

DISABILITY RIGHTS FUND  
OUR FIRST YEARS

# ONE IN SEVEN

HOW ONE BILLION PEOPLE ARE REDEFINING  
THE GLOBAL MOVEMENT FOR HUMAN RIGHTS

Supported by



DISABILITY  
RIGHTS  
FUND



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The Disability Rights Fund (DRF) started as a project of the Tides Center in 2008 and began independent operations as the Disability Rights Fund (a 501c3 organization) and the Disability Rights Advocacy Fund (DRAF, a 501c4 organization) in April 2012.

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This report was written and produced in partnership with Free Range Studios and photographer/journalist Andy Isaacson. All photography is by Andy Isaacson.

**Cover Photo:**

Bahri Fedou is an advocate for the rights of youth with disabilities in Tunisia and across Africa. He has been actively involved in the inclusion of disability rights in the new Tunisian constitution.

# Dear Friends,

As we enter our sixth year — the first full year of independent operations — we reflect on the remarkable growth of the Disability Rights Fund — which parallels the progression of the UN Convention on the Rights of Persons with Disabilities (CRPD) — and celebrate the enormous achievements to date.

With a focus on the rights advocacy work of Disabled Persons' Organizations (DPOs), the Fund has expanded its work from just seven pilot countries to 24 countries across six regions of the world. We have increased our grantmaking from \$800,000 in 2008 to more than \$9 million over the last five years. With the help of our Board, Global Advisory Panel, donors, partners, and staff, DRF has grown organizationally from a project nurtured at Tides Center to two fully functioning legal entities — the Disability Rights Fund and the Disability Rights Advocacy Fund. At the same time, states are taking action. In 2008, there were just 20 ratifications of the CRPD. Today, 129 countries have ratified. People with disabilities are being seen and heard like never before. Revised World Health Organization/World Bank research now counts one billion people with disabilities around the world.

As we assess the progress of our grantees, many of whom had no previous funding or were not recognized as legal entities in their countries, we are humbled by the great strides they have made. The Ugandan Albino Association — not even accepted within the disability community — has now gained governmental recognition of albinos as people with disabilities, meaning albinos can stand for elections and access services previously denied to them. Sociedad Peruana de Síndrome Down, the organization of people with Down syndrome and their families in Peru advocated successfully to restore voting rights of more than 23,000 people with intellectual disabilities and people with psychosocial disabilities. Red Chilegra, the network of people with psychosocial disabilities in Nicaragua demanded a seat at the table and now serves on a committee with the Ministry of Health and the National Assembly to address gaps for people with psychosocial disabilities in the General Disability Act.

We also applaud the growing coalitions within the DPO community and the budding partnerships between the disability community and other rights communities. A DPO coalition in Peru, led by CONFENADIP, which submitted the first DPO-led alternative report to the CRPD Committee and influenced recommendations to the Peruvian government. The National Council of Disabled Women, a network of women with disabilities in Bangladesh that partnered with a mainstream legal aid organization and won

important legal precedents addressing violence against women with disabilities. A group of indigenous leaders with disabilities who addressed the UN Permanent Forum on Indigenous Issues for the very first time.

We also look ahead to the years that come and recognize the hard work that we — all of us — have yet to do. People with disabilities remain invisible within the global funding community. Too often, inclusion is seen as noble, but not necessary. Despite growing evidence of the number and marginalization of people with disabilities, most leaders — whether of governments, human rights NGOs or development organizations — still see people with disabilities as vulnerable recipients of charity, rather than as the powerful agents of change we know them to be.

We have set our goals high and we work hard to demonstrate impact. In 2012, the Fund had its first independent evaluation, which found that “In a little less than four years, DRF has become a recognized donor for disability rights...contributing to the achievement of results for the benefit of persons with disabilities. These results include national and local level changes in legislation, alternative reports on the CRPD submitted to UN mechanisms, a more inclusive disability rights movement in target countries evidenced by grants awarded to marginalized and new DPOs, and increased grantee capacities through the formation of partnerships and growing knowledge on rights of persons with disabilities.” Change of this magnitude requires many hands. We need your support to continue this momentum. Join us in ensuring that people with disabilities everywhere are empowered to demand full and equal participation in society.

Sincerely,



*Catherine Townsend*

Catherine Townsend  
Co-Chair



*William Rowland*

William Rowland  
Co-Chair

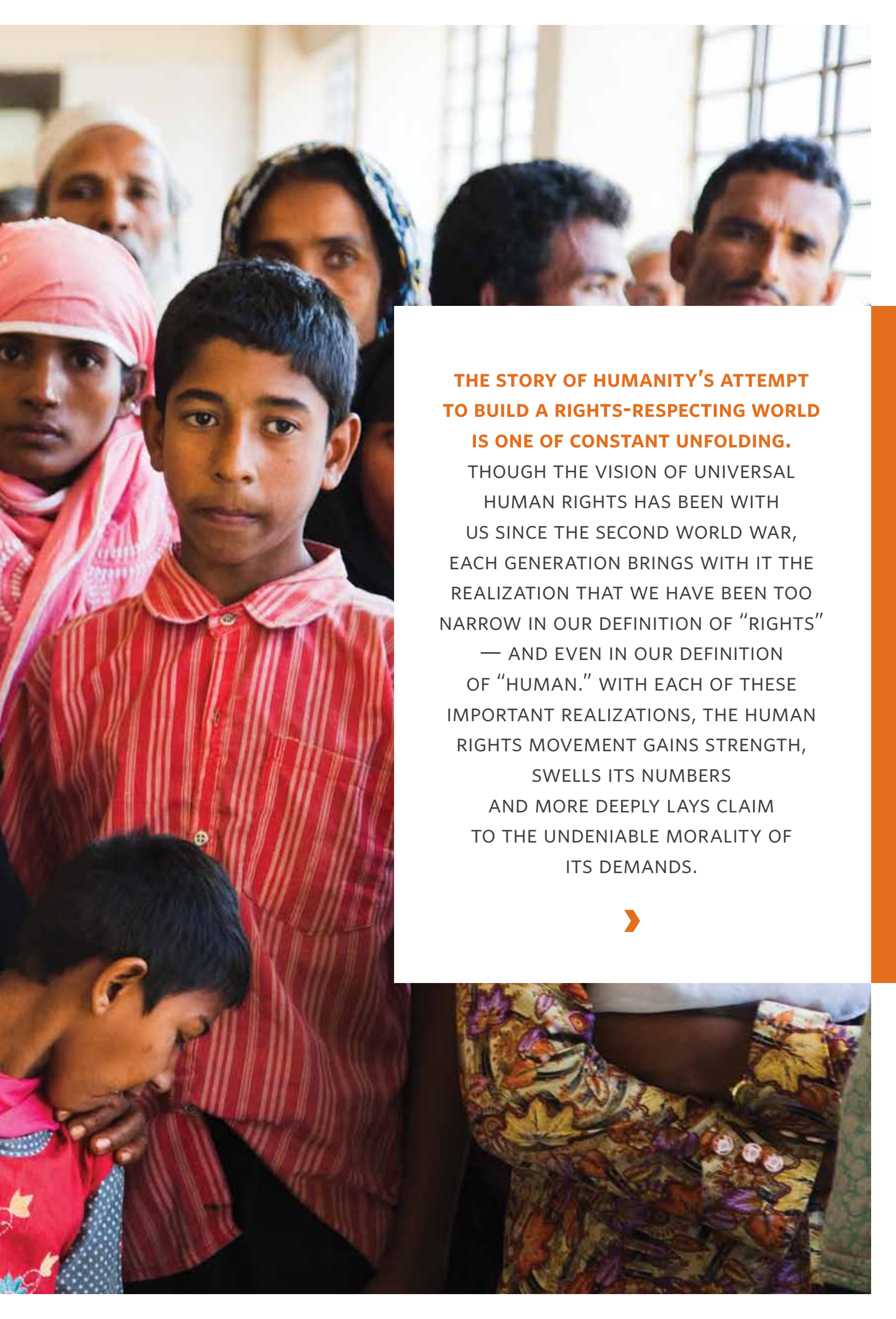


*Diana Samarasan*

Diana Samarasan  
Executive Director



Federation of DPOs Sitakund organizes DPOs in disaster-prone rural villages in Bangladesh.



**THE STORY OF HUMANITY'S ATTEMPT  
TO BUILD A RIGHTS-RESPECTING WORLD  
IS ONE OF CONSTANT UNFOLDING.**

THOUGH THE VISION OF UNIVERSAL  
HUMAN RIGHTS HAS BEEN WITH  
US SINCE THE SECOND WORLD WAR,  
EACH GENERATION BRINGS WITH IT THE  
REALIZATION THAT WE HAVE BEEN TOO  
NARROW IN OUR DEFINITION OF "RIGHTS"  
— AND EVEN IN OUR DEFINITION  
OF "HUMAN." WITH EACH OF THESE  
IMPORTANT REALIZATIONS, THE HUMAN  
RIGHTS MOVEMENT GAINS STRENGTH,  
SWELLS ITS NUMBERS  
AND MORE DEEPLY LAYS CLAIM  
TO THE UNDENIABLE MORALITY OF  
ITS DEMANDS.



1948

UNIVERSAL DECLARATION OF  
HUMAN RIGHTS | UDHR

1949

GENEVA CONVENTION

1954

CONVENTION RELATING TO THE  
STATUS OF REFUGEES | CRSR

1969

INTERNATIONAL CONVENTION  
ON THE ELIMINATION OF  
ALL FORMS OF RACIAL  
DISCRIMINATION | ICERD

1976

INTERNATIONAL COVENANT  
ON ECONOMIC, SOCIAL  
AND CULTURAL RIGHTS | ICESCR



## TODAY, WE ARE WITNESS TO ONE OF THOSE MOMENTS,

as activists around the world reject a charity approach and assert the human rights of the one billion people with disabilities around the world. Their numbers and unique perspectives on rights make them a tremendous asset to the broader rights movement, but as is so often the case, mainstream leaders and funders are only slowly recognizing that disability rights are, fundamentally, human rights.

This report brings to light the countless individuals and organizations — whose voices are so often marginalized and ignored — who are now asserting control over their own lives and insisting on inclusion as subjects and not objects of the rights-respecting world. Their mantra is “Nothing about us without us.” And the foundation of their demands is impossible to ignore: a human rights treaty ratified by 129 countries in the space of four years, codifying a rights-based approach to disability in international law.

In the course of four years of grantmaking, the Disability Rights Fund has uncovered thousands of stories that add up to a single larger story — the story of a movement out to change who is included in the definition of human.

1976

INTERNATIONAL COVENANT  
ON CIVIL AND POLITICAL  
RIGHTS | **ICCPR**

1981

CONVENTION ON THE  
ELIMINATION OF ALL FORMS  
OF DISCRIMINATION AGAINST  
WOMEN | **CEDAW**

1987

CONVENTION AGAINST  
TORTURE AND OTHER CRUEL,  
INHUMAN OR DEGRADING  
TREATMENT OR  
PUNISHMENT

1990

CONVENTION ON  
THE RIGHTS OF THE  
CHILD | **CRC**

2008

CONVENTION ON  
THE RIGHTS OF PERSONS  
WITH DISABILITIES | **CRPD**

**DISABILITY  
RIGHTS  
FUND**

The Disability Rights Fund is a grantmaking collaborative that empowers persons with disabilities to advocate for equal rights and full participation in society. Fueled by the momentum of the Convention on the Rights of Persons with Disabilities (CRPD), DRF funds disabled persons organizations in Africa, Asia, Eastern Europe, Latin America and the Caribbean, the Middle East, and the Pacific. The Fund provides grants for activities such as documentation of rights violations, advocacy for rights fulfillment, and expansion of voice and visibility for particularly marginalized sectors of the disability community, in pursuit of systemic change. Details about DRF's structure and impact can be found on page 29 and at [www.disabilityrightsfund.org](http://www.disabilityrightsfund.org).

African Youth With Disabilities Network join a demonstration during the 2011 International Day of Persons with Disabilities in Nairobi, Kenya.

As grantmakers in this area, we already knew about the incredible impacts disabled persons organizations (DPOs) could make with even very modest amounts of funding. This report documents the potential of these new rights organizations to expand and strengthen the very definition of "universal" human rights.

We are witnessing something monumental happening around the globe — a rapidly growing movement working at the intersection of international legal norms and grassroots impact. The faces and stories that follow are a window into the changes to come. They represent individual and collective struggles against seemingly impossible odds. These frontline human rights leaders need our support.

**"It might appear elementary to point out that persons with disabilities are human beings — as human as, and usually even more human than, the rest."**

—**Leandro Despouy**, UN Special Rapporteur on Disability (Report to the United Nations in 1993)



In rural areas like Requena, a village on the Amazon river in Peru, women with disabilities face some of the most severe consequences of inequality.

T

here are the most disturbing stories, the ones that we tend to hear about: in Uganda, a girl with a disability was buried alive. In

Tanzania, albinos, believed to carry special powers, are hunted for their body parts. In Ghana, adults with psychosocial disabilities are held in “prayer camps” against their will. Two children with Down syndrome in rural Mexico are forced to live in the family’s pigpen. (While atrocities such as these are committed all over the world, DRF focuses on developing countries where — without DPO attention — the compounding impact of poverty, disability, and lack of political voice means that egregious rights violations more often pass unnoticed.)

And there are the stories we don’t hear, those of systemic, devastating, pervasive and ongoing discrimination. Those like Savina’s, a woman in the Solomon Islands. After spinal surgery left her paralyzed from the waist down, her employer fired her, her husband abandoned her, and her seven-year-old old daughter became her primary caretaker because Savina had no other support. In Peru, more than 23,000 people with intellectual and psychosocial disabilities were simply erased from the voter registry in 2011. In Sierra Leone, a boy named Mohammed could not attend school because his parents refused to allow him to, ashamed — cursed, they believed — by his physical disability.

**MORE THAN ONE BILLION  
PEOPLE IN THE WORLD,  
ONE IN SEVEN  
HUMAN BEINGS,  
HAVE A DISABILITY**  
— an astonishing statistic.

More than one billion people in the world, one in seven human beings, have a disability — an astonishing statistic.

And despite their enormous numbers, society has largely ignored people with disabilities. This is a population with a global literacy rate of just three percent, and a ninety percent unemployment rate. Eighty percent of people with disabilities live in developing countries, and there, make up twenty percent of the poorest of the poor, living on less than \$1 a day. They are the single largest population excluded from school.

Women with disabilities are three times more likely to be victims of sexual and physical abuse; children with disabilities are nearly five times more likely to be victims of this abuse. These statistics just begin to scratch the surface. Data on this overlooked population remains insufficient, indeed, scarcely collected. In some parts of the world, children with disabilities are not even registered at birth and so, never officially exist.

**80%**  
OF PEOPLE WITH DISABILITIES LIVE  
IN DEVELOPING COUNTRIES, AND  
MAKE UP **20%** OF THE POOREST OF  
THE POOR **LIVING ON LESS  
THAN \$1 A DAY**

But in this global climate of neglect and outright discrimination, a powerful movement calling for rights and participation is beginning to gain momentum — and, while nascent, it is telling very different stories than the ones we have grown so used to hearing. With the focused support of funders like the Disability Rights Fund, leaders with disabilities are driving this movement, fighting for their own path to equality.

From the Chittagong Hill Tracts in rural Bangladesh to Accra, Ghana, to Sulawesi Island, Indonesia, organizations run by persons with disabilities work on behalf of humanity's most marginalized community — their own. Disabled persons organizations (DPOs) operate in state capitals and rural villages, often on shoestring budgets and powered exclusively by volunteers.

In Uganda, a group of law school graduates with disabilities created Legal Action for Persons with Disabilities. The free legal aid they offer is often the only way for Ugandans with disabilities to seek justice for violations against basic land and property





Grassroots DPOs in the Chittagong Hill Tracts in Bangladesh organize indigenous peoples with disabilities.



THIS IS **JAMES ANIYAMUZAALA** FROM UGANDA.  
HE IS PASSIONATE ABOUT PARTICIPATION AND EMPOWERMENT  
OF YOUTH WITH DISABILITIES.

rights or sexual violations against women. The Jakarta-based Center for Election Access of Citizens with Disabilities advocates for political rights for persons with disabilities in elections, using specially designed voting forms and booths. Through a community radio station operated by people with disabilities, the Federation of DPOs, Sitakund, in eastern Bangladesh, uses drama and song to teach rural people with disabilities about their right to be included in disaster planning and also publicly engages local officials.

While direct services are important, DRF seeks out and supports organizations with advocacy aims: to establish the right to organize, to vote, to have a political voice; to achieve equal access to education, information, employment, and health care; to gain the right to marry and have a family; the right to access courtrooms, to be witnesses and judges. While these are fundamental rights for all human beings, societies often deny these rights to people with disabilities.

Partner Spotlight

AMERICAN JEWISH WORLD SERVICE

Since 2008, the American Jewish World Service (AJWS) has worked with the Disability Rights Fund to support grassroots DPOs in Asia, Africa and the Americas that have a rights-based approach and an advocacy agenda. This partnership, says program officer Jessica Wrenn, has enabled AJWS to expand its reach on disability as well as build the organization’s capacity on the issue. “DRF’s expertise within the grant-making community on disability rights and on working with grassroots groups, and their understanding of the movements and contexts within their priority countries, has been enormously helpful to us,” she says. “DRF has partnered with AJWS to co-fund grantees and DRF has shared resources to support AJWS’s own internal conversations about disability rights.”

**In those moments when I’m with DRF’s staff in a more mainstream human rights context, it is clear how exceptionally valuable their voices are. They raise the question: ‘Where are people with disabilities within this conversation?’**

Wrenn laments that the human rights grantmaking community has been slow to take up disability rights, which historically has been seen more as a service-based category of work. “The Disability Rights Fund has played a key role in bringing disability rights into the conversation. In those moments when I’m with DRF’s staff in a more mainstream human rights context, it is



Members of the DRF Board of Directors, Grantmaking Committee, and Staff

clear how exceptionally valuable their voices are. They raise the questions: ‘Where are people with disabilities within this conversation? Have you considered whether people with disabilities have access to the rights systems that you’ve created?’”

Wrenn says that working with DRF colleagues and serving on DRF’s Grantmaking Committee has been inspirational. “Many of the systems that DRF has put in place, and the ways that the staff, donors, and advisors work together, mirror the changes DRF wants to see globally. They’ve worked hard to create systems that are open and they’ve built trust across communities. The way that DRF works with donors and disability rights activists to make decisions is exciting, and not something you see every day in grantmaking. They’re always excited to learn and encourage the human rights community in our learning, not just on disability rights, but also on how we do our work more generally.”



With support from Access Bangladesh Foundation, disabled street hawkers in Dhaka have joined together to demand official recognition as people with disabilities.

## A TREATY TO CHANGE THE PARADIGM

The global disability rights movement was galvanized to advocate for the landmark passage of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008. The CRPD, which has been signed by 155 countries and ratified so far by 129, laid a framework for disability as an actionable human rights and development issue.

The CRPD signaled a shift from what has been known as the “charity” or “medical” model to the “social” model of disability. Defining disability not as inherent in persons but as a result of “the interaction between persons with impairments and attitudinal and environmental barriers,” for the first time, States Parties have acknowledged the need for a rights-based approach to disability. Drafted with the unprecedented activism and participation of civil society, in particular, people with disabilities, (as elaborated in Article 4), the CRPD also mandates active involvement of people with disabilities and their representative organizations in implementation and monitoring.

**"The Convention on the Rights of Persons with Disabilities is a key measure of our civilization. The rights and opportunities that people with disabilities are able to enjoy reflect directly on our common humanity."**

—Srgjan Kerim,

Former President, UN General Assembly

The Kenyan child with polio who can't get an education because the school refuses to provide reasonable accommodations by moving the classroom to the ground floor. The politically engaged, deaf Bengali man who is excluded from provincial government policy meetings because there are no sign language interpreters available. The Indonesian woman who faces discrimination in her community partly because the government classifies her as a *penyandang cacat* — a “defected person.” In each of these cases, the disability comes not from within but from those — the majority of us — who choose to make it a limitation.

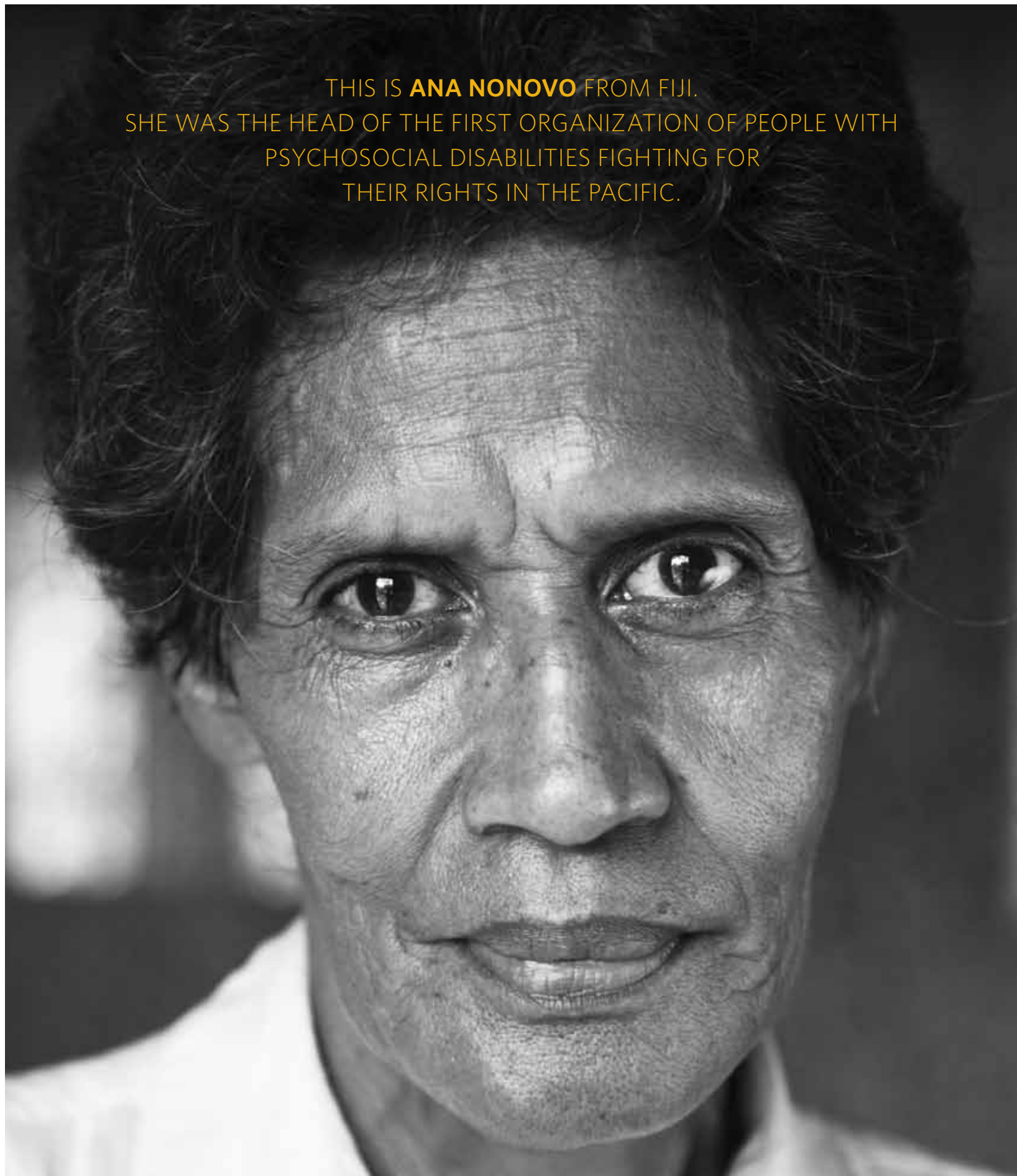
The CRPD calls on nations to make legal and policy changes to ensure full and equal participation for persons with disabilities. It also requires that persons with disabilities be included in this process, giving DPOs across the world a new tool in their collective struggle for equal rights. But its passage is only a first

step, requiring new strategies to leverage it for massive impact. Building and disseminating these strategies has become the shared work of this emerging global movement, and a critical part of the Disability Rights Fund's role as global supporter and convener of these far-flung and diverse DPOs.

Whether they live in Requena, a remote town in the Peruvian Amazon where a group of women with disabilities formed

a small association to learn about their rights, or Krachi, in rural Ghana, where a self-help group performs role-play dramas to explain rights abuses to the community, people with disabilities must be given training and tools to exercise the rights accorded to them by the CRPD. For most, this challenges how society — and in many cases, their own families — have treated them their entire lives.

THIS IS **ANA NONOVO** FROM FIJI.  
SHE WAS THE HEAD OF THE FIRST ORGANIZATION OF PEOPLE WITH  
PSYCHOSOCIAL DISABILITIES FIGHTING FOR  
THEIR RIGHTS IN THE PACIFIC.



Staff Spotlight

CATALINA DEVANDAS

Program Officer for Strategic Partnerships

Catalina Devandas remembers the moment when the disability rights movement called her. She was a 25-year-old lawyer in Costa Rica, and though she had been active in student and gender issues, she had always distanced herself from disability. “Even as a person with a disability, I had a lot of prejudice against persons with disabilities,” she admits. Catalina attended a regional meeting of persons with disabilities from Latin America, and for the first time, “I didn’t feel like I had to hide anything,” she recalls. “I was like, ‘This is where I belong.’” Since then, she has been working at the forefront of the global disability rights movement: as a legal advisor to Latin American DPOs, as a disability specialist at the World Bank, as part of the International Disability Caucus negotiating the UN Convention on the Rights of Persons with Disabilities, and now, at DRF. “The process of the convention was a life-changing experience for everybody who participated,” Catalina says. She joined the Disability Rights Fund soon after its founding.

Catalina helps DPOs with the grant application process, guiding organizations to identify their vision and steering them towards a rights-based approach based on the CRPD. She also networks DPOs to each other through annual grantee meetings. “Many times organizations don’t even know that there are others working on the same issue,” she says. The grantee meetings also put

DPOs in the same room with stakeholders they might not otherwise have access to, including national human rights institutions and government officials, which in turn brings these stakeholders closer to the issue. “We try to build a movement,” Catalina explains. “For us that process is as important as the project outcomes, since the movement will carry advocacy into the future.”

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“We try to build a movement. For us that process is as important as the project outcomes, since the movement will carry advocacy into the future.”

Catalina believes it is important that DRF program officers are themselves persons with disabilities. “For many local DPOs, there are a lot of barriers and little hope,” she says. “Seeing an empowered person with a disability, for instance, who is bringing resources and knowledge to the country, offers them a role model.” Growing up with a sister with an intellectual disability who was afforded little opportunity in life, and facing discrimination as someone with spina bi-fida, Catalina’s work is driven by a passion for social change and transformation. “For me,” she says, “this is a matter of justice.”



DRF Program Officer Catalina Devandas with members of the Sociedad Peruana de Síndrome de Down



Youth with disabilities from fourteen African nations beginning a network to address inclusion of their voices in African policy.

Encouraging governments that sign the Convention to not only ratify it, but fully implement and enforce it, requires dogged, unrelenting advocacy. Many existing national laws are weak or lack the financial resources for implementation, or they reflect outmoded charity or medical models. Some countries, while granting nominal rights to people with disabilities, deny any legal means to assert such rights by failing to make court systems accessible or by denying legal capacity to individuals with disabilities. And many governments need help understanding and carrying out the provisions of the Convention.

For their part, DPOs must learn about the CRPD and gain expertise about how to impact policy. It's one thing to convince a community hospital to install a ramp but yet another to change the national building code to ensure that every new public building in the country is accessible to all persons with disabilities. "It takes constant vigilance, strong enforcement mechanisms, and knowledge about government processes," says Diana Samarasan, DRF's executive director.

This scale of change requires a long-term strategy that supports people with disabilities in moving from the fringes of society into the mainstream as powerful self-advocates. "We have a saying: paper can support anything," notes Javier Diez Canseco, DRF Global Advisor and Peruvian Congressman with disabilities. "The state can sign a lot of things, but...compliance becomes an issue. That means budget, and political pressure — and when you speak about persons with disabilities, you're talking about the lowest level of political influence in the country."



THIS IS **MARIA ALEJANDRA VILLANEUVA.**  
SHE FOUGHT SUCCESSFULLY TO REINSTATE VOTING RIGHTS FOR MORE THAN  
23,000 PERSONS WITH INTELLECTUAL DISABILITIES AND  
PERSONS WITH PSYCHOSOCIAL DISABILITIES IN PERU.

# A MOVEMENT TO CHANGE ONE BILLION LIVES

Despite these challenges, the movement's strategies are taking root and a sea change is underway. Country by country, persons with disabilities are taking their rightful places in the halls of power, effecting change in government policy and

challenging long-held social attitudes about people with disabilities. Many of these gains are incremental. Some seem small at first. And they are largely unprecedented.



In Fiji, compared to both women without disabilities and men with disabilities, women with disabilities experience higher rates of unemployment, are less likely to be educated, and are more likely to be abused.

Country Spotlight

THE ROAD TO RATIFICATION



During DRF Grantee Convenings — such as this one in Jakarta, Indonesia — grantees and other stakeholders discuss strategies to advance CRPD implementation in their countries.

On November 30, 2011, Indonesia became the 107th country to ratify the UN Convention on the Rights of Persons with Disabilities. After four years of dogged advocacy, the occasion was a triumph for the country's DPO movement. Though Indonesia signed the convention in 2007 (and was only the ninth country to do so), it lacked forward movement from government officials towards ratification. "We tried to convince them that we should start now, because, when else?" recalls Happy Sebayang, head of Citizens for Electoral Access, PPUA PENCA, a DRF grantee.

Local DPOs worked with the National Human Rights Commission to draft a legal paper that compared the CRPD with existing disability laws and regulations in Indonesia. They then asked the Ministry of Social Affairs and the Bureau of Law to further refine the draft. DPOs campaigned at the legislature and within ministries. They also drafted new laws at provincial levels that accorded with the UN Convention.

"We kept pushing the government towards ratification in every forum," Sebayang says. With support from DRF, DPOs were able to form a national coalition that included regional organizations trained to advocate at the provincial level. Together, DPOs had a stronger voice. "Government institutions accepted us," says Sebayang. "We were not coming as individual organizations but as representatives of our people."

**DRF supports these collaborations with National Coalition grants as they are critical to movement building and increasing voice and accountability. Between 2008 and 2011, the number of National Coalitions DRF funded increased by 63%.**

In 2011, Indonesia assumed a one-year rotating chairmanship of the Association of Southeast Asian Nations (ASEAN). Countries were to convene in Bali in November, and Indonesia's Ministry of Foreign Affairs asked the national coalition of DPOs to write a document for attending states to sign entitled "Bali Declaration on the Enhancement of the Role and Participation of Persons with Disabilities." At the time, "four other ASEAN countries had already ratified the convention," says Sebayang. "We used that moment to push the government once again, arguing that Indonesia's pride was at stake." To prepare the Bali Declaration, the coalition held a national meeting and legislative hearings that included DPOs from across Indonesia. The effort garnered media coverage, and provided the disability movement with a final push. The legislature agreed to ratify the CRPD before the ASEAN summit and did.

A close-up, black and white portrait of a woman with dark skin and short, dark hair. She is looking directly at the camera with a slight smile. The lighting is soft, highlighting her facial features. She is wearing a dark-colored top.

THIS IS **BARBARA NANDUTU FITZPATRICK** FROM UGANDA.  
SHE IS A PART OF THE STEERING COMMITTEE OF THE AFRICAN YOUTH  
WITH DISABILITIES NETWORK.

BETWEEN 2008 AND 2011,

20%

OF DRF'S TOTAL GRANTS PORTFOLIO WENT TO  
**EMERGENT ORGANIZATIONS**

— DPOs that are less than two years old and that bring the voice of a new population of persons with disabilities into the public realm.

In December 2011, forty youth leaders from thirteen African nations met in Nairobi to form the first-ever African Youth with Disabilities Network. It was a chance for the continent's young activists, representing a range of disabilities, to meet, inspire each other, and coordinate their efforts to influence regional policy and institutions.

The stories that emerged from this gathering paint a picture of a struggle on many fronts that is being fought — and won. A Liberian woman with polio described her experiences speaking publicly about disability rights on radio and television. A young activist from the new South Sudan described how he is helping to convince the government to allocate land to persons with disabilities whose houses were demolished during the civil war. A young deaf man from Zambia wore a shirt that read: "Disability Is Not Inability" while using sign language to explain his vision for the youth network's governing structure.

In a continent where sixty percent of the population is under 25, the youth who gathered in Nairobi represent real hope for rights movements in Africa. "To solve the current problems, we need new ideas," said Fredrick Ouko, who founded Action Network for the Disabled, a national DPO run by and for young people with disabilities in Kenya, and a DRF Global Advisor. "We need innovation. The more we have a strong movement of youth with disability in Africa, the more the status quo is going to be challenged."

As these newly empowered youth challenge the status quo in their corners of the world, their allies of all ages in Peru, Mexico, Bangladesh and Ukraine are learning to navigate their

own legal systems to bring about sweeping change. Armed with the CRPD, governments are finding them increasingly difficult to ignore. (see map on page 30)

These gains mean that the stories of victimization and pity we have grown so used to hearing will be giving way more frequently to stories of empowerment, like that of a young Bangladeshi deaf woman. A survivor of rape, she was aware of her rights and the resources available to her. Working with the Society of the Deaf and Sign Language Users, a DRF grantee, she ensured that she had sign language interpreters at her court hearing, which led to successful prosecution of the perpetrator.

25%

OF RECIPIENTS OF DRF SMALL GRANTS WERE  
SUPPORTED THROUGH FISCAL SPONSORS WHO  
**ASSIST EMERGENT GROUPS  
IN ACCESSING FINANCIAL  
AND OTHER RESOURCES.**

And there's the story of Maria Alejandra Villanueva, a young woman with Down syndrome who was denied the right to vote in Peru's presidential election in 2011. With other self-advocates, she pressured the National Registry of Identification and Civil Status to reissue national identity cards to more than 23,000 people with intellectual and psychosocial disabilities who had been systematically erased from the voter registry. And they won. The government nullified the policies that excluded this population from electoral rolls.

Asked to explain what motivated her, Ms. Villanueva's simple response lays bare the senseless inhumanity of discrimination, and echoes countless civil rights figures throughout history who have confronted injustice: "We are also people," she said. "And we have the right to vote."

Perhaps more astonishing than the fact that fifteen percent of human beings have disabilities is the recent finding

by the Foundation Center that this same population typically receives only three percent of foundation funding.

To address this stark funding gap, we need new narratives and models for thinking about "disability": models like that of Maria Alejandra Villanueva, leading the movement to fight for the right to vote, or the stories of deaf women in Bangladesh and Uganda who are going to court to secure justice for abuses of their rights as women. Indeed, there are countless disabled persons organizations around the world working to secure basic human rights, like Fundación Paso a Paso, a group of indigenous women with disabilities in Mexico advocating for full participation in their indigenous and broader Mexican communities — these are the new stories about "disability" in the 21st century. These are the working models we must support and scale.

Grantee Spotlight

INDIGENOUS WOMEN WITH DISABILITIES

Indigenous Peoples with disabilities have frequently been overlooked by grantmakers. In a quest to spread awareness on their rights, Olga Montufar Contreras, the President of Fundación Paso a Paso in Mexico, spoke at the UN Permanent Forum on Indigenous Issues in May 2012. She expressed her strategy: "The chain of communication is key — you educate one person about our capability and rights and that awakens awareness in that person. Now that person will educate another."

Olga was living in Totolapan — a remote community in rural Mexico — when she contracted polio as an infant. When polio arrived in the area, many people died and many others became seriously disabled. Olga's parents, both teachers, relocated to Mexico City to seek better support for her recovery and to encourage her inclusion in regular schools. Following the completion of her Masters in Social Policy and Development and driven by the discrimination she faces as a woman with a disability, Olga leads initiatives to promote the social inclusion of persons with disabilities in communities.

Olga, who is of Mixtec and Nahuatl origin, can attest to the multiple layers of discrimination faced by indigenous women with disabilities, who often lack

access to basic property rights. They also face a high risk of sexual violence and, as they have extremely limited access to the legal system, it is even more difficult for them to seek justice.

Based in Hidalgo, Mexico, Fundación Paso a Paso demands equal rights through participation of persons with disabilities at local and national levels. They promote inclusion of indigenous peoples with disabilities in traditional ceremonies with leaders of the Nahuatl, Otomí, and Tepehua Peoples. They also support women in rural areas to build a culture of rights of persons with disabilities.

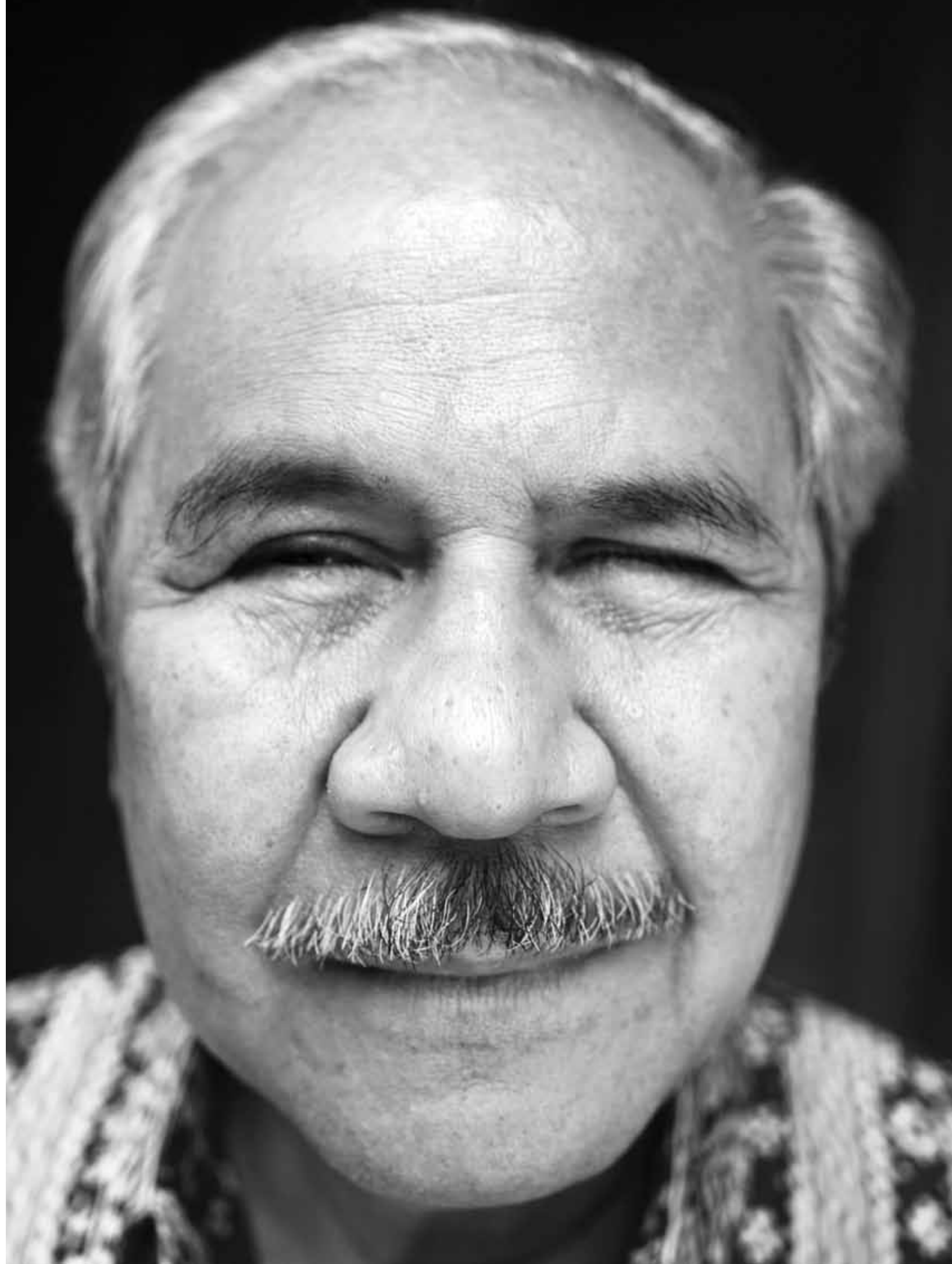
Fundación Paso a Paso successfully advocated for the landmark creation of the Human Rights and Disability Commission in the local Congress of Hidalgo State — this is the only government commission at local level that specifically addresses disability issues. The Commission invites citizens to review all legislative proposals that could potentially impact persons with disabilities.

In reflecting on Fundación Paso a Paso's success so far, Olga says, "We have been successful because we did not ask for wheelchairs; rather we asked for training and the right to present our claims."



Olga Montúfar Contreras, President of Fundación Paso a Paso, a DPO representing indigenous people with disabilities in Mexico, addressing the UN Permanent Forum on Indigenous Issues.

THIS IS **OTJE SOEDIOTO**,  
FIRST VICE PRESIDENT OF THE INDONESIAN BLIND UNION, PERTUNI



# THESE ARE THE INDIVIDUAL STORIES OF DRF'S WORK,

stories that illustrate steady progress toward fulfillment of the highest aims of the human rights movement.

A young girl enters a classroom for the first time. A politically engaged man casts his first vote. A newborn child with a disability is counted as a human being. We are also witness to a more global story emerging, a story greater than the sum of its parts. A recent survey of NGOs working on disability revealed a

15%

OF HUMAN BEINGS LIVE WITH SOME FORM OF DISABILITY YET THIS POPULATION TYPICALLY RECEIVES JUST **3% OF FOUNDATION FUNDING.**

## DRF Global Advisor Spotlight

# JAVIER DIEZ CANSECO

Peruvian Congressman

Peru was one of the first seven countries targeted for Disability Rights Fund support in 2008. That year, Peru ratified the CRPD and its Optional Protocol. Like other Latin American countries, Peru has legislation on persons with disabilities, but these laws were framed by the medical and charity models of disability, and are weakly implemented.

Javier Diez Canseco, a DRF Global Advisor, recently won election to the Peruvian Congress. Before his election, and with DRF support, Javier led the DPO, SODIS, in forming alliances with other DPOs to collect 140,000 signatures towards promotion of a new law on persons with disabilities. The new General Law on Persons with Disabilities, which accords with the standards in the CRPD, focuses on developing capacity of people with disabilities, promoting gender equality, and establishing protections for children with disabilities. It also extends a hiring quota for persons with disabilities to both the public and private sectors, and offers tax benefits for companies that hire persons with disabilities. The new law favors a more inclusive educational system, provides full recognition of legal capacity, and extends the definition of accessibility to include access to new frontiers like mass media.

In 2012, in the wake of the process toward this new law, Canseco successfully advocated that the Ministry of Economy and Finance fund the first national survey on disability (USD 3 million). And, for the first time, the new national budget included funds for programs



Javier Diez Canseco in his Congressional office

that address people with disabilities. With the support of another donor, SODIS formed a partnership with the Pontifical Catholic University of Peru and the National Academy of judges and public lawyers to teach a course on the rights of persons with disabilities, and worked with journalists to denounce rights violations and highlight the achievements of persons with disabilities.

Canseco is quick to point out that even with these successes, enforcement of rights remains a challenge. What Peru's disability movement needs, Canseco says, is more policy ideas that champion the rights and participation of persons with disabilities, and grassroots efforts to make persons with disabilities aware of their rights.

significant shift toward thinking, advocating, and winning battles through a human rights framework, rather than a charity or welfare model. This reveals more than a subtle change in terminology — it represents a shift from pity to equality, from handouts to empowerment, and from looking away to engagement and dialogue.

Yet a persistent challenge remains. Though no human rights defender would explicitly challenge the idea that people with disabilities have equal claim to rights, organizations run by people with disabilities still do not have full, inclusive participation in the global conversation about rights for all. As with individual people with disabilities, the issue of disability rights is too often treated as a nuisance or outlier within the movement, or even as something separate and unrelated.

But like other marginalized communities before, these one billion people — one in seven in our human community — are rapidly learning about and claiming their rights, joining forces, and mobilizing their movement. The CRPD provides fuel for the fire and tools for this struggle. What it mandates, but does not provide, is urgently-needed funds to accelerate the work it will take to achieve fulfillment.

The Disability Rights Fund, born in the window of opportunity created by the passage of the CRPD, supports and connects grassroots movement-builders around the world who are actively dismantling entrenched cultural misperceptions and repairing systemic failures. We channel pooled investments from global partners directly to the most innovative, effective DPOs, accelerating the pace toward full human rights for all. Our first four years have yielded gains in laws amended in accordance with new international standards, participation of people with disabilities in decision-making mechanisms, and rights restored at local and regional levels. These years have also — importantly — enhanced dignity and empowerment of individuals who have for too long been discounted and ignored.

Our work toward equal rights for all people — a vision that can only be achieved through full participation and leadership of persons with disabilities — continues full force.

If you share this vision — of a world where the rights of all seven billion people on our planet are celebrated and respected — we call on you to directly fund the work of Disabled Persons Organizations. The Disability Rights Fund’s unique, participatory model will maximize the impact of your investment. We welcome you to join our movement for the rights of all.

Donor Spotlight

AUSTRALIAN AID

Interview with Darryl Barrett,  
Assistant Director, Disability Policy Section

What are the benefits to AusAID, a bilateral development agency, in supporting a grantmaker like DRF?

Supporting DRF allows us to reach emerging and growing DPOs through an innovative mechanism of providing small grants. The process is a “light” or efficient way for a big aid organization to provide much needed support to marginalized groups.

Though measuring impacts in a short period of time is challenging, we have already observed tangible results.

DRF’s structure allows us to engage regularly with the decision-makers of the organization, the people who oversee and support the grants, and, through grantee convenings, the

recipients of the grants. As a donor, it is crucial that we are able to see firsthand the impact of Australia’s support.

Though measuring impacts in a short period of time is challenging, we have already observed tangible results. In the Asia and Pacific regions, as an example, DRF has contributed to the growth of advocacy from the disability movements, resulting in ratification of the CRPD in Indonesia and submission to Parliament of the CRPD for ratification by Papua New Guinea. At the international level, DRF has opened avenues for inclusion of indigenous people with disabilities at the United Nations Permanent Forum on Indigenous Issues.

Giving people with disabilities a voice in their nation’s development — a role which ultimately impacts their own personal situation — is powerful. Supporting the rights of people with disabilities is one way of ensuring that all other related aid interventions come from an informed and inclusive position.



Island living in the Pacific presents challenging conditions for persons with disabilities.

# About the Disability Rights Fund

## Board of Directors

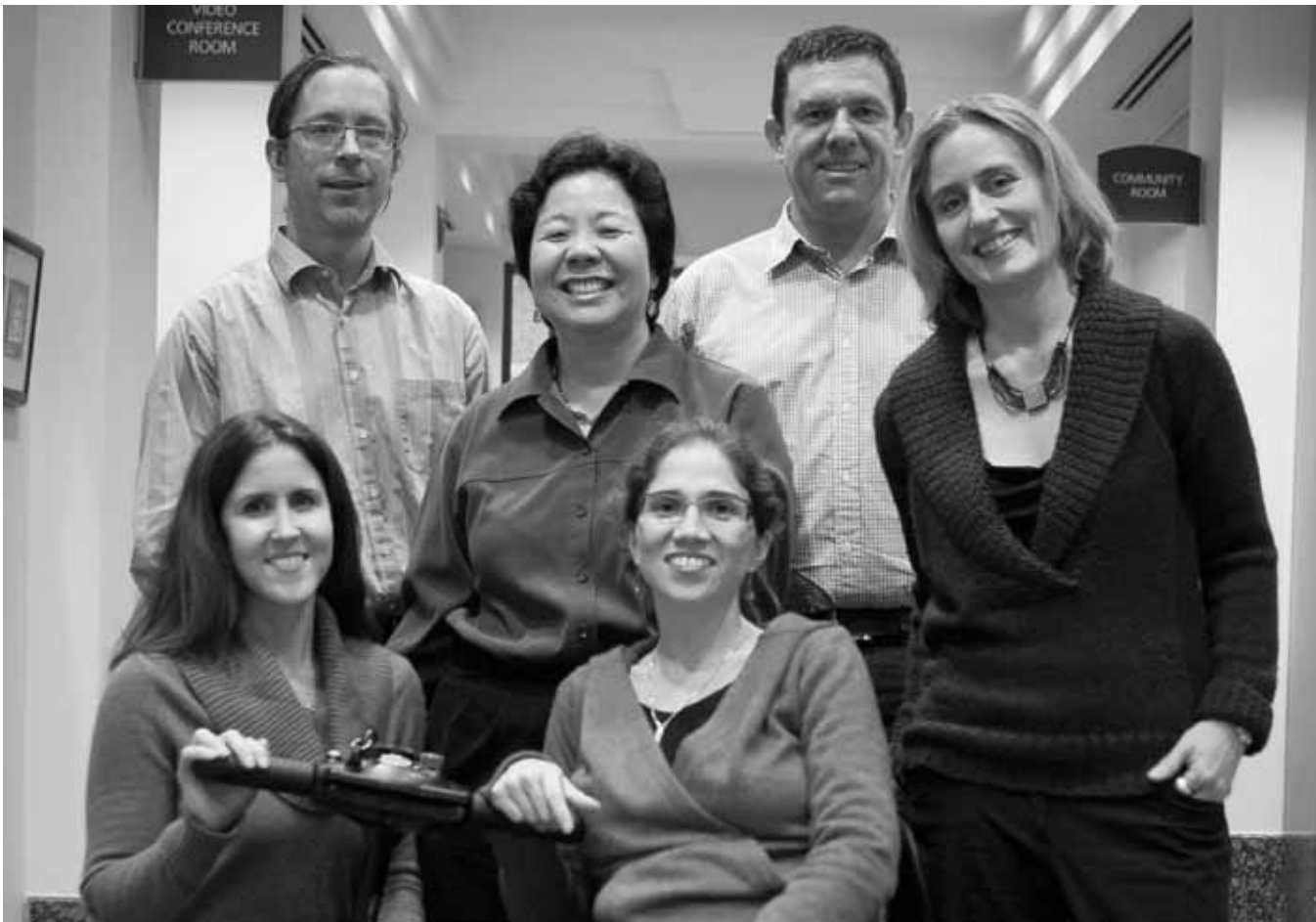
Ola Abu Al Ghaib  
Michael Haroz  
Emily Martinez  
Vinay Mehra  
William Rowland, Co-Chair  
Catherine Townsend, Co-Chair  
Diana Samarasan, Ex-Officio

## Staff

Diana Samarasan, Executive Director  
Paul Deany, Program Officer for Pacific & Asia  
Catalina Devandas Aguilar, Program Officer for Strategic Partnerships  
Yumi Sera, Operations Director  
Michael Szporluk, Senior Program Officer (Africa and Eastern Europe)  
Kerry Thompson, Operations & Program Associate  
Yolanda Munoz Gonzalez (from 2012), Program Officer for LAC and MENA  
Arlene Wilson-Grant (from 2012), Grants Manager

## Global Advisory Panel

Ola Abu Al Ghaib  
Gunta Anca (2008-2010)  
Shamima Ali (from 2012)  
Fredrick Ouko Alucheli  
Karina Chupina (from 2012)  
David Corner (from 2012)  
Bhargavi Davar (2008-2012)  
Shanti Dairiam (2008-2010)  
Javier Diez-Canseco (2008-2012)  
Venus Ilagan (2008-2010)  
Raisa Kravchenko (2008-2010)  
Jabulani Ncube (deceased)  
Martha Lucia Osorno Posada  
Silvia Quan-Chan (2008-2011)  
William Rowland



# DRF At-A-Glance

- In concert with the disability community’s slogan, “Nothing about us without us,” and the principle of participation in the CRPD, people with disabilities occupy majority and strategic roles in DRF — at advisory, governance, and staff levels. The involvement of persons with disabilities at all levels of the organization is a core strength, giving the Fund legitimacy as well as access to worldwide networks of persons with disabilities.
- DRF’s unique structure includes a Global Advisory Panel (GAP), a Grantmaking Committee, and a Board of Directors. The GAP consists of 12 members — the majority of whom are people with disabilities nominated by international and regional networks of Disabled Persons Organizations — and makes grantmaking strategy recommendations. The Grantmaking Committee of the Board is composed of donor representatives and advisors and finalizes recommendations on grantmaking strategy and guidelines and selects grantees. The Board of Directors has oversight of the Fund.
- The Disability Rights Fund operates as a pooled fund — combining the resources of multiple government, private and public donors — enabling these donors to harmonize their efforts, efficiently reach organizations outside their normal purview, and receive important feedback about their investments in this neglected area of human rights.
- DRF’s grantmaking processes adhere to due diligence procedures, including an intensive application review process (with technical aid in project design), one-on-one relationships with and oversight of grantees, and an extensive network and partnerships in the broader disability community to assess and monitor viability of applicants and projects.
- From 2008–2011, DRF awarded 25 National Coalition Grants and 265 Small Grants around the world for a total of almost USD 7 million. In this short time, DRF has documented success around its highest goals: increasing DPO participation in ratification efforts, development of national legislation in accordance with the CRPD, and civil society submissions to international human rights monitoring mechanisms.
- With a focus on marginalized sectors within the disability community and on grassroots and emergent organizations, DRF empowers a more diverse disability movement to advance rights for all.

## ENDNOTES

<sup>1</sup>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), UN General Assembly, 61st Session, 6 December 2006, preambular paragraph (e).

<sup>2</sup>“It bears emphasizing that Article 4.3 embodies the principle of ‘Nothing about us without us.’ That is, DPO[s] must be consulted and listened to...” Quinn, Gerard, “The UN Convention on the Rights of Persons with Disabilities. National Institutions as Key Catalysts of Change,” National Monitoring Mechanisms of the Convention on the Rights of Persons with Disabilities, May 2008: Comisión Nacional de los Derechos Humanos México p. 128.

<sup>3</sup>A/HRC/10/48; Human Rights Council, “Annual Report of the United Nations High Commissioner for Human Rights and Reports of the Office of the High Commissioner and the Secretary-General: Thematic Study by the Office of the United Nations High Commissioner for Human Rights on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities,” 26 January 2009, p. 6.



# DRF Grantee Achievements

## Around the World 2008–2012

### 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

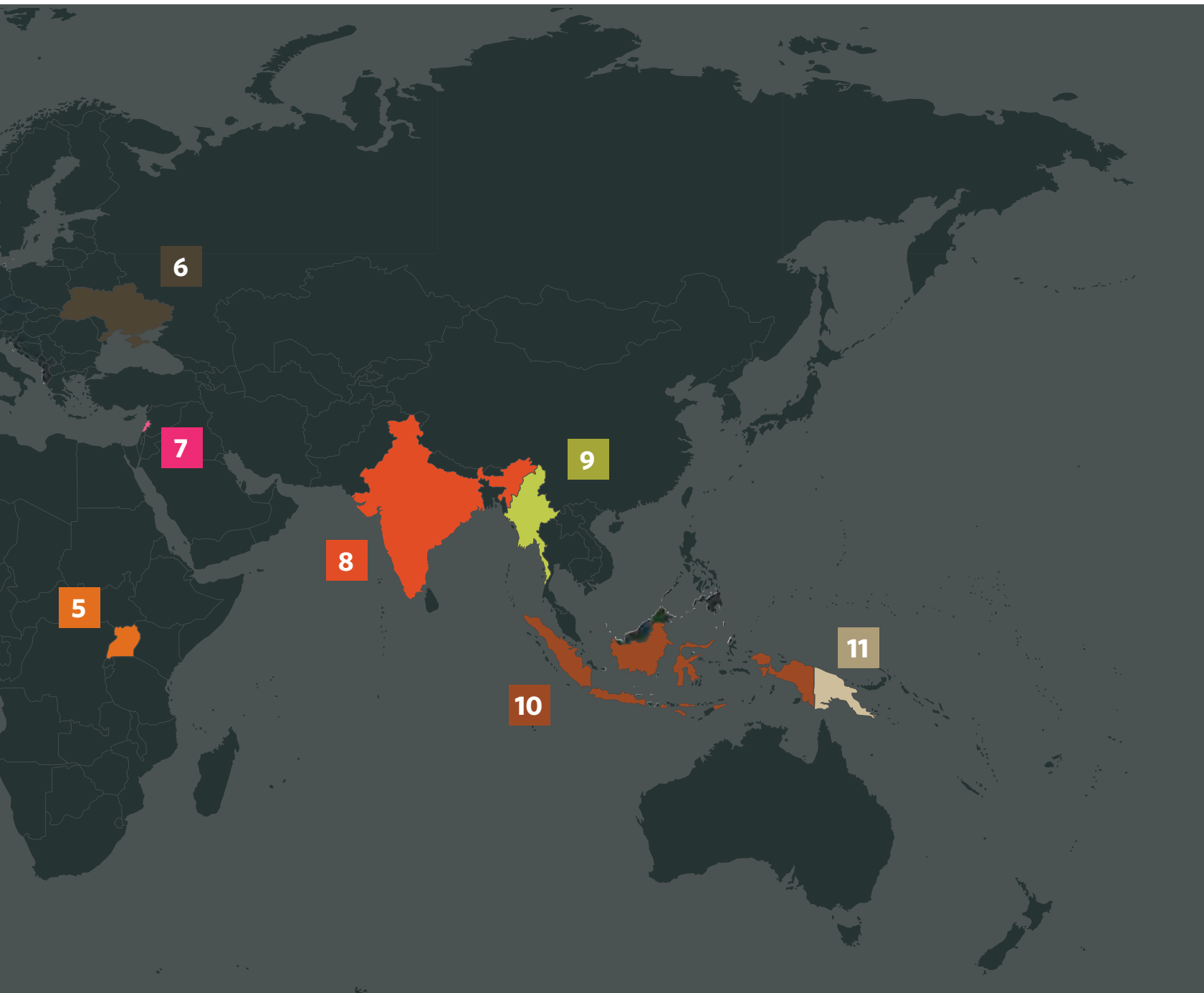
- The Ghana Federation of the Disabled and MindFreedom, a group of people with psychosocial disabilities, led a signature gathering process to advocate for ratification of CRPD, which Parliament ratified in March 2012
- Grassroots DPOs Lakeside and Empowerment Through Community Volunteering pressured 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

# NOTHING ABOUT US WITHOUT US

In November 2011, a workshop led by Free Range Studios in Boston with DRF staff, advisors, donors, and board members explored the pivotal role of the Disability Rights Fund in the broader disability rights movement. The result was a direction, plan and tone for this report. From late 2011 to early 2012, DRF staff travelled with photojournalist Andy Isaacson to capture images and stories from activists with disabilities in remote areas — accessible only by four wheel drives or on foot or by boat — as well as in urban hubs and capital cities. Stories of the struggles, the triumphs, and the aspirations of persons with disabilities were captured along the way. To ensure accurate portrayal of this burgeoning rights movement, known as “nothing about us without us,” the draft report went through a rigorous review process by key DRF stakeholders.

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- 1 Workshop with Free Range Studios and DRF staff, advisors, donors, and board to create our vision of the report
- 2 Operations Director, Yumi Sera and bodyguards while visiting DPOs and Indigenous Peoples in the Chittagong Hill Tracts
- 3 Andy Isaacson taking photographs of street hawkers in the middle of a busy Dhaka street
- 4 Executive Director, Diana Samarasan, working with DPO representatives at a Grantee Convening in Jakarta
- 5 Andy Isaacson interviewing street hawkers in their meeting place in a Dhaka city park
- 6 Crossing the lake in Rangamatti to visit the Chakma Raj and representative of the Indigenous Peoples of Asia to the United Nations Permanent Forum on Indigenous Issues
- 7 African youth with disabilities strategizing their network formation in Nairobi with Michael Szporluk, DRF Senior Program Officer

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