

# Understanding and Integrating Disability Rights: A Funders' Guide



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The guide presented here seeks to introduce disability rights to funders, particularly human rights grantmakers. It seeks to provide a general overview of human rights and disability, and a sketch of the current funding landscape, both present and potential. The disability community has been integral in assisting with this project, offering their disability and human rights expertise, sharing resources and participating in discussions on the funding strategies that could be most effective for advancing the human rights of people with disabilities.

## Brief overview of disability

Almost ten percent of the world's population, an astounding 650 million, is disabled. Eighty percent live in the developing world. Persons with disabilities (PWDs) are among the poorest of the poor, as disability is both a cause and effect of poverty.<sup>1</sup> As a leading cause of poverty, disability has a multiplier effect leading to additional disabilities as a result of poor living conditions, dangerous employment, malnutrition, poor access to health care and education opportunities and increased vulnerability to sexual violence.<sup>2</sup> 97% of children with disabilities live in developing countries without any form of rehabilitation and 98% without any education.<sup>3</sup> Women are more likely than men to become disabled, due in part to gender bias in resource allocation and services provision.<sup>4</sup> In developing countries, women with disabilities face an unemployment rate that is virtually 100%.<sup>5</sup>

Persons with disabilities comprise the world's largest minority. Unlike most minority populations, disability can affect *anyone* at *anytime* whether through injury, disease, violent armed conflict or age<sup>6</sup>. Despite this universality, PWDs are marginalized within society, living as social and economic outcasts due to severe discrimination and the systemic nature of the obstacles they face integrating into their communities. Seven out of ten PWDs have limited or no access to the services they require. Only 45 of the 191 UN Member States currently have laws to protect PWDs from discrimination.<sup>7</sup> Once it enters into force and is implemented, the new UN Convention on the Rights of Persons with Disabilities will dramatically change that statistic.

## Making the connection: Human rights and disability

For over a century, persons with disabilities were viewed as objects of charity and care. Over the past 30 years, however, a human rights perspective has stimulated a gradual, but dramatic shift towards viewing PWDs as subjects rather than objects. Such a shift "entails moving away from viewing persons with disabilities as problems towards viewing them as holders of rights."<sup>8</sup> The new treaty on the rights of persons with disabilities embodies the culmination of this shift.

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<sup>1</sup> "Disability, Poverty and Development," UK Department for International Development Report, February 2000.

<sup>2</sup> "[Poverty and Disability](#)," World Bank.

<sup>3</sup> "[Submission to the Committee on the Rights of the Child Thematic Day on Disabled Children](#)." Child Rights Information Network, October 6 1997.

<sup>4</sup> "[Women and Girls with Disabilities](#)," Human Rights Watch.

<sup>5</sup> "[Factsheets on Women with Disabilities](#)," DAWN Ontario DisAbled Women's Network Ontario.

<sup>6</sup> In countries with life expectancies over 70 years, individuals spend almost 12 percent of their life living with disabilities. [Some Facts about Persons with Disabilities](#), UN website entitled Convention on the Rights of Persons with Disabilities.

<sup>7</sup> "[Some Facts about Persons with Disabilities](#)," UN website entitled Convention on the Rights of Persons with Disabilities.

<sup>8</sup> [Human Rights and Disability](#): The current use and future potential of the United Nations human rights instruments in the context of disability. Theresia Degener and Gerard Quinn (United Nations, New York and Geneva 2002), page 1.

Rather than focusing on a person's impairment using a medical model, a social model (also called the human rights perspective) focuses on the inherent dignity of the human being.<sup>9</sup> The "problem" lies not with the individual, but on the barriers created by social attitudes, public policy and the physical environment. Changing definitions and language reflect these attitudinal shifts. Discarding the term "the disabled", persons with disabilities are demanding that their humanness defines them first. "Disability" is used not as a medical term, but describes the discrimination resulting from society's failure to accommodate and include disabled persons. The new Convention on the Rights of Persons with Disabilities (CRPD) states "that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others."<sup>10</sup>

Several trends have supported and contributed to the shift to a human rights perspective. National human rights institutions around the world are increasingly including disability in their work. Perhaps most importantly, the UN human rights system has authoritatively endorsed this shift through a variety of efforts, declarations, and treaties. The timeline on page six illustrates the shift to a human rights perspective and the relevant UN human rights instruments. In addition, the Office of the High Commissioner for Human Rights now has a disability advisor and plans to expand that staffing capacity in the coming years.

Furthermore, disability activists view their own work as human rights advocacy. In a study carried out by the Office of the High Commissioner for Human Rights, the authors asked NGOs to evaluate their capacity to advance a human rights perspective on disability. Thirty-seven (out of 50) responded that the human rights perspective had been integrated into their organizational charters or missions. All eight international NGOs and regional NGOs identified themselves as human rights organizations and 32 disability NGOs had published materials on the human rights perspective of disability, illustrating the depth of the human rights shift within civil society.<sup>11</sup>

This paradigm shift focuses on the ability of PWDs to enjoy universal rights, such as housing, work or education, rather than on constructing "special" rights. The ultimate goal is to "build societies that are genuinely inclusive, societies that value difference and respect the dignity and equality of all human rights regardless of difference."<sup>12</sup> The process to reach that goal requires clear standards for governments so that PWDs are not consciously or unconsciously discriminated against. As Degener and Quinn have written, "The disability rights debate is not so much about the enjoyment of specific rights as it is about ensuring the equal effective enjoyment of all human rights without discrimination, by people with disabilities."<sup>13</sup>

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<sup>9</sup> Degener and Quinn, 14.

<sup>10</sup> U.N. General Assembly, 61<sup>st</sup> Session. *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities* (A/61/611). 6 December 2006. Preambular para (e).

<sup>11</sup> Degener and Quinn, 246-247.

<sup>12</sup> Degener and Quinn, 14.

<sup>13</sup> Degener and Quinn, 1.

### ***Need for a human rights treaty for people with disabilities***

Despite the increased integration of human rights and disability, the core UN human rights conventions do not explicitly mention persons with disabilities (with the exception of the Convention on the Rights of the Child, [Article 23](#)). Though the rights enshrined in all human rights instruments should apply to PWDs, the reality is that governments by and large overlook the human rights of persons with disabilities.<sup>14</sup> "Most Governments still lack decisive concerted measures that would effectively improve the situation of persons with disabilities."<sup>15</sup>



In many developing countries, PWDs have few advocacy resources or legal tools to effect a change in their status, much less secure their full participation in society. The Coordinator of the talks, UN Ambassador Don MacKay of New Zealand, explained the significance and need for the Treaty: "This major human rights convention represents a shift in the way governments interact with persons with disabilities....Many have said that the rights of persons with disabilities are already guaranteed in existing human rights treaties, but the reality is that persons with disabilities have been deprived of those rights."<sup>16</sup>

In sum, several reasons underline the need for a treaty focused on the rights of persons with disabilities:

- **Invisibility:** Disability is often an invisible issue that requires explicit recognition. Other identity groups (such as women and children) experienced similar marginalization and developed thematic human rights conventions. A disability rights treaty will add visibility and facilitate the mainstreaming of disability within the human rights system.<sup>17</sup>
- **Legal ambiguity:** The human rights instruments that address disability issues are not legally binding. A disability rights treaty will clarify the obligations of governments related to disabled persons and establish a monitoring mechanism to which governments can be held accountable. Human rights norms can now be applied to the specific context of disability.<sup>18</sup>
- **Advocacy focus:** The lack of a human rights instrument focused on disability required civil society to interact with multiple treaty bodies that lacked familiarity with disability. The Treaty's national and international monitoring mechanisms provide powerful legal authority for advocacy around rights implementation.

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<sup>14</sup> Disabled Peoples' International [Ratification Toolkit](#).

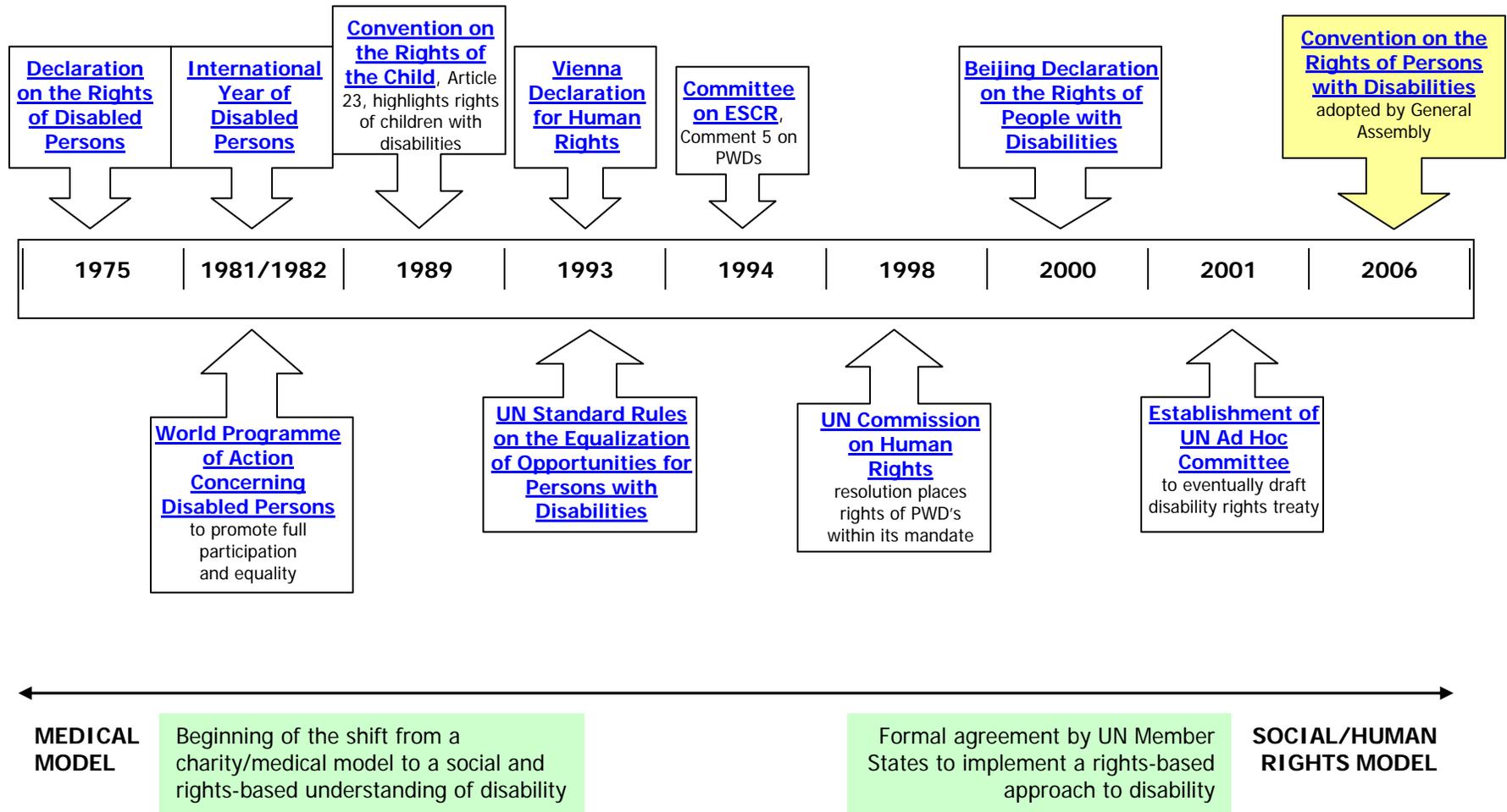
<sup>15</sup> Secretary-General. *Social Development: Questions Relating to the World Social Situation and to Youth, Ageing, Disabled Persons and the Family; Implementation of the World Programme of Action concerning Disabled Persons and the United Nations Decade of Disabled Persons (A/47/4150)*, 11 September 1992.

<sup>16</sup> "Key articles in draft disability treaty approved at UN meeting," UN News Centre, February 6, 2005.

<sup>17</sup> "Why we need a disability Convention," Speech delivered by Robyn Hunt, Human Rights Commissioner. New Zealand Human Rights Commission, March 25 2004.

<sup>18</sup> Degener and Quinn, 14.

## Timeline of disability human rights instruments and shift from a medical to a social model



## Getting to know the Convention on the Rights of Persons with Disabilities

On December 13, 2006, the General Assembly adopted the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD was “the most rapidly negotiated human rights treaty in the history of international law.”<sup>19</sup> The Treaty will be open for signature and ratification on March 30, 2007 and will enter into force one month after 20 countries have ratified the Treaty.

### *The Treaty text*

The CRPD, the first human right treaty in a decade, and the first in the new millennium, provides legal protections for the human rights of the world’s largest minority. The Treaty’s purpose is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”<sup>20</sup> The Convention is comprehensive in scope, addressing civil and political as well as social, economic and cultural rights. It also advances human rights language in explicitly acknowledging “multiple discrimination” and concern for the situation of “persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status.”<sup>21</sup>

Appendix A provides a list of the Treaty’s 50 articles, illustrating the comprehensive nature of the Convention. The CRPD establishes a committee of experts to monitor its implementation at the international level, and provides for independent national level monitoring mechanisms.

Unlike previous human rights treaties, the CRPD explicitly sets forth general principles for use in the interpretation and implementation of the substantive obligations arising under the Treaty. Following a practice used by the Committee on the Rights of the Child, the drafters sought to limit ambiguity in interpretation by outlining general principles that include:

- Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;

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<sup>19</sup> [Secretary-General’s message on the adoption of the Convention of the Rights of Persons with Disabilities](#) (delivered by Mr. Mark Malloch Brown, Deputy Secretary-General), 13 December 2006.

<sup>20</sup> U.N. General Assembly, 61<sup>st</sup> Session. *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (A/61/611)*. 6 December 2006.

<sup>21</sup> Preambular para (p).

- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

The general obligations section includes such requirements as the adoption (or abolishment) of legislation and customs to implement the Convention. It also requires States to take measures that eliminate discrimination by private entities and promotes research and development of universally designed goods and services and technologies, devices, and mobility aids.

The Treaty further details how States must implement the human rights of PWDs. More than just a non-discrimination treaty, the Convention sets affirmative goals for achieving human rights and fostering inclusion of PWDs in society. For example, Article 24 on education specifies that State Parties must facilitate “the learning of Braille...the learning of sign language and the promotion of the linguistic identity of the deaf community....[Education must be] delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.”

**The rallying cry of the disability community, “Nothing About Us Without Us” is now more than just a plea, but a principle of the Treaty.**

The current Special Rapporteur on Disability, Sheikha Hissa Al Thani, explained the significance of the Treaty: “The adoption of the Convention ended decades of struggle for recognition of persons with disabilities and their rights as human rights requiring protection through a strong, legally binding instrument to which States can commit, not only as a moral obligation, but as a legal

one.”<sup>22</sup> The CRPD will both prompt and guide the passage and reform of domestic legislation ensuring substantive equality and non-discrimination for persons with disabilities. Louise Arbour remarked further that “The convention... marks a historic step in ensuring that persons with disabilities enjoy full participation in society and can contribute to the community to their full potential. Speedy ratification... will end the protection vacuum that has, in practice, affected persons with disabilities.”<sup>23</sup>

The implementation of the Treaty will institutionalize a human rights approach to disability within the United Nations, Member States and civil society. As part of this approach, Article 33 on the national monitoring mandates that States must also “consult with and actively involve persons with disabilities” in the development of legislation and policies to implement the Convention and other decision-making related to PWDs<sup>24</sup>. The rallying cry of the disability community, “Nothing About Us Without Us” is now more than just a plea, but a principle of the Treaty.

<sup>22</sup> U.N. Human Right Council. [“Convention on the Rights of Persons with Disabilities: A Progressive Human Rights Instrument”](#) Statement by the Special Rapporteur on Disability Hissa Al Thani, September 2006.

<sup>23</sup> [“Lauding disability convention as ‘dawn of a new era,’ UN urges speedy ratification.”](#) UN News Centre, December 13, 2006.

<sup>24</sup> Article 4(3) on General Obligations also states a similar responsibility of States Parties.



Tina Minkowitz (right) of World Network of Users and Survivors of Psychiatry and Maria Reina (left), represent the International Disability Caucus at the General Assembly adoption of the CRPD.

### ***The drafting process***

The drafting and adoption of the Convention on the Rights of Persons with Disabilities has spurred the maturation and globalization of the disability rights field. Disabled people's organizations (DPOs) from all over the world have strengthened their advocacy efforts and infused their work with a human rights framework. The negotiating process has catalyzed the field into a self-aware human rights movement. The Deputy Secretary General of the United Nations noted that "[i]t was the community of the disabled

themselves that worked tirelessly and insistently to promote this Convention, and the United Nations responded."<sup>25</sup>

Ironically, their very marginalization helped integrate the participation of PWDs into the drafting process. Ambassador MacKay (Coordinator of the Working Group, which developed the core treaty draft) explained that while normal protocol would require that civil society representatives be seated apart from Member States, the UN facilities could not accommodate a separate seating area for persons with physical impairments. As a result, PWDs sat next to delegates working as colleagues, promoting awareness of the real challenges faced by PWDs in their daily lives and cultivating collegial relationships between Member States and DPOs. In addition, many government delegations included PWDs as delegation members.

Janet Lord, formerly an advocacy attorney at Landmines Survivor's Network, noted that "To see a group that is so traditionally marginalized and left out of international and even regional decision-making, having a role – it was very inspiring and empowering." She went on to note the participation of disability groups from developing countries: "It's remarkable and amazing. It's really a South-driven process...They are the countries initiating this, generating tremendous participation in the process."<sup>26</sup>

During the last drafting session of the Treaty, UN High Commissioner for Human Rights, Louise Arbour, stated that she believed the process was "one of the most successful collaborations between States, civil society organizations, national human rights institutions and inter-governmental organizations in any UN forum."<sup>27</sup>

### ***The next steps***

On March 30, 2007, the Treaty will be open for signature and ratification. Given the low threshold (20 countries) and high level of support, the Treaty is expected to enter into force within a year. The table below<sup>28</sup> outlines the timeline for the Convention.

<sup>25</sup> [Secretary-General's message on the adoption of the Convention of the Rights of Persons with Disabilities](#) (delivered by Mr. Mark Malloch Brown, Deputy Secretary-General), 13 December 2006.

<sup>26</sup> "One Step Closer to a Convention on the Rights of People with Disabilities," Landmine Survivor's Network web site.

<sup>27</sup> "Statement by Louise Arbour, UN High Commissioner for Human Rights to the Resumed 8th Session of the Ad Hoc Committee on the Convention on the Rights of Persons with Disabilities," 5 December 2006.

<sup>28</sup> Adapted from Disabled Peoples' International [Ratification Toolkit](#).

December 2001	Mexico sponsored a General Assembly resolution calling for the establishment of an Ad Hoc Committee (AHC)
2001 – 2006	<b>Negotiations ensued</b>
December 13, 2006	<b>Treaty adoption:</b> General Assembly adopted the Convention on the Rights of Persons with Disability
March 30, 2007	<b>Signature:</b> Convention open for signature
2007 or 2008:	<b>Ratification:</b> 20 countries needed for Convention to enter into force
2008 – 6 months after entry	<b>Monitoring body:</b> Secretary-General of the United Nations convenes the Conference of the States Parties
2010	<b>Reporting:</b> Filing of first country reports to the monitoring body
Ongoing	<ul style="list-style-type: none"> <li>• Additional ratifications until all UN Member States are States Parties</li> <li>• States Parties draft national disability action plans – a process carried out with leadership from, and close consultation with PWDs</li> <li>• UN bodies, such as UNICEF, start to comprehensively integrate disability and persons with disabilities into all their programming</li> <li>• National and international development agencies integrate disability and persons with disabilities into all their programming</li> </ul>
2010 – 2020	States Parties implement national disability action plans

In the years to come, the challenge will be to translate this remarkable document into real changes in the lives of persons with disabilities. The Special Rapporteur on Disability reported to the United Nations Human Rights Council in September of 2006:

Adopting, signing and ratifying this Convention has to go hand in hand with the serious work of raising awareness about the rights stated in it, changing the social attitudes, ideas and behaviour towards persons with disabilities, and finally legislating for change and monitoring the implementation and enforcement of that change. Without such actions, this Convention cannot live up to the potential for which it was created.<sup>29</sup>

## Top five reasons to support disability rights now

The development of the CRPD underlines the imperative to improve the human rights of the 650 million people with disabilities around the world. Several catalysts working together provide compelling reasons for funders to support disability rights. Supporting this work now will allow funders to:

- End the human rights movement’s marginalization of 650 million people;
- Ensure that the most progressive international human rights treaty enters into force;
- Build on the forward momentum created by the treaty process;
- Achieve compelling impact with small grants due to relative lack of funding; and
- Increase effectiveness of current grantmaking through inclusion of disability.

<sup>29</sup> U.N. Human Right Council. [“Convention on the Rights of Persons with Disabilities: A Progressive Human Rights Instrument”](#) Statement by the Special Rapporteur on Disability Hissa Al Thani, September 2006.

### ***End the human rights movement's marginalization of 650 million people***

The birth of a new core UN human rights treaty presents an opportune moment for funders to support a burgeoning and energized human rights constituency. The disability community has embraced human rights. However, the human rights community, advocates and funders alike, have not recognized this new and incredibly large constituency of human rights advocates. At the same time, disability groups are only just beginning to develop their human rights expertise. In a UN survey done in 2000, disability NGOs stated that they saw themselves primarily as human rights NGOs. However, most "felt inhibited by a general lack of material and human resources and were deterred by the seeming inaccessibility of information about how the human rights treaties worked in the context of disability."<sup>30</sup> In addition, few mainstream human rights organizations have developed disability expertise or even explicitly acknowledge disability as a human rights issue. Disability and human rights organizations need the resources to ensure that the larger human rights movement incorporates the human rights of persons with disabilities.

### ***Ensure that the most progressive international human rights treaty enters into force***

If implemented, the Convention offers a powerful normative tool for human rights advocacy work. As the new authoritative statement on how human rights principles apply to disability, it has the potential to accelerate disability rights advocacy. While PWDs make up the world's largest minority, disability rights activism remains at relatively low levels compared to other constituencies/issue areas such as children, women, torture etc. Once in force, the Treaty can be used to highlight human rights abuses. It frames a policy agenda for the field, providing an invaluable advocacy and organizing tool for monitoring and implementation. The challenge will be to build on the Convention's adoption by supporting the capacity of DPOs and their allies to secure ratification, implementation and monitoring. Support must be given to organizations working to ensure that the Treaty, in fact, fulfills the rights of persons with disabilities around the world.

The Convention also highlights the interconnections between multiple forms of discrimination. A recent UN survey revealed a striking example when 37 countries reported that they do not provide education for women with disabilities or disabled members of minority groups.<sup>31</sup> The Treaty's progressive language around issues such as sexual rights, women, and participation of civil society in policy development has the potential to be leveraged and duplicated in other human rights settings.

### ***Build on the forward momentum created by the Treaty process***

The drafting and adoption of the CRPD has created a unique focus, momentum, and organizing tool for the disability rights field and provides a strong leveraging point. The drafting process led to an extraordinary focus on disability issues by UN Member States, intergovernmental agencies, NGOs and funders alike. Not only did the process increase

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<sup>30</sup> Degener and Quinn, 6.

<sup>31</sup> Commission for Social Development, 45<sup>th</sup> session. *Monitoring of the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (E/CN.5/2007/4), 16 November 2006.

awareness of those involved in the negotiations, it also raised public awareness of disability rights and their meaning. It energized civil society exemplifying how it can advance disability rights at the international level. This momentum must now be channeled to stimulate the development of legal protections and policy change at the national and local levels. Funders have a unique opportunity to help make this change a reality.

The drafting process started to build the human rights capacity of DPOs. Organizations sharpened their policy-advocacy skills, gained the attention of power brokers and helped develop a comprehensive human rights treaty for people with disabilities. Given the severe and routine marginalization of people with disabilities, this is an enormous accomplishment and one that presents follow-up opportunities for action. Without additional activities and investment, this momentum will not be maintained. Disability groups need the resources to channel the political focus into substantive social change.

Lastly, the disability field has been able to engage countries that lack previous positive involvements with the UN human rights system. Disability may be a vehicle for general human rights principles to gain traction in certain regions of the world, such as the Middle East. It is worth noting that many developing countries were among the most active participants in the Treaty negotiations. Human rights funders should seize this opportunity to further advance human rights.

### ***Achieve compelling impact due to relative lack of funding***

Private philanthropic support of international disability organizations is almost non-existent, as few grantmakers have included disability within their programming (several exceptions are noted below in the section on current funding). Given the relative dearth of funding, there are many openings for grantmaker impact, and donor engagement could easily leverage vital additional resources. The movement possesses great potential for progress and success. Looking at the Convention process, the International Disability Caucus achieved remarkable advances with almost no budget and little outside help. By supporting initiatives that build local capacity, nurture creative advocacy at the field level, and build education and awareness tools, donors could make implementation and progress possible. Donors are also well-poised to add considerable value by identifying and catalyzing opportunities for grantees to better coordinate their efforts and share best practices.

### ***Increase effectiveness of current grantmaking through inclusion of disability***

Grantmakers can enhance the effectiveness of current programs by including people with disabilities. Due to its connection with multiple forms of discrimination, disability is relevant to the constituencies that many funders care about, including women, ethnic minorities and the poor. Across issue areas, grantmakers often strive to reach marginalized populations to achieve social change. By widening the circle of inclusion to include particularly marginalized groups, funders can advance a rights-promoting culture to the benefit of all. Whether the focus of grantmaking is on poverty, HIV/AIDS, women, education, human rights, etc., if grantmaking support ignores the most marginalized populations its effectiveness is diminished. If grantees exclude PWDs, "inclusive" projects are actually excluding a population that has the potential to experience (and advance) meaningful social, economic and political change. Grantmakers do not need to

change guidelines or area focus, but they should seek to ensure that the projects and groups supported are inclusive of PWDs. Just a few facts illustrate the marginalization of PWDs:<sup>32</sup>

- **Poverty:** The World Bank estimates that 20 percent of the world's poorest people are disabled, and within their communities they are regarded as the most disadvantaged.
- **Education:** UNESCO estimates that 90 percent of children with disabilities in developing countries do not attend school.
- **Labor:** Unemployment for PWDs is as high as 80 percent in some countries.
- **Children:** For every child killed in warfare, three are injured and permanently disabled.

## Strategies for funding the human rights of people with disabilities

Funders could employ many different strategies and approaches to advance the human rights of people with disabilities. After extensive field consultations, several overarching recommendations for disability grantmaking are outlined below to complement the five strategies for disability rights funding.

### *Considerations for disability funding*

The disability funding field remains open and relatively untainted by common grantmaking pitfalls. As the field grows, it is important for funders to continue to support the active participation of PWDs at all levels of activity, and to nurture collaboration and collective learning experiences. The following recommendations summarize the learning of current funders as well as the advice of the grantseekers themselves:

- The disability community lives by the mantra, "Nothing About Us without Us." While many non-DPO organizations are highly qualified to advance this work, efforts led by DPOs or PWDs (including support organizations for families of PWDs) should be prioritized as they empower the community to help itself. If the DPO lacks capacity, one grantmaking tactic would be to support DPOs in collaboration with other NGOs that can offer professional staff, fundraising experience, and sometimes local knowledge.
- As with many other fields, particular sub-groups are sometimes excluded from programming intended to create change for all. Within the disability field, people with physical disabilities are sometimes involved to the exclusion of people with mental disabilities, the deaf, blind etc. In addition, women and youth are often excluded. Grantmakers should pay particular attention to projects that incorporate cross-disability perspectives (bringing together people with all types of disabilities), and that include women and youth.
- Mainstream human rights organizations have not yet embraced disability rights. Collaboration between disability organizations and human rights organizations could bring about more effective advocacy, incorporate disability more fully into general human rights advocacy and build capacity within the disability field. However, many disability rights advocates worry that these larger, better

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<sup>32</sup> ["Some Facts about Persons with Disabilities,"](#) UN website entitled Convention on the Rights of Persons with Disabilities.

financed nonprofits lack disability expertise and do not represent the disability community. Grantmakers could support such collaborations by directing the support through disability organizations to empower the disability voice.

### ***Capacity building***

Capacity building may be an overused catchword, but it is the number one need for the disability field to be able to fulfill the rights of persons with disabilities. Many of the international organizations in this field are quite small (most have annual budgets under \$500K). While they often have sophisticated board or committee structures, many lack paid executive directors, program staff or fundraising experience. Many already have a strategic vision, but lack the ability to implement it. Several funding methods can be used to strengthen the field:

- General support for disability organizations that currently lack staff and/or require a stronger organizational structure before they can take on rights initiatives;
- Funding for international and national groups to provide training, technical assistance and other forms of capacity building to grassroots organizations;
- Program staff support for human rights initiatives;
- Project support for disability organizations seeking to enhance their human rights capacity; and
- Support for the development of tools or education materials that can be widely disseminated to raise awareness and knowledge of disability rights, particularly the CRPD, among disability and human rights professionals.

### ***Trainings, convenings and coalitions***

During the drafting process of the CRPD, hundreds of disability advocates strengthened their understanding of the UN human rights system, honed their arguments around the realization of disability rights and networked with colleagues from all over the world. Yet thousands more seek to learn about how the Convention can impact their work, how they can use it to change national legislation and how they can learn from fellow advocates around the world. Disability organizations have used the Internet, email list serves and other electronic media to help educate and raise awareness of disability rights, and the CRPD in particular. However, much more work is needed to educate and empower greater numbers of disability advocates and organizations.

In addition, electronic media are inaccessible to many PWDs, either because they lack technological resources or because they face barriers due to their impairment (for example, not all electronic formats are accessible to the screen-readers used by many blind people). In-person conferences and convenings are integral to help the movement maintain the cohesion that was nurtured during the years of the Convention's drafting. Funding for trainings, convenings and networks would educate PWDs about their human rights, raise their voices within their communities and empower PWDs to advocate for their rights.

- Training and convening (networking) support could take several forms:
  1. Provide basic knowledge on the Convention and how it can be applied to local legal and social systems as well as particular impairments;
  2. Help disability rights advocates learn to engage the UN system, particularly the treaty body system;

3. Strengthen advocacy and lobbying skills at the national level with particular focus on the Convention as a tool;
- Support for PWDs to participate in trainings via travel grants; and
  - Ongoing support for international networks and coalitions.

### ***Advocacy***

Like the efforts supporting the Convention, the advocacy work of potential grantees should focus on strengthening the protective environment for people with disabilities. Many organizations will be working to convince policymakers, governments and multinational institutions to support and implement legislation and policies that give effect to the rights enshrined in the CRPD. For example, article 32 calls on States parties to ensure that development aid is inclusive of and accessible to persons with disabilities. Advocacy at the national and local level will be critical, since this is where policies and programs are implemented and where most PWDs will experience positive change (and/or rights violations). The strength of the field's advocacy will be pivotal in continuing to generate attention and international engagement around disability rights and ensuring that the movement retains its momentum.

Advocacy projects that promote, protect and ensure the full and equal enjoyment of all human rights by all persons with disabilities could take many different forms.

Grantmakers could consider supporting advocacy directed at:

- National policy makers to sign, ratify and implement the Treaty provisions;
- Development agencies and humanitarian agencies to mainstream disability and ensure that resources are available to implement the Treaty's commitments;
- Government officials, judges and legislators to increase their awareness and inclusion of disability rights in their work;
- Regional human rights mechanisms, such as the Inter-American Court of Human Rights and the European Court of Human Rights to address disability issues; and
- International human rights NGOs to take on disability rights work, preferably in collaboration with disability organizations.

### ***Treaty monitoring and reporting***

Once the Treaty enters into force, the disability community will need to be ready to monitor and report on how countries implement the Convention's provisions. Like other international human rights treaties, the CRPD establishes an expert body that requires State Parties to report on their progress in complying with the Convention's obligations. The CRPD goes further, and specifies that civil society, including PWDs, should participate fully in the monitoring process. The practical ability for PWDs and their organizations to participate will be key to addressing the structural causes of the abuses that PWDs experience and the barriers they face in enjoying their human rights.

Due to the historic invisibility of PWDs in the international human rights system, few groups have experience with the UN system of treaty bodies or the skills to monitor and report human rights abuses. Monitoring and reporting activity entails the compilation of reliable data about rights violations, the generation of reports for advocacy (particularly shadow reports), and the raising of awareness of violations of the rights of PWDs.

Grantmakers could support several different efforts around monitoring and reporting:

- Funding for collaborative efforts to ensure comprehensive data collection, the targeted dissemination of reports and more effective advocacy. Such collaboration might take the form of a standardized NGO monitoring and reporting system that could impact the future treaty body of the CRPD;
- Since most existing monitoring/reporting efforts combine the work of international organizations with those of grassroots groups, grants could take the form of subgrants to local groups, or could cover larger organizations' costs for training local groups in monitoring and reporting; and
- Support to convene regional or national gatherings to share research, consolidate reporting or provide training in this area.

### ***Applied Research***

While most disability NGOs are not engaged in research, several universities around the world have focused centers and/or staff around the issue of disability and human rights. These centers seek to undertake research around disability legislation and the use of human rights law as applied to disability. Legal research and training around disability rights provides an integral resource of expertise and information from which advocates can draw. Such academic institutions include: Syracuse University's Center on Human Policy, Law, and Disability Studies, the Law Department at the National University of Ireland, Galway; and the Diplomacy Training Program affiliated with the Faculty of Law, University of New South Wales.

## **Current funding of disability rights**

Private funding of disability rights is almost non-existent. Disability funders often focus on US work, and human rights funders have not yet integrated disability into their programs. Public funding of disability is limited, yet more readily available to international disability groups. Development agencies, such as the Swedish Agency for International Development Cooperation (SIDA), the Canadian International Development Agency (CIDA), the UK's Department for International Development (DFID) and the United States Agency for International Development (USAID) all provide project funding to disability groups.

The UN Voluntary Fund on Disability has been particularly active around human rights issues. Its funding priorities are targeted at building the capacity of non-governmental organizations to participate in the Convention process and its future implementation. The Fund also provides small grants to support catalytic and innovative action in order to promote greater awareness of disability issues, facilitate exchanges of knowledge and experience, and permit wide dissemination of appropriate disability technologies.

The **ABILIS Foundation** is a public charity, founded by people with disabilities in Finland in 1998. ABILIS seeks to promote the human rights, equal opportunities and independent living of people with disabilities in the Global South through supporting organizations run by people with disabilities. In 2005, ABILIS made grants awards totaling 834,110 euros and managed 162 projects. ABILIS awards small grants ranging from 500 to 20,000 euros initiated by PWDs and gives special priority to activities developed and implemented by women with disabilities.

Through grants to grassroots organizations, volunteer service, advocacy and education, **American Jewish World Service (AJWS)** fosters civil society, sustainable development and human rights for all people. AJWS strives to address disability rights both by supporting projects specifically targeted to the needs of the disabled and by encouraging partners to address disabled individuals' needs within broader programming in areas such as education, health, economic development and HIV/AIDS. AJWS currently partners with three innovative groups undertaking disability rights work: Women and AIDS Support Network in Zimbabwe that targets women and girls with disabilities; Cambodian Volunteers for Community Development which works with individuals and their families who have been disabled by landmines; and the Association of Disabled Females International in Liberia, which seeks to promote and protect the fundamental human rights of women with disabilities in Liberia.

The **Fund for Global Human Rights (the Fund)** works to ensure a strong, effective human rights community worldwide by supporting frontline organizations challenging abuse wherever it occurs. The Fund supports campaigns that otherwise might falter for lack of resources, brings financial stability to groups, and helps organizations take their work to the next level in terms of visibility and impact. The Fund supports organizations that promote the human rights of persons with disabilities. In 2006, the Fund awarded \$57,500 to disability rights organizations in Morocco, Liberia, Guatemala and India with a median grant size of \$10,000.

**The Global Fund for Women (GFW)** advocates for and defends women's human rights by making grants to support women's groups around the world. GFW prioritizes groups that are organized and led by women from marginalized populations, including women with disabilities. It provides significant funding to organizations led by and/or serving women with disabilities. In its 2005-2006 fiscal year, GFW distributed \$274,600 to 28 grassroots disability organizations in 21 countries; the median grant size was \$6,000. About one-third of the grantees reported no other sources of formal funding.

The **Inter-American Foundation (IAF)** is an independent U.S. government agency that provides grants to nongovernmental and community-based groups in Latin America and the Caribbean. The IAF helps marginalized communities to overcome biases and achieve full participation in economic and civic life. The IAF has supported projects designed and managed by a variety of DPOs that focus on prevention, education, rehabilitation, and job development. The IAF has also provided travel grants so that disability activists from Latin American could attend the drafting sessions of the disability rights treaty. From 2004 to 2006, the IAF has invested over \$2 million in projects that actively include and benefit persons with disabilities.

**Mama Cash** supports innovative initiatives by women who advance women's rights worldwide. Its niche is to support pioneering women's rights initiatives. Mama Cash supports small groups, often newly established, that have difficulty finding resources elsewhere because of their small size or innovative approach. Mama Cash explicitly targets women with disabilities for support. In 2005, Mama Cash provided more than \$150,000 to support to women's disability rights organizations.

The **Open Society Institute's** (OSI) disability funding is focused in its human rights and governance program as well as its Mental Health Initiative (MHI). Working in Central and Eastern Europe and the former Soviet Union, MHI aims to ensure that people with mental disabilities, including intellectual disabilities, are able to live as equal citizens in the community and to participate in society with full respect for their human rights. MHI's activities seek to end the unjustified and inappropriate institutionalization of people with mental disabilities by advocating for the closure of institutions and the development of community-based alternatives. OSI's Human Rights and Governance Grants Program supports national and international advocacy organizations promoting political and civil rights at local, national and regional levels. Priority is given to projects that address the needs of vulnerable and marginalized groups and those that have strong monitoring and legal advocacy components.

## **Potential grantees: international disability rights organizations**

The breadth of organizations potentially involved in disability rights is quite broad (i.e., any human rights organization). To provide focus, the following organizations were selected based on several criteria:

- The organization's work is dedicated to disability with some rights component;
- The organization works internationally on disability rights; or
- The organization is a disabled people's organization (DPO), which means it is a member organization of PWDs controlled by a board composed of at least 50% people with disabilities.

Organizations in the disability rights field could be classified into the following categories. The organizations described here fall into the first three:

- Cross-disability international focus (e.g., Rehabilitation International)
- Impairment specific international focus (e.g., World Federation of the Deafblind)
- Cross-disability regional focus (e.g., European Disability Forum)
- Country focus/grassroots (e.g., Lebanese Council of Disabled People)

The [International Disability Alliance](#) (IDA) represents more than 650 million people in the world with a disability. The alliance is composed of eight international organizations of and for people with disabilities (DPOs), which are briefly described below. IDA does not currently have a formal organizational structure.

### ***IDA Members***

Many IDA members do not have paid staff for their headquarters. As membership organizations, however, almost all have regional or national members that employ staff.

[Disabled Peoples' International](#) is a cross-disability international network of national organizations or assemblies of disabled people, established to promote the human rights of disabled people through full participation, equalization of opportunities and development. DPI has assemblies in 135 countries and operates regional offices in Africa, Asia/Pacific, Europe, Latin America and the Caribbean. Eighty percent of DPI's assemblies are located in developing countries. DPI's main objectives are to: promote

the human rights of disabled persons; promote economic and social integration of disabled persons; and develop and support organizations of disabled persons.

[Inclusion International](#) (II) is a grassroots organization of persons with intellectual disabilities and their families. With member societies in over 115 countries, it advocates for the inclusion of people with intellectual disabilities in all aspects of their communities, based on shared values of respect, diversity, human rights, solidarity and inclusion. II's priorities include: UN Disability Convention, Poverty Reduction, Inclusive Education, Children and Families, Millennium Development Goals, Self-advocacy and Human Rights.

The [International Federation of Hard of Hearing People](#) (IFOH) consists of national associations of and for hard of hearing and late deafened people, and parents' and professional organizations. IFOF provides a platform for co-operation and exchange of information between hard of hearing organizations and promotes understanding of and a positive attitude by society towards hard of hearing people.

[Rehabilitation International](#) (RI) is a global network of persons with disabilities, NGOs, service providers and government agencies working together to advance the rights and inclusion of people with disabilities. RI is composed of over 700 members in nearly 100 nations. RI works toward increasing international collaboration and advocates for policies and legislation recognizing the rights of PWDs and their families. It provides training and technical assistance on accessibility and technology, education, rehabilitation and habilitation, health, national policies and services, employment, social inclusion and participation, and sports and leisure activities. With regional leadership in Africa, the Arab region, Asia, Europe, Latin America and North America, RI provides a forum for the exchange of information on research and practice.

[The World Blind Union](#) (WBU) represents 180 million blind and partially sighted people in over 160 countries, representing approximately 600 organizations. The WBU advocates for the human rights of blind and partially sighted people and seeks to strengthen their organizations and advance the participation of women and youth. It seeks to promote prevention and treatment of blindness; improve the living conditions of blind people, particularly in developing countries; ensure the right to education and rehabilitation; and strengthen self-awareness of blind and partially sighted people.

[World Federation of the Deaf](#) (WFD) represents deaf people worldwide. WFD works for human rights and equal opportunities for deaf people everywhere. At present, emphasis is placed on: improving the status of national sign languages, improving education and access to information and services, improving human rights for deaf people in developing countries and promoting the establishment of deaf organizations.

[World Federation of Deafblind](#) (WFDB) is a society of national organizations of deafblind persons, deafblind individuals, and of other concerned individuals, organized to advance the economic, educational and social welfare of deafblind persons. The aim of WFDB is to improve the quality of life of deafblind people world wide and identify deafblind people in order to break their isolation. WFDB also seeks to educate the public about deafblindness and the services needed for deafblind people to live independent lives.

World Network of Users and Survivors of Psychiatry (WNUSP) is a global forum and voice of users and survivors of psychiatry to promote their rights and interests. WNUSP seeks to protect the human rights, self-determination and dignity of users and survivors of psychiatric treatment worldwide.

### ***Regional DPOs/NGOs***

The [Asia Pacific Disability Forum](#) was established in 2003 to promote, participate in and evaluate the implementation of the Biwako Millennium Framework of Action Towards an Inclusive, Barrier Free and Rights Based Society for Persons with a Disability in Asia and the Pacific. The regional NGO network seeks to promote the principles of the Asian and Pacific Decade of Disabled Persons, 2003-2012.

[European Disability Forum](#) (EDF) is an umbrella organization representing more than 50 million people with disabilities in Europe. Its mission is to ensure disabled citizens' full access to fundamental and human rights through their active involvement in policy development and implementation in the European Union. EDF member organizations include the national councils of disabled people from all EU Member States. The EDF runs policy actions, networks with EU Institutions, international and European organizations and seeks to help integrate a disability perspective. They campaign to dismantle the barriers that deny people with disabilities equal opportunities and address universal access. EDF strengthens civil society in the accession countries by supporting the establishment of national councils of PWDs and preparing disability organizations for full status as members of the EU and the EDF. The EU provides 80% of EDF's funding.

The [Inter-American Institute on Disability \(IID\)](#) seeks to empower people with disabilities and their families in the Inter-American region. The Institute is dedicated to advancing human rights of persons with disabilities (in legislation and in practice) and promoting the political participation of their organizations. IID has been integral to the development of Project South, which seeks to strengthen the participation of disabled leaders and movements from developing countries during the process of signature, ratification and implementation of the Convention. IID also disseminates information and provides training and technical assistance to advance inclusive development.

The [Mental Disability Advocacy Center](#) (MDAC), based in Budapest, seeks to promote and protect the human rights of people with mental health problems and intellectual disabilities across central and eastern Europe and central Asia. MDAC works through litigation, research and international advocacy. It files applications in domestic and international courts, advises governments by commenting on draft legislation, and provides legal materials. The research and monitoring program addresses inhuman or degrading treatment or punishment by focusing on the issue of cage beds. MDAC advocates for the human rights of people with mental disabilities at the international level. Working with local lawyers, NGOs and key stakeholders, MDAC elevates local issues into international concerns through shadow reports, press releases, and position papers.

### ***International NGOs***

[Disability Rights Promotion International](#) (D.R.P.I.) works to establish an international monitoring system to address disability discrimination worldwide. D.R.P.I.'s goal is to

support monitoring with an individual, systems and media focus and capture the depth and scope of the disability discrimination. D.R.P.I. believes that thorough and accurate data is a valuable advocacy tool, and offers documentation for governments to develop policies inclusive of PWDs. D.R.P.I undertakes: 1) Fact-finding of individual violations, monitors violations to raise awareness of the nature and extent of violations and provides facts for advocacy efforts; 2) Documents how laws violate or protect disability rights, how laws are implemented and enforced and tracks how courts address, interpret, and enforce laws related to disability rights; and 3) Tracks media coverage of disability.

[Handicap International](#) (HI) supports the needs of people with disabilities in countries affected by poverty and conflict through prevention, rehabilitation, inclusion, capacity building and emergency relief. It provides both emergency relief and long term development support. HI's seeks to work in partnership with local organizations and government institutions, build capacity, transfer knowledge and training, raise awareness on disability and landmine issues, mobilize civil society and serve people with disabilities in emergency situations.

[Landmine Survivor's Network](#) (LSN) empowers individuals, families and communities affected by landmines to recover from trauma, reclaim their lives, and fulfill their rights. LSN provides healthcare and rehabilitation services, social and economic reintegration programs and works to ban landmines around the world. It advocates for systemic changes at the local, national and international levels to ensure the rights of all persons with disabilities. LSN played a crucial role in the Convention negotiating process, developing operative drafts and commentaries that were used by the broader NGO and government participants.

[Mental Disabilities Rights International \(MDRI\)](#) promotes the human rights and full participation of persons with mental disabilities worldwide. It publishes reports on human rights conditions and enforcement, and promotes international oversight of the rights of people with mental disabilities. MDRI trains and supports advocates seeking legal and service reform and assists governments to develop laws and policies to promote community integration and the fulfillment of human rights for people with mental disabilities. MDRI forges alliances throughout the world to challenge discrimination and abuse, and works with locally-based advocates to promote citizen participation and human rights for children and adults.

[Mobility International USA](#) (MIUSA) is a cross-disability organization that seeks to empower people with disabilities around the world to achieve their human rights through international exchange and development. MIUSA pioneered short-term international exchange programs in the disability field, and has worked with PWDs from over 90 countries. MIUSA promotes the inclusion of people with disabilities in international exchange programs and provides technical assistance, information, and training to international development, relief, and refugee agencies for the full inclusion of PWDs at every level of the development process. MIUSA also works for empowerment, equal opportunities and human rights for women and girls with disabilities. It seeks to infuse the perspectives of women with disabilities into international women's movements and development agendas.

[World Institute on Disability](#) (WID) is a research, training and advocacy center that promotes the civil rights and full societal inclusion of PWDs. WID has earned a reputation for groundbreaking research and public education and serves as a center for the international exchange of information and expertise on disability policy. WID is committed to aiding disability organizations throughout the world to create networks, programs and services that promote the full inclusion of disabled people in their societies. Internationally, WID's activities include training, technical assistance, program development and evaluation, legislative and policy development, exchange programs, research, conferences, materials development and international resource and referral.

## Disability rights resources

A wealth of information is available on disability and human rights. Below is a small sampling of publications and websites that provide in-depth analysis of this issue.

### *Publications*

"Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard," Groce, Nora E. (Harvard University Press, 1988).

Nothing About Us Without Us: Disability Oppression and Empowerment. Charlton, James I. (University of California Press, Berkeley 2000).

Human Rights and Disability: The current use and future potential of the United Nations human rights instruments in the context of disability. Theresia Degener and Gerard Quinn (United Nations, New York and Geneva 2002).

Understanding the Role of an International Convention on the Human Rights of People with Disabilities: An analysis of the legal, social, and practical implications for policy makers and disability and human rights advocates in the United States (National Council on Disability, June 12, 2002).

### *Websites*

Organization	Resource
Convention on the Rights of Persons with Disabilities (UN)	<a href="#">Some Facts about Persons with Disabilities</a>
Disability Rights and Education Fund (DREDF)	<a href="#">Resource links</a>
Disability Rights Promotion International (D.R.P.I.)	<a href="#">A Human Rights Approach to Disability</a>
Disabled Peoples' International	<a href="#">Ratification Toolkit</a>
Inter-American Development Bank	<a href="#">Rights of Persons with Disabilities resource page</a>
Mobility International	<a href="#">Locating Disability Organizations</a>
Source	<a href="#">Disability and human rights</a>
Syracuse University, Center on Disabilities Studies, Law and Human Policy	<a href="#">International and Comparative Disability Law Web Resources</a>
UN Enable	<a href="#">UN's central resource on disability</a>
UN Enable	<a href="#">History of Disability and the United Nations</a>
UN Enable	<a href="#">International Norms and Standards Relating Disability</a>
UN High Commissioner for Human Rights	<a href="#">Human Rights and Disability</a>
World Bank	<a href="#">Disability and Development</a>

## Appendix A

### Convention on the Rights of Persons with Disabilities

Annex I	Preamble
Article 1	Purpose
Article 2	Definitions
Article 3	General principles
Article 4	General obligations
Article 5	Equality and non-discrimination
Article 6	Women with disabilities
Article 7	Children with disabilities
Article 8	Awareness-raising
Article 9	Accessibility
Article 10	Right to life
Article 11	Situations of risk and humanitarian emergencies
Article 12	Equal recognition before the law
Article 13	Access to justice
Article 14	Liberty and security of the person
Article 15	Freedom from torture or cruel, inhuman or degrading treatment or punishment
Article 16	Freedom from exploitation, violence and abuse
Article 17	Protecting the integrity of the person
Article 18	Liberty of movement and nationality
Article 19	Living independently and being included in the community
Article 20	Personal mobility
Article 21	Freedom of expression and opinion, and access to information
Article 22	Respect for privacy
Article 23	Respect for home and the family
Article 24	Education
Article 25	Health
Article 26	Habilitation and rehabilitation
Article 27	Work and employment
Article 28	Adequate standard of living and social protection
Article 29	Participation in political and public life
Article 30	Participation in cultural life, recreation, leisure and sport
Article 31	Statistics and data collection
Article 32	International cooperation
Article 33	National implementation and monitoring
Article 34	Committee on the Rights of Persons with Disabilities
Article 35	Reports by States Parties
Article 36	Consideration of reports
Article 37	Cooperation between States Parties and the Committee
Article 38	Relationship of the Committee with other bodies
Article 39	Report of the Committee
Article 40	Conference of States Parties
Article 41	Depositary
Article 42	Signature
Article 43	Consent to be bound
Article 44	Regional integration organizations
Article 45	Entry into force
Article 46	Reservations
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Article 49	Accessible format
Article 50	Authentic texts
Annex II	Optional Protocol to the Convention on the Rights of Persons with Disabilities