



Building community capacity to achieve the human rights of all persons with disabilities

Framework for a Disability Rights Fund

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Overview

The Disability Rights Fund (“the Fund”) is a collaboration designed to address the human rights of persons with physical, sensory, psycho-social and intellectual disabilities in the Global South and in Eastern Europe/former Soviet Union. Building on the momentum of the ground-breaking UN Convention on the Rights of Persons with Disabilities (CRPD), this pooled fund is a unique partnership between disparate groups of funders and the disability community to enlarge the resources available for realization of rights at country level. A bridge to local disability activists and civil society networks, the Fund provides a simple and secure way for donors to address a new area of human rights grantmaking, as well as a means for Disabled Persons’ Organizations (DPOs) to directly communicate priorities to the donor community. Via intelligent grantmaking that involves both donors and persons with disabilities (PWDs) in its governance, the Fund will empower DPOs around the world to participate effectively in the implementation and monitoring mechanisms mandated by the CRPD.

Mission

With the adoption of the CRPD in December 2006, a rare window of opportunity has opened for donors interested in social justice to support a growing social movement. Over the last thirty years, human rights activism has spurred a paradigm shift in the way that PWDs are seen and treated, “moving away from viewing persons with disabilities as problems towards viewing them as holders of rights”.¹ Still, only 45 of the 191 UN Member States have laws to protect PWDs from discrimination, and in many of these countries there are serious gaps in the quality of the legislation, its implementation and enforcement; worse yet, in many cases PWDs are not even recognized as persons before the law. For the most part, therefore, despite advances, PWDs remain impoverished and excluded from all aspects of community life.

The CRPD, signed by 128 countries and entering into force May 3, 2008, offers the potential to dramatically improve this situation. Defining disability not as inherent in persons but as a result of “the interaction between persons with impairments and attitudinal and environmental barriers,”² States Parties have acknowledged for the first time the need for a rights-based approach to disability. In the words of UN High Commissioner for Human Rights Louise

Selected Disability Demographics

Of the 650 million PWDs, 520 million live in the developing world. Disability, which can affect anyone at anytime, is both a cause and an effect of poverty; PWDs constitute a disproportionate number of the poor (15-20% in developing countries). 97% of children with disabilities who live in developing countries do not have any form of rehabilitation; and 98% do not receive any education, making disability the single largest factor keeping children from attending school. The global literacy rate for all PWDs is as low as 3% and as low as 1% for women. Women are more likely than men to become disabled, due in part to gender bias in resource allocation and services provision. In developing countries, women with disabilities face an unemployment rate that is virtually 100%. Women with disabilities are twice as likely to experience domestic violence. And PWDs acquire HIV/AIDS at a rate of up to 3 times greater than that of people without disabilities. The World Bank has noted that without paying attention to the rights and needs of PWDs, Millenium Development Goals are unlikely to be achieved.

¹ *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), p.1.

² *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)*, U.N. General Assembly, 61st Session, 6 December 2006, preambular paragraph (e).

Arbour, “this new instrument comes at a time when there are broad shifts in attitudes within societies towards the rights of persons with disabilities.”³ Reflecting these changing attitudes, the CRPD—drafted with the strong activism and unprecedented participation of PWDs—radically alters the conception of disabilities “from one focused solely on social development to one that acknowledges the human rights consequences of discrimination and the unjust treatment of disabled individuals.”⁴ As perhaps the most important step towards instituting rights, the Convention records States Parties affirmation of the legal personhood of PWDs and mandates State recognition and support of their legal capacity. It also formally recognizes that self-representation is essential to rights-fulfillment and mandates the involvement of PWDs and their representative organizations in implementation and monitoring.

Globally, 80% of all PWDs live in the developing world and DPOs are their representative organizations. Yet, perhaps because of the challenges inherent in international grantmaking (due diligence, accountability), few donors are funding programs addressing disability in the Global South; even fewer work with DPOs; and fewer still explicitly use a human rights framework. Indeed, prior to the Convention, DPOs themselves have not had recourse to a widely-recognized rights-based framework. (If US data are any guide, only 4% of total foundation and corporate spending goes to disability and very little of that, if any, goes towards rights.⁵) Moreover, recent surveys of Southern DPOs suggest that what little funding exists is usually routed through and controlled by Northern INGOs.⁶ Given the resulting power differential, PWDs and DPOs in the South “often have little or no control over what is being done ‘to us’ ‘for us’ or ‘on our behalf.’ [...] As a consequence, development projects can leave behind little but disappointment.”⁷ In short, making human rights grants to DPOs in the South without using Northern INGOs as a channel has required a significant investment of time and resources impossible for most donors.

Addressing the lack of donor involvement in this area and seizing the historic opportunity afforded by the Convention, the Disability Rights Fund is a needed innovation. By working with the disability community

CRPD, Equal Recognition

Article 12, Paragraphs 1, 2, 3

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

CRPD, General Obligations

Article 4, Paragraph 3

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.

³ UN News Service, “UN human rights chief urges States to implement new treaty to protect disabled,” 26 March 2007, at

<http://www.un.org/apps/news/story.asp?NewsID=22016&Cr=rights&Cr1=council>

⁴ Georgetown Law Human Rights Institute, *Contemporary Issues in Human Rights*, March 28, 2007 (paraphrasing Ambassador Don Mackay of New Zealand, chair of the Ad Hoc Committee on the Convention), at <http://www.law.georgetown.edu/humanrightsinstitute/contemporaryissues.3.28.html>

⁵ Disability Funders Network, “Bridging the Knowledge Gap: Working with Foundations to Attract Disability Funding,” at <http://www.disabilityfunders.org/attractdisfund.html>

⁶ Unpublished report, Workshop on Capacity Building of Southern Disabled People’s Organisations, Dhaka, Bangladesh, May 2007

⁷ International Disability Equality Agency, Overseas Development Group, University of East Anglia, “Equalise It ! A Manifesto for Disability Equality in Development Cooperation,” 6 July 2007.

to identify the most effective grantmaking strategies and country-level DPOs, and by making grants directly to these groups, the Fund will:

- afford donors the opportunity to support DPOs as they work to translate the CRPD into domestic reform processes,
- via its regranting, enable large donors to efficiently reach small organizations,
- provide (primarily Northern) donors with access to grantees outside their normal purview,
- build capacity of these DPOs to act as centers for rights-based organizing and advocacy,
- mobilize civil society to build networks within (and between) countries to support ratification, implementation and monitoring of the CRPD,
- document and publish the best practices of its grantees as they work to implement the CRPD, as well as its own best practices in disability rights funding,
- enhance the depth of the international disability rights movement, and thereby
- help realize a society that fully includes PWDs in every aspect of life, as envisioned by the CRPD.

Scope

Utilizing the Convention as an organizing principle, the Fund aims to build the capacity of DPOs in the Global South and in Eastern Europe/fSU to achieve the full spectrum of human rights. Currently seen as a three-year effort to capitalize on the immediate opportunity presented by the Convention, its tenure may be extended contingent upon need and resources. In the first year of operation (2008), to build momentum and test strategies for advancing the achievement of rights outlined in the CRPD, the Fund will conduct a pilot scheme, in 5-7 countries where activists are well-positioned to make changes, where there is political will to incorporate the CRPD in national legislation, and where there has been some investment in DPO capacity-building by other donors.

Working with a smaller set of grantees in the first year offers several benefits. It allows for: 1) careful development of oversight mechanisms that enhance transparency, accountability, due diligence and information-sharing, 2) an evaluative learning process such that feedback from participants and grantees guides structural and strategic change for subsequent years, and 3) development (*e.g.*, in tool kits, training packages, and advocacy strategies) of model methodologies such that South-South, peer-to-peer capacity building is made possible in successive years.

While specific grantmaking strategy will be formulated by the governance structure in early 2008, in general grants will be modest, restricted to DPOs operating from a rights-based perspective in the Global South and Eastern Europe/fSU, and given to (a) increase participation of PWDs in their communities through trainings, convenings and networks, (b) develop awareness of the CRPD among stakeholders, and (c) support advocacy projects that promote, protect and ensure the full and equal enjoyment of all human rights by PWDs.

Other parameters to be determined:

- whether there will be separate funding streams by theme or for different types of organizations, *i.e.*:

- to best focus on the policy and legislative level, allot the majority of funds to cross-disability, umbrella-type organizations (where democratic)
- to address gaps in participation in cross-disability work, define separate funding streams for specific recipient groups, *e.g.*, women with disabilities, people with psycho-social disabilities, people with HIV
- to address advocacy on particular articles of the CRPD, define separate funding streams, for example Article 32 on international cooperation
- size of grants in each funding stream
- whether applications will be accepted only via a formal grants process or also via referrals (to accommodate organizations that lack technical fundraising capacity but are doing good work)
- how the application process can meet the requirements of reasonable accommodation (measures for accessibility include, *e.g.*, rolling deadlines)
- which languages may be used in grant applications
- what kind of reporting, monitoring and evaluation mechanisms to put in place

Upon reaching its initial goal of US \$2 million for start-up, the Fund will begin grantmaking in 2008.

Governance

To minimize the creation of new administrative and oversight structures, the Fund will take advantage of resources available through fiscal sponsorship of the Tides Network. The Tides Center will serve as the fiscal sponsor for the operational activity of the Fund. The Tides Foundation will serve as the legal home for the grantmaking fund. Grantmaking strategy and grant recommendations will be the purview of the Fund.

For too many years, PWDs have been treated as objects of charity rather than as active community participants. The CRPD mandates a change in this dynamic by underlining the participation of PWDs as a principle, a legal obligation and a right.

“Many of the change agents in philanthropy today [also] understand that exclusiveness in grantmaking is a problem”⁸, and they are making changes to better listen to grantee communities and to redefine the relationship between grantmaker and grantee in the interest of more effective grantmaking.

Affirming the inherent logic of a participatory approach and building on the positive results of inclusion in the treaty drafting process, the Fund will integrate PWDs in strategic management with the express goal of ensuring an intelligent grantmaking process that is responsive to the needs of the disability community in different regions of the world.

A Model of Inclusion

The International Disability Caucus (IDC) included 70 international, regional and national organizations representing people with disabilities from all regions of the world and from all groups of people with disabilities. Throughout the negotiation and drafting of the CRPD, IDC was the unified voice of disability communities around the world. 12 members of the IDC were included alongside 27 Member State representatives and 1 representative from National Human Rights Institutions in the 40-member working group which drafted treaty text. Of the 12 members, 7 were chosen from the (then) 7 International Disability Alliance (IDA) organizations and 5 were regional representatives from Europe, the Americas,

International Disability Alliance

⁸ Grantmakers for Effective Organizations, “Listen, Learn, Lead: Grantmaker Practices that Support Nonprofit Results,” 2006, p.4.

Governance of the Fund will be organized as follows:

- Global Advisory Panel
- Steering Committee
- Fund Staff

A **Global Advisory Panel** will be formed to:

- help articulate grantmaking strategy
- explore additional roles for the Fund beyond grantmaking (i.e., technical expertise, convening or policy)
- support fundraising.

The Global Advisory Panel of 12 members will consist of a majority of representatives with disabilities, nominated by disability networks including the International Disability Alliance (IDA) and regional networks such as the Asia-Pacific Disability Forum and the African Decade of Persons with Disabilities, as well as a couple of representatives from other human rights communities. These latter representatives will serve on the Panel in a “bridge-builder” capacity, connecting disability rights advocates with other human rights movements. Every effort will be made to ensure a diverse Panel whose members (a) span the broadest range of (physical, sensory, psycho-social and intellectual) disabilities; (b) originate from Fund target regions; and (c) are experts on particular themes of interest to the Fund, e.g., gender and disability, HIV and disability, conflict and disability, children and disability.

To identify Panel members, DPO networks will be asked to provide candidates, keeping in mind the general principles of the CRPD (Article 3) and based on specific criteria (candidates must be PWDs⁹ from the membership networks of IDA or other DPO networks in the Global South or Eastern Europe/fSU, experienced in DPO management, broadly respected in their community, and able to speak to cross-disability issues of their region). Once a broad selection of candidates are identified, donor representatives and the management of the Fund will identify a final slate of 10 based on qualifications, references and added value. Donors will nominate an additional 2 Panel members from other human rights communities.

Formed in 1999, the International Disability Alliance is composed of the following 8 global networks: Inclusion International, International Federation of Hard of Hearing People, World Blind Union, Disabled Peoples International, Rehabilitation International, World Federation of the Deaf, World Federation of the Deafblind, World Network of Users and Survivors of Psychiatry. IDA's networks comprise national organizations from around the world and represent more than 600 million PWDs. Taking on the role of spokesperson for the international disability movement in global policy matters, the Alliance facilitates cooperation and exchanges of information among the 8 global networks, primarily in relation to multilateral organizations.

CRPD, General Principles

Article 3

The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

⁹ DPO networks representing people with intellectual disabilities may put forward candidates who are not PWDs but rather advocates or family members. Such candidates will be considered in terms of their ability to represent people with more severe intellectual disabilities.

To carry out its activities, the Global Advisory Panel will meet twice annually. To minimize logistical expense, as possible, Panel meetings will coincide with the meetings of the Grantmaking Committee.

Consistent with the pilot approach of the Fund's first year, the initial advisory structure may evolve thereafter. As grantmaking expands, it may become more practical to create formal relationships with regional advisory bodies (started by the Fund or already in existence via a host organization or through frameworks such as the African Decade or the Asia-Pacific Disability Forum) which can maintain closer relationships with local DPOs and provide technical expertise and monitoring & evaluation as needed.

A Steering Committee will be formed to:

- finalize grantmaking guidelines
- vet applications pre-screened by Fund staff for match with selection criteria
- make final grant decisions
- monitor compliance of grants terms and evaluate grantee performance.

The Steering Committee will consist of donor representatives and a subset of the Global Advisory Panel (4 members with disabilities who will be chosen by consensus from among their peers to help present the Advisory Panel's strategic priorities¹⁰). Operating by loose consensus to the extent practicable, the Committee—with the help of Fund staff—will create grantmaking guidelines which integrate Global Advisory Panel recommendations with accommodations for donor interest in particular geographic and/or thematic areas.

Fund Staff will be responsible for drawing up Fund by-laws and policies; coordinating the meetings of the Global Advisory Panel and the Steering Committee; taking guidance from the two bodies and articulating strategy, creating practical & accessible grantmaking tools (such as guidelines for applicants, application materials, web-based resources, outreach materials, reporting and evaluation mechanisms); communicating and managing grantee and prospective grantee relationships; evaluating and ranking applications for match with selection criteria; monitoring grantee progress through site visits, written reports, et cetera; working with donors; and

Potential Advisory Networks

The African Decade of Disabled Persons, 1999 – 2009, formed by the Organization of African Unity, is a Pan-African project to strengthen regional cooperation in the achievement of the full participation and equality of persons with disabilities.

The Asian and Pacific Decade of Disabled Persons, 2003-2012, which aims at implementation of the Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights based Society for Persons with Disabilities in Asia and the Pacific, is supported by the Asia and Pacific Disability Forum (APDF), a regional NGO network on disability.

The Decade of the Americas for the Rights and Dignity of Persons with Disabilities (2006-2016) was declared by the Permanent Council of the Organization of American States on June 6 2006, with the theme: "Equality, dignity, and participation," the objectives of which are the recognition and full exercise of the rights and dignity of persons with disabilities and their right to participate fully in economic, social, cultural, and political life and in the development of their societies, without discrimination and on an equal basis with others.

The Arab Decade of Persons with Disability (2003-2012) declared ten main objectives: education; health; legislation; rehabilitation and employment; the disabled woman; the disabled child; accessibility and transport; globalization, poverty and disability; information and awareness; recreation and sports.

¹⁰ Steering Committee members will be required to state potential conflicts of interest; Advisory Panel members on the Steering Committee will be required to recuse themselves from decision-making during consideration of any proposals from their organizations.

promoting and developing the Fund within the philanthropic community. Staff will also set up systems for documentation of best practices.

To minimize overhead expenditures, thereby ensuring the greatest flow-through of money to grantees, staff hires will be carefully planned to best complement the resources available via Tides, participating donors and partner organizations.

Any staff positions will be explicitly advertised within the disability community with the aim of ensuring that the Fund staff includes persons with disabilities.

Expected Utilization & Outcomes

Grants given by the Fund will be aimed at systemic change. Possible grant scenarios include the following real cases as they relate to various articles of the Convention:

- *Article 12, Equal recognition before the law and Article 13, Access to Justice:* Country W has ratified the CRPD. Within the country, many people who have been labeled with "mental disabilities" are institutionalized for life and have little hope of leaving the institution because they are under guardianship, are not considered legal persons, and therefore, cannot access a lawyer or a judge. A DPO which has been working with these institutionalized populations would like to hire a human rights lawyer to begin a process of legislative reform for people under guardianship, including casework aimed at challenging the abrogation of rights.
- *Article 4, General obligations:* Country X has a relatively strong umbrella DPO which has created a national plan of action on disability to be considered by the government. With the government's ratification of the CRPD, this plan needs revision to ensure that it embodies the rights set out in the Convention. The umbrella DPO must convene its member organizations within a short period of time in order to make changes and build an advocacy strategy which ensures their full and effective participation in the development of legislation and policies to implement the Convention.
- *Article 6, Women with disabilities:* Country Y, which is considering how to domesticate the Convention in national legislation, has an umbrella DPO which is involved in policy advocacy at government levels. Many women with disabilities in the country do not feel well-represented by the umbrella DPO. They have started a cross-DPO partnership campaign to educate leaders on issues of gender and disability and need support in advancing this campaign to ensure that their needs and perspectives are included at policy levels.
- *Article 32, International Cooperation:* Despite a strong international development community presence in post-conflict Country Z, not much development funding has addressed PWDs. Three active DPOs are trying to change this situation and have developed a joint advocacy plan for work in-country, linked to an international campaign to increase development funding for disability.

Especially in the first year of the Fund, grantee work under the various articles of the Convention will be tapped for successful replicable models, which can then be disseminated and leveraged for wide use.

Measurement of success is an inherently thorny endeavor; it is not easy to draw causal links between investment and outcome. While some process indicators, such as number of meetings held, educational materials produced, and number of cases prepared are easily measurable, systemic change resulting from these and other factors is more difficult for grantees to quantify. Measures for grantee evaluation will be discussed with the Global Advisory Panel, decided upon with the Steering Committee, and carried out by Fund Staff in conjunction with Tides grantmaking staff. Looking at success more broadly, the Fund will not only evaluate its grantees, but through evaluative learning will seek to improve its own processes, strategies, and even structure so that it can become a viable ally to a larger social movement which is addressing the unjust marginalization of the world's largest minority. Measures to facilitate this process will be developed and implemented with the help of the International Disability Equality Agency (IDEA), an agency run by persons with disabilities.