such option.
- Overpayments must be repaid. One well articulated fear is that if people receive something they are not entitled to (or gain employment and become disqualified) they will have to pay back the money. Few people have an income that includes extra resources to pay back. For that reason participants say they avoid many new programs or incentives because they are unsure how this will impact other supports they receive. One such program is the government drug plan for persons with substantial prescription drug costs.
- One example of fear of unknown rules concerns Canada Pension Plan-Disability (CPPD). Frequently well-paid workers develop a disability and are forced to seek employment in areas with a much lower rate of pay simply because s/he has a disability.

There are many unanswered questions. If a person worked, became disabled and received full CPPD, what would happen to the persons CPP if s/he was to later return to another job at a much lower rate of pay?

Not knowing what will happen having unanswered questions and the subsequent fear and anxiety of the unknown, tends to make persons with disabilities feel they are a forced to make uninformed choices.

- B. Issues around medication coverage are a huge source of anxiety for persons with disabilities both within the workforce and those thinking of labour market entry.
- When person with a disability supported by (Human Resources, Labour, and Employment, and/or Health and Community Services) income support systems returns to work within two months both rent

(if using low cost government supported housing) and drug card access changes drastically. Two major expenses that change very quickly and simultaneously, increase stress substantially.

- Loss of income and/or a sense of security in not knowing how to pay for medications, when to apply for what program, or if the cost of medication would be negated by a (low) hourly wage.
- Participants reported going without drug coverage (and therefore medications) during the transition between no job and gaining any form of employment (employment ranged from few hours bi weekly to full time).
- Participants strongly agreed that the availability of prescription medications is vital part of their ability to work because the cost of medication is considered by participants as a vital part of their cost of daily living.
- Mental health consumers expressed strong concern because it is the availability of medication that enables them to work and remain at work. People report gaps in service while gaining labour market entry places them at a serious disadvantage compared to others seeking employment.
- When availing of government drug plans, participants report feeling their privacy is violated as they are required to answer very personal questions as to what the intended use of some medications might be why these medications are necessary and so on. (A medication can be acceptable to treat one diagnosis but the same medication may not be available for another type of diagnosis.)
- Participants said the 'new' government drug plan differs from the HRLE medication program as the authorization process within the two programs is different. Although informed differently, participants reported a varying availability of medication coverage from one program to another program, as some medications are covered on one plan and not the other. Participants fear complaints about this would result in an overall reduction of medications covered.
- The drug formulary plan is understood to be a medically controlled system that is defined outside of this province however, medications frequently prescribed here in NL are not necessarily the medications frequently prescribed by physicians in other parts of Canada.

- Once you get your medication needs met on one program participants report feelings of frustration from their physicians when you change to another program, i.e. return to work, because this will involve another new set of forms and paper work.
  - With more and more physicians leaving the province and increasing paper work to gain access to government supports and services some persons with disabilities are reluctant to seek out services for fear of being too much of a burden on the medical system.
  - It is such a fight to get your needs met through government programs and services that it seems redundant to leave those services to go through the whole process again in another area.
  - Some employers have a medical plan that does not cover pre-existing conditions. This type of coverage excludes persons with disabilities.
  - Medical examinations prior to employment are also viewed as holding the potential to 'weed out' anyone with a disability.
- C. Lack of access to affordable, reliable transportation is a major disincentive to employment for all persons with disabilities. This topic has been covered extensively in the ILRC Focus Groups concerning Transportation report (2008) therefore this topic was not discussed in full but the following observations were apparent.
- Affordable, reliable, and accessible for persons with disabilities is not available in NL.
  - Bus passes cost more than the allowable 50.00 allotment.
  - City bus passes have been issued to persons with disabilities using wheelchairs. Buses are not accessible.
  - If you can get Wheelway to bring you back and forth to work you will likely have to leave 1-2 hours in advance and get home hours after the work day has ended.
  - Many Newfoundlanders and Labradoreans with disabilities have few, if any, options in regards to transportation.
  - There is no provincial transportation plan that addresses disability inclusion.
- D. Home Support continues to be another area of intense concern when persons with disabilities seek employment. This topic has been covered extensively in the ILRC Focus Groups concerning Home Support report

(2008) therefore this topic was not discussed in full but the following observations were apparent.

- Home Support services must be removed from Income Support. Any increase in income usually results in a corresponding loss of Home Support Services.
- A participant reported losing home support services because the individual made a very small amount over the cut off amount (\$3.00).
- Participants report getting minimum wage jobs (\$8.50), while home support is \$9.29/hr. Working low paying jobs do not enable an individual to pay his/her own disability –related supports.
- There are actually times in one’s career that it is not economically beneficial to earn a pay increase! This is because there are cut offs between eligible earning status and ineligibility. Becoming ineligible means a person must pay his/her own disability –related supports which financially may be less beneficial than having a lower pay with the same supports coming from government sources.
- The above type of rules and regulations (while some are necessary) promote the sense that if you have a disability it is exceedingly difficult to “get ahead” and away from systems.

### **ADDITIONAL POINTS**

- Added support for mothers with disabilities is essential. Because mothers with disabilities are a very small group within the disability community their voice is often silenced. Participants stated this is a very real problem and one that is largely ignored.
- Participants agree stress from the uncertainty of government bureaucracy makes them physically/mentally ill.
- There is a sense that participants feel less valued if they are not trying to find work.
- There are unpredictable disability related rules within systems that are not readily apparent to people who may think they will qualify for a program but actually will not. For example, if a Canadian is working outside the country and develops a disability s/he has to work within Canada for the past four (4) of six (6) years to qualify for CPPD. While a federal government rule, the impact is that those affected by such

legislation come home to poverty and likely Income Support, as other traditional forms of support are not available.

- Duty to Accommodate: persons with disabilities know this is a legal right but were unable to elaborate as to exactly what that means.
- Participants suggested the success of obtaining workplace accommodation is more individually focused, as in the louder voice gets heard.
- The disability tax credit should be given to the person to be used for her/his own purposes and not clawed back.

## **WHY DON'T THOSE PEOPLE WORK ...? WE HAVE SOME ANSWERS**

The complexities of these problems are substantial. Concerns projected by the ILRC stem from the feedback from services and supports provided within the centre. While employment is one of our biggest concerns, there are other issues, such as availability of accessible and affordable transportation, housing and disability-related supports. It is imperative we examine globally all of these areas of concern, because isolating one produces only band aid results.

The mandate of the Independent Living Resource Centre is to provide individuals access to specific services and supports. We build awareness as to how Independent Living can be applied to existing generic community and government services/programs and, how it can form the foundation of any new initiative/service/program. The key to success in these processes is the recognition that persons with disabilities are the experts in identifying what does and does not work for them in their daily lives.

As a primary component of research and development, the ILRC regularly undertakes consultation and planning processes to ensure it is effectively responding to current and emerging issues that impact our consumers. The ILRC brings to policy makers the voices of the lived experience of disability.

We ask government to support the:

- development of the voices of women, men and children with disabilities in NL.
- removal of Disability-Related supports from Income Support.

- increased transparency within systems so that users of these systems are guided towards informed choice.
- changes in attitudes, so that women, men and children with disabilities in this province can feel valued and permitted to contribute in meaningful ways of their choice.
- conversations with community leaders who have an entrenched knowledge of the issues. To evoke positive change it is critical the Disability Policy Office and policy makers within government work with community disability leaders and develop direct links to community organizations serving persons with disabilities.
- gendering of disability issues to highlight seldom referenced topics such as mothering as a woman with a disability, preparing to work (or working) as a mother with a disability, women and men's health, so on.
- development of grass-roots, disability-focused research.

In summary, one of the most alarming findings of this focus group study is the widespread sense that persons with disabilities believe they are not contributors to the well-being of Newfoundland and Labrador. Consumers and persons with disabilities can and do want to work. In fact many consumers donate to their community endless hours of volunteer time and various types of expertise.

But, in some ways we have become dependent on others to solve our problems, in part because women, men and children with disabilities are seldom asked. It is pivotal to develop pathways in which persons with disabilities are both heard and valued.

Consumers who participated in all of the ILRC surveys and focus groups over 2008-2009 anticipate changes in the future and want to be part of the energy that ensures the changes positively impact the citizenship of all persons with disabilities in this province.