

Supporting the Empowerment of Organizations of Persons with Disabilities: A strategy to promote poverty eradication, using the Convention on the Rights of Persons with Disabilities (CRPD) ¹

Catalina Devandas, September 2013

This paper aims to provide concrete suggestions on how to advance the empowerment of persons with disabilities and their representative organizations to promote poverty reduction, using the Convention on the Rights of Persons with Disabilities (CRPD) as a tool of sustainable development. The strategy that will be presented addresses mainly organizations working at national and subnational levels, however mention to experiences at international level will also be made.

▪ Persons with Disabilities and poverty: Snap shot

Persons with disabilities – who make up one billion people around the world² -are the world's largest and most disadvantaged minority. 80 per cent of all people with disabilities live in the developing world and there, make up 20 per cent of the world's poorest people. In the developing world, less than 5 per cent of children and young persons with disabilities have access to education³ and the global literacy rate for adults with disabilities is as low as 3% and 1% for women with disabilities⁴. Women with disabilities are up to three times more likely to be victims of sexual abuse and rape.⁵

As the Director-General of the World Health Organization and the President of the World Bank Group stated in their preface to the World Report on Disability, "To achieve long-lasting, vastly better development prospects that lie at the heart of the 2015 Millennium Development Goals and beyond, we must empower people living with disabilities and remove the barriers which prevent them participating in their

¹ Paper prepared for the Expert Group meeting on "Policies and strategies to promote empowerment of people in achieving poverty eradication, social integration and full employment and decent work for all" organized by UNDESA Division for Social Policy and Development-Social Perspective on Development Branch.

² World Health Organization, "World Report on Disability," 2011, p.xi.

³ Secretary-General of the United Nations in his report on the Implementation of the World Programme of Action concerning Disabled, A/56/169, paragraph 79

⁴ UN DPI fact sheet

⁵ Nora E. Groce, HIV/AIDS and Individuals with Disability, HEALTH AND HUMAN RIGHTS, Vol. 8, No. 2 (2005).

communities; getting a quality education, finding decent work, and having their voices heard.”⁶

- **The CRPD as a legal framework to promote empowerment**

Adopted by the General Assembly in 2006 and entered into force in May 2008, the UN Convention on the Rights of Persons with Disabilities (CRPD) articulates a profound shift in understanding the rights of persons with disabilities. It replaces the charity and medical model with one in which persons with disabilities are recognized as rights-holders who have the same rights as everyone else. It is the first human rights convention of the century, a comprehensive treaty that includes anti-discrimination and substantial provisions to allow human rights enjoyment by persons with disabilities. The Convention is also a development tool, “it highlights the concrete, pragmatic steps that States Parties should take to support inclusion of persons with disabilities into all areas of development –including poverty reduction, it also recognizes the importance of international development cooperation in supporting national implementation efforts”⁷.

Negotiated in a highly participatory manner the CRPD mandates State parties to closely consult and actively involve persons with disabilities and their representative organizations in the development and implementation of legislation and policies for treaty implementation.⁸ This principle of participation of persons with disabilities in decision-making is central to the Convention in line with the disability movement motto: “Nothing about us without us”.

Nonetheless, the obligation to consult with representative organizations of persons with disabilities (DPOs) presented a significant challenge: how to make sure that DPOs in the developing world would be ready to respond to the consultation in an informed and effective manner? The question raised concerns among the international disability community and among human rights donors that were following the CRPD negotiation process. Were national DPOs in the developing world ready to demand substantive consultation at all stages of implementation? Were they ready to participate in a meaningful way in such consultation? The answer in most of the cases was no. DPOs in the developing world lacked the capacity to do rights advocacy; they used to operate under the medical or charity models mostly by providing direct services to PWDs.

⁶ WHO, *ibid*, p.xi.

⁷ Handbook for Parliamentarians. IPU, pag. 7

⁸ CRPD, article 4.3

To be able to monitor the implementation of the treaty persons with disabilities and their organizations were faced with the challenge of increasing their capacity. But how to build the capacity of national, grassroots, rural/remote DPOs on the CRPD to inform legislative and policy change? How to enhance DPO participation in rights achievement and poverty reduction? Would DPOs be able to use the CRPD as means of empowerment?

- **Rights based approach to development: Participation as key component.**

The CRPD responds to a rights-based approach to development, blurring the distinction between human rights and development. According to the Office of the High Commissioner for Human Rights (OHCHR) under this approach, the plans, policies and processes of development are anchored in a system of rights, which helps to promote the sustainability of development work, empowering people themselves— especially the most marginalized—to participate in policy formulation and hold accountable those who have a duty to act.⁹

Participation is thus a key component of rights-based approach to development and a key component to achieve people's empowerment. The OHCHR understands that "Participation means ensuring that national stakeholders have genuine ownership and control over development processes in all phases of the programming cycle: assessment, analysis, planning, implementation, monitoring and evaluation."¹⁰ That definition is very much in line with the principle instituted by the CRPD in article 4.

Also important, the human rights based approach to development, aims both at strengthening the capacity of duty bearers and at empowering the rights holders.¹¹ In this document I will only address strategies to support right holders empowerment, however, when it comes to the CRPD, it is as important to pay attention to the urgent need of building the capacity of the duty bearers¹².

The CRPD enshrines the human rights based approach to development by

9

10

¹¹ Gneiting, Uwe; Bruno-Van Vijfeijken, Tosca; Schmitz, Hans Peter (2009). "Setting Higher Goals: Rights and Development". *Monday Development* 27 (12): 19–20. Retrieved 4/5/2011

¹² Government officials should also get substantive training to understand the CRPD scope. Effective implementation can't occur if the national authorities don't have the technical capacity to develop their obligations.

encompassing both human rights and development dispositions that are interrelated and interdependent. It introduces –for the first time in a human rights treaty- a specific article on international cooperation, stating that all development programmes must be inclusive of persons with disabilities. It gives participation of persons with disabilities a prominent role aiming to ensure sustainable solutions that would also empower a strongly marginalized sector. The nothing about us without us is not an empty declaration; the Convention¹³ can't rightly be implemented without the meaningful participation and progressive empowerment of PWDs. The same applies to any other development strategy or program, from national poverty reduction strategies to the MDGs or the post 2015 agenda. PWDs must participate and be consulted in the national and international debates on the development agenda; not doing so will jeopardize the success of any of those poverty reduction plans. No one must be left behind!

▪ **Strategy to Promote DPO empowerment: Consultation and Participation**

So a clear strategy to promote the empowerment of Persons with Disabilities and their organizations is to promote their meaningful participation and consultation while designing, approving and implementing legislation, policies and programs.

But how should that participation happen? Empowerment can't be an individual process only; it should also aim to increase collective power, both in terms of organizational as well as advocacy capacity. Persons with disabilities will be empowered by participating in a unified manner (represented by organizations) but also by forming strategic alliances with other social sectors. As much as possible participation should allow PWDs to interact with other civil society groups and with relevant/high level authorities.

As mentioned before, a big challenge to secure that meaningful participation is the lack of capacity of marginalized groups. A strategy to overcome that gap needs to focus on building that capacity to advocate for social inclusion. Several international and national stakeholders have opted for this strategy, including the international organizations of persons with disabilities, as multiple interventions are needed to close that gap. In a policy paper published by Handicap International in 2011¹⁴, four major areas for DPO support were identified: 1) organizational and technical

¹³ Article 32

¹⁴ Support to Organisations Representative of Persons with Disabilities, Policy Paper. Handicap International, Technical Resources Division. July 2011.

weaknesses; 2) lack (or low) strategic and advocacy skills; 3) little concrete experience using human rights monitoring mechanisms and structures; and 4) lack of actions to empower individual members.

I would like to present the case study of the Disability Rights Fund, as an entity that was created exclusively to promote participation of DPOs from the developing world in CRPD advancement.

- **The Disability Rights Fund**

The Disability Rights Fund (DRF) is a grantmaking initiative that supports DPOs in the developing world to advocate for the human rights of persons with disabilities, utilizing the CRPD¹⁵. A key aspect of the DRF is that it supports directly and exclusively DPOs, regardless of their level of capacity, as long as their activities are focused on CRPD advancement. Financial and technical support is provided to marginalized/ emergent groups¹⁶ to build their internal capacity and advocacy skills, and to more structured organizations to advance joint advocacy efforts at national level. Grants, allow organizations to begin to address the systemic exclusion and stigma, which drastically affect the livelihoods of persons with disabilities.

In addition to a rights-based approach, the fund also uses a *movement building approach*. This approach means that grants are given not to strengthen individual organizations but to enhance the achievements of disability movements at country level for all PWDs. This leads to more sustainable outcomes, because it is considered that DPOs – and grant dollars– will be more effective if there is a joint voice / joint demand for rights. As part of the strategy to support movement building, the organization:

¹⁵ The Disability Rights Fund (DRF) is a grantmaking initiative that supports DPOs in the developing world to take the lead in advocating for the human rights of persons with disabilities, utilizing the mechanism of the CRPD. It operates as a pooled fund, combining the resources of multiple governmental and private donors¹⁵, and in doing so, enables these donors to harmonize their efforts and provides them with an efficient way to reach organizations of marginalized populations outside their normal purview. In accordance with the CRPD, DRF's structure incorporates people with disabilities at all levels – governance, advisory, and staff; which enhances DRF ability to outreach to, assess and support DPOs, and increases DRF understanding of context.

¹⁶ The fund strongly encourages applications from emergent organizations and marginalized sectors of the disability community.

- Assess the situation on the ground in terms of structural conditions for rights achievement – legislative situation, government bodies responsible for disability, and gaps in the disability movement;
- Creates country strategies/objectives, used to select and support grantees;
- Holds annual grantee meetings—to learn about each other activities and avoid potential overlap. Grantees also work toward building an agreed advocacy strategy, and have the opportunity to meet with important external stakeholders that are brought in to the meetings, who they may otherwise not have the possibility to meet (government, NHRI, other donors, etc):
- Provides technical assistance to specific projects working on national scope projects on legal or policy harmonization and on international monitoring.

Achievements of DPOs in advancing the CRPD

Supporting the capacity building and direct participation of PWDs in decision-making process is starting to show important results, just to show an example, in **Peru:**

- Inclusion of persons with disabilities as beneficiaries of the participatory budgeting process in Cusco and Puno (two DPO projects have been already funded using this mechanism)
- Organizations of women with disabilities from the Lima slums are strongly advocating for their inclusion as beneficiaries of poverty reduction programs.
- Organizations of Persons with Intellectual and Psychosocial disabilities successfully challenged the decision of the electoral authority to exclude more than 23,000 persons with such disabilities from the voter's registry.
- A national platform of DPOs promoted the approval of a new disability act in accordance with the CRPD. The act was promoted as a citizen's initiative supported by more than 100, 000 signatures.
- For the first time the Ministry of Treasury allocated substantial budget as part of the “presupuesto por resultados” (results based budget) for disability rights projects.

Other key achievements are¹⁷:



5

target countries with formal DPO participation in government CRPD mechanisms (Mexico, Peru, Nicaragua, Uganda, Ukraine) -- with DRF grantees participating;

¹⁷ An additional list with DPO achievements around the world can be found as an annex

→	target countries with national legislative changes addressing rights of PWDs (Indonesia, Mexico, Nicaragua, Peru, and Ukraine) -- including new Disability Acts in Mexico, Peru, Nicaragua, and Ukraine	5
→	With grantee input, 13 national level legislative, policy, and program changes secured; 24 underway;	-
→	With grantee input, 26 local level legislative, policy, and program changes secured; 4 underway;	W
→	Alternative reports (Peru and Mexico) submitted (Peru was first DPO-led report to be submitted to CRPD Committee, and both reports were funded and technically supported by DRF);	2
→	DRF-funded alternative reports to the CRPD Committee reflected the interests of marginalized sectors of the disability community	-
→	Universal Periodic Review reports with DRF grantee input (Uganda, Peru, Mexico and Nicaragua);	4
→	7 grants to new organizations representing groups of PWDs not previously active in the public realm (21%);	6
→	4 grants to partnerships among DPOs and between DPOs and other civil society groups (29%);	9

Bridging the *Indigenous* and *Disability Rights* Movements

The Disability Rights Advocacy Fund, sister organization of DRF, provides grants to support the bridging of international human rights movements. These grants are aimed to increase the voice and presence of PWDs within other international rights movements, to enhance information available about persons with disabilities in these movements, including among funders of these movements; and to promote collaboration between movements towards the rights of all.

In 2012, DRAF made its first grant in this area to the International Disability Alliance (IDA) to:

- Promote the human rights of indigenous persons with disabilities by raising awareness of their situation within both the indigenous community and the

- disability community, and
- Mainstream the rights of indigenous persons with disabilities in the UN mechanisms that deal with indigenous persons and with persons with disabilities. The project has included the drafting of a UNPFII Study on situation of indigenous persons with disabilities, which was officially presented at the May 2013 UNPFII session.
- **The Post 2015 Agenda: Successful advocacy work by the International Disability Alliance (IDA)**

Persons with disabilities were absent in the Millennium Development Goals, which showed the low levels of capacity of the disability movement by the time the MDGs were adopted. Not being part of the main target groups of the international development agenda resulted in additional exclusion; since concrete strategies designed to achieve the goals did not consider person with disabilities.

The CRPD human rights based approach has contributed to bring visibility to the importance of including PWDs in the development agenda. The International Disability Alliance, (an umbrella organization comprised by the major international and regional DPOs) has been successful in advocating for the inclusion of references to persons with disabilities in two of the main outcome documents informing the post 2015 agenda: The Report of the High-Level Panel of Eminent Persons on the Post 2015 Development Agenda and the report of the Secretary general: A life of dignity for all: accelerating progress towards the Millennium Development Goals and advancing the United Nations development agenda beyond 2015.

Conclusions

Multiple interventions are needed to support the structural lack of capacity and power of individuals with disabilities and their organizations. Much more needs to be done to overcome capacity (information, relationship, skills, strategic) gaps DPOs have in the rights and development arena. Because most PWDs from the Global South have been denied education and participation in decision-making, organizations of PWDs generally have lower levels of organizational, managerial and advocacy skills. This situation is slowly changing, thanks to the adoption of the CRPD, but there are still many obstacles.

The process of movement building requires long term investment both in terms of financial and human resources, one year or project intervention or even multi year

funding may not be sufficient to promote sustainable organizational empowerment. This is especially true with grassroots/ marginalized or emergent organizations. Groups need continued support and for that reason it is important to provide DPOs with a scope of tools to continue developing their empowerment processes according to their own timelines and context.

Following the CRPD human rights based approach; participation of Persons with Disabilities and their organizations is a key element to achieve rights enjoyment. Resources, including international cooperation, should be allocated to secure their informed and meaningful participation.

In general there is little understanding of the CRPD and its human rights based approach to development both by governments and civil society groups. Promoting adequate implementation of articles 32 -on international cooperation- and 28 -on adequate standards of living and social protection-, could have a significant impact in poverty reduction. But more attention needs to be given to the development components of the CRPD, especially by international development stakeholders.

ANNEX

1. MEXICO

- COAMEX — a coalition of Mexican DPOs — submitted an alternative report to the CRPD Committee, and together with others, successfully advocated for the elimination of Mexico's interpretive declaration on Article 12 (legal capacity) of the Convention
- Confederación Mexicana de Organizaciones en favor de la Persona con Discapacidad Intelectual and Asociación Pro Personas con Parálisis Cerebral achieved recognition from the Congressional Committee on Education to reform the General Education Law to enable equal access to public schools for children with disabilities, including children with intellectual disabilities
- Fundación Paso a Paso advocated successfully for establishment of a Disability Commission in the Hidalgo State Congress, which includes indigenous representatives with disabilities

2. NICARAGUA

- Umbrella DPO, FECONORI, led a coalition to collect more than 45,000 signatures to usher passage of the Law on the Rights of Persons with Disabilities (Law 763), which accords with the CRPD
- Asociación de Discapacitados Fisico Motores successfully advocated that the Managuan municipality purchase its first fleet of accessible buses

3. PERU

- Sociedad Peruana de Síndrome de Down successfully advocated that the National Electoral Authority reinstate the right to vote for more than 23,000 people with intellectual and psychosocial disabilities
- Umbrella DPO CONFENADIP, together with Sociedad y Discapacidad, collected more than 140,000 signatures to support passage of the General Law on Persons with Disabilities as a citizen's initiative — the law, which accords with the CRPD, was enacted in 2012
- CONFENADIP, with a coalition of DPOs, submitted an alternative report to the CRPD Committee, and influenced the Committee's recommendations to the

Peruvian government

4. GHANA

- The Ghana Federation of the Disabled and MindFreedom, a group of people with psychosocial disabilities, led a signature gathering process to advocate for ratification of CRPD, which Parliament ratified in March 2012
- Grassroots DPOs Lakeside and Empowerment Through Community Volunteering pressured district assemblies to set up structures including representatives who are persons with disabilities to administer 2% Common Fund

5. UGANDA

- Uganda National Association of the Deaf, Legal Action for Persons with Disabilities, and Mental Health Uganda together led a comprehensive consultation process to develop an amendment to the 2006 PWD Act — now being considered by Parliament
- The National Union of Persons with Disabilities of Uganda led a coalition to develop a draft alternative report for submission to the CRPD Committee, and successfully advocated for the government to submit its state report

6. UKRAINE

- The National Association of Persons with Disabilities advocated that the Cabinet of Ministers endorse ratification of the CRPD, resulting in ratification in February 2010
- Aurveda and the National Association have been officially involved in amending the Law on General Secondary Education to bring it in line with article 24 of the CRPD
- The All-Ukrainian Coalition of Organizations for People with Intellectual Disabilities has been invited to work closely with senior government officials on strategies to deinstitutionalize people with intellectual and psychosocial disabilities

7. LEBANON

- A new national coalition of eight Lebanese and Palestinian organizations of refugees with disabilities is working towards the creation of equal opportunities for all in the country, in the field of universal access

8. INDIA

- The Human Rights Law Network led national consultations with DPOs and developed recommendations for legislative reforms to align national laws with the CRPD; the majority of which have been incorporated into the new Rights of Persons with Disabilities Bill
- A National Forum of Women with Disabilities has been formed by the Shantha Memorial Rehabilitation Centre, and is working with the women's rights movement on CEDAW reporting

9. BANGLADESH

- The Bangladesh DRF Grantee Coordinating Committee successfully advocated for extended opportunities for DPO consultation on a draft Disability Rights Act
- The Society of the Deaf and Sign Language Users partnered with pro-bono lawyers to ensure that persons with hearing impairments are gaining access to the courts and to justice
- The Coastal DPO Alliance worked with local authorities to raise awareness of risks posed to persons with disabilities by climate change in the coastal area of Chittagong Division that is prone to storm surges, cyclones and regular flooding

10. INDONESIA

- Umbrella DPO PPCI led a coalition of DPOs, including PPUA PENCA (a DPO focusing on electoral rights) and HWPCI (the national women with disabilities organization), to successfully advocate for ratification of the CRPD in November 2011, several years earlier than anticipated
- Yogyakarta DPOs, CIQAL and UCP-RUK, worked with provincial government officials to create regulations (Perda) for implementation of rights in the CRPD
- The Indonesian Mental Health Association — the first organization of persons with psychosocial disabilities in the country — began conversations about the rights of people with psychosocial disabilities with the broader disability community, government, and the public

11. PACIFIC ISLAND COUNTRIES

- National Umbrella DPO, Fiji Disabled Persons Association, successfully lobbied the Government of Fiji to sign the CRPD
- Psychiatric Survivors Association Fiji formed the first self-advocacy association in the Pacific led by persons with psychosocial disabilities, working across Fiji to build awareness of the CRPD and break down stigma
- The Papua New Guinea Assembly of Disabled Persons successfully advocated for government signature on the CRPD; final steps are now being made toward ratification
- The Pohnpei Consumer Organization also gained government signature on the CRPD.

