



Disability Support Services in Newfoundland and Labrador and Canada: Impacts on Labour Market Participation for Individuals with Disabilities

Prepared by the SafetyNet Centre for Occupational Health and Safety in partnership with The Coalition of Persons with Disabilities- Newfoundland and Labrador (COD-NL)

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1.0 Introduction

While there has been progress in providing supports to persons with disabilities in Newfoundland and Labrador, there is a concern that many policies are not really adequate and do not align with one another to provide integrated support and to encourage a search for work. Some research has shown that the design of social security programs can inadvertently worsen the financial and employment standing of some disabled people (Kim et al, 2010). These unintended consequences can arise both directly in terms of the level of support provided and indirectly through funding criteria that make it disadvantageous for disabled people to seek employment. While the direct disincentives to seeking employment are a concern, we still do not have a solid understanding of how indirect disincentives inherent in social support programs are impacting people within this province, especially from a cross-disability perspective. In addition, the existing research is limited to specific contexts and disability support programs, such as pre-employment programs, rather than comparing the total impact of the interaction of various programs with a wide range of disability populations.

This research project was initiated and conducted by the SafetyNet Centre for Occupational Health and Safety Research and the Coalition of Persons with Disabilities - Newfoundland and Labrador. The goal of the project is to explore potential barriers to labour market participation related to disability support services in our province. The research engaged policy makers and individuals with disabilities in order to consider different perspectives and experiences with both designing/allocating and utilizing disability support services. This report presents our findings on the impact of different disability support services on the labour market participation of individuals with disabilities in Newfoundland and Labrador, with a focus on disability-related supports attached to income support programs. The report also examines some broader issues that pertain to the overall set of disability support programs including eligibility, portability, financing, and delivery, as well as how improved coordination, efficiency, flexibility, and accountability could improve employment outcomes in the local labour market for people with disabilities.

2.0 Background

According to the Public Health Agency of Canada (2013), “paid work provides not only money, but also a sense of identity and purpose, social contacts and opportunities for personal growth”; its absence reduces life expectancy and creates significant health problems. For many Canadians with disabilities, “gainful employment is regarded as an essential part of economic and social citizenship with its attendant rights and responsibilities, including the right to take responsible risks” (Prince, 2014, p. 11). This type of social engagement also alleviates some health burdens and can be a key factor in combating their underlying causes. Considering the stigma of being different that has been historically attached to people with disabilities, pursuing equality through economic independence is also a step toward achieving social justice and moving away from being marginalized and ignored.

While the importance of equal and just opportunities for employment is widely recognized in theory, the reality often differs. Persons with disabilities have traditionally struggled to achieve economic independence through employment, mostly because they have been perceived as objects of care and dependent individuals who require societal protection and support to compensate for their inabilities (UN Convention on the Rights of Persons with Disabilities, 2015). Disability has commonly been understood as an individual pathology. This medical perspective had significant implications beyond medicine and bioethics, in areas such as housing, employment, and education. If an individual's incapacity to undertake certain occupations is explained by his or her deficits, there is no need to alter the social organization of work (Vehmas and Shakespeare, 2014). By contrast, the social model of disability provides opportunities to see disability differently and uncovers structural and systemic causes of inequality (Oliver, 2004). The 2007 United Nations Convention on the Rights of Persons with Disabilities, ratified by Canada in 2010, offers a much more holistic definition of people with disabilities as people with "physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations Enable, 2007, p. 2).

Despite the endorsement of the social model of disability, numerous advances in treatment and assistive technology, and commitment by governments and economic stakeholders to social equality and inclusion, there are still real challenges in ensuring meaningful labour market participation for individuals with disabilities in this country. In 2011, the employment rate of Canadians aged 25 to 64 with disabilities was 49%, compared with 79% for Canadians in the same age group without disabilities (Turcotte, 2013). In 2010, the self-reported median total income of people aged 15 to 64 with disabilities was \$20,420, compared with \$31,160 for those without disabilities. A report from the Canadian Panel on Labour Market Opportunities for Persons with Disabilities (2012) states that 795,000 persons with disabilities in Canada are unemployed, even though their disabilities do not prevent them from working and almost half of them have post-secondary education. Individuals with disabilities are also more likely to work part-time, intermittently, or in precarious employment. Finally, they are also more likely to live in low-income households. According to the Conference Board of Canada (2013), "Canada's working-age poverty rate increased from 9.4 per cent in the mid-1990s to 11.1 per cent in the late 2000s." In contrast, the poverty rate for persons with disabilities in 2013 was 13.6%. No numbers have been reported for Newfoundland and Labrador. However, prior to 2006, Newfoundland and Labrador had the second highest poverty rate in Canada (Canada Without Poverty, 2015). As of 2014, according to the provincial government, Newfoundland and Labrador has the lowest level of poverty in Canada based on Statistics Canada's Low Income Cut Offs – After Tax (LICO-AT) for 2013. In the light of the recent economic constraints, this progress may now be losing momentum.

Most Canadian governments address these issues of unemployment and poverty through legislated provisions that seek to improve the financial security and stability of people with

disabilities. These provisions are, for the most part, features of income support programs and may also include housing, home care, transportation subsidies, drug coverage, and other supports that address basic daily living needs of persons with disabilities. A number of studies have expressed a concern, however, that “because of the way earnings and income-tested disability supports provided by provincial and territorial governments are treated, the combined loss of income-tested benefits and disability supports outweighs the earnings obtained from work and for some persons with disabilities acts as a strong disincentive to find or return to work” (House of Commons, 2012). While not everyone is in a position to look for a job, those who are willing and able to go to work may feel trapped within the system. The challenge in overcoming this problem, according to some analysts, is that “once cast in a particular mold of compensation, systems do not evolve as times and values change” (Stapleton, Tweddle, & Gibson, 2013). Combined with specific economic and labour market circumstances, including increases in precarious employment, reduction of employer benefits, and the absence of eligibility for other types of disability income, these issues all point to a trend referred to as “welfareization of disability incomes”. More and more individuals with disabilities are relying on general income support rather than on social assistance disability benefits. This trend has been observed in Ontario and it extends to other provinces as well. It is believed that this trend discourages employment and perpetuates poverty, as well as “reinforces systemic stigmatization of recipients by disallowing recipients to improve their situations in ways that most Canadians would take for granted” (Stapleton, Tweddle, & Gibson, 2014).

It is argued that addressing these problems requires a fundamental reform of social assistance programs. This is not a novel idea and it has already been discussed in a recent report, *Brighter Prospects: Transforming Social Assistance in Ontario* (Lankin, & Sheikh, 2015). Similarly, in the *Employment Action Plan for Persons with a Disability in New Brunswick 2012-2017*, the government recognizes that progress on addressing access to transportation and reform of social assistance policies and programs are crucial aspects of an Employment Action Plan, and it has made clear commitments to, among other things, introduce a new and distinct income program for persons with disabilities (as part of a broader social assistance reform initiative). In British Columbia, a study on flexible employment options for persons with disabilities argued that by “allowing workers with a disability to cycle into and out of the labour market without risking their access to disability benefits and helping them gain part-time or part-year work, it is possible to maximize labour market participation among people with a significant disability” (Cohen, Goldberg, Istvánffy, Stainton, Wasik, & Woods, 2008).

While no studies have been conducted in Newfoundland and Labrador on the relationship between disability support services and labour market participation for individuals with disabilities, two reports examine related issues – employer attitudes and perceptions of workers with disabilities. A 2015 study, *Employers’ Perspectives on Inclusive Employment in Newfoundland and Labrador*, provides some insight into local employers’ hiring practices, incentives, and main concerns when it comes to hiring persons with disabilities in the province.

A second study of conditions in NL is the *Report of Research on the Awareness and Perceptions of Oil and Gas Industry Careers Among Young Persons with Disabilities and Recommendations for Improvement*, produced in 2014 by Goss Gilroy Inc. It shows that lack of awareness, accurate information, and proper guidance in the early years of a person's education can lead to misperceptions, insecurities, and unnecessarily cautious career choices. Both studies raise crucial questions regarding education and life choices, as well as the level and timing of necessary supports prior to and during the transition period from youth to adulthood.

The findings of these two studies suggest that the conditions documented in other provinces are equally worrisome here and that research is needed to identify specific gaps in the organization and delivery of services and to find ways to address these challenges in our particular context.

3.0 Project Methodology

This study began with a literature review and a scan of the relevant online documents on disability support programs in Newfoundland and Labrador. We also conducted a scan of relevant peer-reviewed and gray literature on disability support services across Canada. We used the findings of these reviews to draft a schedule for our key informant interviews and discussion guidelines for our focus groups.

We conducted eleven key informant interviews and two focus groups. Interview participants were recruited through purposive sampling from three different groups identified as relevant for the study: government policy makers, representatives of regional health authorities, and representatives of support agencies for persons with disabilities in Newfoundland and Labrador. Interviews were conducted in person and over the telephone at an average length of 50 minutes. All interviews were conducted between October 2015 and January 2016. Interviews were conducted by the project's research assistant, Aleksandra Stefanovic, and were facilitated by an interview guide encouraging broad discussion of disability support services and disability policy in the province. The interview guide is included as Appendix A. The interviews addressed the allocation of disability support services, barriers to transitioning to employment from income support, design and evaluation of relevant programs and services, and recommendations for decision tools and improved practices. Interviews were audio-recorded and transcribed verbatim. Notes were taken during interviews as well. All textual data were analyzed and coded manually using an iterative process. The initial coding framework was based on the key themes reflected in the interview guide, participants' comments and the interviewer's notes. Several other themes emerged as the recordings were analysed and these were added to the analytic framework.

The two focus groups each consisted of seven participants. Each focus group lasted two hours. Focus group participants were individuals with various types of disabilities, including mobility and physical impairments, hearing disabilities, cognitive and learning disabilities, psychological disorders, as well as chronic illnesses such as fibromyalgia. The study was conducted from a cross-disability perspective in order to collect general information on supports and services for

individuals with all types of disabilities. During the meeting, the participants had the opportunity to discuss their experiences with disability support services in our province as well as their experience in seeking to make the transition to employment.

4.0 Limitations

This report does not attempt to provide an exhaustive or systematic review of the literature or to thoroughly explore all aspects of disability supports at the federal and provincial levels. The report also focuses on the St. John's Metro region. Although all provincially legislated provisions would apply across the province, employment opportunities and economic conditions can be vastly different in smaller, more isolated areas of the province, and the delivery and funding may vary in some rural areas as well, which makes it a subject worthy of further examination.

5.0 The Newfoundland Labrador Policy Context

The Newfoundland and Labrador government introduced a comprehensive Poverty Reduction Strategy in June 2006 – *Reducing Poverty: An Action Plan for Newfoundland and Labrador* – with an explicit goal of achieving the lowest poverty rate in the country by 2014. Beginning in 2007, a number of changes were made to the province's disability support services. Among other strategic directions, the government called for strengthening disability-related supports by increasing flexibility, improving access, and reducing financial costs associated with living with a disability. In 2014, the government issued a report on its poverty reduction strategy, describing some of the actions undertaken to meet the goals of the inclusion strategy. There were increases in funding for programs within Health and Community Services, including home support and special assistance programs, family board and lodging, and child welfare allowance. In addition, there were also improvements to general supports targeting poverty, inequality, and social exclusion, such as increased access to affordable housing and increased income support rates. The report also notes that, in recent years, some changes have been made that have reflected the economic constraints confronting the provincial government and that have cut into some of the previous achievements. These recent changes include:

- reduction in the number of placements in the Linkages Program (19 fewer in 2016-17)
- integration of the Post-Secondary Training Services Program for persons with disabilities into the Student Loan Program, a decision that standardizes programming offered to similar clients throughout the province
- amendment of the income test financial assessment for subsidy applicants under the Home Support Program and Special Assistance Program, increasing the maximum client contribution from 15 percent to 18 percent of net income
- introduction of a two hour per day cap on free homemaking hours subsidized under the Home Support Program

- elimination of coverage under the Adult Dental Program for clients of the NL Provincial Drug Program under the Access and 65+ plans

Employment-related Government Programs and Initiatives

In Newfoundland and Labrador, the Department of Advanced Education and Skills, the Department of Health and Community Services, and the Human Resource Secretariat all provide programs and services to assist persons with disabilities. In addition, the provincial government partners with community agencies to deliver specific programs and services. Interventions to improve the employability of persons with disabilities are provided in response to individual need. Accordingly, assistance with employment preparation and attachment to the workforce, or to address vocational crisis tends to vary in intensity and duration.

Advanced Education and Skills

The Department of Advanced Education and Skills, with funding under the Canada-Newfoundland and Labrador Labour Market Agreement for Persons with Disabilities (LMAPD), provides a range of services and programs to help persons with disabilities acquire the skills, experience and supports necessary to successfully prepare for, obtain and maintain employment. The LMAPD provides cost-shared funding for a range of provincially-delivered programs and services that enhance the labour market participation of working-age adults with disabilities.

The Department of Advanced Education and Skills provides four types of programs:

- Training Services and Employment Supports
- Supported Employment
- Disability Supports to Post-Secondary Institutions
- Grants to Community Partners

The Department of Advanced Education and Skills also delivers income support to all eligible clients. This is particularly important for persons with disabilities “as the single largest component of the incomes of working-age poor people with disabilities is social assistance” (Crawford, 2013). The Department provides financial benefits and other services to eligible low-income people to assist in meeting daily living expenses. Some basic benefits include family and individual benefits to assist with expenses such as food, clothing, personal care, shelter, household maintenance, and utilities. Additional benefits may include medical transportation, child care, eye exams and prescription glasses.

Health and Community Services

The Department of Health and Community Services provides funding to a variety of community agencies to support individuals with disabilities and to regional health authorities to support persons accessing addictions services. Rehabilitative services are provided to help individuals adapt to a disability, maintain their health, and address barriers to meaningful participation in

society. Home support services, personal care, residential options, prescription drugs, and medical equipment and supplies are funded through this department.

The Human Resource Secretariat

The Human Resource Secretariat delivers the Opening Doors Program which provides opportunities for individuals with disabilities to obtain employment within the provincial public service.

Opening Doors Program

The Opening Doors Program is an employment equity initiative of the Government of Newfoundland and Labrador. It is the foundation program of the Office of Employment Equity for Persons with Disabilities of the Human Resource Secretariat, out of which the Office's other services have emerged. The Opening Doors Program involves full-time, permanent Opening Doors positions throughout the provincial public service in various locations of the province. The Opening Doors Program positions have been designated for persons with disabilities and may be filled only by members of this employment equity group who have been accepted for inclusion on the Office's client registry.

The Opening Doors Program recognizes that one of the major obstacles to employment for persons with disabilities is their lack of job experience. Therefore, much less emphasis is placed on experience when recruiting to fill Opening Doors positions. The positions are also protected from bumping by more senior employees so as to ensure they are not lost during periods of downsizing.

Opening Doors positions are filled based on merit. Those persons who have the education and experience requirements as identified in the competition poster/statement of qualifications are identified by the registry system and "screened into" the competition, i.e., they are referred to the hiring department for the interview process. The candidate who best meets the qualifications for the job and who demonstrates this in the interview process is then offered the position.

Community-based Agencies

A number of disability-specific agencies at the community level offer various pre-employment preparation services and supports, as well as wage subsidies for employers. These agencies work directly with consumers to assist with their labour market attachment.

6.0 Key Issues

The following section presents the findings from our key informant interviews and focus groups. Study participants included policy decision makers, community agency representatives, and consumers/individuals with disabilities. If a specific category of informant is being discussed, we identify it. The term "decision maker" refers to officials of the provincial government or of the

regional health authorities. Informants from the disability community agencies will be referred to as “disability advocates”. The term “consumer” is used to refer to private individuals with disabilities who participated in our focus groups. It is worth noting that we received strong support in our interviews and focus groups for our decision to conduct this study from a cross-disability perspective. All participants expressed their approval of all-inclusive studies, feeling that there are many common issues, barriers, and challenges affecting all individuals with disabilities and that these should be examined prior to looking at any specific disability group.

The consultations with our key informants focused on how, in Newfoundland and Labrador, eligibility criteria for disability support services such as home care, pharmaceutical expenses, and transportation, affect the ability and willingness of individuals with disabilities to participate in different segments of local and larger labour markets. There was a high level of agreement among study participants that, despite considerable progress in the area of disability supports, there is a need for further analysis, evaluation, and continuous conversation with the disability community. Throughout the interviews and consultations, a number of key issues/challenges regarding disability supports in the province were identified by all informants:

- coordination in the design and delivery of services;
- access to services and reliable information;
- continuity of supports through transitional periods;
- real and perceived negative incentives;
- better education and training in the delivery of services; and
- employer engagement.

6.1 Coordination in the design and delivery of services

While all informants agreed that significant progress has been made in providing meaningful supports to individuals with disabilities in this province, they also stressed the need for further improvement of coordination and harmonization of disability support services. All informants agreed that existing social programs still operate in traditionally divided “silos”, which creates challenges for effective internal communication and information sharing. It can also create gaps and add unintended negative consequences for consumers.

A decision maker explained that the government has been actively working on improving collaboration among various departments and coordination of services. One successful example of a more integrated approach to policy development is the Poverty Reduction Strategy. The Strategy, initiated in 2006, brought together 11 ministers from across government in an Inter-Ministerial Committee, as well as a number of senior representatives from a total of 13 government departments and agencies, in order to reduce poverty through innovative programs. Within this collaborative environment, it was much easier to identify gaps in services and prioritize them for funding through a separate budget process. Two of the gaps that were identified by an individual department and brought forward for action through the Poverty

Reduction Strategy were pharmaceutical costs and dental coverage for people with low incomes. New funding was secured for both issues.

The same decision maker further stated that engaging various departments in a collaborative decision making process can help identify roles within the process that may not have been clear in the past. When certain departments are not directly involved in delivering services, they may not know how these services affect consumers. For example, many of the programs developed and administered by the Department of Finance, and more specifically the Taxes, Programs, and Incentives Division, were identified by the Poverty Reduction Strategy as unintentionally affecting disabled individuals.

According to another decision maker:

When introducing new policies or changing them, there is a need to consider all potential scenarios and consequences, no matter how small they may be. Even still, it may always have some negative effect on a small number of people. The question is whether it is better to still do it or not. Additional shelter assistance was proposed with the best intentions, and even as such, it had unintended negative consequences for some...Even though all the work has been done from the departmental perspective and should have worked, it didn't factor in some element of the tax system, or benefit part that was income tested or means tested...

This highlights the complexity of policy development and the need for collaboration among various departments that are directly or indirectly involved with specific policies, as well as the need for continuous revision of policies through consultations with consumers.

The consumers in our focus groups all felt that it is not appropriate to deal with persons with disabilities in a standardized way and that there is occasional miscommunication among departments.

6.2 Access to services and reliable information

All key informants described the province's disability support systems as complex and difficult to navigate. There are real challenges for consumers in accessing relevant supports and services, and in accurately determining their eligibility for those supports in a timely fashion should they transition to or from employment. A decision maker stated that they are aware of the complexities within a system where four regional authorities are responsible for service delivery and each may have its own processes in place. Furthermore, the assessment process can be a challenge, as it involves both verifying a disability through a clinical assessment process and determining financial eligibility through a financial assessment process. This official explained that the process of assessment takes the client through a number of different departments, starting with Health and Community Services for clinical assessment, then Advanced Education and Skills for income support, and finally to the regional health authorities in order to access

disability support programming and other financial benefits. For other services, such as educational supports, an additional journey through a different part of the system and a new set of directions are required. Once an individual is assessed and approved by the regional health authority, a case manager is assigned to provide further assistance. Until that point, however, clients have to navigate on their own. The same applies to the reverse process of leaving income support and transitioning to employment. When asked if there is a standard pathway for determining changes in disability supports and their implications for employment, the decision makers explained that each case is unique and requires individual consideration.

Another issue that came up in a number of consultations involved access to information on eligibility for various disability support services and programs, particularly when exploring the option of looking for employment. A decision maker told us that, without knowing exactly what to look for, clients found it quite challenging to find the right information. Program names can be confusing since they often do not refer clearly to their actual contents. A good example we found on the government website would be the Access Plan and the Assurance Plan under the Newfoundland and Labrador Prescription Drug Program (NLPDP). Another decision maker agreed that the current descriptions of many programs are outdated, incorrect, and/or convoluted.

Decision makers agreed that available printed and web-based information may not be clear enough and that this poses a barrier to accessing the appropriate supports. According to this decision maker information provided orally, either on the telephone or in person, can also often reflect the subjective perspective of the person providing that information. As an example, a decision maker mentioned Self-Employment Assistance as one of the employment programs provided by the government that consumers may be prevented from knowing about because of the existing stigma regarding their capabilities, so that “the people who have the information may not see that person as benefiting from it, and that gets in the way in terms of misconceptions.”

Disability advocates in our focus groups also felt that accessing information can be a challenge. Even for them as professionals in a counselling or coordinating role, “there is no one place to go to retrieve all the relevant information.” They often have to rely on Google or telephone calls to locate information about government programs. Government websites are accessible but they can be difficult to navigate, especially considering that there are often a number of exceptions to various rules. The individual circumstances of each client can be significantly different and, as one disability advocate stated, “there is no amount of training that can cover everything.” Many different community agencies cooperate, network, and share knowledge and experience, but it is not uncommon for them to be competitors because of the nature of government contracts.

In addition to logistical issues, there are other challenges faced by individuals with disabilities when it comes to accessing information and services. A decision maker explained:

When we talk about accessing services for individuals with disabilities, there are so many other barriers that people are running into. It sounds easy to get into an employment centre, you know to have the appointment. But there is a lot more barriers there, transportation barriers, understanding barriers, sometimes the information may not be clear enough, barriers about confidence, barriers about even knowing that it's feasible that I look for employment or that I transition into employment.

Disability advocates also believe that there is an additional psychological barrier to requesting information and asking questions. This is especially true if there is only a 1-800 number to call, in which case “a lot of people are afraid to ask questions, because they are afraid that means they are going to get cut off of their services, just by asking.”

Promoting programs in an understandable way is, according to a disability advocate, essential. Programs and services should have guides written in plain language, and department staff should be encouraged to use that language as well. When asked about program promotion, a decision maker stated that promotion and advertising are usually the first to lose funding, and this is a particular challenge as programs are constantly changing. At one time, for example, there were three staff members in charge of access and promotion for the Poverty Reduction Strategy but those activities have now been completely discontinued. In addition, according to several decision makers, government is not relying on social media as much as it could.

6.3 Continuity of supports through transitional periods

Both decision makers and disability advocates told us that appropriate investments are not currently being made in services for the early days of a person's life. Continuity of disability support services beginning in childhood is necessary for seamless transition through different stages of life. A decision maker explained that it would be a good idea “if you have a piece of equipment or aid that was provided to you in school, that stays with you and goes with you if you transition, so you don't have to go look for a new funder for the same product.” This would ensure that individuals with disabilities have supports along the lifespan, “personal and social across the board, education K-12 and beyond, and finally employment.” However, in fact “the level of supports available for individuals with disabilities on a continuum is very uneven, very unfair, and for the most part non-existent.”

A consumer provided a similar perspective on the continuity of disability supports:

Supports that are needed by persons with disabilities shouldn't be an additional cost, they shouldn't be another item, they are part and parcel of the person...They have to be called basic needs, and not additional supports. I have to buy my own hearing aids and I do and I'm not moaning and whining and I say I think with my twenty-five years of service in my organization that it would have been nice to get a contribution towards the cost of my hearing aid, but it didn't happen...That even the cheapest is between a thousand dollars and \$1500 a hearing aid and I need two, I am not getting away cheap

and they have to be upgraded and I got some money back. The reality is my employer needs my hearing so I can do a good job.

The research team found that other provinces have already discussed the notion of services being attached to the individual rather than to government departments as a desirable option. This “backpack” of services would be tailored to the individual’s unique needs. It could potentially prevent interruptions in services, minimize stress, and reduce fear of the unknown for consumers.

6.4 Real and perceived negative incentives

A major focus area is removing barriers for the income support clients to go to work. We know we have a lot of people on income support, we have employers who can’t find employees and we know that most people on income support want to work. But they are not stupid; if they are not going to be financially better off, they are not going to risk finding work. Some single parents still do it, breaking the intergenerational cycle.

This statement from a decision maker is especially true for persons with disabilities. A number of real and perceived negative incentives with impacts on individuals’ decisions regarding employment and livelihood were described in detail during our consultations.

Home support

Home support was emphasized as one of the most significant negative incentives when it comes to transitioning to work from income support. In discussing home support, decision makers emphasized that home support is exclusive to home and not transferable to work. It does extend to shopping and socializing, but due to insurance and liability issues, it cannot be extended to work. Activities such as going to the washroom or getting food at work may be insurmountable problems. They further state that, for the perhaps small number of people who may encounter these issues, the result would be to prevent them from living inclusive lives and having a decent income. A disability advocate indicated that for “individuals with walkers, canes, wheelchairs, mental health issues, [there is] no support in the workplace.”

An individual with a mobility disability described their experience with home support when looking for employment:

At times it felt like it would be better to not get employment or lose things and have to pay in more money and you have less money overall. But part of the issue was that my home support I had based for the things that I needed at home. I wasn’t being funded support by the government to go to work, and I only had 26 hours a week. So...the jobs that it seemed you needed to kind of do to get the experience in the mental health field...required overnights and shelters where you would have to do housekeeping and cooking which I particularly at the time was not in a position [to do], and I had a home support worker at home to support me in those things so that I could go out and work. My home support

wasn't going to do overnights; that wasn't within the arrangement that we had...I couldn't take her to work to do my job, if I was going to apply for those things [entry-level jobs]. So it ruled out those jobs and I was trying to find other ones that didn't need those things.

Not having adequate and much-needed home support for the times when it is most needed was not the only issue discussed in our focus groups and interviews. Another individual with mobility problems describes experiences with the employment contribution required to cover the cost of necessary home support:

I also had to have a home support in place, because I need that in order to go to work. I have a Bachelor of Commerce, so when I finished my degree, I started working right away at [a federal government agency] which was great. But one of the main barriers that I found and I wasn't aware of at this point, was within a week or so, or a month or so of working at [a federal government agency], I found out I had to pay a client contribution towards my home supports which I didn't realize, but it was a bill of \$800 a month in employment contribution which I thought was ridiculous at that point. Because it was pretty much all my disposable income had to go to client contribution which...didn't motivate me to work....Even when I was receiving EI, I had to make a client contribution. Well I didn't work for a year and a half because I was trying to fight this policy or see if I could change it or work around it.

Asset limitations

Asset limits are an issue not only when it comes to work but also when it comes to establishing common living arrangements and child care. Both government decision makers and individuals with disabilities identified family planning and child care as significant challenges with current disability support systems. A person with a disability described how asset limits affected decisions about home support:

We waited for a long time, because once I got married the way that they financially assess you, you're only allowed to have very little money as a couple overall in savings, which my partner already had, so it would have disqualified us. So we were together for over eight years before we even moved in together, because if I moved in with him I lost everything. So I mean it is not just work that these things affect but yet it was affecting work. Once I got married I am paying for home support myself which is a ridiculous amount of money and we had a baby last year and he took the year off and I laid off the home support worker and now I don't know where we'll be, but that makes a huge difference, because I am taking up more of what's going on at home and trying to be a parent, so there is just constant work wherever I go is what it feels like. So I get to work, yay, and that sounds great, but there are times I feel I don't have the energy for anything

and I'm being pulled in so many ways just to be able to try to keep meeting all the stuff that I need to do to have everything I need.

Fear of change and loss of security

Although some of the barriers in securely transitioning from income support to employment are less real than perceived, the fear of change and of the potential loss of significant supports for basic needs is often very real. This is especially true for those thinking of leaving income support for the first time. While the prospect of having a job, becoming a contributing member of society, and achieving partial or full independence is appealing, the fear of increased personal contribution and the loss of basic supports is a problem. This is especially true these days since many jobs are precarious and there is no guarantee that they will provide long-term security.

The fear associated with transition is not just about entering the labour market but also of what will happen if it becomes necessary to go back to income support if the employment comes to an end. Transitioning back to income support can be equally stressful and take time and resources that may not be available to the person. This fear is especially pronounced for individuals with disabilities due to their dependence on the provision of basic needs in order to maintain their lifestyle. As a result, this fear can have emotional and health consequences.

A decision maker recalled hearing from income support clients that they could not go to work because of their drug costs. While that used to be a major financial disincentive, changes in 2007 altered the situation. Health and Community Services expanded the prescription drug program from seniors-only to cover all low-income earners as well as individuals and families with prescription drug costs that were high relative to their income. When the program was introduced, it was promoted and advertised to the public for a short time, but not after that. Even though some barriers were removed, clients' fear and lack of confidence persist. Most decision makers agree that many individuals with disabilities are afraid to take risks. They believe that "sometimes it is perceived as they don't know or are afraid of losing services, 'not comfortable that the system would treat you well', based on the past experience over the years when it did not treat them well."

A consumer describes how it felt to contemplate changes:

And if I was to be on my own, I don't know where I would be and I would have to reapply back for those things. Which it was very scary to come off of it. It is harder to get the services now, and I don't know if I would qualify for what I had and I probably wouldn't get as many hours as I had. So, when you walk away, you're doing a lot of risks and I was in housing as well because I had been on income support for quite some time while I was in school.... With housing, no matter what, at least you always pay 35 percent of your salary or something like that. So if I could have stayed in that housing for the rest of my life I would have known no matter what happened I would always be ok.... "

This consumer felt scared and insecure and did not have enough accurate, up-to-date information. When asked whether technology and information sharing via the internet could result in a better flow of information, a decision maker remarked that it works for some, and it certainly provides better access to persons living in remote areas. However, it cannot be compared with having an assigned person “who would navigate for you and work through the system for you or get to know you and understand your needs.” This notion of navigability is often discussed among academics and disability advocates and it can refer to sophisticated web-portals or to personal navigators/‘sherpas’.

6.5 Better education and training in the delivery of services

Decision makers agree that there needs to be adequate education and training for the staff in the delivery of services, especially when catering to complex and individualized needs of consumers who are also increasingly more skilled.

For many disability advocates, knowledge comes through experience or through networking with colleagues. They feel they require more clarification and more education, especially about subsidies and related programs. As changes in programs occur relatively often, receiving regular notifications or perhaps attending seminars organized on specific topics would be valuable. They felt that this is even more important given the frequent turnover of staff in support agencies and not-for-profit organizations.

Consumers still feel that they are the ones educating others on all disability-related issues. They feel that there is still much reluctance and fear among co-workers or service providers, and not enough disability training. As one consumer stated:

People are quite willing, there's just a lack of understanding and then sometimes there is, there can be a fear or a sense of awkwardness because people don't know. Sometimes there can be that kind of you don't want to do the wrong thing because then someone is going to get upset. So I just, I advocate that we need more education and [to] keep working together, having advocates, especially those who have gone through it. It does make a huge difference.

6.6 Employer engagement

Even though they believe that employers cannot affect policy, disability advocates recognized the importance of employer engagement in improving labour market outcomes for individuals with disabilities. They believe that employers still do not completely appreciate the value of individuals with disabilities and that they are still “caught up by stigma and stereotypes.” For these advocates, inclusive workplaces are still an issue, which suggests that policies have failed to move from paper to practice. Another issue mentioned in our discussions was the charitable orientation of many employers, even the ones who are leading examples of encouraging and

creating inclusive and diverse workplaces. Disability advocates felt that this charitable attitude is not helpful with either disability support services or employment.

Decision makers indicated that “when employers think about their labour force, intellectually they do not see individuals with disabilities there, and it is simply a cultural issue.” In other words, they do not think about it until someone comes to them.

Disability advocates believe that more employer champions should encourage hiring individuals with disabilities by “sharing their positive experiences and the kind of valuable employees that persons with disabilities make.” They add that this is the kind of employer-to-employer networking needed to build increased demand and increased comfort with hiring people with disabilities.

A disability advocate pointed out that when it comes to employment and workplace accommodation, individuals with mental health conditions face unique challenges, such as disclosure issues or issues related to conditions that are sporadic in nature. Many employers and workplaces may not be equipped with the necessary knowledge and skill to appropriately attend to this issue, so special attention should be given to this type of disability.

All our informants believe that government should be a model employer and take the opportunity to lead by example.

7.0 Proposed Solutions

In both key informant interviews and focus group consultations, we asked participants to identify potential strategies for improving eligibility criteria for disability supports and access to services, reducing the cost of living and working with a disability, and encouraging labour market participation. The proposed solutions included:

- early intervention for successful transition from youth to adulthood;
- flexible and individualized supports;
- engagement of impartial assessment teams for continuous revision of services and programs;
- self-advocacy and open communication; and
- extended authority of the Disability Policy Office beyond advocacy and promotion.

7.1 Early intervention for successful transition from youth to adulthood

A common belief among the participants in our interviews and focus groups was that the focus for supporting transition from youth to adulthood for individuals with disabilities should move from improving income support programs to providing better supports and encouragement in schools. Many stressed building confidence and projecting higher expectations as essential for creating an early positive educational trajectory. Both disability advocates and decision makers

agreed that early intervention in the life of a person with a disability could potentially lead to much better outcomes in terms of labour market attachment in adult years. One disability advocate suggested that “barriers begin at the age of five.” The lack of investment in the early years of skills development to raise expectations leads to “terrible self-confidence and the beginning of life with barriers.” The vision should be to “support people with disabilities along the lifespan both personally and socially across the board, from kindergarten to grade 12 and beyond, and then through employment, because the return on the investment is worth it.”

Decisions makers agreed that leaving the school system can be quite a shock and that “people dread the 21st birthday”, simply because “schools are inclusive with the community, but then things change.” This is true for both individuals with disabilities and their families, especially those with low income or on income support. Most young people become independent at the age of 18, but some youth with intellectual disabilities can remain within the school system until the age of 21. While this provides additional relief for youth and families, decision makers believe it may only postpone the inevitable.

Disability advocates were convinced that prevention is the most effective way of avoiding the complexities of the disability support system. They state that “the best way of ensuring that there isn’t a large number of people with disabilities on the income support case load is to prevent them from ever getting there in the first place.”

For the decision makers, early intervention means working closely with families supporting children and youth with disabilities and focusing on individual goals for each young person. It also means that the Department of Advanced Education and Skills should work in close collaboration with the Department of Education to identify ways for successful transition to employment and less reliance on income support as people with disabilities leave school.

7.2 Flexibility and individualized supports

According to all key informants, the proper design of disability support programs is a key to fair and meaningful distribution of services. Both government decision makers and disability advocates agreed that flexibility and increased personal choices are important features to emphasize in revising disability support programs. A decision maker suggested that it may be more prudent to have a person-centered approach and build policies around people, rather than have people fit prescribed programs and policies. For example, a person receiving 40 hours a week of home support might be able to use them in a more efficient and effective way if the guidelines were less rigid.

Another decision maker highlighted home support as a top priority in the design of a more individualized approach, a position that corresponds with concerns and challenges expressed by consumers throughout our study. Flexibility and individualized supports would not only allow consumers to have better control of how money is spent but they would also not require increased resources. Disability advocates told us that people want individualized funding,

because currently “the programs are not giving them what they need.” They stated that having rigid criteria does not help individuals with disabilities; if they can have better control of how to spend the money they receive, outcomes will improve. These advocates emphasized the fact that every person and/or family had a unique story and a particular combination of needs.

This approach would be in line with other reforms of social assistance programs whose aim is to dismantle rationed, block-funded government purchasing of a narrowly defined suite of services and transfer the funds to individuals with a disability, allowing them to define their values and work towards a life of participation in the community, and giving them the purchasing power to choose what their supports look like (Price Waterhouse Coopers, 2011).

7.3 Engagement of impartial assessment teams for continuous revision of services and programs

On a number of occasions, the issue of evaluation and assessment was brought up as a way of providing accountability. Consumers propose the use of impartial assessment teams for disability support services and programs and greater engagement of individuals with disabilities in both the assessment of existing programs and the design and delivery of new or improved ones. In addition, we heard a request for accountability and transparency through independent audits of employment programs including reporting of withdrawal rates, retention rates, costs, and best practices. The findings from these audits should be used to guide future funding decisions.

A good example of a program seen to be in need of a careful evaluation is the Opening Doors program which has persisted unchanged for an extended period of time, according to disability advocates. Both disability advocates and consumers felt that the program was neither valuable nor necessary for individuals with disabilities. While they recognized that the program supported many people in finding work, they described it as restrictive in terms of the type of disability, job mobility, and fair wages. They would prefer to see more understanding and acknowledgement within the government rather than a specific job program. They asserted that “when given the proper chance and respect, individuals with disabilities could compete fairly in the open, inclusive, public competition.” A decision maker agreed with them, asserting that general population initiatives can benefit people with disabilities more than specific ones such as Opening Doors. Similar preferences were expressed by several study participants concerning income support: that it would be better to rely on a general income support program rather than having a separate disability support program.

7.4 Self-advocacy and open communication

Our interviews and focus groups made it clear that the fears and insecurities involved in deciding to leave the security of income support and look for work are real and important. The risk, as all consumers and their advocates agreed, is sometimes too great and the gain too small. Still many said that, without trying, they would never know whether they can be successful in finding work and achieving independence. Disability advocates told us that they encourage some level of risk-

taking and have seen clients achieve small victories on their own when fighting to maintain certain supports as they transition into employment. They would also advise their clients not to give up and to fight for what they believe is their right. Disability advocates agreed that acquiring the appropriate information is a basic entitlement and people with disabilities should make sure to find out everything that could have an impact on their future.

A decision maker also noted that there should be open and honest communication between consumers and service providers/counsellors, especially when it comes to major life decisions. Choosing a career is an important step in a person's life, and employment specialists are sometimes reluctant to talk openly about career goals with clients with disabilities. While they are there to listen, fear of behaving in a discriminatory way may lead employment specialists to provide inappropriate and unrealistic advice and guidance. This may create future problems in both education and employment. This decision maker suggested that prudently and honestly matching consumers in the early stages of their education based not only on their desires but also on their abilities can be the best way to help them avoid income support in the future.

A community worker suggested creating an information package with all the relevant information regarding support services and income supports and making it widely available in the community.

7.5 Extended authority of the Disability Policy Office beyond advocacy and promotion

According to a key informant, the Disability Policy Office has a mandate to promote inclusion and accessibility for persons with disabilities in our province. The main purpose of the Disability Policy Office is: promoting inclusion of persons with disabilities, engaging persons with disabilities in identifying and removing barriers, raising awareness of disability issues, and promoting positive attitudes. The Disability Policy Office also works with community organizations, businesses and other government groups to break down all sorts of barriers: in buildings, attitudes, and policies.

Many informants in this study agreed that the mandate of the Disability Policy office may be too narrow. There is a common desire expressed by consumers to elevate the power of the Disability Policy Office beyond advocacy and promotion. A strong opinion has been expressed that more can be accomplished for persons with disabilities by taking the human rights route. Many consumers felt that the real change happened for them only after they advocated on their own behalf but they also feel that, as a group, they could be better represented. In their opinion, Disability Policy Offices ought to hold the government more accountable when it comes to disability-related policies.

8.0 Conclusion

The purpose of disability support services is to encourage full inclusion of individuals with disabilities and remove the barriers they face in all aspects of our society, including employment.

Our study confirmed that some disability support services may inadvertently discourage labour market participation of individuals with disabilities in our province. The study also revealed a number of real and persistent systemic, logistical, and psychological barriers to employment, as well as some perceived ones. The main issues raised by our key informants fit well with the issues currently observed in other provinces and internationally. They include: coordination of supports and services; continuity of supports; navigability of, and access to, information; education and training; and persisting negative attitudes towards disability in the workplace. They evoke further philosophical and human rights issues related to fairness, justice, equality, and dignity of every person in our society.

Our study confirmed that existing social programs still operate in isolation from each other, often creating policies that do not align well and produce gaps in program coverage. The Poverty Reduction Strategy's collaborative approach to policy development was effective in improving a number of services, but it is unclear whether these outcomes and the strategy itself can be considered long-term solutions.

The study also shows that some of the province's disability supports and benefits are seen as restrictive, confusing, and complex and thus difficult to access. This leads consumers to continue to have doubts about a system that has been sluggish in addressing inclusion and diversity in the labour market. Fear of change and attachment to the security and generosity of social assistance prevents many persons with disabilities from searching for employment.

Most key informants believe that additional resources and funding may not be necessary to implement some positive and lasting changes to the disability support services in the province, such as increased flexibility in the provision of services or improved navigability of government websites and documents for consumers. They also believe that ongoing conversations between policy makers and consumers would be beneficial for successfully identifying and addressing existing issues and challenges.

All key informants agreed that more needs to be done to encourage and support persons with disabilities to find jobs and keep them. Each department within the government should clarify its role vis-a-vis disability support services and be aware of the potential impact of their decisions and actions on outcomes for individuals with disabilities. The province should also evaluate the outcomes of its programs and policies on a regular basis.

As a follow-up from our study, we would recommend cross-provincial, comparative research on disability support services and their impact on labour market participation. This could result not only in sharing of the best practices and outcomes, but also in more consistent, comparable, and reliable data on individuals and families living with a disability.

Our study was carried out from a cross-disability perspective focusing on many common issues, barriers, and challenges affecting all individuals with disabilities. From the consultations with study participants it was evident that more research and insight is also needed for specific

disabilities and related supports and services, in particular for mental health disabilities. Individuals with various disabilities experience unique, complex problems and have distinctive needs. These issues require special attention and should be studied independently.

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Appendices

Appendix A. Interview Guide

Disability Support Services in Newfoundland and Labrador: Impacts on Labour Market
Participation for Individuals with Disabilities

Research Proposal Appendices

Interview Guide – Government Policymakers

- Briefly describe your role and responsibilities within your organization.
- What mandate does your organization have regarding persons with disabilities?
- What is your current system of allocating disability support services?
- Does your organization have any policies on transition supports for persons with disabilities who are actively looking for employment or joining the workforce?
- Does the allocation of support services change and how?
- Do you have any concerns with this process?
- Have individuals receiving disability support ever expressed/reported concerns about their experience transitioning into the workforce?
- In your experience, do individuals with disabilities receiving support services experience any difficulties when they secure employment?
- What do you believe the goals of the transition into the workforce should be for both the individual and for the government?
- How well are these goals met by the current model/policy?
- What do you see as enablers/barriers to successful transition into the workforce?
- What suggestions do you have for improving existing policies?
- Is there anything else you would like to say/add that we did not mention in the previous questions?

Thank you very much for your time and consideration.

Appendix B. Focus Group Guide

Disability Support Services in Newfoundland and Labrador: Impacts on Labour Market Participation for Individuals with Disabilities

Research Proposal Appendices

Focus Group Guide

Consent Process

Thank you for agreeing to participate in this focus group discussion. It will be valuable for us to hear about your experiences and opinions on how allocation of disability support services can affect labour market participation of individuals with disabilities in our province.

- The purpose of this study is to learn how existing various disability support services such as home care, pharmaceutical expenses, transportation and others affect the ability and willingness of individuals with disabilities to participate in different segments of local and larger labour markets. We hope to learn things that the government departments can use to improve allocation of support services and encourage labour market participation.
- Everything you discuss with us today is completely confidential, and we will not associate your name with anything you say in the focus group.
- We would like to record the discussion so that we can make sure to capture the thoughts, opinions, and ideas we hear from the group. No names will be attached to the focus group and the tapes will be destroyed as soon as they are transcribed.
- You may refuse to answer any question or choose to withdraw from the study at any time during or after the discussion. Withdrawal from the focus group after the meeting will not result in removing individual data.
- We understand how important it is that this information is kept private and confidential. We ask participants to respect each other's confidentiality and not disclose any information outside of this meeting. While we will make every effort to maintain your confidentiality, full confidentiality cannot be guaranteed, as participants may not maintain it.
- If you have any questions now or after the focus group, please contact the researcher.

Introduction

This focus group discussion will gather relevant information about your personal experience with disability support services and transition to employment. The questions are designed to help us explore this topic in more detail, and my role as a moderator will be to guide the

discussion. You are encouraged to talk about any positive or negative experiences. There are no right or wrong answers, only various points of view. Turn off your mobile phones, and if you need to answer a call, please do so discreetly and quietly. This focus group discussion is recorded, so please try to speak one person at a time.

The focus group will last for approximately 2 hours. Feel free to make yourselves comfortable in a way that suits you the most.

If you have any questions before we begin, please do not hesitate to ask.

Questions

- I would like to start our discussion by asking you to describe individually your current situation in terms of employment and support services. Tells us if you are/were employed and if you are receiving any support services.
- Explain your circumstance prior to employment.
- What are some of the positive aspects of being employed? How did the employment change your lifestyle?
- What are some of your concerns with being employed? Have you had an opportunity to express your concerns to anyone? How?
- Did you experience changes in availability of services due to your transition into the workforce? If yes, please explain how.
- In your opinion, when it comes to the allocation and provision of the disability support services, what are the main barriers to successful, long-term employment?
- What suggestions do you have for improving the policies around the allocation of disability support services for employed individuals?



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