



DISCUSSION SUMMARY

NEWFOUNDLAND AND LABRADOR PROVINCIAL CLUSTER MEETING

March 28th, 2014, 11:00 am – 2:00 pm

St. John's (Genesis Boardroom, Bruneau Centre for Research and Innovation, Memorial University)

This document summarizes the discussions that took place at the first Newfoundland and Labrador provincial cluster meeting of the Centre for Research on Work Disability Policy (CRWDP), which took place at the St. John's campus of Memorial University on March 28th, 2014.

The meeting was chaired and facilitated by Stephen Bornstein and Barbara Neis, Newfoundland and Labrador provincial co-leads. In addition to Drs. Bornstein and Neis, the following individuals were in attendance:

- Gordon Cooke – Academic Co-Investigator (Business Administration)
- Catherine de Boer – Academic Co-Investigator (Social Work)
- Sandra Small – Academic Co-Investigator (Nursing)
- Doreen Dawe – Academic Co-Investigator (Nursing)
- Marie Ryan – Social Policy Committee Chairperson, Council of Canadians with Disabilities
- John Reardon – Workers' Advisor, Newfoundland and Labrador Federation of Labour
- Kelly White – Executive Director, Coalition of Persons with Disabilities Newfoundland and Labrador
- Wayne Penney – Executive Director, Independent Living Resource Centre
- Yvonne Collett – Employment Equity Officer, Department of Human Resources, Memorial University
- Kathy Skinner – Academic Program Administrator, Glenn Roy Blundon Centre, Memorial University
- Kathy Fitzpatrick – PhD Candidate (Sociology)
- Stephen Czarnuch – PhD Candidate (Biomedical Engineering)
- James Rosario – Masters Student (Health Ethics)
- Chrissy Vincent – Newfoundland and Labrador Provincial Coordinator
- Amanda Butt – Program Coordinator, SafetyNet Centre for Occupational Health and Safety Research

INTRODUCTORY REMARKS

1) OVERVIEW OF THE CENTRE FOR RESEARCH ON WORK DISABILITY POLICY

Emile Tompa and Ellen MacEachen, national co-chairs of the Centre for Research on Work Disability Policy, joined us from Ontario via video-conference and opened the meeting by providing a brief overview of the Centre's key goals and characteristics. The CRWDP is a large, seven-year partnership initiative funded by the Social Sciences and Humanities Research Council (SSHRC) with an overall aim to examine the future of work disability policy in Canada. It combines population health and human rights approaches to the concept of



disability, and defines disability in very broad terms as any inability to participate in the labour market due to health reasons. Under this definition, disabilities include not only issues that are permanent, but also those that are temporary or episodic. Research conducted by the CRWDP will be organized into three main themes:

1. Population Analysis
2. Labour Market Analysis
3. Law and Policy Analysis

In addition to its overall mandate and three major research themes, the CRWDP is characterized by several other important features. These include:

- **Interdisciplinarity.** The initiative will involve people from many different disciplines, backgrounds, sectors, and disability frameworks all working together to achieve common goals.
- **Partner Involvement.** The initiative will encourage a high level of community partner involvement at all stages of research, from initial discussions for the identification of knowledge gaps and priority areas to hands-on involvement in specific projects and the practical application of results.
- **Student Capacity Building.** The initiative boasts a large number of funding opportunities for students, including 60 student-years' worth of stipends for Masters and PhD students to do research associated with the Centre through their theses or research papers. There are also funds set aside for 20 seed grants (\$10,000 each), which will ideally be used to hire graduate students to develop and submit additional research funding applications.
- **Knowledge Mobilization.** The initiative has launched its own website, which is intended to be used as a central hub where people associated with, or otherwise interested in, the project can meet virtually. Visitors to the website will be able to access video stories of workers' experiences with the work disability policy system, summaries of individual research projects, and annual reports profiling all research activities taking place over the course of each year. The website will also be expanded in the future to include chat forums and repositories aimed at fostering national-level communication among those who are involved with the Centre.

2) OVERVIEW OF THE NEWFOUNDLAND AND LABRADOR COMPONENT

Barbara Neis and Stephen Bornstein, provincial co-leads for the Newfoundland and Labrador region, provided a brief synopsis of this provincial cluster's current priorities in terms of the initiative:

1. **First and foremost, this region needs to acquire more community partners.** At present, there is only one formal partner within our province (The Newfoundland and Labrador Injured Workers Association), which is not enough. Community organizations may choose to participate in the CRWDP as either formal partners or stakeholders/observers, but those that choose the formal partnership route will need to work with the provincial co-leads to develop a partnership letter that lays out what they plan to contribute to the CRWDP (generally "in-kind") as well as the benefits they expect to derive. Formal partners will be asked to provide an annual summary of their contributions, which is a requirement of our funder (SSHRC) and involves completing a relatively simple form.



2. **Researchers and community partners (both current and potential) in this region will work together to identify research priorities**, as well as a set of overall principles to guide the work.
3. **Student involvement with the initiative needs to be promoted within this province.** Student involvement is a particularly important priority as it will function both to train students in this particular field (which has previously lacked representation at Memorial University) and to build research capacity within community partner organizations – everyone wins. The Newfoundland and Labrador provincial cluster has been allotted enough money to fund a PhD student for each of the project's seven years (which would work out to be two PhD students over the course of the project), as well as funding for a post-doctoral fellow to work with Dr. Neis on her research examining the intersection of employment-related geographical mobility and work disability policy. In addition, there will be opportunities for student internships within community partner organizations.

SETTING THE STAGE: SHARING OUR EXPERIENCES AND INTERESTS

1) WORDS FROM OUR ACADEMIC TEAM MEMBERS

In advance of the meeting, academic attendees were asked to be prepared to speak briefly regarding their own research expertise, their past experiences (if any) with conducting research on work disability, public policy, or both, and their personal areas of interest in relation to this project.

- **Barbara Neis** has had a significant amount of research experience on topics that are relevant to the CRWDP initiative. She has a strong background in studying work-related disabilities in rural and remote fishing communities – for example, she has done work on occupational asthma and musculoskeletal disorders within populations of fish processing workers. She is interested in the interplay between various public policies and compensation systems in serving workers who have incurred these types of disabilities, and she is also interested in issues around prevention and how they can be negotiated within work environments with many (and changing) challenges. In particular, her current work with the On the Move Partnership has prompted her to question the ways in which the rules around compensation and rehabilitation for various types of disabilities might be navigated by the increasing numbers of workers who are engaged in employment-related geographical mobility, ranging from daily commuting (often to transient workplaces) through to employment-related mobility across provincial and national borders.
- **Catherine de Boer** is a primarily qualitative researcher who has limited experience in studying policy. Her work has mostly been in the area of direct practice, with a focus at the level of individuals and families. As such, she is mainly interested in the ways in which work disability policy can play out at the individual level. She has had some experience in studying the forced identity transitions that occur among people who have been injured, and is therefore interested in using small-scale data to study the lived experiences and day-to-day realities of such people as they negotiate policy systems and return to their workplaces. In addition, she is interested in examining the types of workplace services and programs that are most helpful to workers who are living with episodic illnesses, particularly in the mental health domain.



Specifically, she would like to learn more about the work experiences of military personnel with post-traumatic stress disorder (PTSD). Finally, she is also interested in preventative policies with respect to mental health issues. Her biggest strength will be in analyzing the stories of workers with disabilities.

- **Sandra Small** is primarily a qualitative researcher who does not have a background in disability research. She has, however, done work examining the experiences of people who are living with chronic illnesses. With regard to this initiative, she is interested in pursuing a project that is focused on stress, coping, and quality-of-life issues relating to disability and workplace policy. She is also interested in employers' perspectives of policy and policy implementation.
- **Doreen Dawe** has also been primarily involved in qualitative research but not specifically in disability research. Her past work has largely focused on the ways in which psychosocial issues and coping mechanisms can impact health outcomes, particularly with breast cancer. Over the course of her work she has listened to and analyzed patients' stories – a skill which will certainly be an asset to this team. She also has a very personal reason for wanting to become involved with this initiative. Ten years ago, she acquired a spinal cord disability and has therefore had quite a bit of first-hand experience in negotiating work and disability, in particular going through rehabilitation and then returning to work. She feels that her own struggles with many of these issues have left her better positioned to study work disability policy from a uniquely personal perspective.
- **Gordon Cooke** is a mainly quantitative researcher who has neither directly nor indirectly worked on the topic of disability. What he does do, though, is study degrees of privilege, vulnerability, and marginalization among different populations. Specifically, he has examined ways in which demographic factors such as age, gender, location (urban/suburban/rural/remote), skills, and family status may affect access to work. He is very interested in the concept of life stages, and the intersection of life stages with various types of work schedules – particularly those that are non-standard (anything other than full-time, full-year work). As such, he is keen on the prospect of studying temporary and/or episodic disabilities, as these types of disabilities may act to define life stages for affected individuals (which may, in turn, affect the ways in which social policies impact them throughout their lives). He likes to incorporate cross-cultural comparisons into his work, and hopes to continue to do so.
- **Steve Czarnuch** is a PhD candidate in Biomedical Engineering, who will be finishing his degree and beginning a post-doctoral fellowship within the coming months. Most of his research involves the application of intelligent technologies to help support people with cognitive disabilities. Although his focus to date has largely been on the use of such technologies within the home, there is potential for many of these same concepts to be extended to the workplace as well. He has done quite a bit of work on the testing of these technologies in order to determine their efficacy as well as their impacts on users' quality of life. He is very interested in the possible future use of technology to identify and predict situations that might contribute to causing disabilities, as well as to provide objective measurement of a person's readiness to return to work following rehabilitation.



- **James Rosario** is an incoming Masters student in health ethics within the Faculty of Medicine. He is interested in research on immigration to Canada, and the factors that may affect new immigrants' access to work – in particular, ageism and perceptions of disability. Many new immigrants who are looking for work may be seniors, or may have disabilities that are common in their home countries but are not often seen in Canada. He is fascinated by the unique challenges that such immigrants may face when attempting to enter the Canadian labour market system, as well as the ways in which our social policy system responds to these challenges.
- **Kathy Fitzpatrick** is a PhD candidate in Sociology who has been carrying out research on home-care workers for her dissertation. Specifically, she has been conducting a case study focusing on the aspects of employment-related geographical mobility involved in home-care work, and the ways in which such mobility may affect working conditions and workers' health. She is particularly interested in the gaps in existing Canadian work disability policy that have come to her attention through her interviews with these home care workers – for example, work that is done in clients' homes is much more difficult to regulate than work that is done in more traditional workplaces, and time spent traveling from one client's home to another is not covered under any current Canadian work disability policies at all. Issues within her personal life have also served to pique her interest in this field, as her husband has previously experienced a work-related back injury that left him temporarily disabled.
- **Stephen Bornstein** has a background in Political Science, and he has had experience conducting research on various types of policy issues. He is currently working with the policy component of the On the Move Partnership to analyze how Canada's federal and provincial health policy systems do and do not function to cover workers who are engaged in employment-related geographical mobility – a research area that had received little to no attention up until this point. He has also conducted research on aspects of work-related disability policy through his work on the Baie Verte Miners' Registry (which focused on asbestos-related disease), among other projects. Additionally, in his role as the director of the Newfoundland and Labrador Centre for Applied Health Research, he has gained a great deal of experience in knowledge synthesis. The methodology developed within the Contextualized Health Research Synthesis Program has provided him the opportunity to hone his skills with respect to summarizing research findings for non-scientists and policy makers. He is, therefore, very well-positioned to work with other researchers in Ontario and across the country on the comparative policy analysis piece for this new initiative.

2) WORDS FROM OUR CURRENT AND POTENTIAL COMMUNITY PARTNERS

In advance of the meeting, representatives from current and potential community partner organizations were asked to be prepared to speak briefly regarding their own experiences of the labour market system around disability, particular policy issues that they have identified and believe need to be addressed, and their key priority areas for research.



- **John Reardon** (Workers' Advisor, Newfoundland and Labrador Federation of Labour) considers himself to be, above all things, an advocate for injured workers. He was involved with the work on the Baie Verte Miners' Registry, and through that experience, he was able to witness some of the problems faced by workers who have tried to access compensation for their asbestos-related diseases. He is interested in anything that might possibly affect injured workers within this province, but is particularly concerned with those health conditions – such as chronic stress, for example – that should be compensable but currently are not. One specific policy issue that he feels deserves some attention relates to the cost-benefit analyses associated with labour market re-entry services for injured workers. More often than not, the current process concludes that such workers are capable of returning to work and earning an income in minimum-wage or low-wage jobs, doing work that is very different from their pre-injury work. If this option is determined to be a cheaper route to labour market re-entry than the provision of retraining or re-skilling, then it is the option that is chosen. He feels that this process fails to consider the negative impact that such a drastic change in work and reduction in income may have on an injured individual (who might already be coping with issues such as chronic pain), and therefore, he believes that substantial change is required to the system in order to better benefit injured workers. He is also keenly interested in cases where workers are dealing with two or more concurrent disabilities (such as a congenital or chronic disability coupled with a work-related injury) and how accommodations for such cases are negotiated when returning to the workplace. He would love to see research focusing on that issue.
- **Yvonne Collett** (Employment Equity Officer, Memorial University) comes to this initiative with what is essentially an employer's perspective. She is interested in the methods by which employers might accurately gauge how many of their employees have disabilities of varying types, the kinds of barriers that might prevent workers from self-identifying as having a disability, and the ways in which employers can best support employees with disabilities. She would be particularly interested in research focusing on best practices used by higher education institutions with regard to disability and work.
- **Kathy Skinner** (Academic Program Administrator, Glenn Roy Blundon Centre, Memorial University) deals primarily with students who have disabilities, and is responsible for coordinating special accommodations for their exams. She is extremely interested in the transition from school to work, and the unique challenges that this might present for students with disabilities. Such a transition often involves a move from a very supportive environment to a new one where there may be fewer supports, or it may be unclear how to access them. Compounding this issue, students with disabilities have often had fewer opportunities to build their resumes through part-time work, and many students who have disabilities that are less immediately visible (such as autism or mental health issues) could be reluctant to disclose this fact to potential employers for fear of discrimination. She would like to see research exploring these types of experiences, and the ways in which the transition period might be made somewhat easier.
- **Marie Ryan** (Social Policy Committee Chairperson, Council of Canadians with Disabilities) is a member of the Executive Committee of the CRWDP, and she made an effort to draw our attention to several important cautionary items:



- It is important to recognize the distinction between disabilities that are acquired, and those that are congenital. There are crucial differences in the experiences of people with each of these types of disabilities, and there are also differences in the experiences of people who acquire disabilities at different ages and stages of life. We must be careful not to lump them all together.
 - It is important to not only examine policies relating to the labour market, but also policies relating to the education system. The “streaming” of individuals with disabilities out of some sectors and into others often begins long before their entry into the workforce.
 - It is important to always focus on transforming the work, not transforming the worker. This is particularly important when considering some of the new realities within the world of the work (such as the increase in precarious work and non-standard work schedules) and what they might mean for workers with disabilities.
 - It is important to remember that formal diagnoses and the “medicalization” of disabilities can sometimes be one of the biggest barriers to people with disabilities reaching their full potential. This approach tends to over-simplify things, when in fact, people with the same medical diagnosis can often differ widely with respect to what they can and cannot realistically do. We are all individuals.
 - It is important to use the definition of “disability” that is put forth in the United Nations Convention on the Rights of Persons with Disabilities. That is the only way that we can all reach a consensus on what should and should not be considered a disability.
 - It is important to be extremely cautious about the kinds of language that we use with regard to these issues. Words like “burden”, “suffering”, and “confined” have very negative connotations for many members of the disability community, and they may be unwilling to talk to anyone who is not using appropriate and respectful terminology.
 - It is important to consider not only the question of whether individuals with disabilities are working, but also the types of positions that they occupy. There is a major difference between a front-line position and a managerial one, and people with disabilities who are indeed employed may still lack the opportunities afforded to their non-disabled counterparts. If we are going to truly talk about “employment equity”, it is important to thoroughly dissect these issues.
- **Kelly White** (Executive Director, Coalition of Persons with Disabilities Newfoundland and Labrador) is primarily concerned about the shockingly large proportion of people with disabilities who are living below the poverty line. She believes that one of the major factors contributing to this poverty is employers’ perceptions about what it would mean to employ someone with a disability and provide appropriate workplace accommodations. She pointed out that in many cases, employers simply see a person with a disability as a potential risk to the workplace (for example, a potential cause for accidents). In fact, even when offered financial subsidies to hire individuals with disabilities, many employers will still decline due to these types of fears. She would like to see research aimed at changing these perceptions, and helping employers look past disabilities to instead see the skills and assets that people can bring to the workplace.



- **Wayne Penney** (Executive Director, Independent Living Resource Centre) strongly feels that issues around disability and employment are still very poorly understood, both here in Newfoundland and Labrador and in Canada as a whole. He believes that the level of labour market participation of persons with disabilities is a national disgrace, and emphasizes the importance of conducting research on work disability policy in an effort to get the matter back on our government's agenda. In his opinion, one of the biggest problems with our current policies is that they are much too focused on the actual individuals with disabilities – the focus should instead be shifted to employers, and the ways in which they can be better supported to employ people with disabilities. He feels that this is the reason why, despite an abundance of programs and services to educate, train, and support people with disabilities, these individuals still do not get access to the labour market. Employers are not being adequately engaged and supported, and it would be useful if we had some research exploring the best ways in which this might be accomplished.

GROUP BRAINSTORMING SESSION: IDEAS FOR FOCUS AREAS AND PROJECTS

This section of the discussion summary groups and briefly interprets the ideas that were generated during the open group brainstorming segment of the meeting. For ease of reporting, these items are not necessarily presented in the same order in which they were raised. Rather, they are loosely organized into three major categories – general over-arching thoughts, ideas for specific research themes or projects we may want to pursue, and suggestions for additional community organizations or people we might invite to join our team.

1) GENERAL THOUGHTS

- Overall, there is a preference that research conducted as a part of this initiative should have some degree of practical applicability. In other words, it should be able to be used to somehow “make the world a better place”. Although it is recognized that there may be some merit in allowing room for a small amount of theoretical work – particularly where student training and development is involved – there is a broad consensus that the bulk of this team's work should be practical in nature.
- Where possible, a cross-disability approach is generally preferred. That is, the team should prioritize research that is widely applicable across many different types of disabilities. This type of work is likely to have much broader impacts on policy.
- It may be useful to fund somebody (perhaps a student) within the coming year to work on creating an “orientation package” for all researchers and students who will be involved with this initiative. The package could contain important background information on a number of critical issues such as inappropriate assumptions and language use, and could therefore help academics who are unfamiliar with this field of study avoid common pitfalls in interacting with the disability community.
- Since this is a seven-year initiative, it may be possible for our team to conduct multi-year, longitudinal data collection – which would be an advantage, since longitudinal designs are quite powerful. However, the collection would need to start relatively soon. Seed funding may be able to be leveraged for this.



- It may be possible for some large-scale analyses associated with this initiative to be done using the tax-filer data set – the disability tax credit could be used a marker of disability among respondents. One problem with this, however, is that individuals with certain types of disabilities (such as mental health issues) may be less likely to self-identify and claim the tax credit, resulting in potentially biased data.

2) IDEAS FOR SPECIFIC RESEARCH THEMES/PROJECTS

- A study focusing on Post-Traumatic Stress Disorder (PTSD) in the workplace, particularly (but not necessarily exclusively) among military or ex-military personnel
- A study focusing on the forced identity transitions experienced by individuals with acquired disabilities, of which there are at least two types:
 - 1) Movement from an understanding of oneself *without* a disability to a new understanding of oneself *with* a disability
 - 2) Recognition that challenges faced with respect to accessibility are not a problem with *oneself*, but rather a problem with the *system*
- A study aimed at identifying the ways in which employers can be better engaged and supported to employ workers with disabilities, and how successful strategies might differ between companies of different sizes and also between the public and private sectors
- A study exploring the processes of self-selection (and also other-selection by family members, teachers, and so on) of people with disabilities either into or out of certain educational programs/streams or careers
- A study examining some of the different approaches to employing people with disabilities, and identifying those that work well and those that do not (for example, a comparison between the “charitable” approach and other practices)
- A study exploring the range of individual variability among people with the same formal diagnosis of disability
- A study examining various income security systems, and their effects on the likelihood of individuals with disabilities seeking and securing employment
- A study focusing on “claw-back” issues with regard to Canada Pension Plan Disability Benefits
- A study aimed at identifying current gaps in Canadian work disability policy, such as those that exist for home care workers that are traveling from one client’s home to another
- A study exploring employers’ perceptions/concerns about the ways in which employing people with disabilities might affect insurance assessments, and determining which are myths and which are reality



- A study focusing on the economic impacts resulting from the non-employment (and under-employment) of individuals with disabilities

3) **SUGGESTIONS FOR ADDITIONAL PARTNERS**

There were a number of suggested individuals/organizations whose involvement would likely benefit the Newfoundland and Labrador provincial cluster of this initiative as a whole. These were:

- A representative from the Workplace Health, Safety and Compensation Commission
- A representative from the Employers' Council
- A representative from the Human Rights Commission (Government of Newfoundland and Labrador)
- More employer representatives, including the following possibilities:
 - Kim Mullins from Exxon-Mobil
 - Margaret Allan from Husky Energy
 - A representative from the Royal Bank of Canada (RBC)
- A representative from Statistics Canada
 - A good candidate would be James Chowhan – he is located in Ontario, but would be a fantastic resource to the project at a national level. An alternative would be Michael Haan, a Canada Research Chair at the University of New Brunswick who is currently studying employment-related geographical mobility using census and tax-filer data.

It was also suggested that it might be a good idea to get other individuals/organizations involved on a smaller scale, at the level of steering committees for specific sub-projects. For example, a sub-project on Post-Traumatic Stress Disorder (PTSD) might benefit from the involvement of a military or police representative.

NEXT STEPS

In order to move forward with the work on this initiative, two major actions items were identified as crucial next steps for the Newfoundland and Labrador provincial cluster:

- 1) Determine which of the potential community partners in attendance at the meeting would be interested in becoming full-fledged formal partners, and obtain letters of formal partnership; and
- 2) Schedule a second provincial cluster meeting, preferably in May, for the purpose of holding an in-depth discussion regarding possible governance structures for our cluster.