



DISCUSSION SUMMARY

NEWFOUNDLAND AND LABRADOR PROVINCIAL CLUSTER MEETING

May 6th, 2016, 10:00 am – 12:00 pm

St. John's (Boardroom, Coalition of Persons with Disabilities Newfoundland & Labrador, 460 Torbay Road)

SUMMARY OF MAJOR ACTION ITEMS

In order to move forward with the work on this initiative, seven **major action items** were identified at this meeting as important next steps for the Newfoundland and Labrador provincial cluster:

- 1) **Barbara Neis and Kathy Hawkins** will both attempt to contact Patricia Dodd of the Newfoundland & Labrador Injured Workers' Association to determine if she wishes to continue her involvement with the initiative;
- 2) **Stephen Bornstein** will follow up with Ellen MacEachen regarding the possibility of developing a national webinar series, in which seed grant recipients across the country can present on their work;
- 3) **Aleksandra Stefanovic** will expand/enrich the findings presented in her seed grant report by a.) examining the 2016 Census to determine whether it includes any questions on disability, b.) speaking with Kathy Fitzpatrick about the potential for access to RDC data on disability, and c.) working with Kathy Hawkins in an effort to create a conceptual bridge with the results of Empower NL's recent employer survey;
- 4) **Susan Tobin** will provide the team with a link to a presentation on the "backpack concept" of disability supports/services that she found to be particularly helpful;
- 5) **Chrissy Vincent** will request copies of any publications and/or presentations produced by team members so that they may be shared via the listserv and, where appropriate, posted to the CRWDP project page of the SafetyNet website (<http://www.mun.ca/safetynet/projects/CRWDP/crwdp.php>);
- 6) **Kathy Hawkins** will share copies of the letters that were sent to federal cabinet ministers by the national community caucus group; and
- 7) **The NL cluster** will develop a proposal to be submitted in response to the recent special seed grant call.

This document summarizes the discussions that took place at the fifth Newfoundland and Labrador provincial cluster meeting of the Centre for Research on Work Disability Policy (CRWDP), which took place in St. John's on May 6th, 2015.

The meeting was chaired and facilitated by Barbara Neis, Newfoundland and Labrador Provincial Co-Lead. In addition to Dr. Neis, the following individuals were in attendance:

- Stephen Bornstein – Newfoundland and Labrador Provincial Co-Lead



- Catherine de Boer – Academic Co-Investigator (Social Work)
- Sandra Small – Academic Co-Investigator (Nursing)
- Emily Christy – Executive Director, Coalition of Persons with Disabilities NL (COD-NL)
- Kathy Hawkins – Manager of Employer Supports & Services, Empower NL (formerly the ILRC-NL)
- Susan Tobin – Program Policy Development Specialist, Disability Policy Office, Government of NL
- Aleksandra (Saska) Stefanovic – PhD Student (Community Health), CRWDP Student Fellow
- Chrissy Vincent – Newfoundland and Labrador Provincial Coordinator

INTRODUCTORY REMARKS

The meeting opened with a round of brief introductions, intended primarily for the benefit of those attendees who were either new to the provincial cluster or unable to attend previous cluster meetings. We were pleased to welcome one individual who was completely new to the initiative and had not previously attended any CRWDP-related meetings or events – Emily Christy, Executive Director of the Coalition of Persons with Disabilities Newfoundland and Labrador (COD-NL), who has recently taken over that role from previous Executive Director Kelly White.

REVIEW OF ACTION ITEMS FROM PREVIOUS MEETING

At our previous provincial cluster meeting on November 26th, 2015, six major action items were identified as being important next steps in moving our cluster forward. The current status of each of these action items is as follows:

- 1) Synopses of both NL-based CRWDP-funded student research projects are now available on the CRWDP project page of the SafetyNet website (<http://www.mun.ca/safetynet/projects/CRWDP/crwdp.php>).
- 2) The National Manager was made aware of the need for a national student directory comprising names and contact information for all CRWDP student fellows across Canada. She decided that this need could be filled by including students' e-mail addresses within their online biographies (posted on the national website), but due to staff turnover within the national office, no action has yet been taken on this.
- 3) There has not yet been any follow-up with the National Co-leads regarding the possibility of developing a national webinar series (in which seed grant recipients from across the country could present on their work). Stephen Bornstein has now offered to touch base with Ellen MacEachen on this matter.
- 4) Steve Mantis has remained in his paid position of Community Caucus Lead.
- 5) The anticipated special seed grant call for proposals has only just recently been circulated. The NL cluster's response to this call was the primary agenda item for the current meeting.
- 6) The current advertisement for a student/trainee (to receive fellowship funding beginning in September 2016) has been distributed as widely as possible by team members. This will continue to be done for all such advertisements in the future.



At one point during our discussion at our previous meeting, it was revealed that nobody within our provincial cluster has been successful in making contact with Patricia Dodd (President of the Newfoundland and Labrador Injured Workers' Association, and a formal CRWDP partner) for the past several months. Barbara Neis and Kathy Hawkins both offered to make a renewed effort to touch base with her in order to determine whether she wishes to continue her involvement with the initiative.

ACTION: Barbara Neis and Kathy Hawkins will both attempt to contact Patricia Dodd to determine if she wishes to continue her involvement with the CRWDP initiative.

ACTION: Stephen Bornstein will follow up with Ellen MacEachen regarding the possibility of developing a national webinar series in which seed grant recipients across the country can present on their work.

UPDATES ON RESEARCH PROGRESS

1) WORDS FROM OUR STUDENT FELLOWS

Both of our cluster's student fellows were given an opportunity to provide a brief update in relation to their CRWDP-funded research activities to date. **Aleksandra (Saska) Stefanovic** was present at the meeting and was able to deliver her update in person. **Daniella Simas Medeiros** was out of the province at the time of the meeting, but sent along an update via e-mail that was read aloud to attendees in her absence.

- **Aleksandra (Saska) Stefanovic** is a PhD student in Community Health, under the supervision of CRWDP co-investigators Dr. Stephen Bornstein and Dr. Rick Audas. She is actually involved with two separate pieces of CRWDP-funded research – her own doctoral research, and research for a seed grant project (jointly led by Dr. Stephen Bornstein and COD-NL) on which she was hired as a part-time research assistant. She was pleased to report that her work on the seed grant project, which examined disability support policies in NL and their impact on labour market participation for persons with disabilities, is now nearing completion. Fieldwork (consisting of interviews and focus groups) has all been finished and transcribed, and the analysis/writing phase is currently drawing to a close. As such, she was able to provide a brief summary of some of the key findings that have resulted from that piece of research:
 - There is a clear lack of reliable data on persons with disabilities within the province of NL. In fact, the most detailed and accessible source of information currently available seems to be the results database from the Participation and Activity Limitation Survey (PALS) – a survey conducted by Statistics Canada using the Census as a sampling frame. Unfortunately, this survey was last conducted in 2006, so the data is now old and almost certainly inaccurate. At one point during the discussion of this particular finding, it was suggested that it may be a good idea for Saska to examine the 2016 Census to see whether it includes any questions on disability, and it might also be worthwhile for her to check the RDC for the presence of accessible data on disability-related issues. In addition, it was mentioned that there may be a good opportunity for her to bridge the results of this seed grant study with the ones from a recent survey of employers conducted by Empower NL.



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- Coordination of supports and services is a major issue for persons with disabilities in NL, as providers are largely operating in isolation from one another. This means that the task of coordination typically falls to the consumer.
- Consumers often seem to put more faith in human rights court as a pathway to receiving supports and services than they do in service providers themselves.
- It is difficult for consumers to access useful information on how to apply for supports and services, and frequent changes to application processes and procedures add to the challenge.
- Once they have qualified for income support, consumers are often afraid to accept employment, as they know that a job loss would force them to go through requalification from scratch.

Although the above issues uncovered by this research are complex and difficult to solve, Saska was able to identify a number of ways in which the situation might be somewhat improved. These include:

- For people with lifelong disabilities, early intervention so that they can enter the labour market as soon as possible and never need to avail of income support.
- Individualized support that provides persons with disabilities the flexibility and choice that they need, ideally set up prior to the start of their career. This idea is sometimes referred to as the “backpack concept”. Susan Tobin mentioned that she remembers seeing a presentation that was very helpful in explaining this, which she is willing to track down and share with the cluster.
- Reconceptualization of all types of disability support as a “basic need”, which should be provided without question to any individual who requires it.
- Thorough assessments/evaluations of current support programs to determine how well they work.

Saska also provided a brief update on the status of her doctoral research. One of her supervisors (Dr. Rick Audas) has recently decided to remain on leave in New Zealand for one more year, and for this and other reasons, there has now been a shift in the format of Saska’s program from dissertation-based to manuscript-based. This means that instead of producing one large thesis, she will instead be producing three smaller, publishable manuscripts. Her plan is to produce one paper from the research she conducted for the seed grant project, and two others focused on autism and employment (one of which may include Evergreen Recycling as a community partner). She is now in the process of re-writing her proposal to reflect this new program model. In the meantime, she has successfully published an article entitled “Is miscarriage a disability?” on www.healthydebate.ca, which Chrissy has agreed to find and share with the cluster.

- **Daniella Simas Medeiros** is a Master’s student in Sociology, under the supervision of CRWDP co-investigator Dr. Rose Ricciardelli. The aim of her thesis research is to explore the occupational health and safety experiences of provincial correctional officers, with a particular focus on mental health, and it is being conducted in partnership with the John Howard Society of Newfoundland and Labrador. She



was pleased to report that in November 2015, her thesis proposal was approved. Since then, she has put together an extensive literature review and has coded and analyzed all transcripts and policies (occupational health and safety act/regulations and collective agreements) to be included in her research. During this time, she also had the opportunity to tour a Canadian provincial prison – an experience that she found to be extremely valuable. She is currently in the midst of the results-writing process, which she is hoping to complete by the end of May. There are also two conferences in May at which she will present her work: 1) The Canadian Society for the Sociology of Health (Ottawa, May 5-6, travel funding provided by CRWDP); and 2) The Conference on Workplace Harassment & Violence Research, Policy and Practice (Memorial University, May 13). Chrissy will ask Daniella to send along the slides used for these presentations so that they may be shared with the cluster.

ACTION: Aleksandra Stefanovic will expand/enrich the findings presented in her seed grant report by a.) examining the 2016 Census to determine whether it includes any questions on disability, b.) speaking with Kathy Fitzpatrick about the potential for access to RDC data on disability, and c.) working with Kathy Hawkins in an effort to create a conceptual bridge with the results of Empower NL's recent employer survey.

ACTION: Susan Tobin will provide the team with a link to a presentation on the "backpack concept" of disability supports/services that she found to be particularly helpful.

ACTION: Chrissy Vincent will request copies of any publications and/or presentations produced by team members so that they may be shared via the listserv and, where appropriate, posted to the CRWDP project page of the SafetyNet website (<http://www.mun.ca/safetynet/projects/CRWDP/crwdp.php>).

2) WORDS FROM OUR CO-INVESTIGATORS AND PARTNERS

After hearing from our student fellows, our co-investigator and partner attendees were given an opportunity to provide an update of their recent CRWDP-related activities.

- **Catherine de Boer** and **Sandra Small** reported that they are still working alongside Michelle Swab (Liaison Librarian for Nursing, MUN) to produce a systematic review of the literature on the topic of chronic physical disability and barriers to employment. This is being undertaken in partnership with the Joanna Briggs Institute (using their methodology), and is intended to be a precursor to a future qualitative study focusing on individuals with chronic physical disabilities and their personal experiences in navigating the work disability policy system. At this stage, they have already successfully published their review protocol, and have moved on to the work of conducting the review itself.

Catherine and Sandra are also part of a seed grant team led by Rose Ricciardelli (CRWDP Academic Co-Investigator), which was successful in receiving funding this past fall to examine mental health policies for protective services workers. Work on this project is now moving forward, with two students (one of which is Daniella Simas Medeiros) currently conducting literature and policy reviews. The intention for this project is that it will result in the development of a larger, related grant application.



- **Barbara Neis** reported that she and Katherine Lippel (Canada Research Chair on Occupational Health and Safety Law, University of Ottawa) were successful in their search for a post-doctoral fellow to examine the intersecting spectrums of mobility and disability with respect to work. Dana Howse, who is finishing up a PhD in Public Health, will hopefully be joining the team in late fall 2016. Dana is currently turning her Expression of Interest into a draft proposal for submission to the co-leads for approval.
- **Kathy Hawkins** reported that the national community caucus is currently working to strengthen its framework. The caucus has recently written letters of introduction to three federal cabinet ministers (whose roles relate in some way to disability), which Kathy is happy to share with the members of our cluster. Kathy has been helping to support Steve Mantis in his role as Community Groups Lead, but nevertheless, she reported that there seems to have been a noticeable drop in engagement within the national caucus as of late.

ACTION: Kathy Hawkins will share copies of the letters that were sent to federal cabinet ministers by the national community caucus group.

DISCUSSION SESSION: SPECIAL SEED GRANT CALL FOR PROPOSALS

A substantial portion of this meeting was dedicated to a discussion/brainstorming session regarding our cluster's approach to the recent special seed grant call for proposals. (One seed grant will be made available to each of the four provincial clusters of the CRWDP, and the deadline for proposal submission was originally May 27th but has now been changed to June 30th.) This discussion addressed five different aspects of the team's intended approach to proposal development:

- 1) **Focal regions.** The call for proposals dictates that each cluster's proposal must focus on two different provinces – the cluster's own province, and one other province where there is no CRWDP cluster. Both New Brunswick and Manitoba were discussed as possible options for inclusion as our second focal province, as they are both fairly comparable with NL in terms of disability programs and services offered. In the end, the team decided to opt for New Brunswick, as it is within Atlantic Canada and team members may have better connections with individuals within that province who might wish to become involved.
- 2) **Focal populations.** The team discussed the possibility of focusing on two disability populations which, when taken together, cover the entire spectrum of disability – the first being work-related disability, and the second being disability that is not work-caused. Within these two populations, the team seemed interested in studying access to mental health services for individuals with hearing loss (which may be either work-related or not) and individuals with PTSD (which also may be either work-related or not). Autism was briefly mentioned as well, but since autism cannot be work-related, it would fall under only one focal population rather than both. It was pointed out that these themes would build nicely upon work that has already been done (or is currently underway) in conjunction with the two seed grants previously awarded to our cluster.



- 3) **Team composition.** Kathy Hawkins volunteered to be the lead investigator on the proposal. Emily Christy also expressed interest in being a part of the team, as did Susan Tobin (however, Susan must first check in with Mary Reid to ensure that the Disability Policy Office's participation is feasible). Barbara Neis and Stephen Bornstein both volunteered to join the team as academic co-investigators, and Sandra Small is also potentially interested (she will take some time to think about it, and then decide). Those members of the NL cluster who were not present at the meeting will be given an opportunity to join the team as well, if they so desire. Other suggested possibilities for additional co-investigators or partners were:
- Dr. Victor Maddalena, a professor in Memorial University's Faculty of Medicine who has done some work with Deaf populations. Stephen Bornstein knows him and could invite him to join the team.
 - Representatives from local branches of mental health organizations, such as the Canadian Mental Health Association (CMHA) and the Consumer's Health Awareness Network of Newfoundland and Labrador (CHANNAL). Kathy Hawkins has contacts within these organizations with whom she could connect to invite their participation.
 - A representative from the New Brunswick counterpart to the Government of NL's Disability Policy Office. Susan Tobin will look into the possibility of forging that connection.
 - A representative from the New Brunswick chapter of the Council of Canadians with Disabilities (CCD). This is essentially a counterpart of COD-NL, and Emily Christy will attempt to make contact with someone there who might be able to join the effort.
- 4) **Methodology.** It was suggested that the team propose a methodology very similar in nature to that which was used within the seed grant project recently completed by Aleksandra Stefanovic (led by Stephen Bornstein and COD-NL). That project's methodology relied primarily upon key informant interviews and focus groups with consumers. By using methodology that is relatively similar, the process of applying for ethics approval should be greatly simplified (the only potential difference will relate to the use of consumers' personal stories in the development of case vignettes). Aleksandra has agreed to prepare and send a brief summary of her project's methodology and results, so that the team can ensure that this new proposal builds upon that project without duplicating its content.
- 5) **Budget.** It was agreed that most of the proposed project's \$10,000 budget would need to be allocated to the hiring of a student, who would be responsible for completing the work and aiding in the preparation of a larger grant application. There may also need to be some funds allocated for travel to New Brunswick.

ACTION: Develop these ideas into a full a proposal to be submitted in response to the special seed grant call.

WRAP-UP

During wrap-up, it was emphasized that our most important priority at the current time is to develop a strong response to the special seed grant call for proposals.