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**DISABILITY RIGHTS FUND**

**DISABILITY RIGHTS ADVOCACY FUND**

Pelaige Muhorokeye (RNADW), Mirriam Kiconco (LAPD), Dwi Ariyani (DRF), Elizabeth Kayanga (IDIWA), Nicodeme Hakizimana (OIPPA) and Diodoune (OIPPA).  
Image: 7 people (from Uganda, Rwanda, and Indonesia) smiling with thumbs-up sign in outdoor setting. Photo credit: David Nkurunziza

# NOTHING WITHOUT US

**1 IN 7 people have a disability.**

Join us and expand the disability rights movement to "leave no one behind."

*“The Convention on the Rights of Persons with Disabilities requires the transformation of existing social structures, systems, and conceptions that perpetuate discrimination against persons with disabilities.*

*The 2030 Agenda for Sustainable Development presents a unique opportunity for concerted efforts to reduce inequality for persons with disabilities and ensure their inclusion and participation.”*

— UN Office of the High Commissioner for Human Rights (OHCHR)



The Disability Rights Fund and the Disability Rights Advocacy Fund have integrated the Sustainable Development Goals into our Strategic Plan and grantmaking so that Disabled Persons' Organizations have the financial and technical resources needed to use the CRPD to advance disability-inclusive development, and ensure no one is left behind.

In 2016, the Disability Rights Fund was supported by donors including the Ansara Family Fund of the Boston Foundation; the Joseph P. Kennedy Foundation; the Foundation to Promote Open Society; the UK's Department for International Development; and individual donations. The Disability Rights Advocacy Fund was supported by the Australian Government Department of Foreign Affairs and Trade. The views expressed in this report do not necessarily reflect the official policies of any of our donors, or the governments they represent.



For an accessible Microsoft Word version of this report, please contact [info@disabilityrightsfund.org](mailto:info@disabilityrightsfund.org)

# REFLECTIONS ON 2016

A decade after the adoption of the Convention on the Rights of Persons with Disabilities at the United Nations, the global disability movement is leading radical change.

Change so that Agenda 2030, the global development framework, references disability for the first time and is being used by organizations of persons with disabilities on the ground to ensure they are not left behind.

Change so that a key human rights funder, Ford Foundation, was called out by disability activists and issued a public *mea culpa* about leaving disability out of their new strategy.

Through grantmaking, technical assistance, and advocacy with the donor and rights communities, the Disability Rights Fund and the Disability Rights Advocacy Fund are resourcing, strengthening, and connecting organizations of people with disabilities to capitalize on these changes.

What we find most heartening — and where we focus more than 50% of our grantmaking — are the rising voices of those people previously marginalized by their intersectional identities — indigenous peoples with disabilities, women with disabilities, youth with disabilities.

We see the emergence of these voices as the sign of a movement expanding its size, strength, and impact, a movement at the tipping point. This is when barriers get broken.

**This is when old paradigms crumble and needed cultural shifts are made.**

Read — in this annual report — in stories about us and our grantees — about the escalating call to action from the world's one billion people with disabilities to expand global movements addressing climate change, gender inequality, human rights, and development.

We are proud to share this work with you. Join us and make a difference. In solidarity,



Diana Samarasan,  
Founding Executive  
Director



William Rowland,  
Board Co-Chair



Catherine Townsend,  
Board Co-Chair

# “WE WERE MADE FOR THESE TIMES.”

— Clarissa Pinkola Estés



Image: Clare Nakigozi (VAU), Angella Balaba (SIA-U), and Dwi Ariyani (DRF). 3 women (from Uganda and Indonesia) gesturing with high fives in celebration. Photo credit: David Nkurunziza

*This is a moment of much instability and uncertainty — from disaster risk and funding flows to struggling democracies. There is also much that we know and can build on. Our shared challenges and risks require each one of us, people with and without disabilities, to fully participate.*

*A new era of collaboration, effectiveness and scale is emerging*

There are times when a movement leaps forward, making progress swiftly, in rhythm with greater forces. New alliances emerge. A critical mass of greater consciousness takes hold.

Even when it seems to happen all at once — as with the ending of apartheid, and the civil rights movement in the United States — these moments in time are not arbitrary, and they are not stoppable. They are the result of decades of work, building relationships and understanding. These moments are the outcome of strategic, participatory planning and effective mobilization.

#### **THE POWER OF MANY SMALL GRANTS**

The Disability Rights Fund and its sister organization, the Disability Rights Advocacy Fund, have a proven model for equipping disability movements with the right resources and the right training to make measurable, tangible progress for all persons with disabilities in their communities.

Between 2008 and 2016, DRF/DRAF distributed over US\$20 million in 932 grants to 290 organizations in 33 countries, refining a highly effective, agile grantmaking process. Persons with disabilities are engaged at every level, from our staff and Global Advisory Panel, to our Board and grantees themselves.

#### **OUR WORK**

Our grantees are increasing access to education, ensuring that all children have the opportunity to discover their strengths and nourish their wisdom, and contribute to their communities.

Our grantees are finding, connecting, and equipping women in remote, rural areas, to educate them about their rights, and build their capacity to address violence.

Our grantees are working on access to justice, in legal and political systems that are rarely designed with persons with disabilities in mind, and where persons with disabilities are often not seen as viable witnesses.

Our grantees are working on access to basic information, in particular in parts of the world that experience natural disasters, and have no mechanisms in place to reach deaf or visually-impaired populations in case of emergency.

#### **THE OPPORTUNITY**

We are ready to scale what we do well, and leverage our learnings so that many inter-related movements benefit from advancements in the rights and inclusion of persons with disabilities.

At a moment of increasing instability — particularly for those in parts of the world that are prone to natural disaster, and for the most marginalized persons with disabilities — our grantees — Disabled Persons Organizations — are making sure that “leaving no one behind” “Isn’t just a slogan,” as Esther Louis, Executive Director, L’Union des Femmes à Mobilité Réduite d’Haïti said at the Conference of States Parties to the CRPD, United Nations.

DRF and DRAF are resourcing, connecting and contributing to resilience among people with disabilities, in communities all over the world.

Growth in political will and public funding follow our initial philanthropic investments.

*Discover more about the impact of our work, and join us in partnership, as we build on what works in advancing rights and inclusive development for all throughout the world.*

# “VOICING OUT”

## WOMEN WITH DISABILITIES

often face stigma and negative attitudes from the community, making them feel disempowered and lowering their self-esteem. Girls with disabilities often do not attend school, especially if families must choose those children they can afford to send to school. Isolated from society, women and girls with disabilities are further excluded from information or services that could benefit them.

## POVERTY AND ISOLATION

— combined with society’s perception that persons with disabilities are weak and vulnerable — set up women and girls with disabilities to be at higher risk of violence. Communication or transportation barriers, as well as a lack of awareness, prevent access to counseling and legal services. In rare cases, when a woman with disability reports a rape or other violation, she is not seen as credible. To add to the injustice, perpetrators are often not punished.

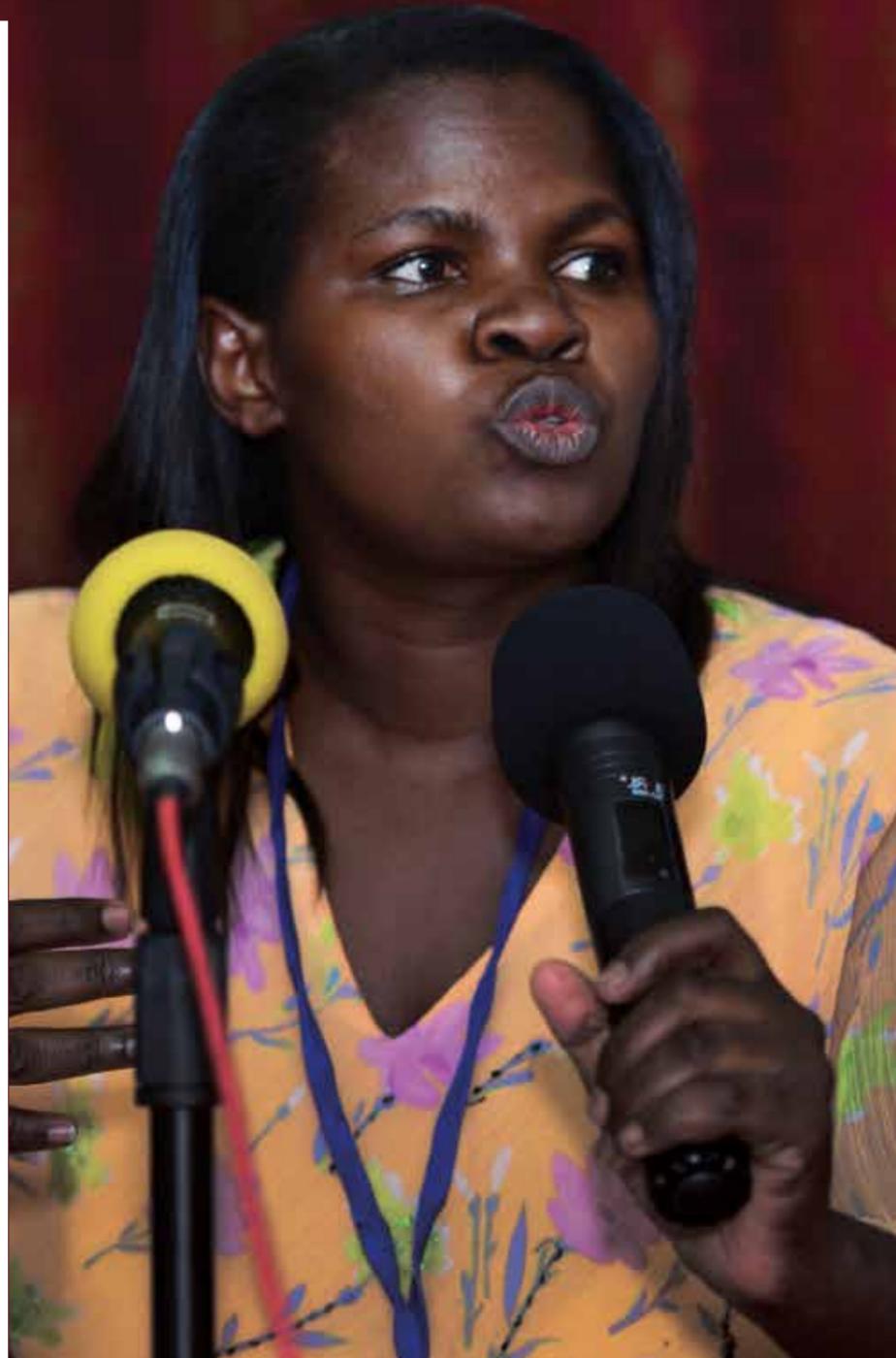


Image: Gaudence Mushimiyimana (UNABU). Rwandan woman speaking into microphone at a meeting. Photo credit: David Nkurunziza

## *Women with disabilities speak out against gender-based violence*

**RWANDA HAS MADE GREAT PROGRESS** in promoting gender equality. After the Rwandan genocide in 1994, women demanded equality in politics, land inheritance, marriage, and credit. Yet women with disabilities — 90% of whom live in rural areas — have not benefited from the economic growth and educational opportunities in the same way as women and men without disabilities. And despite the growing numbers of women in leadership positions in Rwanda, women with disabilities rarely hold or have access to positions of power. Many are unable to escape the cycle of poverty, getting left behind in the nation’s economic progress.

Umuryango Nyarwanda w’Abagore Bafite Ubumuga (UNABU) aims to make a difference through a project they call “Voicing Out,” which has reached nearly 500 women with disabilities. They believe that if they can empower women to gain self-confidence, they can help not only prevent violence, but also start healing for those who have been affected.

With DRF funding, an assessment by UNABU showed that women and girls with disabilities experience a high incidence of sexual and gender-based violence. Their assessment showed that 47% of women with disabilities surveyed reported having personally faced sexual and gender-based violence. And in spite of a national public campaign on the prevention of gender-based violence, many women with disabilities are not aware of the laws and services available for women survivors.

As a start, UNABU has trained community mobilizers to organize community advocacy groups of women and girls with disabilities and raise their awareness about their rights. They’ve initiated this work in the two rural districts of Muhanga and Rwanmagana and hope to expand nationwide in a few years. UNABU is also advocating that public services and NGO initiatives that prevent gender-

based violence should accommodate the specific needs of women with disabilities.

Women’s empowerment and community mobilization are not new tactics for development workers. But UNABU is working to reach a population that has been largely left out of mainstream women’s and poverty reduction programs.

UNABU’s community organizers are using the Convention on the Rights of Persons with Disabilities Article 6 (women with disabilities) and Article 16 (Freedom from exploitation, violence, and abuse) to advocate directly to duty bearers and service providers to demand that, in Rwanda, which has ratified the CRPD, the rights of women with disabilities are acknowledged, respected, and defended.

**The Disability Rights Fund’s work in Rwanda has an explicit objective to ensure that women with disabilities are fully included in the disability movement**, which is still relatively young and consists of urban and male-dominated groups. Through grantmaking, technical assistance, and outreach, DRF is encouraging groups like UNABU to create collaborations which highlight the diversity in the disability community and builds their capacity to work on issues affecting women.

# TRAGEDY CATALYZES COOPERATION

*In many parts of the world, people with disabilities face barriers to full participation in society. In some places, having a disability puts them in physical danger.*

In Haiti, many persons with disabilities are still isolated and excluded, especially those facing multiple layers of discrimination (disability, age, gender). High levels of poverty among women and girls with disabilities put them at greater risk of violence and abuse. Groups like L'Union des Femmes à Mobilité Réduite (UFMORH) responds to these challenges, promoting rights and advocating for changes in policies to ensure women and girls with disabilities enjoy the same rights as others.

In February 2016, with funding from the Disability Rights Fund, women with disabilities from UFMORH participated in civil society briefings of the Committee on the Elimination of Discrimination Against Women (CEDAW) in Geneva. Joining together with other Haitian women's rights actors for the first time, they outlined major challenges faced by women and girls with disabilities.

Then, on March 19, 2016, three women — Vanessa Previl, Monique Vincent, and Jesula Gelin — were murdered because they were deaf. The perpetrators held a belief that women with disabilities are bad or evil spirits. This belief imperils individuals with disabilities in Haiti, especially women with disabilities.

"Violence against women with disabilities is believed to be two or three times higher than against non-disabled women," says Lisa Adams, Program Director of the Disability Rights Fund. "Disability, gender and sexuality compound to present cultural myths and stereotypes about women with disabilities — ranging from infantilising them to making them hyper sexual....that has a lot to do with the violence experienced by women with disabilities in Haiti — these three women in particular."

After the murders, and with the CEDAW report in hand, disparate movements came together to demand justice. Jo-Ann Garnier Lafontant, DRF Haiti Grants Consultant, said, **"We are now beginning to see cross-sector collaboration and commitment to a collective goal, with activists and students organizing marches together with human rights, women's rights, and disability rights organizations."**



Image: Group of DRF/DRAF grantees at a Grantee Convening, Haiti.

Tragedies, both natural and man-made, reveal the depth of the challenges facing persons with disabilities. At the same time, they propel activists with disabilities into leadership roles and make new coalitions possible. As the movement grows, activists are increasingly able to articulate gaps in rights for persons with disabilities, including in times of disaster.

When Hurricane Matthew hit Haiti in late 2016, after a season of collective activism, Emilio Neas, lawyer

and coordinator of RANIPH Sud (National Association Network for the Integration of Disabled Persons, Southern Coalition), a grantee of both DRF and DRAF, remarked, "We recognize the efforts to respect the human rights of persons with disabilities, but we must also acknowledge that these rights are not always respected." Though the protection of persons with disabilities in situations of risk and humanitarian emergency is a right guaranteed under the CRPD and the Loi sur l'Intégration des

Personnes Handicapées [the Law for the Integration of Persons with Disabilities in Haiti], the state's preparation for and response to Hurricane Matthew illustrated continued deficiencies communicating with and providing accessible services to persons with disabilities.

The struggle to ensure that persons with disabilities receive equal access to information and services, and are not made additionally vulnerable due to gender or other identities, is ongoing.

Thanks to the work of DRF and DRAF grantees, more activists are involved, and stories of exclusion are reaching the media and the government. Organizations are working on violence prevention and gender policy reform, as well as working with municipalities on inclusive reconstruction and disaster risk management. A chorus of voices is now involved in demanding change.

# BUILDING RIGHTS IN RURAL AREAS



Image: Elizabeth Kayanga (IDIWA) and Jolly Acen (NUWODU). Two women from Uganda shaking hands in greeting in outdoor setting. Photo credit: David Nkurunziza.

In the rural areas of many developing countries, persons with disabilities are often isolated and face unbearable stigma and discrimination. Schools and health facilities are hard to reach for children and other persons with disabilities because of the long distances they must travel on rural roads, the inaccessibility of buildings or communication, or the lack of professionals trained to meet the needs of the disability community.

In 2016, a quarter of the grants made by the Disability Rights Fund and Disability Rights Advocacy went to organizations working in rural areas.

DRF's long-term support of Iganga District-based organization, Integrated Disabled Women's Activities (IDIWA), has led to successful advocacy in this rural area, which depends on subsistence agriculture and has a high level of poverty.

With DRF funding, IDIWA led advocacy for a district ordinance, passed in 2013, that addresses discrimination and promotes equal rights for persons with disabilities in the Iganga District. Nearly 62,000 persons with disabilities in Iganga are beneficiaries of this ordinance.

IDIWA's on-going work on sexual and reproductive health rights for women with disabilities gained them a permanent seat on the district health planning council. With fellow DPO, Iganga District Action on Physical Disability (IDAPD), and the Civil Society Budget Advocacy Group, they are now pushing for increased budget accountability for

disability inclusion in education and health programs in two other rural districts.

With 700 members, IDIWA has turned to planning for their sustainability. They hope to build a mango juice processing plant, a social venture which will employ persons with disabilities and provide a sustainable revenue stream for the organization. The members have come to realize that the more organized they are and the more people they can mobilize, the stronger their voices will be when standing up for their rights.

*“There was an intensive consultative process involving all stakeholders, making Iganga the pioneer in legal reform and domestication of the CRPD at the local level in Uganda. The ordinance works in synergy with the Constitution of Uganda, the Disability Act, and other related legal frameworks on disability.” – Elizabeth Kayanga*

## BUILDING BLOCKS FOR ENSURING INCLUSION AND RIGHTS OF PERSONS WITH DISABILITIES

By Elizabeth Kayanga

- 1. Generate credible information and data.** Conduct baseline research to inform plans, educate the community and measure progress.
- 2. Consult with local stakeholders.** Network with and learn from the realities on the ground, including persons with disabilities, local and district representatives and civil society groups.
- 3. Raise awareness of disability rights.** Use local media, such as community radio and drama, to raise the voices of persons with disabilities. Remember to ensure accessibility of communication.
- 4. Leverage funding.** Leverage DRF funding to ask for support from local government and local funders, based on results and credibility of your work.
- 5. Develop policy with a technical expert and ensure alignment with national laws and policies.** Use legal expertise for guidance on language and process, before presenting a draft to local and national governments. Aim to ensure proposed legislation aligns with national government policies and international frameworks, including the CRPD and the SDGs.
- 6. Create alliances.** Work with other civil society organizations, including women's groups and groups working with persons living with HIV/AIDS to expand the agenda for equality and inclusion.
- 7. Build on achievements, learn from lessons, and envision next steps.** Grow organizational capacity, master the issues, and continue to be an influence for positive change.

# PATHWAY TO CHANGE

A decade after the adoption of the **Convention on the Rights of Persons with Disabilities** and with the new **Sustainable Development Goals**, there is an unprecedented opportunity to ensure that persons with disabilities are at decision-making tables.

The Disability Rights Fund and the Disability Rights Advocacy Fund are resourcing, strengthening, and connecting disabled persons' organizations to contribute to development and the achievement of rights.

## SUPPORT TO DPOs

To advance disability-inclusive development and rights



Grants



Technical Assistance



Advocacy

## BUILDING MOVEMENTS

Disability movement strengthened to advocate for rights

- Persons with disabilities equipped with skills and knowledge
- Disability movement broad and diverse
- Disabled persons' organizations engage in other human rights movements

## DRIVING THE AGENDA

Persons with disabilities are at decision-making tables

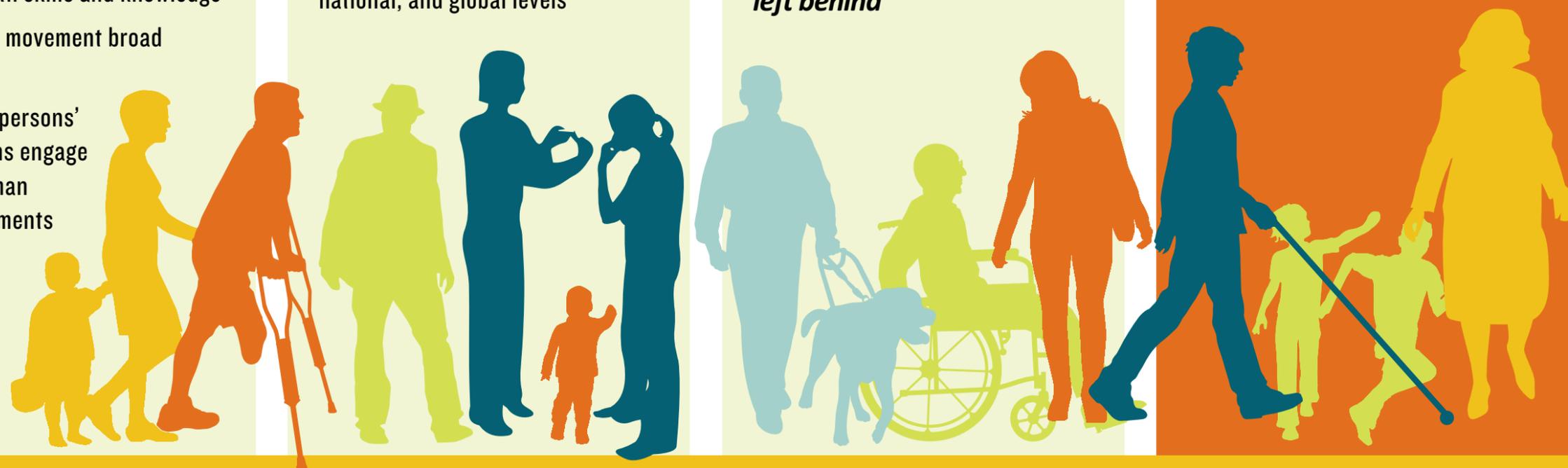
Disabled persons' organizations participate in human rights and development processes at local, national, and global levels

## ACHIEVING RIGHTS

Rights of persons with disabilities achieved through systems change

Legislation, policy, government and development programs and budgets in accordance with the Convention on the Rights of Persons with Disabilities, *ensuring no one is left behind*

Persons with disabilities participate fully in society and enjoy equal rights and opportunities



# ADAPTING TO SHIFTING ENVIRONMENTS

*Pacific Region*

Disabled Persons' Organizations have led advocacy in the Pacific region to ratify the CRPD; to align legislation and policy with international standards on rights of persons with disabilities; to develop disability inclusive disaster risk reduction strategies; to ensure inclusion of remote island communities and marginalized persons with disabilities; and to be recognized as part of the Indigenous People's movement.

In 2016, Samoa and the Federated States of Micronesia became the latest Pacific Island countries to ratify the CRPD after years of advocacy by DPOs supported by the Disability Rights Fund and Disability Rights Advocacy Fund.

**An interview with Setareki S. Macanawai, CEO of the Pacific Disability Forum and Global Advisor on the Grantmaking Committee of the Disability Rights Fund, describes the disability movement's growth.**

***The fight for disability rights has come a long way.*** *In the 1960s, service providers and international NGOs supported special schools and traditional community-based rehabilitation. These services emphasized a charity approach to persons with disabilities. They exacerbated the attitudes of society by treating persons with disabilities as incapable, to be looked after by others, and as recipients of goodwill.*

*In the 1980s, a handful of us began to challenge the charity model. Persons with disabilities mobilized, establishing disabled persons' organizations that advocated for the right to access all services. We started to work against the stigma faced by persons with disabilities.*

*With the Convention on the Rights of Persons with Disabilities (CRPD) — including the early signing or ratification by the Cook Islands, Tonga, and Vanuatu — we finally had a tool and language to push for our rights. We used the CRPD to activate persons with disabilities and raise awareness among elected officials. We also participated in advocating at the regional level to create a unified strategy towards the rights of persons with disabilities.*

With Disability Rights Advocacy funding in the Pacific Islands — including in Fiji, Papua New Guinea, Samoa, Solomon Islands, and Kiribati — DPOs have strengthened the capacity of their members and built alliances so that they can lead disability inclusive development efforts. They have expanded their activities to rural and outer islands, bringing new voices to national-level advocacy efforts, to support the adoption of CRPD-compliant national disability acts, as in Papua New Guinea and the Solomon Islands.



Image: Naomi Navoce, Yumi Sera (DRF), Mereseini Bolaira, Faatino M. Utiumapu, Pratima Gurung, Jo-Ann Garnier Laftontant (DRF), Ipul Powaseu, Kelera Taveta. 7 women (from the Pacific, U.S., Nepal, and Haiti) posing at AWID meeting, Brazil.

## DRAF Facilitates Contributions of Pacific Women with Disabilities

At the UN Climate Change Conference 2016 in Morocco, Ipul Powaseu, head of the Papua New Guinea Assembly of Disabled Persons, spoke on behalf of the Women and Gender Constituency about the importance of inclusive participation of all in civil society in disaster risk reduction:

*"The eroding shorelines are threatening our way of life and livelihoods. Decreasing food security; decreasing access to clean water, sanitation, and hygiene; reduced access to infrastructure, shelter and basic services; and increasing displacement — these are realities that I, as an indigenous woman with disability, from a small island in the Pacific, am faced with."*

In September 2016, with the support of DFAT (Australian Government), DRAF, and the Pacific Disability Forum, 6 women with disabilities from the Pacific joined 1,800 other women to participate in AWID's (Association of Women in Development) International Forum in Brazil.

Nellie Caleb of the Disability Promotion and Advocacy Association in Vanuatu and co-chair of the Pacific Disability Forum echoed the sentiment of all the participants:

***"AWID inspired us to start the work to strengthen alliances with other women's groups in the broader women's movement."***

# THE MOVEMENT FOR UNITY AND CHANGE

*The campaign for the Indonesian disability movement urges everyone to raise their voices for the rights of people with disabilities*

## TEN TIPS TO STRENGTHEN THE DISABILITY MOVEMENT

By Maluani Rotinsulu



Image: Ramadhani, Lindawati, Maulani Rotinsulu, Elva Susilawati, Ellyana Sitio, Yustitia Arief. 6 women posing in front of sign "Bergerak Untuk Disabilitas".

*Thanks to the consistent funding for the last five years from the Disability Rights Advocacy Fund and the Disability Rights Fund, the movement has grown and we've had some considerable wins. The support raised our dignity — especially in front of the government. Now they consider us as professionals and equals, and treat us as partners.*

Maluani Rotinsulu, Chair, Indonesian Association of Women with Disabilities

Four years after Indonesia's ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2012, the disability movement celebrated a new achievement. On March 17, 2016, the Persons with Disabilities Act (Law No. 8 of 2016) passed. The new bill adopts a human rights approach to disability and complies with the CRPD.

Behind this major legislative reform was a National Coalition funded by the Disability Rights Advocacy Fund and the Disability Rights Fund. The coalition included: the Center for Election Access for Citizens with Disabilities (PPUA Penca), the Center for Indonesian Law and Policy Studies (PSHK), the Indonesian Association of Women with Disabilities (HWPCI), the Indonesia Blind Union Indonesia (PERTUNI), the Indonesia Association of Persons with Disabilities (PPDI), and the Indonesia Association for Mental Health.

The members of the coalition consulted persons with disabilities and their representatives across Indonesia. They then drafted the legislation and drove advocacy for its passage. **The new law is a significant political and social milestone for Indonesia's estimated 36 million people with disabilities** (15% of total population).

What is especially remarkable and inspiring about the movement in Indonesia is that more and more women with disabilities have stepped into leadership roles in what has been a traditionally patriarchal society. Serving as role models, they are fighting at the local and national level for equal access to health care, education, employment, and political rights.

One of these leaders is Maluani Rotinsulu, who has been deeply involved since the lead-up to her country's 2012 ratification of the CRPD. She is committed because as a woman with disability, she knows first-hand what discrimination means.

During the International Day of Persons with Disabilities on December 3, 2016, Maluani received an award from the Minister of Social Affairs for her dedication to promoting the rights of persons with disabilities. The National Coalition (POKJA) received an award for their contribution to the new Persons with Disabilities Act.

True to their campaign, "Bergerak untuk Disabilitas, the disability movement has joined together and moved forward to advance disability rights.

Their next target is to ensure that a National Commission on Disability is established to monitor the State's commitments under the new Law, and that Indonesia's implementation of the Sustainable Development Goals is disability-inclusive and gender-sensitive, for women with disabilities.

1. Empower marginalized persons with disabilities by inviting them to join the movement
2. Mobilize diverse people to participate in rallies as a sign of solidarity
3. Strengthen coalitions by learning about the CRPD and building capacity for advocacy
4. Ensure that voices from the most marginalized groups, such as persons with psychosocial disabilities, Deaf people, persons with intellectual disabilities or persons with multiple disabilities, are heard
5. Create messages and tactics for different audiences — the public, politicians, government bureaucrats, and media
6. Form allies across movements, including the women's and labor movements and other human rights groups, to find common ground and pursue common goals
7. Reach out to the media to share stories about persons with disabilities
8. Be inclusive of women with disabilities, including as new leaders of the movement
9. Make an impact by working with legal and policy experts to draft laws and policies that reject the charity model and embrace a rights based framework
10. Advocate to government for the passage of disability inclusive legislation

# ACCEPTANCE BEGINS WITH THE SELF

Violence against persons with albinism in Malawi has been escalating in recent years at an alarming rate. Fueled by the widespread belief that their body parts possess magical properties that can bring luck and wealth, persons with albinism are being abducted, killed and maimed, their body parts sold to traditional healers for large sums of money. Even after death, persons with albinism cannot rest in peace; grave robbers exhume their bodies to steal and sell their bones.

In communities gripped by poverty and lack of education, the promise of payment and potential for fortune lead to choices often made out of desperation. With insufficient law enforcement capacity to monitor, document, or respond to the increase in violence, perpetrators have enjoyed a climate of near impunity while persons with albinism are left in fear and vulnerable.

Bonface Massa, national coordinator of Associations of Persons with Albinism in Malawi (APAM), the only organization representing persons with albinism in Malawi, is working to ensure that this crisis is addressed, that persons with albinism are brought into the light, and that the barriers that



*Swift significant progress for persons with albinism in Malawi – and still so far to go*



prevent them from fully enjoying rights guaranteed by the Constitution of the Republic of Malawi and the Convention on the Rights of Persons with Disabilities (CRPD), which Malawi ratified in 2009, are removed.

As a highly marginalized, isolated group, there is very little data on the current situation of persons with albinism. With a grant from the Disability Rights Advocacy Fund, APAM first researched baseline data to illustrate the scale of existing harassment and violence. APAM worked closely with law enforcement to document incidents of violence, intimidation, abduction, and murder involving persons with albinism. Using this data, they approached the government, advocating for greater protections for persons with albinism.

Together with the Federation of Disability Organizations in Malawi (FEDOMA) and Disabled Women in Africa (DIWA), APAM advocated for the successful amendment of the Penal Code and the Anatomy Act. The amended laws criminalize and give stiffer sentences for abductions, killings, and other acts of violence against persons with albinism.

APAM is now a key interlocutor on issues of albinism in Malawi — evidenced by their inclusion in the national technical committee on persons with albinism. APAM has also established strong networks with other human rights organizations and policy makers. They have mobilized persons with albinism and the general public, raising awareness among their members and the community about albinism and shattering myths and superstitions about it. They have also revealed challenges that persons with albinism are facing in getting access to health, education, justice, and livelihood in addition to the physical threats they face.

*“There are people out there who are suffering because their parents are not aware. There are people out there, even relatives, who are treating us differently, just because they don’t know us. It really moves me to say, I need to keep fighting. It’s really very complicated. As a community leader, I need to step up for the rest of my colleagues. At the same time, I am a target and we are dealing with a criminal issue. One thing I make sure I always do: I always say I cannot stop and I must continue to fight.”*

—Bonface Massa, national coordinator of Associations of Persons with Albinism in Malawi (APAM)

Albinism is a rare, non-contagious, genetically inherited condition which occurs worldwide regardless of ethnicity or gender. It most commonly results in the lack of melanin pigment in the hair, skin and eyes. Albinism is still profoundly misunderstood, socially and medically. The physical appearance of persons with albinism is often the object of erroneous beliefs and myths influenced by superstition, which foster their marginalization and social exclusion.

—UN Office of the High Commissioner for Human Rights (OHCHR)

Image at left: two persons with albinism marching with others, holding a sign that says “Same blood different colours.” Above: Tumeliwa Mphepo, a young woman in pink speaking to a crowd, holding umbrella.

# 2016 GRANTEEES

## DISABILITY RIGHTS FUND

### Africa

#### Ghana

National Coalition  
Inclusion Ghana

#### Mid-Level Coalition

Lakeside Disability Rights  
Advocacy Initiative  
Voice of People with Disability Ghana

#### Small Grants

Future Hope International  
Ghana Federation of Disability Organisations  
Ghana National Association of the Deaf  
Ghana Society of the Physically Disabled  
Kekeli Foundation

#### Off-Docket Grants

Ghana Federation of Disability Organisations

### Malawi

#### Small Grants

Nkhotakota Association of Visually  
Impaired Persons  
The Registered Trustees of Disabled  
Women in Development  
The Registered Trustees of the Association  
of the Physically Disabled of Malawi

#### Technical Assistance

Federation of Disability Organizations  
in Malawi

#### Off-Docket Grants

Federation of Disability Organizations  
in Malawi

### Rwanda

#### Small Grants

African Initiative for Mankind Progress  
Organization  
Human Rights First Rwanda Association  
Initiative for Refugees with Disabilities  
Organisation d'Integration et de Promotion  
des Persones Atteintes d'Albinisme  
Rwanda National Association of Deaf Women  
Rwanda Union of Little People  
Umuryango Nyarwanda w'Abagore Bafite  
Ubumuga  
Uwezo Youth Empowerment

#### Technical Assistance

Institute for Policy Analysis and Research  
National Union of Disabilities Organisations  
of Rwanda

#### Off-Docket Grants

National Union of Disabilities Organisations  
of Rwanda

### Uganda

#### National Coalition

National Union of Disabled Persons  
of Uganda  
National Union of Women with Disabilities  
of Uganda

#### Mid-Level Coalition

Action for Youth with Disabilities Uganda  
Integrated Disabled Women Activities  
Spinal Injuries Association  
Youth with Physical Disabilities  
Development Forum

#### Small Grants

Brain Injury Support Organisation of Uganda  
Lira District Disabled Women Association  
Triumph Uganda Mental Health Support and  
Recovery Program  
Uganda Albinos Association  
Uganda National Action on Physical Disability  
Vituligo Association of Uganda

#### Special Opportunity

National Union of Disabled Persons of Uganda

#### Uganda Capacity Fund

Bududa Deaf Women's Organisation  
Buganda Disabled Union  
Gulu Women with Disabilities Union  
Masaka Association of Persons with  
Disabilities Living with HIV & AIDS  
Mubende Women with  
Disabilities Association  
My Story Initiative Ltd.  
National Union of Disabled Persons of Uganda  
Uganda Albinos Association  
Uganda National Association of  
Cerebral Palsy  
Uganda Parents of Person with Intellectual  
Disabilities

#### Off-Docket Grants

National Union of Disabled Persons of Uganda

### Asia

#### Bangladesh

##### National Coalition

Access Bangladesh Foundation

##### Mid-Level Coalition

Access Bangladesh Foundation

#### Small Grants

Association for Research Development and  
Rights Implementation of Disabilities  
Bangladesh Visually Impaired People's Society  
Protibandhi Kallyan Songstha  
Society of the Deaf and Sign Language Users

#### Off-Docket Grants

Access Bangladesh Foundation

### Indonesia

##### National Coalition

Perhimpunan Organisasi Harapan Nusantara  
Pusat Pemilihan Umum Akses Untuk  
Penyandang Cacat

##### Mid-Level Coalition

Center for Improving Qualified Activity in Life  
Himpunan Wanita Disabilitas Indonesia  
Lembaga Sapda (Sentra Advokasi Perempuan  
Difabel Dan Anak)

#### Small Grants

Himpunan Wanita Penyandang Cacat  
Indonesia Sulawesi Selatan  
Paguyuban Sehati Sukoharjo  
Perhimpunan Jiwa Sehat  
Persatuan Penyandang Cacat Indonesia  
Sasana Integrasi dan Advokasi Difabel  
Yayasan Dria Manunggal  
Yayasan Keluarga Tuna Rungu Sehjira  
Yaysan Pusat Pemberdayaan Penyandang  
Disabilitas Indonesia Bali

#### Technical Assistance

Himpunan Wanita Disabilitas Indonesia

#### Off-Docket Grants

Himpunan Wanita Disabilitas Indonesia

### Myanmar

##### National Coalition

Myanmar Council of Persons with Disabilities

#### Small Grants

Disabled Development Initiative  
Disabled People's Development Organization  
Future Stars Self-Advocacy Organization  
Myanmar Deaf Community  
Development Association  
Myanmar Physically Handicapped  
Association  
Shwe Min Tha Foundation

#### Off-Docket Grants

Myanmar Federation for Persons with  
Disabilities

### Caribbean

#### Haiti

##### Small Grants

Association des Femmes Handicapées  
des Gonaïves et l'Union des Femmes a  
Mobilité Réduite d'Haïti  
Association des Femmes Handicapées du  
Sud  
Association des Sourds de Leveque, Haïti  
Association Filles et Femmes au Soleil  
Coalition Nationale des Organisations pour  
l'Intégration des Personnes Handicapées  
Fédération Nationale de Sourds d'Haïti  
Organisation des Enfants Demunis et  
Handicapes d'Haïti  
Reseau Association National pour  
l'Integration  
des Personnes Handicapees

#### Special Opportunity

Reseau Association National pour  
l'Integration des Personnes Handicapees  
(2)

### Pacific Islands

#### Republic of the Marshall Islands

##### Small Grants

Marshall Islands Disabled  
Persons Organization

### Tuvalu

#### Small Grants

Fusi Alofa, Inc.

### Vanuatu

##### National Coalition

Disability Promotion and  
Advocacy Association

## DISABILITY RIGHTS ADVOCACY FUND

### Africa

#### Ghana

National Coalition  
Ghana Blind Union  
Ghana Federation of Disability Organisations

### Malawi

##### National Coalition

Federation of Disability Organizations  
in Malawi

##### Mid-Level Coalition

The Registered Trustees of Disabled Women  
in Africa

#### Small Grants

Association of People with Albinism in  
Malawi  
The Registered Trustees of Disabled Women  
in Africa  
The Registered Trustees of the Malawi  
National Association of the Deaf

#### Strategic Partnerships

Centre for Girls and Interaction

### Rwanda

##### National Coalition

National Union of Disabilities Organisations  
of Rwanda

##### Mid-Level Coalition

Rwanda National Union of the Deaf

### Uganda

##### National Coalition

Uganda National Action on Physical  
Disability

#### Small Grants

Uganda National Association of the Deaf

### Asia

#### Bangladesh

##### National Coalition

Jatiyo Trinomul Protibandhi Sangstha

##### Mid-Level Coalition

Federation of DPOs Sitakund  
SEID (Society for Education and Inclusion  
of the Disabled)  
Women with Disabilities Development  
Foundation

#### Small Grants

Protibandhi Narider Jatio Parishad  
Turning Point Foundation

### Indonesia

##### Mid-Level Coalition

Himpunan Wanita Disabilitas Indonesia

#### Small Grants

Forum Komunikasi Masyarakat  
Berkebutuhan  
Khusus Aceh  
Lembaga Pemberdayaan Tunanetra  
Paguyuban Penyandang Cacat Klaten

### Caribbean

#### Haiti

##### National Coalition

Reseau Association National pour  
l'Integration des Personnes Handicapees  
Société Haïtienne d'Aide aux Aveugles

#### Small Grants

Fondation J'Aime Haïti

### Pacific Islands

#### Fiji

##### National Coalition

Fiji Disabled Peoples Federation

#### Small Grants

Fiji Association of the Deaf

### Kiribati

#### Small Grants

Te Toa Matoa

### Papua New Guinea

##### National Coalition

Papua New Guinea Assembly of Disabled  
Persons Association

### Samoa

#### Small Grants

Deaf Club Samoa

### Solomon Islands

#### Small Grants

Disabled Peoples' Association of  
Solomon Islands

### International

#### Canada

##### Strategic Partnerships

Association for Women's Rights  
in Development

### Switzerland

##### Strategic Partnerships

International Disability Alliance (2)

### Regional

#### Africa

##### Strategic Partnerships

African Disability Forum

### Southeast Asia

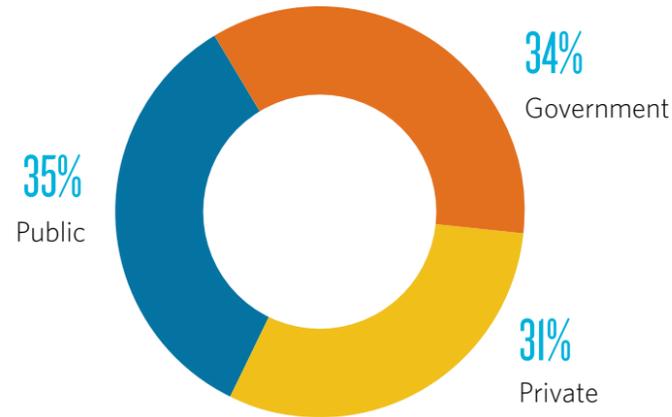
##### Strategic Partnerships

ASEAN Disability Forum

# 2016 FINANCIALS

## DISABILITY RIGHTS FUND REVENUE\* TOTALING \$2,572,563 (USD)

Public **\$909,452** (35%)  
Private **\$791,273** (31%)  
Government **\$871,838** (34%)



## DISABILITY RIGHTS FUND EXPENDITURE TOTALING \$3,040,027 (USD)

Grantmaking/Program **\$2,538,887** (84%)  
Administration **\$313,544** (10%)  
Fundraising **\$187,596** (6%)



## DISABILITY RIGHTS ADVOCACY FUND REVENUE\* TOTALING \$1,413,192 (USD)

### EXPENDITURE TOTALING \$1,503,348 (USD)

Grantmaking/Program **\$1,455,693** (97%)  
Administration **\$35,672** (2%)  
Fundraising **\$11,983** (1%)



\*Under US Generally Accepted Accounting Principles (GAAP), the organizations are required to use accounting that recognizes revenues on the full amount of a contract as they are signed but release the money over multiple years as the money is spent down. Due to the difference in timing of how revenue and expenses are recorded for US GAAP, this can result in numbers that look like deficits when in fact the organizations have positive increases in their bottom line. More information is available as needed. DRF had a carry forward of \$690,685 from the previous year and DRAF had a carry forward of \$504,685.

## WHO WE ARE

DRAF and DRF include persons with disabilities at all levels, from advisors and staffing to governance. Our Global Advisory Panel members come from all over the world and reflect a cross-section of the disability and broader human rights communities. Advisors help us tackle key questions arising from our work. DRAF and DRF Grantmaking Committees are composed of donor representatives and advisors and make strategy and grant recommendations to the board. The boards of directors have experience in disability and human rights and philanthropy, as well as financial, legal, and organizational development expertise. Our expert global staff also includes persons with disabilities and represents diverse geographies. This structure grounds our programming in reality and centers our work on learning and participation.

### BOARD OF DIRECTORS

William Rowland, Co-Chair  
Catherine Hyde Townsend, Co-Chair  
Ola Abu Al Ghaib  
Charlie Clements  
Kai Dickerson, Treasurer  
Andrew Ferren, Clerk  
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Kristen Pratt  
Diana Samarasan, ex-officio member  
Lorraine Wapling

### GLOBAL ADVISORY PANEL

Jenipher Jane Akinyi  
Fedi Behri  
Dan Ghattas, Bridge Builder  
Pratima Gurung  
Kerryann Ifill  
Mirna Cunningham Kain, Bridge Builder  
Setareki Macanawai  
Edwin Sangara Osundwa  
Ignacio Saiz, Bridge Builder  
Sanja Tarczay  
Alberto Vásquez

### GRANTMAKING COMMITTEE

Pratima Gurung, Advisor  
Setareki Macanawai, Advisor  
Edwin Osundwa, Advisor  
Alberto Vasquez, Advisor  
Penny Innes, Department for International Development, United Kingdom  
Mika Kontiainen, Department of Foreign Affairs and Trade, Australia  
Kimberly O'Haver, Open Society Foundations  
Catherine Hyde Townsend, Wellspring Advisors

### STAFF

Diana Samarasan, Founding Executive Director  
Lisa Adams, Program Director  
Paul Deany, Program Officer Pacific & Asia (Bangladesh & Myanmar)  
Jorge Manhique, Program Officer Africa (Malawi & Rwanda)  
Med Ssengooba, Program Officer Africa (Ghana & Uganda)  
Dwi Ariyani, Indonesia Grants Consultant  
Jo-Ann Garnier Lafontant, Haiti Grants Consultant  
Melanie Kawano-Chiu, Project Officer  
Christina Parasyn, Technical Assistance Coordinator  
Yumi Sera, Director Partnerships & Communication  
Alice Phinizy, Finance & Operations Manager  
Arlene Wilson-Grant, Grants Manager  
Kerry Thompson, Information & Program Coordinator

### DISABILITY RIGHTS FUND

The Disability Rights Fund supports persons with disabilities around the world to build diverse movements, ensure inclusive development agendas, and achieve equal rights and opportunity for all.

The Disability Rights Fund (DRF) is a pooled fund combining the resources of multiple governmental and private donors, harmonizing efforts to efficiently reach marginalized groups of persons with disabilities. Our grantmaking includes groups such as women with disabilities, youth with disabilities, people with psychosocial disabilities, people with intellectual disabilities, persons with albinism, little people, indigenous persons with disabilities, and the Deafblind.

### DISABILITY RIGHTS ADVOCACY FUND

The Disability Rights Advocacy Fund supports persons with disabilities in the developing world to advance legal frameworks to realize their rights.

The Disability Rights Advocacy Fund (DRAF) supports country-level Disabled Persons Organizations (DPOs) to lobby for ratification of the Convention on the Rights of Persons with Disabilities (CRPD) and to ensure legal frameworks advance inclusion. We support DPOs to use global rights and development frameworks, such as the CRPD and the Sustainable Development Goals (SDGs), ensuring no one is left behind. The DRAF also supports regional and global initiatives, such as the Indigenous Persons with Disabilities Global Network, which strengthen cross-movement efforts by highlighting diverse voices.