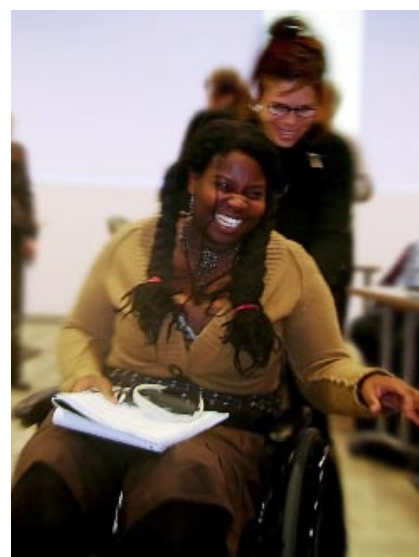




From Personal Stories to Disability Rights



A disability rights monitor is congratulated for completing her training.



Mirlande Demers learned to be a monitor.

“Some people can find work, but even with a job, can only afford to live in bug-infested shelters. For these people, living on the street sometimes seems easier. Some people do not receive proper health care because of being HIV-positive and the stigma that goes with that. The trauma and the horror some people have gone through almost seem impossible to be true.”

THESE ARE ONLY A FEW patches of a whole tapestry of real stories faced day by day by people with disabilities in their struggle to have a decent life. These are the kinds of stories that make a saga so different from the one told by laws and policies.

It is the right time now, with the adoption of the Convention on the Rights of Persons with Disabilities, to transform the words of the Convention into a real change in the lives of people with disabilities. And it is the right time to put into effect the disability rights demand of “Nothing about us without us.” There is a long journey from rights on paper to

rights in daily life, and there is need for evidence-based data about the human rights situation of people with disabilities in order to get to the destination of this journey.

An essential means to make this transition possible is what is referred to as *rights monitoring* – research involving the documentation and verification of information regarding otherwise unreported human rights violations. Monitoring is central to an effective way of enforcing the equal enjoyment of human rights by Canadians with disabilities.

It is the mandate of the *Disability Rights Promotion International Canada* (DRPI Canada) project to develop monitoring tools that empower people with disabilities themselves to take ownership of disability rights monitoring.

To fulfill its mandate, DRPI Canada is working in partnership with national disability and human rights organizations with a strong network of local affiliates. The local affiliates are key to the success of monitoring as they are the most knowl-

edgeable about the situation and challenges their members face. They are also the gate to those who are isolated, whose problems aren’t usually given a voice.

In line with this, DRPI Canada’s local partners are taking the leadership in coordinating the monitoring sites and supervising the data collection. At two of its monitoring sites – Toronto and Quebec City – DRPI Canada benefits from the strong support and dedication of great partners, *Centre for Independent Living Toronto* (CILT), *Regroupement des organisations de personnes handicapées de la région 03 (ROP-03)* and *Centre Interdisciplinaire de Recherche en Réadaptation et Intégration Sociale* (CIRRIS).

With their support, people with a broad range of disabilities were recruited as *monitors* – persons with disabilities who interview other persons with disabilities about their personal experiences of human rights violations.

It is essential that the people about whom the data is collected collect this data themselves. This makes monitoring

available, accessible and empowering to those traditionally viewed as objects of research.

Before going into the field and interviewing their peers, four monitors from each of the two sites were trained at a five-day seminar held in November 2007 in Toronto.

Throughout the training, the monitors were introduced to the intricacies and challenges of conducting interviews in the field and how to use the project interview guide, already tested in several countries, to interview people about their lives. They also learned how to obtain free and informed consent of the interviewees and how to protect the confidentiality of information collected.

Equipped with strong knowledge and skills and an even stronger desire to effect change in their communities, our monitors embarked on a very challenging journey, made more difficult by a harsh winter rarely seen even in Canada. For most of them, the first experience as monitors was a transforming journey, as one of the monitors declared: *“Meeting the interviewees has changed my life; their personal stories are incredible, truly a journey through ability.”*

It was amazing how the monitors were building connections and solidarity with

each other and with those whose stories resonated with their own experiences. It is an intense emotional charge to get the sad confirmation, story after story, that *“the greatest obstacle to the social participation of people with disabilities is the lack of respect and sensitivity from the mainstream society,”* and that *“so many people face situations of extreme exclusion and discrimination but they are scared of being judged if they ask for their rights.”*

However, there is always a bright side, that of *“being able to gain the confidence of those nobody has confidence in – it gives confidence in yourself.”* It is that kind of confidence that lets you fight a worthy battle for a shift in consciousness of people with disabilities to a rights-based or entitlement focus, which is the only one making people full participants in society and fully respected. It is that kind of confidence that is possessed by all of those involved in this project.

It is also that kind of confidence that *Mirlande Demers*, one of our monitors, lived with throughout her life, one that was too short but so rich in achievements. *Mirlande* died last June during a trip in Asia. She left us with the image of a vivid spirit, a pioneer in monitoring who was determined to make rights a reality for people with disabilities.

Special thanks to the monitors and site coordinators for their great work and dedication:

Matthew Christie
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ABOUT DRPI CANADA

Disability Rights Promotion International Canada (DRPI Canada) is a community-university alliance headed by Dr. Marcia Rioux at York University in Toronto. DRPI Canada brings together community members, people with disabilities, researchers, lawyers, media experts, statisticians, policy experts and students to create a holistic and sustainable system to monitor disability rights in Canada. DRPI Canada is funded by the Social Sciences and Humanities Research Council of Canada (SSHRC).

For more information, please visit www.yorku.ca/drpi/Canada.html.