



***Disability Rights Promotion International Canada
(D.R.P.I.-Canada)***

MONITORING THE HUMAN RIGHTS OF PEOPLE WITH DISABILITIES IN THE QUEBEC CITY AREA

SUMMARY REPORT

Centre for Interdisciplinary Research in
Rehabilitation and Social Integration (CIRRIS)
Quebec City, 2011

ACKNOWLEDGEMENTS

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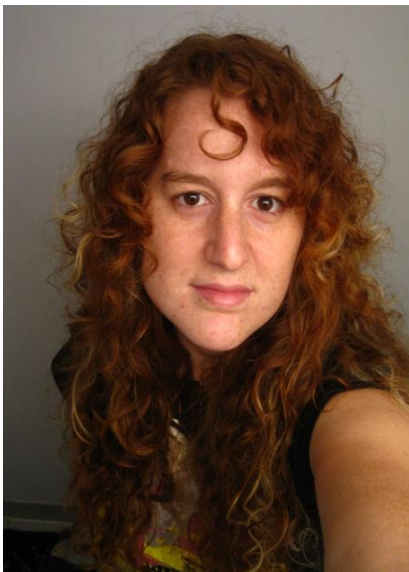
A special thank to our DRPI colleagues from Toronto, mainly Paula Pinto (Postdoctoral fellow), Mihaela Dinca-Panaiteanu (DRPI-Canada Coordinator),

Rita Samson (DRPI International Coordinator) and Marcia Rioux (DRPI-Canada Director and DRPI-International Co-Director). We thank them for their scientific, technical and financial support. Finally, we thank the Council of Sciences and Humanities Research Council (SSHRC) and the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRS) for having financially supported the monitoring project in Quebec City.

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FOREWORD

At the invitation of the former UN Special Rapporteur on Disability (1994-2002), Mr. Bengt Lindqvist, an international seminar on human rights and disability had been held in 2000 in Stockholm, Sweden. The objective was to bring together international organizations of persons with disabilities, human rights experts and UN officials to develop a set of practical guidelines in order to support the groups defending the rights of people with disabilities to identify and report on human rights violations. As pointed out by Dr. Lindqvist during the event, "*The doors of the human rights system are open and there are no barriers to using the international human rights norms and standards for persons with disabilities. The world is waiting for a response from the disability field.*" The Disability Rights Promotion International project (DRPI) was one of the responses to this call.

DRPI is an international project which aims to establish a sustainable system to monitor human rights of people with disabilities globally. Since its inception in 2002, the project unfolds actively and several teams of monitors are at work in various countries such as Australia, Cameroon, India, Kenya, Bolivia, Philippines, Sweden and Canada. Guided by the principles of human rights, these teams work around the world to document the exercise of human rights by people with disabilities on the ground. This initiative, both in Canada and

internationally, contributes with evidence-based information to the current state of knowledge regarding disability rights in various contexts. In Canada, the monitoring activities have been conducted under the DRPI-Canada project funded by the Social Sciences and Humanities Research Council (SSHRC) through the University Research Alliances (CURA) program. DRPI-Canada is headed by Professor Marcia Rioux of York University in Toronto and coordinated by Mihaela Dinca-Panaitescu.

We hope that the monitoring work done in Quebec City area, one of the four monitoring sites of DRPI-Canada, provides a rich source of information to support the disability community in its efforts to voice and defend the rights of people with disabilities. We also hope that this work and the experiences gained through the monitoring activities will be used by people with disabilities and their organizations to continue and expand monitoring initiatives beyond the life of this project.

INTRODUCTION

People with disabilities from the Quebec City area have been participating in the DRPI-Canada project since 2006. The project adopts a holistic framework to disability rights monitoring by coordinating work in *four focus areas*: **individual experiences monitoring** (gathering information about the actual human rights situations of people with disabilities in the communities where they live); **media monitoring** (examining the depiction of disability issues and persons with disabilities in the media); **systemic monitoring** (examining the effectiveness of laws, policies, and programs in protecting disability rights); and **monitoring survey datasets** (examining the information collected by Canadian population surveys on the situation of people with disabilities from a human rights perspective). DRPI-Canada is also grounded in the general human rights principles: **dignity, autonomy, non-discrimination, inclusion, respect for difference, and equality**.

Four monitoring sites were involved in the individual experiences monitoring stream of the Canadian project: *Quebec City, Toronto, Vancouver and St. John's*. A core dimension of the individual experiences monitoring process advanced by this project is the direct involvement of people with disabilities as **monitors** and of local disability organizations as **partners** that take

leadership on all stages of the monitoring process.

In Quebec City, the monitoring project was implemented in collaboration with the local partner, the Regroupement des Organismes de Personnes handicapées de la région 03 (ROP 03). It was co-directed by Normand Boucher PhD, researcher at the Centre for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRS) and Olivier Collomb d'Eyrames, site coordinator. Four people with disabilities - Mirlande Demers, Rachel Fillion, Réal Pelletier and Raynald Guérette – have been trained as *monitors* by means of a training workshop that took place in Toronto. Following the workshop, the monitors conducted 46 interviews to document the human rights situation of persons with disabilities in the Quebec City area.

It is with great pleasure that we invite you to read this summary report and to continue the monitoring activities of the human rights of people with disabilities. We also invite you to consult the full report (available in French only) available at:

[http://www.cirris.ulaval.ca/fr/Normand Boucher](http://www.cirris.ulaval.ca/fr/NormandBoucher)

I. The fundamental principles of human rights

The DRPI-Canada project is grounded in the general human rights principles as enshrined in the **UN Convention on the Rights of Persons with Disabilities**¹: dignity - independence - participation, inclusion and accessibility - the non-discrimination and equality - the respect for difference.

- **Dignity** refers to the inherent worth of every person and means the impact of a particular life experience on how a person perceives himself.
- **Autonomy** is the right of a person to be placed at the heart of all decisions that concern him/her self and make his/her own choices independently.
- **Participation, inclusion and accessibility** means that systems of society, both public and private, are organized to enable all people to participate fully. To achieve full participation, create a physical and social environment accessible and barrier-free is required.
- **Non-discrimination and equality.** The principle of non-discrimination means that all rights are guaranteed

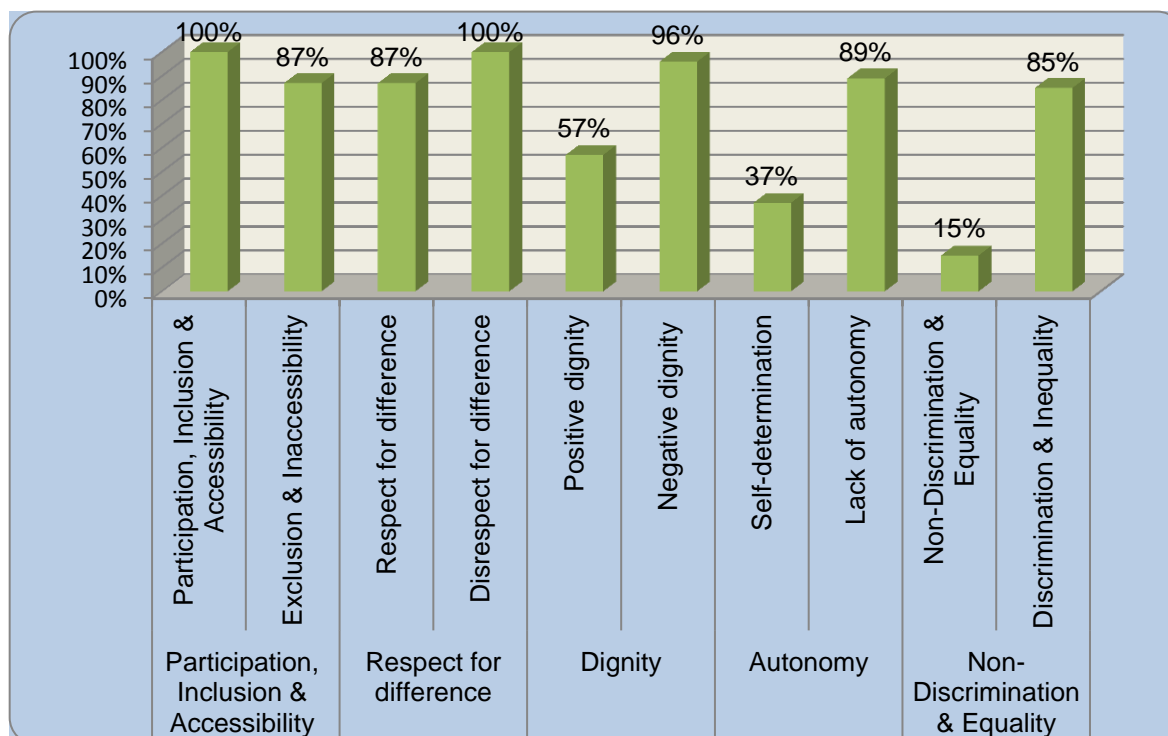
to everyone without distinction, exclusion or restriction based on disability or race, sex, language, religion, political or other opinion, national or social origin, property, birth, age, or any other status. According to the principle of equality, societal conditions that respect difference, address disadvantages and ensure that all people participate fully on equal terms must be created.

- **Respect for difference** constitutes acceptance of people with disabilities as part of human diversity and humanity and states that it is not the individual to change, but the State and civil society to accept diversity and satisfy the difference represented by the disability.

The experiences of the participants in the Quebec City area are mostly situations of denial and violation of human rights. Indeed, except for Participation, Inclusion & accessibility situations (100%), life experiences reported denounce situations of disrespect for the difference (100%), negative dignity (96 %), lack of autonomy (89%), exclusion & inaccessibility (87%) and discrimination and inequality (85%).

¹ To read the text of the UN Convention : <http://www.un.org/disabilities/default.asp?id=150>

Principles that characterize the quality of the human rights exercise of Québécois with disabilities



Although the principles underlying the exercise of human rights are indivisible and interdependent, it is possible to analyze a given life experience under each of these five principles taken independently. Indeed, each of these principles refers to a distinct dimension of the human rights exercise. For example, the principle of dignity spreads over a continuum from positive dignity to negative dignity, i.e. from self-evaluation and self-esteem to self-negation and withdrawal.

Experience of negative dignity:

"Since I'm in a wheelchair, I hardly left the house. Every time I went out, there was always someone: "I will not serve

you, you take too much space. You should leave your scooter outside." Why go out to be told things like that? I left, bought some donuts, stuffed myself with chocolate and I sulked. You know, I have as many rights as you."
(DQD07, Female, 44 years)

Experience of positive dignity:

"I think I am very lucky to work in a place that meets my feminist values. I find it pretty extraordinary. Yes, and I asked to work three days a week and is that I do. I think we're very lucky when we do what we want, what we like and what suits us best. I have the chance to travel and take vacations. There you have it. I have friends around me, I have a healthy family. It's wonderful."

All is well (laughs).” (DQC16, Female, 53 years)

II. The exercise of human rights by domains of life

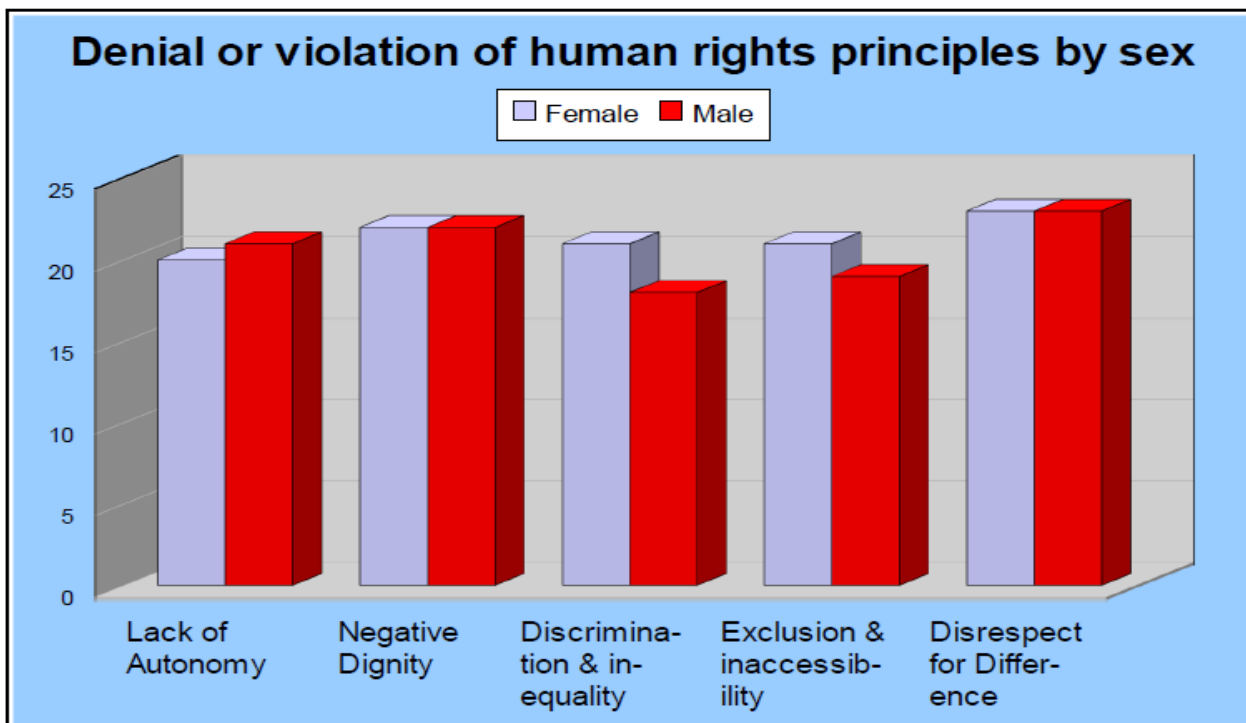
Situations of **denial and violation of human rights** were more frequently reported than situations where people were able to access and exercise their rights. Except for the area of social participation, this was true for all other areas examined in this study - **education, work, income security and supports, privacy and family life, information and communication, health, adaptation and rehabilitation, access to justice.**

- Issues related to **social participation** were raised most often by the 46 interviewees. They reported **high incidences of disrespect for difference (83%), lack of dignity (80%), exclusion (72%) and discrimination (61%)** affecting their enjoyment of social participation rights. At the same time, participants also spoke of many situations of participation and inclusion (93%) and respect for difference (74%).
- **Women** were more likely than men to report cases of discrimination and inequality (46% vs. 39%) and exclusion and inaccessibility (46% vs. 41%) while

men were more likely than women to report lack of autonomy (46% vs. 43%).

- **A large proportion of interviewees (70%) made a report or took legal action** when faced disability-based discrimination.

Figures and voices: A snapshot of the human rights experiences of Québécois with disabilities



"Well, sometimes I can't even get into some places just because I'm not capable. Even to government offices which are supposed to be accessible, I am unable to get there because they are not accessible." (DQD08, Male, 50 years)

"The famous transportation ... it is not always evident ... but in the end they do not provide the hours we want, they cut our time ... or there are delays that seem to last forever." (DQC11, Female, 30 years)

"When you get into ... like convenience stores or anywhere else because you do not have access everywhere, because I'm using a scooter ... worse comes when people say to the owner or even the

cashier "you cannot park that here, that shouldn't be here". It is also difficult in restaurants..." (DQD09, Male, 55 years)

"The plane was supposed to arrive at five. On the information board the flight was marked as cancelled. I looked at the board and thought "What's going on?" I didn't understand anything. I didn't hear anything. Everyone heard the announcements but not me because I'm deaf. We were there waiting. Why is everyone walking; is it because of the cancellation? What's going on? It is obvious that I missed a lot of information because I am deaf." (DQD10, Female, 47 years)

III. **Social participation**

Of all rights exercise domains, rights related to **social participation** have been most discussed by the 46 respondents (100%).

- Life experiences related to this domain are, in order of importance:

1) **Accessibility of public services and infrastructure**

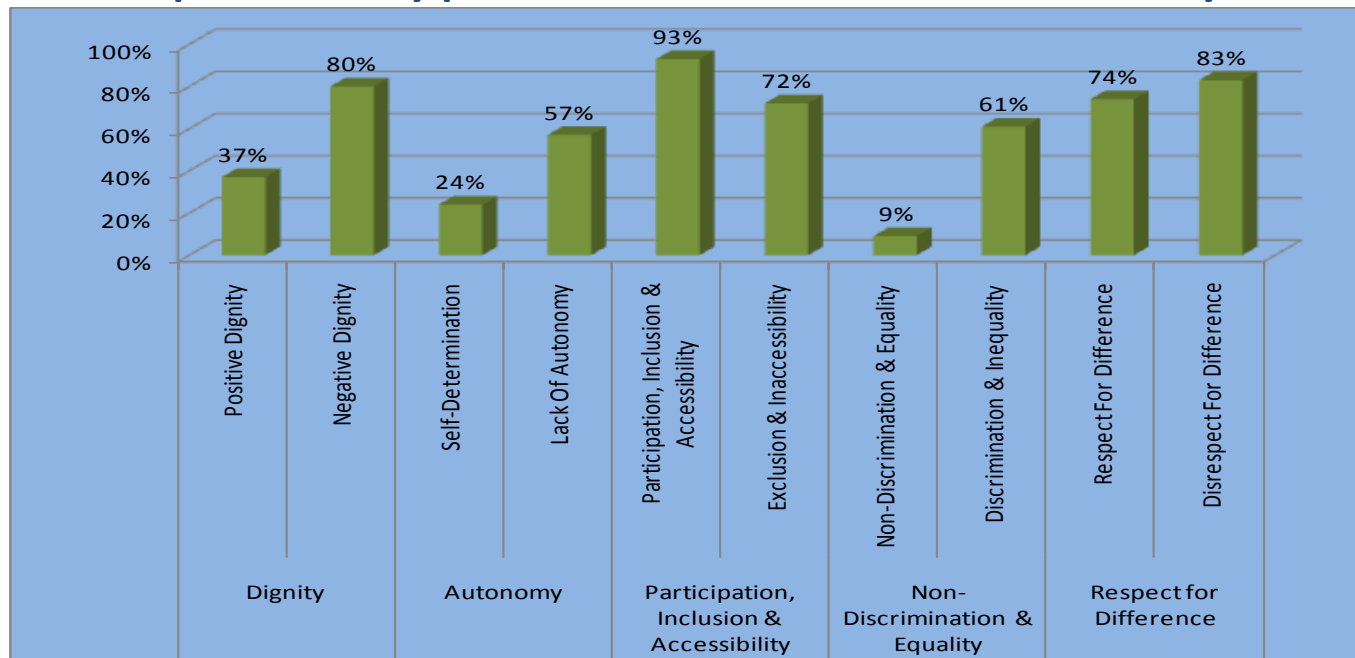
2) **Participation in cultural life, recreation and sports**

3) **Participation in public and political life** 4) **Free choice of place to live**

- By declaring a high incidence of cases of disrespect for difference (83%), negative dignity (80%), exclusion (72%), discrimination (61%) and lack of autonomy (57%), participants in the Quebec City area have shown that rights related to the social participation domain are often violated. But in return, they also reported many cases of participation, inclusion and accessibility (93%) as well as respect for difference (74%).

- The **main barriers to social participation** mentioned by participants are access to public infrastructure (roads, buildings and public spaces), transport (individual and collective), shops (convenience stores, restaurants, etc..), cultural and sports facilities, social exclusion (attitudes, judgments and disrespect), lack of awareness about people with disabilities and the lack of measures to support cultural and sports activities.

Social participation according to human rights principles as experienced by persons with disabilities in Quebec City



Experience of participation, inclusion & accessibility:

"I travel to the United States, to Florida especially and ... I get involved in many things and organizations. I'm on the board of three organizations at this time. It's still volunteering, for nonprofits organizations." (DQD09, Male, 55 years)

Experience of lack of autonomy and disrespect for difference:

"Sometimes I go on the street, and there, people see that I have difficulty to get on the sidewalk. Since they are there, they take my cart. It shocks me because they don't ask me if I need help. I feel they don't respect me, they force me to accept their rules.

I do not need this. " (DQC06, Female, 69 years)

Experience of exclusion and inaccessibility:

"Situations and frustrations... a group of deaf, we're excluded, it's like... there is not enough support for the deaf, we do not have... things that might help us, not many..." (DQD19, Male, 63 years)

Experience of discrimination and inequality:

"Since I'm in wheelchairs, eight years ago, there's no sensitivity. Sensitivity towards you, I mean. When you go to the restaurant, they look at you oddly and they refuse to serve you. Still, my money is as good as theirs. In those situations, I leave. I go home instead of arguing and I just crash at my

house. You cry, it's normal, when you are told that you're not welcome, because you're disabled. I'm not interested in being told that anymore."
(DQD07, Female, 44 years)

IV. Transportation

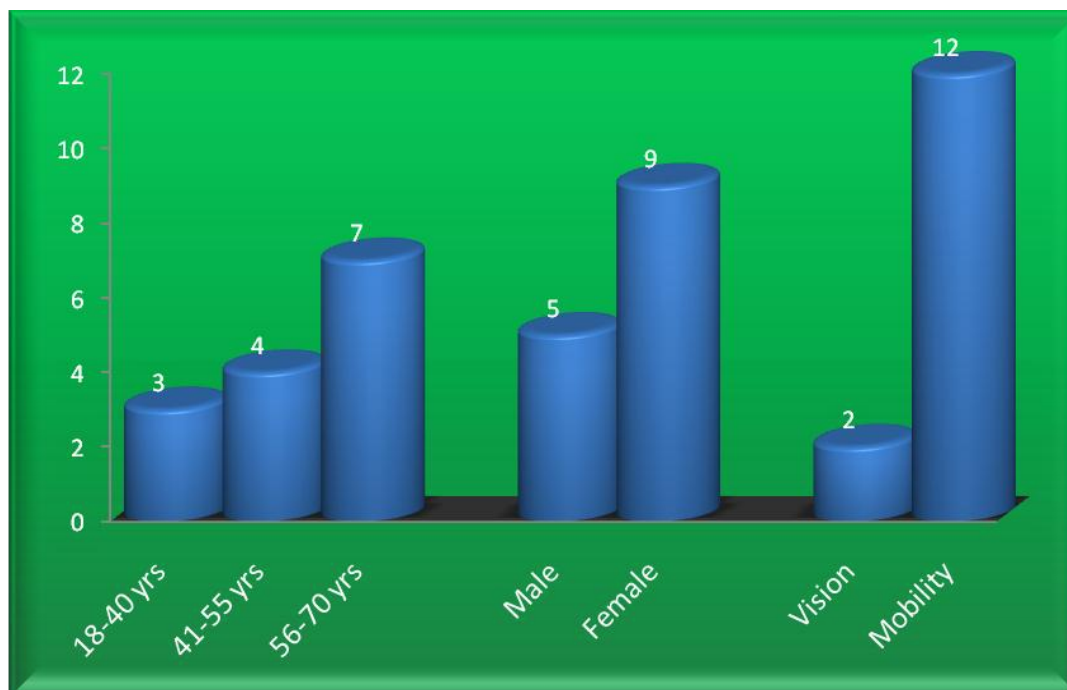
Transportation was identified as an **issue of concern** for almost two thirds (63%) of participants in the Quebec City area.

- Indeed, 13% of participants have experienced situations of denial of human rights related to public transport, 30% related to taxis and 30% related to paratransit.
- About paratransit, the most discussed experiences by participants are related mainly to two rights principles: **lack of autonomy and disrespect for difference**. Other situations have also revealed experiences of lack of dignity, exclusion and inaccessibility.
- Experiences related to paratransit concern (in order of importance):
 - 1) **delays and waiting times**
 - 2) **inflexible schedules**
 - 3) **service interruptions**
 - 4) **lack of courtesy**

5) lack of service in certain areas

- Over a third (36%) of participants had negative experiences with paratransit said they **had complained** to the service provider.
- The main recommendations made by participants are: to provide a better listening of needs; improvements to the reservation system; improving route planning; increase the number of hours of service, cars and drivers; respond and monitor complaints to ensure a courteous and respectful service; offer more flexible schedules.

Portrait of participants has had experiences of human rights denial related to transportation in the Quebec City area (n = 14)



"It happened to me, there's maybe two weeks. I took the paratransit almost every day and there were delays both on the way out than the way back... half-hour, forty five minutes every day... it was a never-ending week... I don't remember exactly when, once I was eating out at a restaurant and I got about 20 minutes to eat because they brought me late and they came to get me early, so, that's it... Situations like this happen... and they hinder our leisure, , shorten our time out..." (DQC11, Female, 30 years)

"Oh, yeah. Paratransit. Last week, I went to the doctor... they came to take me at midday. My appointment was at 11:30. I arrived late. They have to pick me up, I asked at 1:30, and they scheduled my pick up for 1:00. At 12:50, I call to tell them I

was not yet in the doctor's office. The girl said, "Call us when your appointment is over." "Sure." After my appointment, I call on my cell, but I had been waiting for so long now. So then, I tell them I'm done. The girl said, "Everything has been canceled. You have no more transportation." (DQC15, Female, 61 years)

"... There was a driver that at some point... it's been 17 years since he's there... but the guy is aggressive... he has the right to be late, he has the right to do what he wants... but if you are even a minute late "you got to tell them to send you before, I do not wait for you..." only for being a minute late you know... wow wow ... Worse, I saw him roughing

disabled people, I had to help some, he doesn't have to help me but... but one time I'll get angry... then I'll get him..."
(DQD05, Male, 52 years)

"When the doctor calls you for an appointment, he calls you the day before. So you gotta go, you got no choice, but you have to take a taxi, because you have to call paratransit twenty-four hours in advance. That, I think is ridiculous. The bus is two and a half bucks and it costs sixteen, twenty bucks to take a taxi. I often go to the hospital. It is quite expensive." **(DQD07, Female, 44 years)**

RECOMMENDATIONS

In order to continue the participatory research process advanced by DRPI-Canada, the Quebec monitoring team organized a consultation meeting on June 2, 2011. This event bringing together people with disabilities and representatives of advocacy organizations aimed to discuss the study results, obtain feedback from participants in the project, and provide recommendations on how to improve the exercise of disability rights in reality based on the experience and expertise of people directly connected to disability community . The exchanges with the participants helped to validate and enrich the content of the research report.



Participants at the consultation meeting
(Photo by David Fiset)

The day began with the presentation of Dr. Normand Boucher, co-investigator in DRPI project and researcher at the CIRRIIS. Besides unveiling the results, this presentation was also an opportunity to explain the international deployment of the DRPI project, the Canadian component and its activities in the four sites, and the steps of the project in Quebec City. Participants then had the opportunity to discuss about the results and, during the afternoon, on proposed recommendations for improving the human rights exercise.



Exchange session during the presentation of results
(Photo by David Fiset)

The results presentation generated several comments from participants. Overall, they were not surprised at the

portrait of the human rights exercise found by the study. In fact, participants noted that the results represent a true picture of what they hear on the ground and in the various advocacy organizations. Moreover, they emphasized and appreciated the practical and structured aspect of the study. For them, it's a tool to advance human rights and claim them.

In particular, accessibility, public transit, compensation measures and disrespect for differences are among the most discussed topics. Participants noted that many situations of human rights denial were related to attitudes and social behavior. They denounced these cases by recalling that too often situations arise that a person interacts with a person with disabilities, sensory or intellectual, for example, first via its accompanist or interpreter, not the person himself. From respect for difference to the accessibility of the physical and social environment, participants stressed that people with disabilities had themselves a role to educate actively the population to their needs and rights as well as the importance of finding universal solutions satisfying all needs, regardless of the type of disability. In this sense, "there is no point in robbing Peter to pay Paul" states a participant.

According to them, making society more inclusive is necessary to enable people with disabilities to exercise their rights

equally and offer them real access, the ability to choose and use the same services and facilities that those offered to the general population. But it also means, according to some participants, to change practices and attitudes and to remove "psychological barriers" that some people build up themselves. The requirement of this perspective was reported by a participant who asked, "Do we really want to be included? ". What is important, another participant answers, is to have a choice, in other words the possibility of using the same public services and facilities than people without disabilities".



Participants exchange of proposals for recommendations (Photo by David Fiset)

The second part of the day was devoted to a recommendations session to improve the conditions for exercising the human rights of persons with disabilities. Participants focused on several priorities for action such as health and social services, legislations, advocacy, complaints mechanisms and access to information. One observation seems to emerge from these

discussions: "It's exhausting; we are tired of fighting for having access to services which we are entitled." Consequently, several recommendations were proposed:

- In order to change negative attitudes towards people with disabilities, the "Office des personnes handicapées du Québec" should implement more outreach programs and public education.
- Making the *Act to secure handicapped persons in the exercise of their rights with a view to achieving social, school and workplace integration* more stringent to improve its implementation and enforcement of its provisions: "The stage of rhetoric is over, it is time to move now."
- Require the City of Quebec to meet the standards and obligations of the mechanisms in place to improve accessibility.
- Promote the empowerment of people with disabilities to encourage them to overcome obstacles, to practice and claim their rights.
- Change negative attitudes and inflexibility of stakeholders who often

impose their solutions without giving the choice to the person and without considering their needs.

- Increase CLSCs (community healthcare centers) human and financial resources to enable them to offer more services and reduce waiting lists. Currently, there is a lack of monitoring and information in health and support services between hospitalization and return to the community. People need more services and do not know where to ask. CLSCs should be able to support more effectively the social participation of persons with disabilities. They should also better train their stakeholders to the reality of people with disabilities and all existing services for these people.
- Improving complaints mechanisms to ensure continuity and quality of services after a person has complained. Several participants said they fear retaliation, like services cut, and denounce the power of stakeholders within the unit. "It does not encourage a person to complain and to claim their rights ..."
- Recognize Sign Language (ASL) in the "Charte de la langue française" to guide its use and thus extend its use to the different spheres of activities, such as education.

According to participants, it is essential to further support people with disabilities to fully participate in social, economic, cultural and political and that they are not as they feel socially perceived, seen as a burden on society, service recipients or just "funded people." For this, participants recommend, on the one hand, to make available the necessary resources to increase support services and to ensure, on the other hand, the application of standards and legal provisions contained in the legislative framework. However, despite the recognition of rights and the existence of laws and policies, people with disabilities have to exercise and claim their rights in order to make them existing. Because rights do not apply themselves, they are exercised in a constant balance of power forming a political process. In discussions surrounding complaint mechanisms and how they work, it is interesting that the fears of "reprisal" or negative consequences expressed by participants are similar to those that have been identified in the monitoring activities. This is important and deserves to be more thorough in terms of analysis but also to be considered in the development of outreach activities. And it is by closely monitoring this process that the exercise of these rights can be promoted. Moreover, looking to the past, participants noted with happiness the progress in the field of the human rights exercise of people with disabilities.

CONCLUSION

In conclusion, several elements must be highlighted in order to clarify the key role they played and still play in this unique approach of monitoring of the human rights exercise of people with disabilities. Likewise we must emphasize about the nature of individual autonomy and the capacity of collective actors that drive this process both locally and internationally by focusing on people with disabilities and their associations. Their participation in development of the approach, especially through the training seminar, which is sometimes on human rights applied in the field of disability and other times on how to achieve a individual interview in order to obtain information about situation (often sensitive) experienced by the person with disabilities, feeds the dynamic of the monitors team.

Results presented in this report highlight the importance of certain obstacles to the rights exercise such as the inaccessibility of information, the built environment, transportation, etc. The fact that the sample² is mainly comprised of people with motor disabilities may explain the predominance of certain barriers

² This sample was based on regional statistics available from the 2001 Quebec survey on activity limitation.

related to accessibility. The same factor may also explain the low representation of domains such as education or the preponderance of others such as social participation. Reading testimonies, we unfortunately note still many prejudices and negative attitudes towards people with disabilities that are obstacles to their participation in ordinary activities of society. This gives rise to several of them, when questioned in this respect, a sense of what we call in the study negative dignity, i.e. to be disrespected and be treated differently because their functional differences.

It seems that this situation is not confined to the Quebec City area according to survey data on participation and Activity Limitation Survey (PALS) Statistics Canada. Indeed, one person with disabilities aged 35-54 in four (25%) claimed to have been discriminated against while 61% of people with disabilities consider that attitudes and behavior with respect to people with disabilities have not changed over the past five years in Quebec (ISQ, 2010). In this regard, it is not surprising that the first recommendation of participants is to conduct outreach activities of the population with regard to their situation.

When addressing the question of the reaction about discrimination situations, data analysis reveals ambivalence or even an ambiguity among participants.

Indeed, part of them denounced the situation either by filing a complaint either by pointing to a third party while a second party preferred to do nothing for reasons of low efficiency of existing mechanisms or lack of energy. The element related to the inefficiency of the existing system should be further explored in the context of other reflexions, because it does exist in the Quebec and Canadian context, a set of procedures and mechanisms that allow people who consider that their rights are violated to appeal. Based on the experiences identified, it is clear that there is a lack of confidence in them or that the process is too long and complicated, so better to drop it because it does not "give us anything anyway."

At the end of this exercise, we must emphasize that disability rights monitoring by people with disabilities themselves is a must in order to translate the rights on paper into reality.