



Moving Forward

— Progress in Global
Disability Rights Monitoring



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Printed in Canada.

Published by Disability Rights Promotion International (D.R.P.I.)
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Library and Archives Canada Cataloguing in Publication

Lindqvist, Bengt, 1936-
Moving forward : progress in global disability rights
monitoring / Bengt Lindqvist, Marcia H. Rioux, Rita M. Samson.

Includes bibliographical references.
ISBN 978-1-55014-481-9

1. People with disabilities--Civil rights. 2. People with
disabilities--Legal status, laws, etc. 3. Discrimination against people with
disabilities--Law and legislation. I. Rioux, Marcia H. II. Samson, Rita M., 1969-
III. Disability Rights Promotion International IV. Title.

K3242.4.L46 2007

342.08'7

C2007-902880-2

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This document has been financed by the Swedish International Development Cooperation Agency, Sida. Sida does not necessarily share the views expressed in this material. Responsibility for its contents rests entirely with the author.

Front and back cover design, text layout and printing by is five communications, Toronto, Canada,
<http://www.isfive.com>.

This report is available electronically in PDF and HTML formats on the Disability Rights Promotion International website: <http://www.yorku.ca/drpi/>.

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Foreword

The publication you now have in front of you is a progress report, which means that it is part of a larger context, which has to be understood in order to interpret the activities described. It is the report of the second phase of the Disability Rights Promotion International (DRPI) project. The aim of DRPI is to build capacity and to develop tools and methods for the effective monitoring of the human rights of people with disabilities. During Phase Two of this project, a number of tools are being developed and tested in a series of pilot projects around the world. The work is being done in close cooperation with organisations of people with disabilities and human rights experts.

To better understand the role and importance of DRPI in general and, in particular, the achievements presented in this report, it is useful to view them in light of modern international disability history.

The struggle to have disability accepted as a human rights issue on the same level as, for instance, gender rights and children's rights, was initiated by the various international organisations of people with disabilities in 1981, during the International Year of Disabled Persons (IYDP). To some extent, these efforts were reflected in the World Programme of Action concerning Disabled Persons, adopted in 1982 as the outcome of the IYDP. The world community, however, was still reluctant to abandon the traditional view of disability as solely a social development issue. In 1987, during a United Nations Expert meeting, representatives of the international disability movement urged the United Nations (UN) to elaborate a convention on the rights of people with disabilities. Proposals for such a convention made from within the UN were turned down by the General Assembly at the end of the decade.

However, the efforts made during the 1980's were not in vain. Both the 1993 adoption of the UN *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities* and the 1994 report by the first UN Special Rapporteur on Disability, Leandro Despouy, significantly contributed to paving the way for a human rights perspective in international disability policy.

During the 1990's, disability was introduced and analysed as a human rights issue by the UN Committee on Economic, Social and Cultural Rights. The result was published in 1994, in the Committee's *General Comment No 5*. The final breakthrough came, when the UN Commission on Human Rights, actively supported by Mary Robinson (UN High Commissioner for Human Rights 1997-2002), identified and recognised disability as a human rights concern for the UN in a series of resolutions issued in 1998, 2000 and 2002. As a logical consequence of this development, in 2001, the UN General Assembly accepted a proposal by the Government of Mexico to elaborate a UN convention on the rights of persons with disabilities. Following the work of a UN Ad Hoc Committee and the active

participation of the disability movement, the international *Convention on the Rights of Persons with Disabilities* was adopted by the UN General Assembly in December 2006, signalling the successful end of a struggle waged by the disability movement for more than 25 years.

This great achievement to get recognition of disability as a human rights concern for the UN is a victory in principle. Yet, as is often the case, the step from principle to reality is a steep one. Analysis of the consequences of living with a disability from a human rights perspective is a new endeavour and constitutes a great challenge for the international human rights system, as well as for the disability movement. There are many unknown forms of discrimination and exclusion in the field of disability which must now be identified, exposed and reported. The instruments needed to do this work were simply not available at the time of the great break-through in 1998.

This critical observation was made at an international seminar, held at Almåsa, Sweden in 2000, at which representatives of all major international disability organisations, human rights experts and UN representatives participated. The seminar agreed that an extensive development plan had to be launched to adapt and develop tools, training programmes and methods of analysis to meet this new challenge in the human rights field. This is the historical background of DRPI, which was established as a direct consequence of the recommendations made by this seminar. A five-year plan was elaborated, a coordination centre for the project was established at York University, Toronto, Canada, and long-term financial support was obtained from the Swedish International Development Cooperation Agency (SIDA)

The first report of DRPI (*Phase I Report: Opportunities, Methodologies and Training Resources for Disability Rights Monitoring*, 2003) did an inventory of opportunities for using international human rights instruments to enforce disability rights; types of monitoring tools used by human rights monitoring projects; potential partners for human rights monitoring in the disability field and existing training resources for human rights monitors and general human rights education.

This second DRPI report describes the progress that has been made, in collaboration with national disability organisations and human rights experts in a number of countries, to develop and test tools and methods adapted for monitoring the situation of people with disabilities. When we planted an oak tree at the Almåsa seminar in 2000, I remarked that it is from little acorns that great oak trees grow. Thanks to the efforts of a great number of dedicated people working for and with DRPI around the world, there are now several tools, training materials and guides for monitoring ready to be used and further developed in a much wider context. As monitoring takes place, our understanding of the human rights situation of people with disabilities is growing, providing new and strong arguments for change for all those of us who fight for better living conditions for people who happen to live with a disability.

Bengt Lindqvist
Co-Director, Disability Rights Promotion International

Executive Summary

INTRODUCTION

This report is prepared and published by Disability Rights Promotion International (DRPI), a collaborative project, working to establish a comprehensive and sustainable global system for monitoring the human rights of people with disabilities. DRPI was initiated in response to the recommendations of an international disability rights seminar (Almåså Seminar) held in 2000 and hosted by Dr. Bengt Lindqvist, UN Special Rapporteur on Disability (1994-2002).

The project involves three phases:

- Phase One, completed in December 2003, investigated opportunities for using international human rights instruments to enforce disability rights; types of monitoring tools used by human rights monitoring projects; and current training resources for human rights monitors and general human rights education. The *Phase I Report: Opportunities, Methodologies, and Training Resources for Disability Rights Monitoring*, is available on the project website (www.yorku.ca/drpi).
- Phase Two involves the development and field testing of a broad range of tools, methodologies and training resources that can be used by people with disabilities and their organizations around the world to monitor disability rights in three focus areas (systems, individual experiences and media). This second phase emphasizes: capacity building within organizations of people with disabilities and international and national human rights institutions; monitoring; and raising awareness and encouraging action.
- Phase Three will use the instruments and tools developed and field-tested during Phase Two to expand capacity-building, training and monitoring activities to many countries. Monitoring activities run by people with disabilities will be supported in five regions and will act as focal points for disability rights monitoring activities and training throughout Phase Three and following the completion of the DRPI project.

This report outlines DRPI's progress mid-way through Phase Two.

In keeping with the recommendations of the Almåsa Seminar, DRPI has adopted a holistic approach to disability rights monitoring. A holistic approach involves monitoring in three focus areas:

- *monitoring systems* (assessing the effectiveness of laws, policies, programs and case law in protecting and promoting the rights of people with disabilities);
- *monitoring individual experiences* (gathering information about the actual human rights situation of people with disabilities on the ground); and
- *monitoring media* (examining both the coverage and depiction of people with disabilities in the media).

In many cases, human rights monitoring has involved primarily an examination of relevant laws, policies and programs or carrying out service audits to determine whether they meet national and international human rights standards. By expanding the focus of monitoring in the disability rights context to monitoring personal experiences and media coverage and depiction along with systemic monitoring, DRPI's approach is an innovation in the field of human rights monitoring. More importantly, DRPI maintains that monitoring in all three focus areas is not only innovative but *necessary* in order to gain a comprehensive understanding of the extent to which people with disabilities either enjoy, or are denied, their human rights. Individually, each element tells only one piece of the story. Together, the information provides a more complete picture. By developing tools and mechanisms for each of the three monitoring focus areas, DRPI is ensuring that a holistic view of the human rights situation of people with disabilities is presented and addressed.

The information gathered through disability rights monitoring is used to bring about positive change in the lives of people with disabilities. It promotes greater awareness of disability discrimination, informs advocacy for equal rights, encourages the development of inclusive policies and laws and contributes to monitoring State responsibilities under international and regional human rights treaties, including the new UN *Convention on the Rights of Persons with Disabilities* (Disability Convention).

PHASE TWO ACTIVITIES

Background

Chapter 1 of this report sets out the background, context and methodology for the DRPI project. It notes the following five general principles that guide all project work:

- Full involvement of people with disabilities and organizations of people with disabilities in the DRPI project itself and in all disability rights monitoring activities generally.

- Emphasis placed on working with people with disabilities and disability organizations to build capacity to use the tools developed in the project to conduct disability rights monitoring, analyze the data collected and use the data to advocate for positive change.
- Recognition of the need for cross-disability involvement in monitoring activities, that is, people with a spectrum of disabilities both participate in monitoring and have their personal experiences monitored.
- Use of a holistic approach to monitoring in order to understand the human rights situation of people with disabilities fully, that is, analyzing data from three focus areas (systems, individual experiences and media) to provide a comprehensive picture.
- Engagement of individuals and organizations already involved in human rights monitoring as partners in the development of methodology and as a means of benefiting from past experience and ensuring sustainability of disability rights monitoring efforts.

The remaining chapters outline DRPI's progress in the development of disability rights monitoring tools and methods in its three monitoring focus areas.

MONITORING SYSTEMS

Chapter 2 reviews the methods DRPI has developed to collect and analyze systemic disability rights information in countries around the world.

- Through the **legal education and research project**, DRPI is encouraging law schools to make disability rights research core to the knowledge skills that students learn. Through this initiative, an ongoing interest in the area of disability rights research is being fostered among students working in the field of human rights.
- DRPI has developed a preliminary **country-based template to assist with the collection of legislation, policy and program data** specific to disability rights. The template is designed to gather information addressing all categories of rights (civil, cultural, economic, political and social) and serves as an assessment tool, identifying gaps in legislation and policy.
- DRPI is collaborating with a London-based NGO, Interights, to identify a **strategic disability rights legal case** in support of advancing the status of international human rights law, as a whole.
- DRPI is collaborating with the Asia Pacific Forum of National Human Rights Institutions in the development of a **tool to track disability cases decided by national human rights institutions**.

Monitoring Individual Experiences

Chapter 3 outlines the tools and methodology developed by DRPI to monitor the actual situation of people with disabilities including:

- An **Interview Guide**, including both open-ended and semi-structured questions designed to allow people with disabilities to tell their own story and identify the rights issues that are most important to them.
- A **Training Course** that prepares monitors with disabilities and field assistants to engage in monitoring the individual experiences of people with disabilities in the field.
- A **Training Manual for Monitoring Individual Experiences** which provides information about disability rights generally, monitoring techniques, confidentiality in monitoring and how to work in the field.
- A **Trainers' Manual** that can be used by disability organizations to train others how to monitor on a continuing basis, contributing to the sustainability of monitoring efforts.
- A **Data Analysis Manual** to assist in the process of organizing and analyzing the disability rights data collected during interviews in the field and writing reports outlining results. The manual encourages the development of partnerships with academics from local universities and/or staff of national human rights institutions who can assist with the coding and analysis of the individual monitoring interview data.
- A **Field Methodology Guide** for national organizations of people with disabilities to use when overseeing the administration of monitoring projects.

Each of the above tools and methods is being field tested in a series of **pilot projects** in countries around the world. (Australia, Cameroon, Canada, Croatia, India, Kenya and Sweden). Once they have been further refined, they will be widely available for use by organizations of people with disabilities, human rights organizations, government, the media and any others interested free of cost.

Monitoring Media

Chapter 4 reviews DRPI's progress in developing tools and mechanisms to monitor the depiction and coverage of disability in the media, including:

- Collaboration with a team of researchers from the State University at Buffalo, USA and researchers from the University Of Umea, Sweden who have developed both quantitative and qualitative methodologies **to facilitate the analysis of media depiction and coverage of disability** issues around the world.

- Assembly of an **international Panel of Experts** in disability rights, media communications and disability-specific media to draw on their advice and expertise in the analysis of the disability media monitoring.
- Development of an **online media monitoring tool** that will be made widely available and permit organizations of people with disabilities, government, academics and others who are interested to conduct their own studies of disability-related media reports from a wide variety of sources, over a broad time period.

Building Partnerships & Networks

Chapter 5 sets out the collaborations DRPI has undertaken with disability, human rights and other organizations to build on existing expertise and develop the international and multi-disciplinary networks needed to support an international disability rights monitoring system. DRPI is currently collaborating formally with more than forty organizations of people with disabilities, human rights NGOs, university research institutes, human rights institutions and government agencies.

Disseminating Knowledge

Chapter 6 outlines the steps DRPI has taken to disseminate the knowledge created by the project through the development of virtual knowledge networks, an interactive and fully accessible website, oral presentations and written publications.

MOVING FORWARD — TWIN-TRACK APPROACH TO DISABILITY RIGHTS MONITORING

DRPI has made significant progress toward achieving its goal of developing the tools, capacity and infrastructure needed to monitor disability rights globally. When the project began in 2002, disability rights advocates around the world generally agreed that the “twin-track approach” to protecting and promoting the rights of people with disabilities should be adopted. That is, while continuing to advocate for a disability-specific international human rights convention, efforts should also be made to develop the tools and mechanisms necessary to recognize the protection and promotion of disability rights within the existing international human rights system. With the U.N. General Assembly’s adoption of the Disability Convention on December 13, 2006, a new and very important chapter has begun for disability rights monitoring.

In this new era, pursuit of a twin-track approach remains essential to ensuring the full enjoyment of all human rights by people with disabilities and to fighting the battle against the continuing discrimination and sheer abandonment of people with disabilities to social

and political exclusion. The work of the first track is far from complete. States must ratify the Disability Convention before it comes into force in any country. Also, once in force, the Disability Convention will have to be effectively implemented in order to actually improve the lives of people with disabilities. The work of the second track also continues. Efforts must persist to ensure that the monitoring bodies of other international and regional human rights conventions recognize and uphold their obligation to ensure that the rights of *all* people - including people with disabilities – are being protected, promoted and fulfilled. Holistic disability rights monitoring, which involves looking at monitoring systems, individual experiences and media, is important to providing data to test the effectiveness of both the disability-specific and other human rights conventions in achieving these goals.

People with disabilities and disability organizations have a key role to play in the monitoring process, a role clearly recognized in the text of the Disability Convention. In order to play this role, people with disabilities and disability organizations need to build their capacity to monitor obligations under both the Disability Convention and other international human rights treaties. DRPI is now involved in disability rights monitoring on 5 continents, working in close partnership with international and local organizations of people with disabilities. DRPI's monitoring methodology, with its stress on building the capacity of people with disabilities and disability organizations, will provide the means through which the disability community will be able to engage in both national and international monitoring processes.

CHAPTER 1

Background to the Disability Rights Promotion International Project

Disability Rights Promotion International (DRPI) is a collaborative project working to establish a comprehensive and sustainable system for monitoring* the human rights of people with disabilities. DRPI is developing tools and methods to facilitate the gathering and analysis of reliable data on the human rights situation of people with disabilities. Monitoring data provides needed facts about disability discrimination that will bring about positive changes in the lives of individuals with disabilities. These facts will support disability advocates in communicating disability rights issues and provide a basis on which governments can ensure that policy, programs, law, and legislation meet basic standards of human rights.

Five general principles govern the DRPI project during each of its phases:

1. Involvement of people with disabilities and organizations of people with disabilities in the DRPI project itself and in all disability rights monitoring activities. DRPI recognizes that disability rights monitoring belongs to people with disabilities.
2. Emphasis placed on working with people with disabilities and disability organizations to build capacity to use the tools developed in the project to conduct disability rights monitoring, analyze the data collected and use the data to advocate for positive change. All monitoring tools and training resources developed by the project will be accessible, easy to use and freely available to all.
3. Recognition of the need for cross-disability involvement in monitoring activities, that is, people with a spectrum of disabilities both participate in monitoring and have their personal experiences monitored.
4. Use of a holistic approach to monitoring in order to fully understand the human rights situation of people with disabilities, that is, analyzing data from all three focus areas (systems, individual experiences and media) to provide a comprehensive picture.

5. Engagement of individuals and organizations already involved in human rights monitoring as partners in the development of methodology and as a means of benefiting from past experience and ensuring the sustainability of disability rights monitoring efforts after the life of this project.

THE NEED FOR ACTION: GROWING INTERNATIONAL RECOGNITION OF THE RIGHTS OF PEOPLE WITH DISABILITIES

The United Nations* (UN) estimates that 650 million people, at least 10% of the world's population, have some form of disability.¹

People with disabilities are entitled to the full range of rights available to all human beings. The approval of the *Convention on the Rights of People with Disabilities* (Disability Convention)² by the UN General Assembly* on December 13, 2006, was the latest step towards international recognition of the rights of people with disabilities.

The idea that people with disabilities are entitled to rights began with the UN's International Year of Disabled Persons (1981) and the adoption of *The World Programme of Action concerning Disabled Persons*³. The early 1990s saw further development with the adoption of the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*,⁴ and the *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*.⁵

The UN Commission on Human Rights* first discussed the human rights of persons with disabilities in March/April 1998 and adopted a resolution which recognizes that

¹ United Nations, "Some Facts about People with Disabilities", (UN Web Services Section, Department of Public Information, 2006). Available: <http://www.un.org/disabilities/convention/facts.shtml>. (21 Feb. 2007).

² *Convention on the Rights of Persons with Disabilities*, G.A. Res. A/61/611 (2006).

³ UN General Assembly Resolution 37/52 (37th session, December 1982). The resolution can be found at <http://www.un.org/documents/ga/res/37/a37r052.htm> (21 Feb. 2007). The full text of the *World Programme* is available at <http://www.un.org/esa/socdev/enable/diswpa00.htm> (21 Feb. 2007). The *World Programme of Action* recognized the responsibility within the United Nations system of addressing the human rights of people with disabilities, in the following recommendation:

Organizations and bodies involved in the United Nations system responsible for the preparation and administration of international agreements, covenants and other instruments that might have a direct or indirect impact on persons with disabilities should ensure that such instruments fully take into account the situation of persons who are disabled. (para. 164.)

⁴ UN GA res. 48/96, Annex (48th session, December 1993) [hereinafter *Standard Rules*]. The full text is available at <http://www.un.org/esa/socdev/enable/dissre00.htm> (21 Feb. 2007).

⁵ UN GA res. 46/119 (46th session, December 1991).

inequality and discrimination related to disability are violations of human rights.⁶ This resolution was a major breakthrough. It pointed to governments as responsible for protecting the rights of people with disabilities and to the UN as having a key role to play in promoting change on this issue. The resolution made several important statements and recommendations for future developments in this area. In 2000, the Commission adopted a new resolution which called for stronger measures to strengthen the protection and monitoring of the human rights of persons with disabilities.⁷

Further evidence of the growing attention to disability rights was the Quinn-Degener report that examined the current use and future potential of existing UN human rights treaties* to protect and promote disability rights.⁸ The report assessed the effectiveness of the committees that monitor the major international human rights treaties in protecting and promoting disability rights and the potential for improving them.

In December 2001, the UN General Assembly established an Ad Hoc Committee* to consider the idea of a new international convention* specifically to protect and promote the rights and dignity of people with disabilities.⁹

At a meeting hosted by the UN High Commissioner for Human Rights*, with the participation of Dr. Bengt Lindqvist, UN Special Rapporteur on Disability*, over 30 State representatives and NGO* and UN agency participants agreed on a “twin-track approach” to disability.¹⁰ One track would begin immediately to raise awareness of disability within the existing human rights treaties. A second track would focus on drafting a new international convention specifically recognizing the rights of people with disabilities.¹¹

These important events in the human rights field suggested that it was the right time to strengthen the capacity of people with disabilities to exercise their rights, to bring together the human rights movement and the disability movement and to motivate the UN, as well

⁶ UNCHR res. 1998/31, ESCOR Supp. (No. 3) at 117, U.N. Doc. E/CN.4/1998/31 (1998). Full text of the resolution is available at <http://www.unhchr.ch/Huridocda/Huridoca.nsf/TestFrame/98beedb1e094784780256667002f9596?Opendocument> (21 Feb. 2007).

⁷ UNCHR res. 2000/51, UN Doc. E/CN.4/Res/2000/51 (2000). Full text of resolution 2000/51 is available at [http://www.unhchr.ch/Huridocda/Huridoca.nsf/\(Symbol\)/E.CN.4.RES.2000.51.En?Opendocument](http://www.unhchr.ch/Huridocda/Huridoca.nsf/(Symbol)/E.CN.4.RES.2000.51.En?Opendocument) (21 Feb. 2007).

⁸ G. Quinn and T. Degener, *Human Rights and Disability: The Current Use and Future Potential of the United Nations Human Rights Instruments in the Context of Disability* (Geneva: Office of the High Commissioner for Human Rights, 2002). Available: <http://www.unhchr.ch/disability/study.htm>. (21 Feb. 2007).

⁹ UN GA res. 56/168 (88th session, 19 December 2001). Full text available at <http://www.un.org/esa/socdev/enable/disA56168e1.htm> (21 Feb. 2007).

¹⁰ *Report of the United Nations High Commissioner for Human Rights and Follow-up to the World Conference on Human Rights: Human rights of persons with disabilities* E/CN.4/2002/18/Add.1, 12 February 2002. For the full text see <http://www.un.org/esa/socdev/enable/disecon4200218a1.htm> (21 Feb. 2007).

¹¹ See footnote 10, above.

governments and political parties around the world, to recognize violations of the human rights of people with disabilities and move toward the elimination of disability discrimination.

THE CALL TO ACTION: THE ALMÅSA SEMINAR & DISABILITY RIGHTS MONITORING

In November, 2000, Dr. Bengt Lindqvist, UN Special Rapporteur on Disability, held an international “Seminar on Human Rights and Disability” at the Almåsa Conference Centre in Stockholm, Sweden (Almåsa Seminar). Twenty-seven experts from all regions of the world including disability rights activists, experts on human rights and representatives from all of the major international disability organizations, as well as the Office of the UN High Commissioner for Human Rights and the UN Secretariat* were in attendance.

The Almåsa Seminar focused on the need for human rights monitoring to address the discrimination faced by people with disabilities around the world.¹² Historically, disability has been seen as a medical issue (an individual pathology), focusing attention on the individual and his or her particular “problem” while ignoring human rights violations and the social and legal construction of disability (a social pathology). While human rights abuses against people with disabilities, such as appalling conditions in institutions and policies that called for the sterilization of people with disabilities, have been uncovered through sporadic investigations, seminar participants recognized that to effectively enforce the equal human rights of people with disabilities, a more organized approach to investigations and enforcement is required.

Seminar participants called for the adoption of a disability rights monitoring system focusing on society’s disabling environments and barriers, as well as the capacity of people with disabilities to participate in society, rather than on an individual’s impairment. A human rights approach highlights the potential for social change to support greater inclusion and respect for rights. Increased international awareness and specific international human rights measures have directed attention to the situation of vulnerable groups such as women and children, and a similar approach is needed for disability.

The Almåsa participants agreed that monitoring the human rights of people with disabilities around the world would expose the extent of violations experienced and be an essential first step in creating change. International data would provide invaluable information and momentum for change, providing evidence for the UN and State governments to take action to eliminate abuses of the human rights of people with disabilities. Monitoring would support people with disabilities in achieving justice,

¹² See *Let the World Know: Report of a Seminar on Human Rights and Disability* at <http://www.un.org/esa/socdev/enable/stockholmnov2000.htm> (21 Feb. 2007).

equality, self-determination, dignity and worth in their societies.

The Disability Rights Promotion International (DRPI) project emerged directly from the recommendations of the Almåsa Seminar. The project's goal is to establish a comprehensive and holistic method to monitor the human rights situation of people with disabilities throughout the world.

THE RESPONSE: A HOLISTIC APPROACH TO DISABILITY RIGHTS MONITORING

In its initial work, DRPI recognized the many tasks needing to be accomplished in order to move toward a holistic monitoring of disability rights. It was clear that one questionnaire, or one audit or one data collection method would not be sufficient to build towards a comprehensive understanding of the rights of people with disabilities and the discrimination they face. This meant breaking down the work into “doable” tasks, that would require different skills, different time frames and different knowledge bases. Consequently, the first step was to identify potential collaborators to assist in developing the methodology for this work.

DRPI decided to develop partnerships with people in various fields from a number of countries to see if they would be willing to share their knowledge of human rights monitoring or assist in the development of data collection tools and methods of analysis. These supportive partners include people who have given time and energy because of their belief in the need for real change, as well as individuals, organizations and international bodies with established expertise around particular tasks.

A. Guiding Principles of the Disability Rights Promotion International Project:

Five general principles govern the DRPI Project:

1. Involvement of People with Disabilities and their Organizations

In full support of the disability movement's mantra, “nothing about us, without us,” people with disabilities are involved in all aspects of the operation and implementation of the DRPI project. They are members of the executive, the Advisory Committee, researchers, trainers, and disability rights monitors. DRPI pilot projects are put into action in partnership with, and under the guidance of, one or more organizations of people with disabilities at the international, regional, national and/or local levels.

2. Sustainability and Capacity Building in the Field of Monitoring

To achieve real and lasting change, DRPI recognizes the necessity for disability rights monitoring to be owned by people with disabilities themselves. Eliminating disability discrimination cannot be accomplished in the span of one project. Such a goal requires a lifetime of continually gauging where the situation is in terms of the rights of people with disabilities and ensuring that the situation is improving. It is not a snapshot but an on-going video. The sustainability of disability rights monitoring, in the hands of people with disabilities themselves, is a primary goal of the development of DRPI partnerships, tools and training resources.

To ensure that disability rights monitoring activities take place on a regular basis, an emphasis is placed on developing and distributing tools in all three of the focus areas in accessible, easy to use and freely available formats. There is also an emphasis on working with people with disabilities and disability organizations, to build their capacity to use, and teach others to use, these tools to conduct disability rights monitoring, analyze the data collected and use the data to advocate for positive change.

3. Cross-disability Involvement

Consistent with the need to protect and promote the human rights of *all* people with disabilities, DRPI involves people with all types of disabilities in its project management and implementation, thus ensuring representation of the broad range of disabilities.

4. Integrating Three Broad Areas for Monitoring

DRPI has adopted three broad areas for monitoring based on recommendations by the participants at the Almåsa Seminar: monitoring systems, monitoring individual experiences and monitoring media.¹³ Human rights monitoring has been broken down into these areas to find the discrete pieces of knowledge in order to paint a picture of the current situation faced by individuals with disabilities. Data collected during the monitoring activities in all three areas will be used as evidence for advocacy efforts and improved government policies and laws.

Monitoring systems:

Studying legislative frameworks (laws and policies)

Laws not only protect and promote human rights. They may also violate them either through an unfair clause or by not mentioning disability at all. Reviewing how laws violate or protect disability rights, and comparing them to international standards, clarifies the impact laws have on the rights of their citizens and informs the

¹³ See footnote 12.

struggle for legal and policy change.

Tracking case law before the courts and statutory human rights bodies (legal cases and decisions)

Compiling and analyzing legal cases relating to issues of disability produces evidence of how courts and other decision-making bodies address disability rights issues and interpret and enforce relevant laws. Legal cases and decisions are just as important as the written laws of a country – how a law is interpreted may say much more than the law itself.

Analyzing government programs and practices

Beyond laws and how they are implemented, a broad range of government action has a direct impact on the lives of people with disabilities. Documenting government programs, services and practices that violate human rights – either directly or indirectly – provides evidence and awareness for change.

Monitoring Individual Experiences:

Using personal interviews to find out the actual human rights situation of people with disabilities

Monitoring the exercise of a person's human rights by documenting individual experiences provides knowledge and facts about the reality of discrimination faced by people with disabilities in social, legal and economic situations. Discrimination faced by people with disabilities in both the public and private spheres is monitored to address the complex realities of people with disabilities face and the connections between government and the private sector. Monitoring individual experiences can uncover patterns of discrimination that are evidence of larger systemic rights violations.

Monitoring Media:

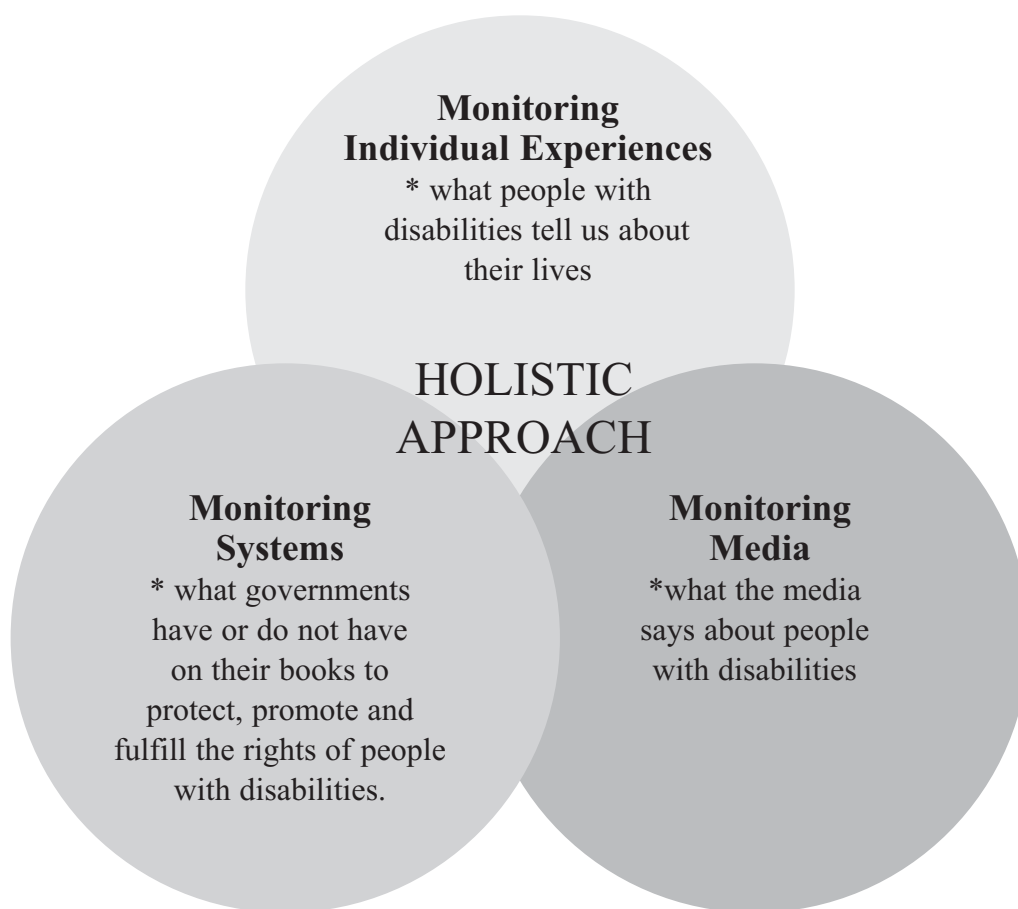
Tracking and assessing media depiction and coverage of disability

The media plays an important role in both reflecting and influencing public opinion. Documenting myths and stereotypes found in media portrayals as well as positive reporting of disability issues provides another way to track the experiences of people with disabilities.

In many cases, human rights monitoring has primarily involved what we call systemic monitoring systems and discrimination, that is, gathering information about laws, policies and programs or carrying out service audits to determine whether they meet national and international human rights standards. By expanding the focus of monitoring to include personal experiences and media coverage and depiction, DRPI's approach is an innovation

in the field of human rights monitoring. The monitoring of all three areas (systems, individual experiences and media) is not only pioneering but also provides a way to get a broader understanding of the extent to which people with disabilities either enjoy, or are denied, their human rights. Individually, each element tells us one piece of the story. Together, the information provides a more complete picture. Laws may say one thing but those laws may not necessarily translate into better lives for people with disabilities. Often the media characterizes disability in a way that contradicts people's real lives and the value of those lives. It is important to look at all three areas together to understand what is really happening. By developing tools and methods for each of the three monitoring areas, DRPI is ensuring that a holistic view of the human rights situation of people with disabilities is presented and addressed.

Figure 1. Holistic Approach to Disability Rights Monitoring



5. Engagement with Multi-Sectoral Organizations

The three monitoring areas point to the multi-dimensional nature of a global disability rights monitoring project and the need to establish and promote communication networks with a broad range of partners, not only geographically but also in other relevant sectors,

including universities, research organizations, the community and government. DRPI also recognizes the importance of developing relationships with organizations currently working in the field of disability rights monitoring as part of their regular activities and connecting people with disabilities interested in engaging in disability rights monitoring with existing resources and expertise within disability and other human rights organizations.

B. Benefits of Establishing Systems to Monitor Disability Rights

The main purpose of disability rights monitoring is to gather and analyze reliable data to influence positive change in the lives of people with disabilities. International human rights standards are the criteria by which social and legal conditions and individual circumstances are evaluated. Effective monitoring of disability rights at the level of systems, individual experiences and media exposes the full extent of discrimination faced by people with disabilities. It also provides the documentation needed to:

- support disability advocates in communicating disability rights issues and calling for change,
- provide evidence on which governments can implement changes to meet their obligations, and
- ensure the inclusion of people with disabilities in society and draw the recognition of courts, legal human rights bodies, and the media to the abuse of rights.

C. DRPI Phase One – Conducting Background Research

DRPI's Co-Directors are Drs. Bengt Lindqvist and Marcia Rioux.¹⁴ The project has a small coordination centre located at York University in Toronto, Canada.

The DRPI project involves three phases.

Phase One began in May 2002 and received funding from the Swedish International Development Agency (SIDA). This phase focused on initial background research to assess the opportunities for disability rights promotion in international and regional human rights systems. Phase One investigated:

- the opportunities for using international human rights instruments to promote and enforce disability rights;
- the types of tools used in projects that monitor human rights; and
- the available training resources for human rights monitors and for more general human rights education.

¹⁴ See Appendix B for a list of DRPI project personnel.

Since the study of international disability rights is new, most of the research produced for the Phase One report involved a review of material relating to human rights more generally and other areas concerned with the equal application of human rights, such as women's rights. These materials were then analyzed within the disability context.

To supplement desk-based research, leading international human rights monitoring and human rights education organizations were contacted. These organizations provided information on the range and content of training resources related to human rights monitoring; the tools used in monitoring human rights violations; whether or not their organizations had participated in any disability related cases before international or regional human rights treaty monitoring bodies* or agencies; and details of other aspects of their work relevant to the DRPI project.

The Phase One research highlighted many opportunities for disability rights advocacy in the state reporting* and individual complaint procedures* of the international human rights system. It also identified existing expertise, models, and methodologies related to human rights monitoring. As well, the need for increased disability rights monitoring activities and for disability-specific monitoring and training resources was confirmed. The *DRPI Phase I Report: Opportunities, Methodologies, and Training Resources for Disability Rights Monitoring*, is available on the project website at www.yorku.ca/drpi.

D. DRPI Phase Two – Making Disability Rights Monitoring a Reality

Building on the background research conducted in Phase One and working with existing disability rights organizations and other organizations active in human rights protection, DRPI entered its 'pilot stage' in 2004. Phase Two involves the development and field testing of a comprehensive set of tools and mechanisms that can be used by people with disabilities and their organizations around the world to monitor disability rights in all three focus areas (systems, individual experiences and media).

Working in close partnership with international and local organizations of people with disabilities and human rights advocates, DRPI is now involved in disability rights monitoring on five continents. People with disabilities and disability organizations are actively involved in this pilot phase. They are gathering and analyzing monitoring data and using this data to engage with human rights systems at the local, national, regional and international levels. The following sections review DRPI's progress in the development of disability rights monitoring tools and methods in its three monitoring focus areas.

CHAPTER 2

Monitoring Systems

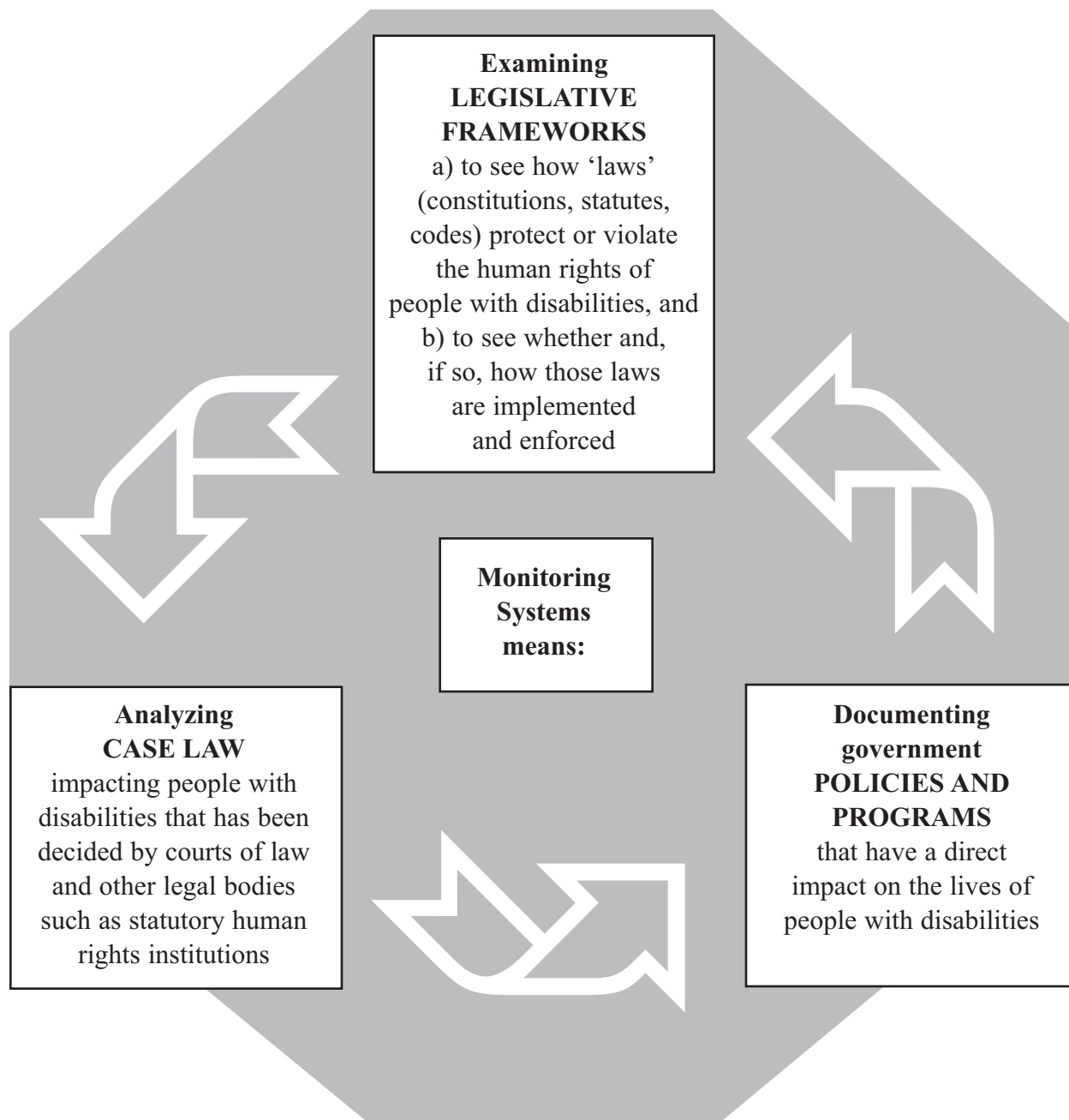
Systemic disability rights monitoring involves reviewing the effectiveness of legislative frameworks, case law, policies and programs in protecting and supporting the rights of people with disabilities

While laws, policies and programs may protect human rights, they may also violate human rights. They may do this either through a discriminatory clause or through their silence on an issue important to the rights of people with disabilities. Documenting the way laws, policies and programs violate or protect disability rights and how relevant laws, policies and programs are implemented, enforced and regulated, will suggest ways to work towards legislative and government reform.

In the area of case of law, collecting and studying cases involving disability issues provides evidence of the way courts and other decision-making bodies, including human rights commissions, deal with issues related to disability rights, understand and enforce relevant laws, and use human rights law. Beyond laws and their enforcement, government action has an impact on the daily lives of people with disabilities. Documenting programs, services and practices that violate human rights – either directly or indirectly – provides knowledge for positive change (see Figure 2).

In many countries, efforts have been made to document systemic disability rights protections. DRPI does not want to repeat this work. Instead, where possible, DRPI is seeking to build on existing data. In many cases, however, previous studies have either been sector-specific or service audits. They have, for example, focused only on particular sectors like education or employment rather than recognizing that it is a web of factors that provides the full picture of the lives of people with disabilities. These studies have also been conducted predominantly in “developed” rather than “developing” countries. DRPI has identified these gaps and is committed to filling them by designing tools that gather comprehensive information from countries in all stages of economic development.

The information collected through systemic disability rights monitoring will contribute to DRPI reports about the overall disability rights situation in various countries. That is, the systemic monitoring data will be added to the data collected through monitoring individual experiences and media in a given country to form a comprehensive view of that country’s disability rights situation in a Country Report. These Reports will ultimately be made widely available through a freely-accessible interactive online database.

Figure 2. Monitoring “Systems”

DRPI has developed a number of ways to collect and encourage ongoing collection of systemic disability rights information about countries around the world – that is, information on national legislation, case law and policies and programs that impact the rights of people with disabilities.

LEGAL EDUCATION AND RESEARCH PROJECT

One approach has been to encourage law students to research issues about human rights and disability in their courses. Through partnerships with law schools around the world, DRPI is establishing a global network of students working in the area of disability and human rights. This is fostering an ongoing interest in the area of disability rights research.

DRPI has prepared a bibliography of disability rights resources which is distributed to all participating students, as well as an online message forum (web forum). Students are encouraged to collaborate with their peers from other universities (by posing questions and exchanging resources and ideas) via the web forum. In each of 2004, 2005 and 2006 a videoconference was held in which students from various countries discussed research methodologies and outcomes. In the coming year, DRPI is planning to use voice and video over internet technology to enable more frequent real-time communication.

Beginning in 2003, with participation by students from two universities, the legal education and research project has now expanded to include students from six universities with another three institutions ready to join in 2007.

Current Participating Institutions:

- La Trobe University (Bundoora, Australia)
- Syracuse University (Syracuse, U.S.A.)
- University of Greenwich (London, England)
- University of Leeds (Leeds, England)
- University of Nairobi (Nairobi, Kenya)
- York University – Osgoode Hall Law School (Toronto, Canada)

New Institutions Joining in 2007:

- Nalsar University of Law (Hyderabad, India)
- Raoul Wallenberg Institute (Lund, Sweden)
- University of Costa Rica (San José, Costa Rica)

To date, students have written papers on a number of different topics. For instance, some compare the disability rights legislative frameworks and case law of different countries, others focus on one country and the legal issues arising in a specific sector, for example education, health care, prisons and employment. Still others examine legislative frameworks as they relate to different types of disability. A sample of the topics that have been addressed by students is found in Appendix A.

With student consent, these papers will soon be posted on the DRPI website. The information collected also contributes to the systemic disability rights monitoring data included in DRPI's Country Reports.

To expand this collaborative effort involving legal education and research, DRPI is establishing a virtual knowledge network to link law instructors involved in teaching and research on human rights and disability. Communication technology will be used to bring together professors from around the world to discuss new issues in disability rights law and policy and strategies to increase and improve teaching in this area. (Further information about the development of virtual knowledge networks is found in Chapter 6).

A list of faculty and students participating in the legal education and research project is found in Appendix A.

FIELD ASSISTANTS

Systemic data on disability rights is also being collected within each of the countries where a pilot project to monitor individual experiences of people with disabilities is taking place. In each of the pilots, information about disability rights legislative frameworks, case law, policies and programs in the host country is collected by local university students who are called Field Assistants.

The information collected by Field Assistants is added to that collected in other areas of systemic monitoring (case law and legislative frameworks data and statutory human rights data) and combined with data collected in monitoring individual experiences and media portrayals to create a complete report on the country's disability rights situation.

TOOL TO COLLECT LEGISLATION, POLICY AND PROGRAM INFORMATION

DRPI has developed a template to help with the collection of legislation, policy and program data specific to disability rights in any particular country. The template is designed to gather data addressing all categories of rights (civil, cultural, economic, political and social). As well as assisting with the collection of data, the template serves as an assessment tool, allowing the identification of gaps in legislation and policy. The template includes cross-references to the relevant provisions of key international human rights treaties, including the new Disability Convention. The template was pre-tested in Portugal¹⁵ and later by Field Assistants conducting systemic research during the pilot projects for monitoring individual experiences.

¹⁵ Paula Pinto, 'At Crossroads': Disability Policy and Human Rights in Portugal and the EU. Presented at the 2006 Canadian Congress of the Humanities and Social Sciences.

MONITORING THE WORK OF NATIONAL HUMAN RIGHTS INSTITUTIONS

DRPI approached the Asia Pacific Forum of National Human Rights Institutions (APF)¹⁶ to collaborate on the development of a tool to track disability cases decided by national human rights institutions (NHRIs). At its Annual Meeting in 2005, the APF agreed to work in partnership with DRPI, to develop and field test this tracking tool. The tool will be pilot tested by APF member institutions as well as other national human rights institutions in Europe, North America and Africa and then will be made available to national human rights institutions in other countries.

In addition to collecting data, by working with and through national human rights institutions themselves, this initiative will bring to light disability rights issues that have often been hidden and increase the likelihood that disability rights data collection will continue in the future.

In light of the requirement in Article 33 of the new Disability Convention that States parties establish “one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation”, it is possible that, in many countries, national human rights institutions may be called upon to take an active role in monitoring disability rights. The tool developed by DRPI and APF will prove to be very useful in this process.

STRATEGIC DISABILITY RIGHTS LITIGATION

DRPI continues to work with the London-based NGO, Interights, to find a strategic disability rights legal case in an important area of disability rights law. While most court cases provide justice or relief for one individual, a strategic litigation case aims to have a broader impact and advance the status of international human rights law as a whole. The strategic disability rights legal case will be significant for the lives of people with disabilities living in many countries around the world.

The first phase of the collaboration with Interights involved the development of a strategic approach to advancing the rights of people with disabilities in court and the background preparation of several possible test cases on disability discrimination. Interights supervised preliminary research in this area. This work was conducted by an intern from the Australian disability community. Interights submitted a report outlining a disability litigation strategy, including an overview of existing international disability rights instruments and mechanisms. The report also identifies a number of priority issues for legal action. Finally, Interights outlined the challenges it foresees when pursuing legal action for disability rights.

¹⁶ The APF is a body comprised of 15 independent national human rights institutions in the Asia Pacific region.

A second report outlining possible test cases on disability discrimination is expected from Interights in the near future. Upon receipt of this report, one case will be selected and steps will be taken to begin proceedings in the appropriate court or tribunal.

DRPI has partnered with Interights because of its well-known expertise in advising on and engaging in legal action involving general human rights issues in various jurisdictions around the world. Prior to its partnership with DRPI, Interights had not engaged in any work regarding the rights of people with disabilities in particular. Since having made contact with DRPI, Interights' Equality Programme has taken a strategic interest in disability rights-related work. DRPI hopes that Interights will continue to work in this area, thus promoting disability rights as a central issue and increasing the possibility that the legal protection and promotion of the rights of people with disabilities will continue to be advanced through the work of similar NGOs in the future.

DRPI is well on its way to developing tools for the comprehensive collection of information about disability rights legislation, case law, policies and programs around the world. By collaborating with partner organizations that are already engaged in similar work and cultivating interest in disability rights issues on the part of academic researchers, DRPI seeks to build upon existing expertise and encourage ongoing interest in disability rights monitoring beyond the duration of the project.

CHAPTER 3

Monitoring Individual Experiences

While it is important to ensure that governments protect, promote and fulfill the human rights of people with disabilities, DRPI recognized at the outset that it is also necessary to assess whether these systemic measures are creating actual improvements in the lives of people with disabilities. Built into the DRPI project is the understanding that monitoring of disability rights obligations should also include a way to assess the actual situation of people with disabilities in a given country or area.

DRPI calls this activity “monitoring individual experiences” and considers it an important part of a “holistic approach” to disability rights monitoring. A holistic approach is necessary to gain complete understanding of the human rights situation faced by people with disabilities. Collecting and analyzing the personal experiences of individuals with disabilities provides us with a way to know if the laws, policies and programs put in place by a country to promote, protect and fulfill rights have any real impact, whether positive or negative, on the actual lives of people with disabilities. It also allows us to examine the personal impact of the myths and stereotypes regarding disability that have been introduced, perpetuated and/or discredited by the media.

Monitoring individual experiences involves the collection of qualitative data through face-to-face interviews. People with disabilities are asked to tell their own story and identify the rights issues that are most important to them. Once collected, the individual stories are considered in light of the larger context (laws, policies, media portrayals) in which the individual with a disability (interviewee) lives.

The interviews are conducted by pairs of monitors who are people with disabilities themselves. The information provided by the interviewees is collected, transcribed, coded, analyzed and presented in a final report that is made widely available. National organizations of people with disabilities oversee the administration of these monitoring projects. Partnerships are fostered with academics from local universities and/or staff of national human rights institutions who can provide assistance with the coding and analysis of the individual monitoring interview data.

GETTING STARTED

A. Choice of Countries:

DRPI conducted research to identify appropriate countries to pilot the methodology and tools for monitoring the individual human rights experiences of people with disabilities and to build capacity to engage in this work in the future.

In order to ensure the use of DRPI's monitoring methods and tools after the life of the project, it was decided that at least half of the pilot sites would be in countries with "developing" or transitional economies. In addition to such considerations, a set of criteria was developed and given priority as follows:

A suitable country would:

1. Have a large number of people with different types of disabilities. (priority: necessary);
2. Have one or more organizations of people with disabilities that could oversee the project and bring it to completion. The disability organization(s) should be interested in engaging in human rights work and be willing to commit to continued engagement with disability rights monitoring past the life of the project. (priority: necessary);
3. Be politically stable with laws, policies and programs that recognize and protect human rights. (priority: necessary);
4. Have a constitutional and judicial framework capable of credible administration of justice (priority: necessary);
5. Be party to major international human rights treaties, and relevant customary international law* (priority: necessary);
6. Have English, Spanish, French or Swedish as a language that is commonly known by people with disabilities as these are the languages spoken by the DRPI Co-Directors and staff. (priority: desirable – but not necessary provided that 4 or 5 principal local contacts for the project e.g. disability organization representatives, Project Coordinator, Lead Researcher speak one of these languages); and
7. Be a country in which DRPI Co-Directors and Advisory Board have pre-existing strong relationships with members of the disability community. (priority: desirable but not necessary – where all of the other criteria have been met, it is possible to develop these relationships during the life of the project).

The countries selected thus far are:

developing / transitional countries:

Cameroon
Croatia
India
Kenya

developed countries:

Australia
Canada
Sweden

DRPI anticipates identifying two additional countries – suitable for pilot projects before the end of 2007 – one in Latin or South America and a second in the Middle East.

B. Partners, Management Committee and Personnel

Each pilot for monitoring individual experiences has been organized by the national and local organizations of people with disabilities involved in the project, with the technical support and assistance of DRPI. No two projects have been organized and carried out in exactly the same manner, as each takes on the characteristics of their own area.

The following are the types of organizations and personnel who have been involved in most of the pilot projects:

(i) Partner Organizations:

1. **Either one national organization of people with disabilities with a cross-disability membership and mandate (NDPO) or, two to three national organizations of people with disabilities with disability-specific memberships and mandates that are willing to work together as a coalition (NDPO Coalition).** Responsibilities of the NDPO or NDPO Coalition include: assisting with the establishment of the project Management Committee; nominating one or more representatives to the Management Committee; where possible, providing office space and infrastructure support to the project; generally overseeing the project and project staff (e.g. Project Coordinator, Lead Researcher), assisting with recruitment of monitors, field assistants and interviewees and assisting with the coordination and support of monitoring activities in that site; and committing to continue to engage in disability rights work in the future.
2. **Local organizations of people with disabilities with cross-disability membership and mandate [LDPOs]** located in each of the pilot's monitoring sites except the site where the NDPO or NDPO Coalition is based. Responsibilities of the LDPOs include: assisting with recruitment of monitors, field assistants and interviewees in their local monitoring site and assisting with the coordination and support of monitoring activities in that site.

3. **One or more national universities.** Responsibilities include: nominating a representative to the Management Committee; providing office space and infrastructure support for the Lead Researcher; providing access to library resources for systemic monitoring research, presenting at the training course regarding the local disability rights situation; providing credit or some recognition for student involvement in the project.
4. **Disability Rights Promotion International (DRPI):** offers technical knowledge and support regarding the organization and coordination of the project; provides the disability rights monitoring tool and the methodology for data collection and analysis; facilitates the training course for monitors and field assistants; supports the organization of the field work, the coding and analysis of data and drafting the report of the results.
5. **Additional partners** have included: international and/or domestic funding agencies, disability-specific and other social justice organizations and human rights institutions, where applicable.

(ii) Management Committee

Most of the key decisions that shape the nature and form of the individual pilot project are made by a local Management Committee. (See: Planning Decisions below). The Management Committee includes the following members:

- 1 representative from NDPO or each NDPO in NDPO Coalition
- 1 representative from University
- Project Coordinator (after he or she is hired)
- Lead Researcher (after he or she is hired)
- Additional members may be added to the Management Committee, with the agreement of the above members.

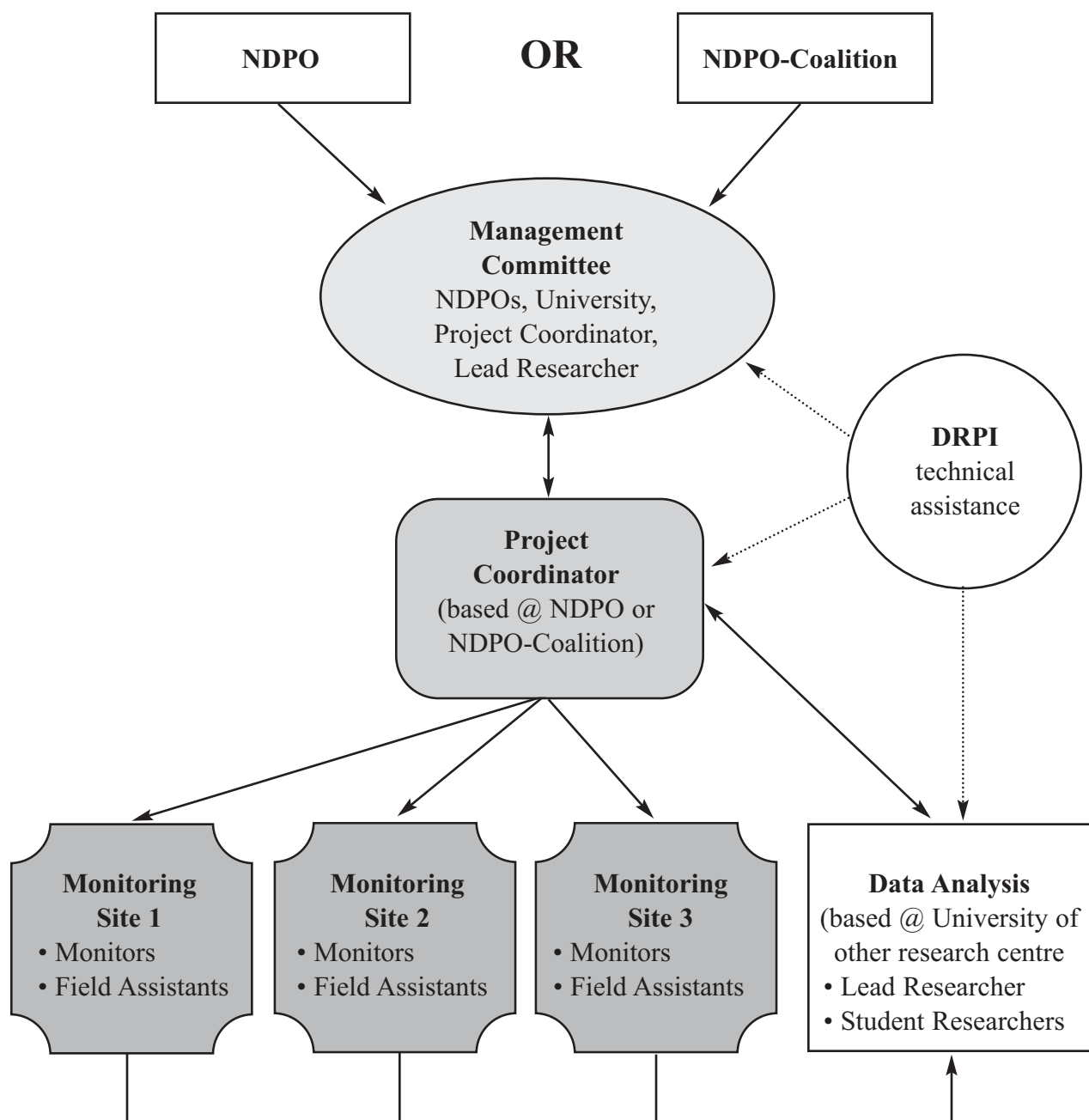
Also, the Management Committee may choose to establish a reference group of any size and composition that it considers appropriate.

(iii) Project Coordinator

Under the direction and with the assistance of the Management Committee and the support of DRPI, the Project Coordinator is responsible for the day-to-day coordination of the project, including administration of the budget; recruiting monitors and field assistants; organizing the logistics of the training course; attending and assisting to facilitate the training course; coordinating, supervising and supporting monitoring in the field; establishing and maintaining systems to safeguard the confidentiality of data collected;

overseeing data analysis, report writing and publication; coordinating dissemination activities; and drafting reports to funder(s), as required.

Figure 3. Project Partners, Management Committee & Personnel



(iv) Lead Researcher

Under the direction and with the assistance of the Management Committee and the support of DRPI, the Lead Researcher is responsible for conducting the qualitative and quantitative analysis of the data collected and writing a report on the results of this research. As part of his or her duties, the Lead Researcher sits on the project Management Committee, coordinates the work of field assistants engaged in systemic research; organizes and supervises the translation (if necessary) and transcription of interview recordings; establishes and maintains systems to safeguard the confidentiality of paper, cassette and electronic interview records; codes the monitoring data and generates reports; and participates in a review of the research report by a consultative group.

FIELD ACTIVITIES

Project activities (and the rough timeframes) are as follows:

- A. Make Preliminary Planning Decisions (2 to 3 months)
- B. Train Monitors and Others to Find Out the Experiences in the Field (7 days)
- C. Find Out the Experiences – Conduct Interviews in the Field (2 to 3 weeks)
- D. Analyze the Experiences and Write Report with Consultations (10 weeks)
- E. Disseminate Results (throughout the project)

A. Make Preliminary Planning Decisions

While the scope of the project implemented in each country varies depending on available resources, the Management Committee is responsible for making a number of planning decisions at the outset. The following are some of the key decisions made:

(i) Hire the Project Coordinator & Lead Researcher

Early on in the planning, the Management Committee hires the Project Coordinator and Lead Researcher who then sit on the Management Committee.

(ii) Determine Number and Location of Monitoring Sites and Collect Background Information:

Number: The number of monitoring sites in the study country is decided, in part based on the available resources. Since these are pilot projects, it is not possible to conduct monitoring in all regions. To date, all of the pilots have had three (3) monitoring sites.

Location: In each case, one of the monitoring sites is located where the NDPO or NDPO Coalition has its headquarters. The remaining two sites are decided by the management committee who has taken in to account such factors as:

- urban/rural
- types of disability
- languages spoken
- ethnic groups
- socio-economic groups
- existence of strong local disability persons organizations
- ease of transport
- cost of transport and accommodation

Background Data: Once the monitoring sites are selected, the Management Committee arranges for the collection of data to inform the writing of a background report (approximately 500 words) setting out the following information with respect to each site:

- land mass
- major religions
- languages spoken
- major cities – name, population
- major cultural and/or ethnic groups
- standard of living, poverty and unemployment
- major economic activities
- prevalence of different types of disabilities
- type of terrain – e.g. mountains, plains, etc.
- description of the “disability community” i.e. degree to which people with disabilities have organized to form “organizations of people with disabilities”
- population

(iii) Enter Relationships with Local Organizations of People with Disabilities (LDPOs)

Once the monitoring sites are identified within the country, relationships are developed with local organizations of people with disabilities (LDPOs).

(iv) Draft Project Budget

The Management Committee develops a budget based on the total available funding. Drafting the budget is an ongoing activity during the planning period. It is important in each project that there is full participation of people with different types of disabilities, thus provisions for adaptations to training and interview materials, attendants, communication and mobility aides must be incorporated in the budget.

(v) Determine Who Will be Interviewed

The number of people interviewed at each site is determined by the resources available and practical issues such as geographic accessibility and time constraints. A

snowball sampling technique has been used, balancing for gender, age (+18), type of disability, socio-economic status and membership in disability organizations.¹⁷

(vi) Determine Number of Monitors per Site and Select Monitors

Monitors attend the training course, conduct interviews and attend project-related meetings.

Number: Monitors work in pairs allowing for mutual support. They take turns asking questions and verifying that all of the relevant information has been collected.

Criteria for Monitors: All Monitors are people with disabilities. The monitors live or have lived for a significant period of time in the monitoring site in which they are working so they are familiar with local languages, customs and transportation systems. On the whole, the pool of monitors is balanced on the basis of gender, age, ethnicity and type of disability.

(vii) Determine Others who will Work in the Field

In addition to Monitors, pilot projects involve Field Assistants and sometimes Aides when the project management committee decides that is the best way to proceed. The roles are varied and flexible.

Field Assistants: Field Assistants spend half of their time providing support and assistance as requested by the Monitors during interviews. Some of the ways they assist and provide support include: mobility support, assistance with travel arrangements and communications, note-taking, operating audio recorders, ensuring that no one interrupts the interview. Field Assistants devote the rest of their time to researching the systemic framework for disability law and policy in the pilot country. Given their research role, Field Assistants are, in many cases, university students, studying law, social policy or a similar discipline. They may or may not have a disability themselves but have a commitment to human rights and furthering the protection and promotion of the rights of people with disabilities. On the whole, the pool of Field Assistants is balanced on the basis of gender, age and ethnicity.

Aides: In addition to Field Assistants, Management Committees also employ Aides to assist during the Field Work. Aides provide additional assistance to Monitors as requested. Generally, they have acted as guides and provided mobility assistance.

¹⁷ Membership in disability organizations is used as a way to roughly indicate the degree of politicization of the people involved in the study. While it is understood that there is a wide spectrum of actual involvement among members, it is used as a less than perfect indicator of political activity. Given that past surveys of people with disabilities in the study countries would have focused on those with membership in organizations, it is hoped that including non-members in the sample will lead to the participation of people with possibly different information and experiences.

Sign Language Interpreters: Every deaf Monitor who uses sign language to communicate has sign language interpreters working with him or her in the field. In addition, sign language interpreters are used where those being interviewed require their services.

(viii) Obtain Government Approval for Field Work

In some pilot countries where official approval is required to conduct field work government authorities have been informed by the Management Team that monitoring will take place. While government approval is needed to proceed, it is emphasized to those being interviewed that the monitoring exercises are being conducted independent of governments. While governments are provided with study results, the information given by interviewees is kept private and confidential.

(ix) Plan Training Course(s) for Monitors and Others Working in the Field

Number of Courses: In the pilots thus far, all Monitors, Field Assistants and others involved have been trained during an intensive seven-day training course.

It would be possible to provide the same training using a country train-the-trainer model, having a centralized training course with representatives from each of the monitoring sites, followed by local training courses at each site in which the site representatives would teach the local Monitors what they had learned. This second approach may lead to the training of more Monitors in each monitoring country and lead to greater sustainability of monitoring activities into the future.

General Course Organization: The Management Committee is responsible for the organization of the course logistics such as: dates, venue (for sessions plus room and board for participants), translation (where necessary), transportation, opening and closing ceremonies, participation certificates and attendees in addition to Monitors, Field Assistants, Project Coordinator and Lead Researcher.

Cultural Considerations: The training materials and course agenda are reviewed to identify any cultural considerations that will affect the manner in which the subject matter is addressed. Attention is also paid to preferred learning styles in each country, for example, role plays, debates, singing, etc.

Disability-Specific Considerations: The course venue is fully accessible to all participants. In addition, all necessary adaptations are made to training materials, teaching techniques and learning styles to ensure full participation by all.

(x) Adapting Monitoring Tool (Interview Guide) and Methodology

Monitoring Tool: In addition to the training materials, the Interview Guide used by Monitors to conduct interviews in the field is also adapted to suit local culture. These adaptations occur in a number of places in the training guide but have been particularly important in the demographics section of the tool where interviewees are asked certain questions in an effort to determine, among other things, their socio-economic status and level of education.

Monitoring Methodology: Consideration is also given to cultural issues that might affect the way interviews are scheduled and take place. As part of the training, there is careful discussion of issues, such as whether it is acceptable for a pair of male Monitors to interview a woman or whether it is appropriate for a Monitor to be, for example significantly younger than the person being interviewed. Strategies are then developed to anticipate and address these concerns in the field.

B. Train Monitors and Others to Find Out the Experiences in the Field

DRPI has developed and field tested several variations of the training materials and monitoring tool used during interviews to document the individual human rights experiences of people with disabilities. As might be expected, after each pilot, variations are made to take into account the feedback from the field. DRPI is working to create materials that are straight-forward and easy to use. At the conclusion of Phase Two, the monitoring tools and training materials will be published in multiple formats and be available on the DRPI website to be used by disability and other human rights organizations to monitor disability rights in the future.

(i) Interview Guide

An *Interview Guide* has been developed for use by pairs of Monitors when interviewing individuals with disabilities. It includes both open-ended and semi-structured questions and is designed to gather information with respect to all categories of rights (civil, political, social, economic and cultural) and in relation to various general human rights principles (dignity, autonomy, non-discrimination, inclusion, respect for difference and equality). People with disabilities are asked to tell their own story and to identify the rights issues that are most important to them.

The Interview Guide was pre-tested in December 2005 and January 2006 in Canada, by a group of people with disabilities living in and around the city of Toronto and associated with three disability organizations: the Centre for Independent Living in Toronto (CILT), the National Educational Association of Disabled Students (NEADS) and the Alliance for Equality of Blind Canadians (AEBC). To date, it has been used in Kenya in

April and May, 2006 and in Cameroon in October and November, 2006. It will be used in Andhra Pradesh, India and Croatia in the spring of 2007 and in Canada in early fall of 2007.

(ii) Disability Rights Monitoring Training Course

In addition, DRPI has developed, field tested and revised accessible, clear language curriculum for a Training Course to prepare Monitors and Field Assistants to engage in monitoring the individual experiences of people with disabilities in the field. During this seven-day course, participants are:

- introduced to the human rights approach to disability in cooperation with people from the local region;
- provided with technical instruction on the knowledge and skills needed to conduct interviews with people with disabilities in the field using the Interview Guide – including, for example, the importance of obtaining the free and informed consent of the interviewee, protecting the confidentiality of the information received, how to elicit detailed information, etc.; and
- encouraged to network and build solidarity both to facilitate working relationships in the field and to develop the basis for future monitoring collaborations between participating groups and individuals.

During the training courses, monitoring teams are provided with opportunities to practice their interviewing skills both through role-playing and conducting actual interviews

(iii) Training Manual for Monitoring Individual Experiences

Participants at the training course are each given a copy of DRPI's *Training Manual for Monitoring Individual Experiences* which provides accessible clear language information about disability rights generally, monitoring techniques, confidentiality in monitoring and how to work in the field. The Training Manual documents the information covered during the training course and provides a reference guide for Monitors once in the field and for others who attend the course.

(iv) Trainers' Manual

With a view to building the capacity of disability organizations and the sustainability of efforts to monitor individual experiences, DRPI has developed a Trainers' Manual that can be used by disability organizations to train others how to monitor in the future. In addition to all of the material contained in the participant manual, the Trainers' Manual includes visual aides to accompany the manual's text, teaching tips regarding ways to introduce and teach certain difficult topics; suggested activities (role plays, debates, discussion groups, etc.) to introduce and/or emphasize various concepts; and checklists summarizing key issues that the training is trying to achieve. This manual is based on past

group experiences. Consistent with a train-the-trainer approach, the Trainers' Manual is designed to be used by people who have been involved in monitoring individual experiences previously to train others to do so in the future.

C. Finding Out the Experiences – Conduct Interviews in the Field

As soon as possible following the training course and before heading into the field, the Monitors and Field Assistants meet with the Project Coordinator to review procedures, ensure clear lines of communication and address any questions. Following this meeting, the monitoring teams begin conducting interviews. In most of the pilots, the collection of data has begun in the monitoring site where the National Disabled Persons Organizations or Disabled Persons Organizations Coalition was located and then subsequently rolled-out to the other sites. Interviewees are identified using a snowball sampling technique.¹⁸

Monitors and Field Assistants are asked to sign agreements in which they commit to conducting the interviews for a set period of time. Each interview takes approximately two hours to complete. Monitoring teams conduct no more than two interviews per day. Mid-way through the field work in each site, the Monitors and Field Assistants have a one-day meeting with the Project Coordinator to ensure that the field work is on track. Upon completion of interviews at all of the sites, a meeting is held with all Monitors and Field Assistants, at a central location, for the purpose of debriefing. In the pilots to date, the field work has been completed within 17 to 21 days.

D. Analyze the Experiences and Write Report with Consultations

As soon as possible after each interview, the Monitors transfer the relevant cassette recording and written notes to the Project Coordinator who gives them to the Lead Researcher. Strict confidentiality protocols are in place so that only the Project Coordinator can identify those interviewed. The Lead Researcher also maintains the confidentiality of the cassette tapes and other interview records according to an established protocol.

The Lead Researcher is responsible for overseeing the translation into a common language and transcription (into electronic format) of the interview tapes. He or she also conducts the data analysis. NVivo computer software is used to support qualitative data analysis. Transcribed interviews are imported into this program and coded using a coding scheme developed during the initial pilot projects¹⁹. Once coded, data is analyzed with a view to examine interviewees' experiences of systemic barriers and discrimination as well as access to human rights. Whenever possible, intersections between gender, type of disability and other socio-economic variables and the respondents' experiences are also explored. DRPI

¹⁸ This is a common sampling technique for studies like this where a random sample is not possible to create given the absence of complete lists of people with disabilities in any given area.

¹⁹ The coding scheme continues to be updated and improved with each new pilot

provides technical assistance throughout this process, offering requested support and feedback particularly with the tasks of interview coding, data analyses and reporting.

A report covering systemic issues as well as individual experiences is drafted by the Lead Researcher and the Project Coordinator as well as others involved in the project. The draft report is circulated among participating partner organizations for their feedback and comments. Added to the interview results are sections of the report outlining: background information on the monitoring sites (collected by the Management Committee during the planning stage); the systemic framework for disability laws and policy in the country (prepared by the Field Assistants), and a history of the disability movement in the pilot country (prepared by a partner NDPO or LDPO). Following extensive consultations and discussions, the report is finalized and disseminated.

E. Disseminate Results

The Management Committee, together with partner organizations of people with disabilities are responsible for developing a strategy to ensure that the information collected about the human rights situation of people with disabilities reaches a wide audience including: the media, government, other civil society groups, society at large and the international community.

DETAILS OF PILOT PROJECTS

The following provides a picture of each pilot's status:

A. DRPI – Kenya

(interviews completed/recommendations for action being prepared)

Partners

- African Union of the Blind (AFUB)
- Kenya Union of the Blind (KUB)
- Kenyan Centre for Disability Rights Education and Advocacy (CREAD)
- University of Nairobi, Faculty of Law
- Moi University, Faculty of Law
- Swedish Association of the Visually Impaired (SRF)
- Swedish International Development Cooperation Agency (SIDA)

Monitoring Sites

- Nairobi (urban), Rift Valley (urban/rural) and Nyanza (urban/rural)

B. DRPI – Cameroon

(data collection completed/data being analyzed)

Partners	<ul style="list-style-type: none"> • African Union of the Blind (AFUB) • Cameroon National Association of the Blind • Cameroon National Association of Disabled Women • Cameroon National Association of the Deaf • Cameroon National Association of Lepers • Cameroon National Association of the Physically Disabled • Cameroon National Commission on Human Rights and Freedoms (NCHRF) • Swedish Association of the Visually Impaired (SRF) • Swedish International Development Cooperation Agency (SIDA)
Monitoring Sites	<ul style="list-style-type: none"> • Menoua Division (rural), Bamenda (urban) and Yaoundé (urban)

In its work in Kenya and Cameroon, DRPI joined efforts with the Swedish Association of the Visually Impaired (SRF) and African Union of the Blind (AFUB)'s Disability and Human Rights Project in Africa. This partnership has permitted DRPI to facilitate individual monitoring pilot projects in two African countries.

C. DRPI – India

(preparations for field work in progress – training planned for Spring, 2007)

Partners	<ul style="list-style-type: none"> • Swadhikaar Center for Disabilities Information, Research & Resource Development • Asmita Resource Centre for Women • NALSAR School of Law • National Institute for Mental Handicap • Swedish International Development Cooperation Agency (SIDA)
Monitoring Sites	<ul style="list-style-type: none"> • 3 monitoring sites – all located in Andhra Pradesh State

D. DRPI – Croatia

(preparations for field work in progress – training planned for April, 2007)

Partners	<ul style="list-style-type: none"> • Croatian Association of the Blind (CAB) • Croatian Union of Associations of Persons with Disabilities (SOIH) • Croatian Union of Physically Disabled Persons Association (CUPDPA) • University of Zagreb • Swedish International Development Cooperation Agency (SIDA)
Monitoring Sites	<ul style="list-style-type: none"> • 3 monitoring sites – located throughout the country

E. DRPI – Sweden

(preparations for field work in progress – training planned for spring 2007)

- | | |
|------------------|--|
| Partner | • Swedish Disability Federation (HSO) |
| Monitoring Sites | • the number and location of monitoring sites are not yet determined |

This pilot study is part of a larger human rights project run by the Swedish Disability Federation (HSO).

F. DRPI – Canada

(preparations for field work in progress – training to begin September, 2007)

- | | |
|------------------|---|
| Partners | <ul style="list-style-type: none"> • Amnesty International Canada • Canadian Association of Independent Living Centres (CAILC) • Canadian Social Sciences and Humanities Research Council (SSHRC) • Centre for Independent Living – Toronto (CILT) • Centre for Interdisciplinary Research in Rehabilitation & Social Integration (CIRRIS), University of Laval • Council of Canadians with Disabilities (CCD) • DisAbleD Women's Network – Ontario (DAWN-Ontario) • Equitas • York University • University of Victoria |
| Monitoring Sites | • Winnipeg, Manitoba; Toronto, Ontario; Québec City, Quebec and St. John's, Newfoundland |

G. DRPI – Australia

(preliminary planning taking place)

- | | |
|----------|--|
| Partners | <ul style="list-style-type: none"> • Australian Federation of Disability Organizations (AFDO) • CAUS – Communication Rights Australia • La Trobe University • Victoria Office for Disability |
|----------|--|

Thus far, DRPI has had enthusiastic participation from disability organizations and people with disabilities in all of the pilot countries. The leading roles played by people with disabilities in all aspects of project governance and implementation have been important in securing cooperation with the disability community and prospective interviewees with disabilities. The links created with human rights academics and policy

makers have served to increase awareness of disability as a human rights issue and promise to contribute to the sustainability of disability rights monitoring efforts into the future. The data collected has been rich and informative.

CHAPTER 4

Monitoring the Depiction and Coverage of Disability in the Media

The media plays an important role in reflecting and influencing public opinion. Given the role that public opinion and attitudes play in facilitating or hampering the enjoyment of human rights by people with disabilities, a holistic approach to disability rights monitoring also examines the nature and extent of media coverage on disability issues. Myths and stereotypes perpetuated and propagated by media portrayals of persons with disabilities are being documented and positive reporting on disability issues recognized.

MONITORING MEDIA AVAILABLE ON THE INTERNET

DRPI is collaborating with a team of researchers from the State University at Buffalo, USA who have developed a methodology and computer software to facilitate the analysis of media depiction and coverage of disability issues around the world. The approach allows the analysis of many thousands of media reports from a wide variety of sources including radio, television broadcasts and newspaper, magazine and internet articles published in over twenty languages. Added to the DRPI and University of Buffalo's research team is a Swedish researcher from the University of Umea whose expertise lies in discourse analysis of media portrayals of disability.

The analysis of media stories will take place on two levels – one quantitative (analyzing media coverage) and one qualitative (analyzing the context of media reporting). Quantitative analysis will involve collecting information: (a) found in different media sources or types of publications (e.g. newspapers, radio broadcasts, magazines, etc.); (b) found in publications from different geographic areas (e.g. from national, regional, local publications); and/or (c) published at a particular point in time (e.g. on the day the UN General Assembly's adopted the Disability Convention). In addition, analysis will be carried out taking into account a number of factors at once. A relational data base will provide a picture of the patterns of how the media portrays disability. Based on

quantitative analyses, a representation of the media coverage of people with disabilities will be constructed. Qualitative analysis will involve looking at differences in the tone and attitude in which disability-related stories are reported.

A Panel of Experts in disability rights, media communications and disability-specific media is being established. The panel will have international membership and scope. At least half of the members will be experts with disabilities. The Panel of Experts will be responsible for making suggestions with respect to the design of the basic research by determining the search terms to be used when reviewing media sources and the ways in which results should be categorized and analyzed.

ONLINE RESEARCH TOOL

In addition to actively engaging in media monitoring, DRPI's collaboration with the Universities at Buffalo and Umea research teams will contribute to the development of an online tool that will be made universally available and permit organizations of people with disabilities, government, academics and others to conduct their own analyses of disability-related media reports from a wide variety of sources, over a broad time period.

CHAPTER 5

Collaborating with the Disability Community — Building Partnerships and Networks

DRPI continues its collaboration with disability, human rights and other organizations identified in Phase One²⁰ in order to build on existing expertise and develop the international and multi-disciplinary networks needed to support an international disability rights monitoring system. To date, DRPI is formally collaborating with more than forty organizations of people with disabilities, human rights NGOs, university research institutes, human rights institutions and government agencies.

For a comprehensive list of DRPI's collaborators, see Appendix B. The list includes:

- A. National and Regional Organizations of People with Disabilities
- B. International Disability Alliance Members
- C. National and Regional Human Rights Organizations & Institutions
- D. Universities & Research Institutes
- E. Government Agencies and Departments
- F. DRPI Advisory Committee, Co-Directors, Research Associates, Consultants and Students

DRPI has built a significant network of people and organizations involved in disability rights monitoring. It is hoped that by developing capacity within disability organizations and interest in disability rights on the part of academics and other human rights actors, a strong foundation will be laid for future disability rights monitoring led by disability organizations. Maintaining momentum and interest in disability rights monitoring among all of these groups is an ongoing challenge and one that is addressed in part, through the initiatives discussed in the next chapter.

²⁰ For further details, please refer to the DRPI *Phase I Report: Opportunities, Methodologies, and Training Resources for Disability Rights Monitoring*, is available on the project website at www.yorku.ca/drpi. (21 Feb. 2007)

CHAPTER 6

Disseminating Knowledge

DRPI recognizes that for an international disability rights monitoring system to be developed and sustained, collaboration with the disability community and other relevant people must be fostered and advanced through the dissemination of knowledge created by the project. DRPI has developed a wide-ranging knowledge dissemination strategy encompassing both traditional and innovative methods.

VIRTUAL KNOWLEDGE NETWORKS

DRPI is fostering its collaboration and dissemination efforts through the development of virtual knowledge networks. A Virtual Knowledge Network uses communication technology to bring together individuals or organizations that are geographically separated. DRPI is working towards establishing Virtual Knowledge Networks to connect individuals with disabilities, disability organizations, activists, scholars, human rights experts, government policy-makers, and UN representatives from around the world who are engaged in monitoring. DRPI is learning from, and building upon, the experience of other organizations with successful Virtual Knowledge Networks such as those in the international development field.

DRPI is creating three distinct Virtual Knowledge Networks. One will serve as a forum for information exchange among those involved in the project and any other people interested in developing similar holistic monitoring initiatives. Two smaller knowledge networks will focus on specific research projects: (a) expanding legal education efforts related to human rights and disability; and (b) examining methodological issues for effectively monitoring the individual experiences of people with disabilities.

DRPI WEBSITE – NEW DEVELOPMENTS

The DRPI website (www.yorku.ca/drpi) is updated regularly to include reports, important resources and links, as well as a photo gallery showing DRPI's international initiatives. The Home Page has been reformatted to provide quick access to information about recent disability rights developments within the DRPI project and the larger disability community in general.

The website has been audited to ensure its full accessibility and compliance with the W3C Web Content Accessibility Guidelines and has been “Bobby-approved”.

The website is the centre for the project’s internet-based activities. It will be linked to separate password-protected web forums established to facilitate communication among members of the DRPI Advisory Committee; students involved in the legal education and research project; and the theme groups of DRPI-Canada. DRPI’s virtual knowledge networks will also be accessed through the website ensuring greater access to the site on a regular basis.

DRPI PRESENTATIONS

DRPI project co-directors, staff and affiliates have disseminated information about the DRPI project and disability rights through presentations at conferences, meetings and courses. The following list highlights some of these. Speaking notes from some of these presentations are available on the DRPI website.

2006

November 20 – SHIA Seminar: “How can we make sure that the rights of individuals with disabilities are not violated?” – “Presentation of the DRPI Project” (Bengt Lindqvist & Marcia Rioux)

November 6 – EU Disability Conference – “Achieving disability rights through mainstreaming at the regional and local level” – Stockholm, Sweden (Bengt Lindqvist)

September 6 – Interface with Organizations of People with Disabilities with a Cross-Disability Perspective – “Introduction to the DRPI project” – Ananthapur, India (Marcia Rioux)

September 4 – Central Institute of English and Foreign Languages - “Disability Rights Monitoring and the DRPI Project”- Hyderabad, India (Marcia Rioux)

August 30 – September 4 – NALSAR University Critical Legal Conference – Panel: “Law and Disability Rights” and Paper: “Charity to Disability Rights”, Hyderabad, India (Marcia Rioux)

August 16 – UN Department Economic and Social Affairs, Discussion Regarding Establishment of Regional Repositories of Disability Legislation – “DRPI’s work in the development of tools and mechanisms to collect and systemic disability rights monitoring data”- New York, U.S.A (Rita Samson)

May 27- June 3 – York University, Congress of the Social Sciences and Humanities – “At a Crossroads: Disability and Human Rights in Portugal and the EU” Toronto, Canada (Paula Pinto)

April 21-22 - Syracuse University School of Education, Inclusion Imperative: A Two-Day

National Conference Honouring Diversity - “Inclusion, Equality and Human Rights”- Syracuse, U.S.A. (Marcia Rioux)

2005

December 9-10 - Council of Canadians with Disabilities, Consultation regarding the Draft Disability Convention – “Possible National and International Monitoring Mechanisms for the Disability Convention” - Ottawa, Canada (Rita Samson)

August 25-26 - Nordic Blind Organizations’ Conference -“Monitoring the Human Rights of People with Disabilities”- Reykjavik, Iceland (Bengt Lindqvist)

August 13-21 – University of Zagreb – Zagreb, Croatia (Marcia Rioux)

July 2-10 – 29th International Congress on Law & Mental Health – “The Legal Construction of the Disabled Person: Locating the Nexus of Disability and Theories of Equality” and “Economic and Scientific Determinism as a Means of Privatizing Disability: the Impact of Globalization of Disability Rights Law”- Paris France (Marcia Rioux)

June 22 - Social Development Canada Consultation on the U.N. Convention on Disability - Ottawa, Canada (Marcia Rioux)

June 5-11 – AFUB/SRF, Disability and Human Rights Conference - “Disability Rights Monitoring and the Disability Rights Promotion International project”- Nairobi, Kenya (Marcia Rioux & Rita Samson)

April - SHIA, Human Rights Training for People with Disabilities – “Monitoring the Human Rights of People with Disabilities”- Almåsa, Sweden (Bengt Lindqvist)

March 18-19 – Council of Canadians with Disabilities, Consultation regarding the Draft Disability Convention – “DRPI’s monitoring projects”- Ottawa, Canada (Marcia Rioux & Rita Samson)

February 24-26 – Fetal Alcohol Spectrum Disorder (FASD) 2005 National Conference – “Writing the Rights: the United Nations Recognizes Disability”- Vancouver, Canada. (Marcia Rioux)

2004

September 8-10 - Disabled Peoples’ International (DPI) World Summit -“Monitoring Human Rights – A Tool for Change”- Winnipeg, Canada (Bengt Lindqvist)

September 8-10 – Disabled Peoples’ International (DPI) World Summit – “Essential Elements of Strong Monitoring” – Winnipeg, Canada (Marcia Rioux)

September – Canadian International Development Agency (CIDA) – “Disability Rights Promotion International” – Ottawa, Ontario (Bengt Lindqvist & Marcia Rioux)

February – Equal Opportunities Commission of the State of Victoria Meeting - “Disability Rights Promotion International”, Melbourne, Australia (Marcia Rioux)

February - Equal Opportunity Commission Victoria Forum – “The Development of the United Nations Convention on the Rights and Dignity of Persons with Disabilities”, Melbourne, Australia. (Marcia Rioux)

February - Government of Victoria Human Rights Alliance Conference - “From Rhetoric to Reality: Making Human Rights Work”, Melbourne, Australia. (Marcia Rioux)

DRPI IN PRINT

In addition to speaking engagements, information about the DRPI project has been disseminated through articles in newspapers, magazines and scholarly publications. While not exhaustive, the following list highlights some of these publications. These are also available on the DRPI website or can be obtained from the DRPI office.

2006

(forthcoming) – *A Comprehensive Guide to Intellectual and Developmental Disabilities* (Ivan Brown & Maire Percy eds.) – “International Human Rights and Intellectual Disability” (Marcia Rioux, Bengt Lindqvist & Anne Carbert)

September – Captus Press, *Disability and Social Policy in Canada* (2nd edition) (Mary Ann McColl & Lyn Jongbloed eds.) – “Trends Impacting Disability: National and International Perspectives” (Marcia Rioux & Rita Samson)

August – *The Leader* newspaper (Nairobi, Kenya) – “Where it’s not the disabled who are unable: A Profile of Marcia Rioux” (staff writer)

June – York University Research Gallery during Congress of the Social Sciences and Humanities – Exhibit: “Addressing Disability Discrimination Worldwide” (Marcia Rioux & York Research)

2004

September - International Bar Association’s *International Bar News* - “New Project Promotes Human Rights Approach to Disability”) (Bengt Lindqvist & Anne Carbert)

August –Interights *Bulletin* - “Disability Rights Promotion International: Monitoring the Human Rights of Persons with Disabilities” (Marcia Rioux & Anne Carbert)

August - Interights *Bulletin* - “UN Standard Rules on Disability Pave the Way for Human Rights” (Bengt Lindqvist)

January - *Toronto Star* newspaper (Toronto, Canada) - “International rights project ready for local feedback” (Helen Henderson)

2003

Autumn - *Abilities Magazine* - “Human Rights Around the World: Disability Rights Promotion International” (Marcia Rioux & Anne Carbert)

July – Amnesty International *The Wire* – “Human Rights and Disability: an interview with Bengt Lindqvist” (staff writer)

CHAPTER 7

Moving Forward — Twin-Track Approach to Disability Rights Monitoring

When the DRPI project began in 2002, disability rights advocates around the world generally agreed that the “twin-track approach” to protecting and promoting the rights of people with disabilities should be adopted.²¹ That is, while continuing to advocate for a disability-specific international human rights convention, efforts should also be made to develop the tools and mechanisms necessary to realize the protection and promotion of disability rights within the existing international human rights system.²²

DRPI has participated in work on both tracks. Through its research in Phase One and the developing and field testing of tools and methods to monitor the human rights situation of people with disabilities in Phase Two, the project has contributed to the effort to promote the recognition and protection of disability rights within the existing international human rights system.

At the same time, DRPI participated in the efforts to achieve a disability-specific human rights convention. DRPI representatives attended and contributed to the following important events:

²¹ See: *Report of the United Nations High Commissioner for Human Rights and Follow-up to the World Conference on Human Rights: Human rights of persons with disabilities* E/CN.4/2002/18/Add.1, 12 February 2002. For the full text see <http://www.un.org/esa/socdev/enable/disecon4200218a1.htm>. (21 Feb. 2007)

²² At the time, the “existing” international human rights system included six main United Nations (UN) human rights treaties and regional mechanisms in the Americas, Europe and Africa. Four of the UN treaties are of ‘universal application’ – that is, the rights guarantees found therein apply to “all people”, including people with disabilities. [*International Covenant on Civil and Political Rights* (ICCPR), *International Covenant on Economic, Social and Cultural Rights* (ICESCR), *International Convention on the Elimination of All Forms of Racial Discrimination* (CERD) and *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment* (CAT)]. The other two UN treaties apply to specific population groups – that is, “all women” and “all children” – and, likewise, apply to all women with disabilities and all children with disabilities. [*Convention on the Elimination of All Forms of Discrimination Against Women* (CEDAW) and *Convention on the Rights of the Child* (CRC)].

- “Meeting on the Comprehensive and Integral International Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities”, organized by the Government of Mexico with the support of the UN Department of Economic and Social Affairs (DESA) and the sub-regional office in Mexico of the Economic Commission for Latin America and the Caribbean (ECLAC) (Mexico City, June, 2002). A DRPI representative was sponsored by the UN to attend the meeting as an Expert.
- Private discussions with Ambassador Luis Gallego Chiriboga (Chair of the Ad Hoc Committee 2002-2005) and Ambassador Don MacKay (Chair of Ad Hoc Committee 2005-2006) (Winnipeg, September, 2004)
- Consultations with Canadian civil society organizations regarding the draft text of the Disability Convention. (Ottawa, March and December, 2005; February, 2006). At these meetings, DRPI facilitated specific discussions about several draft articles including monitoring;
- Ad Hoc Committee Session 7 (AHC7) and Ad Hoc Committee Session 8 (AHC8) (New York, January and August, 2006). As civil society delegates, DRPI representatives distributed project flyers and reports, presented during side meetings, networked among NGO and country delegations and offered expertise during informal consultations, regarding the monitoring methods for the convention.

With the UN General Assembly’s adoption of the Disability Convention* and its Optional Protocol* on December 13, 2006, a new chapter has begun for disability rights monitoring. The need to pursue a twin-track approach to ensuring the enjoyment of all human rights by people with disabilities remains essential to entrenching those rights and to fighting the battle against the continuing discrimination and abject abandonment of people with disabilities to social and political exclusion.

While there is now a text for a disability-specific convention, the work of the first track is far from complete. In order for the Disability Convention to enter into force*, it must be ratified* (agreed to) by a country’s government before it becomes legally binding on that country. Once it is in force, the Disability Convention will have to be effectively implemented and strictly monitored if it is going to result in actual improvements in the lives of people with disabilities.

The work of the second track also continues. Monitoring efforts need to continue to ensure that international and regional human rights conventions are complying with their obligations to protect, promote and fulfill the rights of all people – including people with disabilities. Holistic disability rights monitoring involving the monitoring of systems, individual experiences and media, provides data to test the effectiveness of both the disability-specific and the mainstream human rights conventions in achieving their stated goals.

People with disabilities and disability organizations have a key role to play in these disability rights monitoring processes. This role is clearly recognized in the text of the Disability Convention. In order to play this role, people with disabilities, disability organizations and others will need to build their capacity to monitor obligations under both the Disability Convention and other international human rights treaties. DRPI's monitoring methodology with its emphasis on building the capacity of people with disabilities and disability organizations will provide a means through which the disability community can engage in both the national and international monitoring processes.

CONCLUSION

The DRPI project works with people with disabilities and organizations of people with disabilities, to develop the skills and institutional capacity needed to play an integral role in monitoring international and regional human rights instruments, including the Disability Convention. Information collected through holistic monitoring will be used to report to international and regional monitoring bodies; to provide an evidence base for lobbying governments, civil society and the public sector to bring about change in the situation of people with disabilities; and to develop campaigns to address negative myths and stereotypes about disability currently rooted in public opinion.

APPENDIX **A**

Legal Education and Research Project

PAPER TOPICS ADDRESSED BY STUDENTS:

- European Convention on Human Rights and the rights of people with disabilities (University of Leeds, 2005-2006)
- Employment rights of people with disabilities in Kenya (University of Nairobi, 2005-2006)
- Access to information people with disabilities and freedom of expression (University of Nairobi, 2005-2006)
- Education rights and people with disabilities in Kenya (University of Nairobi, 2005-2006)
- Protection for people with disabilities in equality rights and legislative regimes in Canada and the United States (York University, 2003-2004)
- Canadian law and psychiatric disabilities (York University, 2004-2005)
- A review of UN human rights mechanisms and the protection and promotion of disability rights (York University, 2005-2006)
- Sexuality and people with intellectual disabilities in Canada (York University, 2005-2006)
- Post-secondary education and the rights of people with disabilities in Ontario (York University, 2005-2006)
- Equality rights and Canadian health policy changes related to people with disabilities (York University, 2005-2006)
- UK legal regimes and practice related to the rights of people with disabilities and prison life, employment, transportation, education, and access to entertainment venues (University of Greenwich, successive groups of students, 2003-2006)
- Reforming the definition of disability in the UK Disability Discrimination Act 1995 (University of Leeds, 2005-2006)
- The concepts of reasonableness and justification in UK anti-discrimination law (University of Leeds, 2005-2006)

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²⁴ Arlene Kanter, Faculty of Law, University of Syracuse, has agreed to act as chair for the Faculty discussions for the coming year.

²⁵ At the time of publication, not all of the names of students participating in the 2006-2007 academic year were available.

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Catherine Wasilewski, LL.B Student, University of Leeds
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Arshia Sheikh, LL.B. Student, University of Greenwich
Cara Wilkie, LL.B. Student, York University

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Matthew Harris, LL.B. Student, University of Greenwich
George Karatzas, LL.B. Student, University of Greenwich
Natasha Kennedy, LL.B. Student, University of Greenwich
Brendon Pooran, LL.B. Student, Osgoode Hall Law School, York University
Ioannis Sarakinos, LL.B. Student, University of Greenwich
Cara Wilkie, LL.B. Student, Osgoode Hall Law School, York University

APPENDIX **B**

Collaborating with the Disability Community

NATIONAL AND REGIONAL ORGANIZATIONS OF PEOPLE WITH DISABILITIES

Alliance for Equality of Blind Canadians (AEBC) – John Rae
African Union of the Blind (AFUB) – Elly Macha
Asmita Resource Centre for Women – Kalpana Kannabiran
Australian Federation of Disability Organizations (AFDO) – Maryanne Diamond
Cameroon National Association of the Blind (ANAC) – Paul Tezanou
Cameroon National Association of Disabled Women – Mana Boungani
Cameroon National Association of the Deaf – Alphonse Ntep
Cameroon National Association of Lepers – Georgette Nlang
Cameroon National Association of the Physically Disabled – Simone Tezon
Canadian Abilities Foundation (CAF) – Ray Cohen
Canadian Association of Independent Living Centres (CAILC) – Jihan Abbas
CAUS – Communication Rights Australia – Jan Ashford
Centre for Independent Living – Toronto (CILT) – Sandra Carpenter
Council of Canadians with Disabilities (CCD) – Laurie Beachell
Croatian Association of the Blind (CAB) – Danko Butorac
Croatian Union of Associations of Persons with Disabilities (SOIH) – Branko Bizjak
Croatian Union of Physically Disabled Persons Association (CUPDPA) – Mirjana Dobranovic
DisAbled Women's Network – Ontario (DAWN-Ontario) – Barbara Anello
Kenya Union of the Blind (KUB) – Monica Mbaru
Kenyan Centre for Disability Rights Education and Advocacy (CREAD) – Mike Ngunyi
National Educational Association of Disabled Students (NEADS) – Jason Mitschele
Swadhikaar Center for Disabilities Information, Research & Resource Development – Andhra Pradesh, India – Pavan Muntha
Swedish Association of the Visually Impaired (SRF) – Erik Staaf
Swedish Disability Federation (HSO) – Christina Wahrolin

INTERNATIONAL DISABILITY ALLIANCE MEMBERS

DRPI has entered into a Memorandum of Understanding (MOU) with Disabled Peoples International (DPI) and is negotiating MOUs with other members of the international disability alliance including the World Blind Union (WBU) and the World Network of Users and Survivors of Psychiatry (WNUSP).

NATIONAL AND REGIONAL HUMAN RIGHTS ORGANIZATIONS AND INSTITUTIONS

Amnesty International Canada (Ottawa, Canada)
ARCH – Legal Resource Centre for People with Disabilities (Toronto, Canada)
Asia-Pacific Forum of National Human Rights Institutions (Sydney, Australia)
Asmita Resource Centre for Women (Hyderabad, India)
Cameroon National Commission on Human Rights and Freedoms (Yaounde, Cameroon)
Canadian Human Rights Commission (Ottawa, Canada)
Equitas (Montreal, Canada)
Interights (London, England)

UNIVERSITIES AND RESEARCH INSTITUTES

Centre for Interdisciplinary Research in Rehabilitation & Social Integration (CIRRIS),
University of Laval (Quebec City, Canada)
Institute for Social Research, York University (Toronto, Canada)
La Trobe University (Bundoora, Australia)
NALSAR University of Law (Hyderabad, India)
Moi University (Eldoret, Kenya)
Raoul Wallenberg Institute of Human Rights and Humanitarian Law, University of Lund
(Lund, Sweden)
State University at Buffalo (Buffalo, U.S.A.)
Syracuse University (Syracuse, U.S.A.)
University of Greenwich (London, England)
University of Leeds (Leeds, England)
University of Nairobi (Nairobi, Kenya)
University of Umea (Umea, Sweden)
University of Zagreb (Zagreb, Croatia)
York Institute for Health Research, York University (Toronto, Canada)
York University (Toronto, Canada)

GOVERNMENT AGENCIES AND DEPARTMENTS

Office des personnes handicapées du Québec – Government of Quebec, Canada

Office for Disability Issues – Government of Canada

Statistics Canada – Government of Canada

Victoria Office for Disability – Government of Victoria, Australia

DRPI ADVISORY COMMITTEE, DIRECTORS, RESEARCH ASSOCIATES, CONSULTANTS AND STUDENTS

A. DRPI Advisory Committee

Andrew Byrnes – Professor, University of New South Wales, Australia

Christian Courtis – Professor, University of Buenos Aires, Argentina

Theresia Degener – Professor, University of Applied Sciences, Germany

Steven Estey – Chair, International Committee, Council of Canadians with Disabilities, and Member, Executive Committee, Mines Action Canada, Canada

Kieren Fitzpatrick – Director, The Asia Pacific Forum of National Human Rights Institutions

Judith Heumann – Advisor on Disability and Development, The World Bank, U.S.A.

Nicholas Howen – Secretary General, International Commission of Jurists, Switzerland

Rodrigo Jiménez – Rights of Peoples with Disabilities, Costa Rica

Kalle Konkola – Executive Director, The Threshold – Independent Living Centre, Finland

Lars Lööw – Disability Ombudsman, Office of Disability Ombudsman, Sweden

Anuradha Mohit – Special Rapporteur, National Human Rights Commission, India

Gerard Quinn – Professor, National University of Ireland, Galway, Ireland

Eric Rosenthal – Executive Director, Mental Disability Rights International, U.S.A.

William Rowland – President, World Blind Union, and Executive Director, South African National Council for the Blind, South Africa

Ann-Marit Sæbønes – Politician and Disability Activist, Norway

Christina Wahrolin – Vice Chair, Swedish Disability Federation (HSO), Sweden

B. DRPI Project Co-Directors

Bengt Lindqvist

Marcia Rioux

Brief biographies of the Project Co-Directors are posted on the DRPI website @ www.yorku.ca/drpi.

C. DRPI Project Coordinators

DRPI-International – Rita Samson
DRPI-Cameroon – Carole Leuwe & Cornelius Ojangole
DRPI-Canada – Mihaela Dinca-Panaitescu
DRPI-Croatia – Ljubica Lakacic
DRPI-Kenya – Cornelius Ojangole
DRPI-India – Pavan Muntha
DRPI-Sweden – Maryanne Rönnersten & Annika Åkerberg

D. DRPI Research Associates and Expert Consultants

Annika Åkerberg – Lawyer & Disability Rights Consultant (Farsta, Sweden)
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Anne Carbert – Lawyer & Human Rights Consultant (Toronto, Canada)
Sandra Carpenter – Centre for Independent Living, (Toronto, Canada)
Ray Cohen – Canadian Abilities Foundation, (Toronto, Canada)
Cameron Crawford - Roeher Institute (Toronto, Canada)
Daniel Drache – Faculty of York University (Toronto, Canada)
Christo El Morr – Faculty of Health, York University (Toronto, Canada)
Steven Estey – Council of Canadians with Disabilities, International Committee (Halifax, Canada)
Patrick Fougere – Institut de réadaptation en déficience physique de Québec (IRDQP), Laval University (Quebec City, Canada)
Fiona Given – Lawyer – DRPI & Interights Strategic Disability Rights Litigation Intern (Newtown, Australia – from Interights’ Office in London, England)
Isabel Killoran – Faculty of Education, York University (Toronto, Canada)
Andrew Laing – Cormex Research (Toronto, Canada)
Paula Lau – Lawyer (Toronto, Canada)
Richard Light – Disability Rights Activist (London, England)
Karin Ljuslinder – Senior Lecturer, Media & Communication, Umeå University (Umeå, Sweden)
Allyson Marsolais – M.A.(Critical Disability Studies) Graduate, York University (Toronto, Canada)
Roxanne Mykitiuk – Osgoode Hall Law School, York University (Toronto, Canada)
Yvonne Peters – Disability Rights Legal Expert (Winnipeg, Canada)
Paula Pinto – Ph.D.(Sociology) Candidate, York University (Toronto, Canada)
Michael Prince – Faculty of University of Victoria (Victoria, Canada)
Geoffrey Reaume – Faculty of Health, York University (Toronto, Canada)

Fiona Sampson – Ph.D.(Law) Candidate, Osgoode Hall Law School, York University
(Toronto, Canada)

David Shannon – Lawyer (North Bay, Canada)

Joseph Woelfel – Professor of Communications, State University at Buffalo, State
University of New York (Buffalo, U.S.A.)

Ezra Zubrow – Professor of Anthropology, State University at Buffalo, State University of
New York (Buffalo, U.S.A.)

E. DRPI Graduate Student Research Assistants

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recherche en réadaptation et intégration sociale (CIRRIS), Laval University

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Morgan Huseby – M.A. (History) Candidate, York University

Nadia Kanani – M.A.(Critical Disability Studies) Candidate, York University

Nelson Lai – M.A. (Political Science) Candidate, York University

Christopher Lytle – M.A. (Critical Disability Studies) Candidate, York University

Iphigenia Mikroyiannakis – M.A.(Critical Disability Studies) Candidate, York University

Ilana Mizel – M.A.(Critical Disability Studies) Candidate, York University

Hila Rimón – Greenspan M.A.- (Critical Disability Studies) Candidate, York University

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Donn Short – Ph.D. Law Candidate, York University

Scott Tanaka – M.A.(Critical Disability Studies) Candidate, York University

Samantha Walsh – M.A.(Critical Disability Studies) Candidate, York University

Glossary and Abbreviations

GLOSSARY

An asterisk in the text of the report (e.g. accession*) indicates that the word or phase is defined in this glossary.

accede / accession: the act by which a State becomes party to an agreement already in force between other States (e.g., accession to a human rights treaty*).

ad hoc committee: a committee created with a unique and specific purpose or task. Once it has studied and reported on that task, an ad hoc committee is disbanded.

adoption: the formal approval or acceptance of the text of an agreement, such as a treaty, that has been negotiated within the framework of a legislative body of an inter-governmental organization (e.g. the UN General Assembly*). Formal approval may be by a majority vote or consensus without a vote. After adoption, the treaty is opened for signature and ratification* by States.

convention: an agreement between States requiring them to abide by the agreed upon terms. This term is used synonymously with ‘treaty’ and ‘covenant’; a convention is the term normally used in United Nations practice to designate a multilateral treaty.

customary international law: rules of international law which are based on the consistent practice of States (i.e. what States actually do) and which require them to act in this way.

disability rights: the equal effective enjoyment of all human rights by people with disabilities; “disability rights” and “human rights of people with disabilities” do not refer to extra protections or a separate and special category of rights, but refer to the full range of human rights available to all, as applied to the specific situation of people with disabilities.

entry into force: a treaty* does not enter into force when it is adopted*. Usually, the provisions of the treaty determine the date on which the treaty enters into force, often at a specified time following its ratification or accession by a fixed number of states.

individual complaints procedure: a procedure by which individual persons or groups of individuals lodge a complaint alleging that a State has failed to respect the rights guaranteed by the treaty.*

monitoring: tracking and/or gathering of information on government practices and actions related to human rights; sometimes used interchangeably with “fact finding” and “investigation”.

non-governmental organizations (NGOs): organizations formed by people outside of government; NGOs exist in a variety of forms and carry on work varied in type and scope, depending upon the degree of independence, impartiality and connection with government.

optional protocol: a “protocol” is an additional legal instrument that complements and adds to a treaty* usually by adding extra procedures or substantive provisions – e.g. the optional protocol to the Disability Convention adds an individual complaints procedure. A protocol is “optional” because it is not automatically binding on States that ratify* the original treaty. States must independently ratify or accede* to a protocol.

ratify/ ratification: process by which the relevant body of a State confirms that it is bound to a treaty* after its signature of the treaty.

State party: a country that has indicated its willingness to be bound by the provisions of a treaty*, in the case of multilateral treaties, normally by ratification* or accession* to the treaty.

State reporting procedure: the procedure by which a State party* periodically reports to the treaty monitoring body* about the action it has taken to comply with a treaty.*

treaty: an international agreement concluded between States in written form and governed by international law, whether the written agreement is embodied in a single instrument or in two or more related instruments and whatever its particular designation; treaties define the rights and entitlements of those that are the subject of the treaty and, thus, reflect both what States have agreed to do and what individuals or groups can claim.

treaty monitoring body: the committee with responsibility for supervising the compliance of State parties* with a treaty.*

United Nations: an international organization composed of most of the countries of the world. It was founded in 1945 to promote peace, security, and economic development. The United Nations is headquartered in New York and has offices in Geneva and Vienna.

United Nations Commission on Human Rights: a commission within the framework of the United Nations established in 1946 and composed of 53 member States. It was the United Nation’s principal mechanism and international forum concerned with the promotion and protection of human rights. The Commission met annually for six weeks in Geneva. In March, 2006, the UN General Assembly* voted to replace the Commission with a new body, the **United Nations Human Rights Council** which held its first meeting in June, 2006.

United Nations High Commissioner for Human Rights: the head of the Office of the High Commissioner for Human Rights. The post was established in December 1993. The High Commissioner is the principal United Nations official responsible for United Nations human rights activities, he or she has the broad mandate to promote and protect all human rights: civil, political, economic, social and cultural.

United Nations General Assembly: one of the principal organs of the United Nations* and the only one in which all United Nations member states are represented. It meets annually or in special sessions. It acts primarily as a deliberative body; it may discuss and make recommendations about any issue within the scope of the United Nations Charter. Its president is elected annually on a rotating basis from five geographic groups of members.

United Nations Secretariat: one of the principal organs of the United Nations headed by the United Nations Secretary General and assisted by a staff of international civil servants worldwide. It provides studies, information, and facilities needed by United Nations bodies for their meetings. It also carries out tasks as directed by the UN Security Council, the UN General Assembly, the UN Economic and Social Council, and other UN bodies.

United Nations Special Rapporteur on Disability: the United Nations *Standard Rules for the Equalization of Opportunities of Persons with Disabilities* provides for the appointment of a Special Rapporteur to monitor* the implementation of the Rules. The Special Rapporteur reports yearly to the Commission for Social Development. The reports present findings on the promotion and monitoring of the implementation of the Standard Rules and present recommendations, as requested by the Commission, on their further development.

ABBREVIATIONS

AEBC – Alliance for Equality of Blind Canadians

AFDO – Australian Federation of Disability Organizations

AFUB – African Union of the Blind

Almåsa Seminar – the international “Seminar on Human Rights and Disability” held at the Almåsa Conference Centre in Stockholm, Sweden, in November 2000

ANAC – Cameroon National Association of the Blind

APF – Asia Pacific Forum of National Human Rights Institutions

CAB – Croatian Association of the Blind

CAF – Canadian Abilities Foundation

CAILC – Canadian Association of Independent Living Centres

CAUS – Communication Rights Australia

CIRRIS – Centre for Interdisciplinary Research in Rehabilitation & Social Integration

CREAD – Centre for Disability Rights Education and Advocacy, Kenya

CCD – Council of Canadians with Disabilities

CILT – Centre for Independent Living – Toronto

CUPDPA – Croatian Union of Physically Disabled Persons Association

CURA – Community-University Research Alliance

DAWN-Ontario – DisAbled Women’s Network - Ontario

DESA – Department of Economic and Social Affairs

Disability Convention – *Convention on the Rights of Persons with Disabilities*

DPI – Disabled Persons International

DRPI – Disability Rights Promotion International

HSO – Swedish Disability Federation

KUB – Kenya Union of the Blind

LDPO – local organization of people with disabilities

MOU – Memorandum of Understanding

NCHRF – National Commission on Human Rights and Freedoms (Cameroon)

NDPO – national organization of people with disabilities

NEADS – National Educational Association of Disabled Students

NGO – non-governmental organization

NHRI – national human rights institution

SIDA – Swedish International Development Cooperation Agency

SOIH – Croatian Union of Associations of Persons with Disabilities

SRF – Swedish Association of the Visually Impaired

SSHRC – Social Sciences and Humanities Research Council (Canada)

Standard Rules – *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*

Swadhikaar – Swadhikaar Center for Disabilities Information, Research & Resource Development

UN – United Nations

WBU – World Blind Union

WNUSP – World Network of Users and Survivors of Psychiatry



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