

Social Justice Funders SPOTLIGHT:

Disability Rights Fund

by Johanna Wald

The genesis of The Disability Rights Fund can be traced back to 1999 and a brief exchange that its founding director, Diana Samarasan, had in Macedonia after visiting institutions where people with disabilities had been placed.

Working as a mental health consultant for the American Refugee Committee at the time, Samarasan recalls her shock at seeing, “children...tied to beds for years at a time so their limbs had atrophied and they could not stand.” She recalled walking into a women’s ward “where the same bucket that was used to mop the floor was used to serve soup... These were horrific, horrific scenes.”

When Samarasan questioned local providers about the deplorable conditions, they told her that people with disabilities “don’t have the same feelings as we do.” That response, she says, “started my journey in addressing disability as a rights issue.” Until the advent of the Convention on the Rights of Persons with Disabilities or CRPD (an international human rights treaty adopted by the UN in 2006), she says, almost all donors and most Non-Governmental Organizations (NGOs), including those focusing on human rights, viewed people with disabilities as “objects for charity” rather than “active, empowered members of society or rights activists.” She was determined to make “shifting the paradigm from charity to rights and upsetting the power balance” her life’s work.

The opportunity to create a fund dedicated solely to advancing the human rights of people with disabilities didn’t arise until several years later in 2007, following the adoption of CRPD, through the support of an anonymous donor. Samarasan was hired as a consultant and, in consultation with the broader disability community and donors, built the framework for the new fund.

“This fund had to be different. It could not be your traditional top-down philanthropy,” she recalls thinking at the time. And so Samarasan devised a strategy for supporting organizations run by and for individuals with disabilities and whose central mission was to advocate for people with disabilities’ full participation in society. Samarasan explained that the slogan for the global disability community – “Nothing about us without us” – came to represent the Fund’s central, guiding philosophy.

Over nearly a decade, DRF has grown its donor pool and now makes 100-125

grants annually, distributing between \$2-2.5 million every year.

In keeping with its inclusive philosophy and mission, the Fund practices what’s typically called “participatory grantmaking.”

The Fund’s grantmaking committee includes four donor members and four leaders with disabilities from the regions where DRF works. This model, Samarasan says, “puts decision-making about funding strategy and grants in the hands of disability rights leaders and activists, who have the expertise and perspectives that funders typically do not have.” The DRF grantmaking committee makes sure that at least fifty percent of grantees in each round are “marginalized groups” within the disability community, among which are included groups that may not have received any grants in the past. All grantees are working to effect changes in policy and practice on the ground.

The Fund selects particular countries for grant-making based upon what Samarasan calls “political will and a vibrant rights movement” with a commitment to continue the funding for at least six years. DRF currently funds organizations that work in the Pacific Islands, Haiti, Ghana, Malawi, Rwanda, Uganda, Bangladesh, Myanmar, and Indonesia. Within each country, the Fund selects grantees based on their ability to strengthen the overall

climate for policy change around rights of people with disabilities. It strives to create a holistic advocacy strategy, carried out by a cohort of large, medium-sized, and small organizations of people with disabilities. The fund also encourages cross-movement work involving women, indigenous and LGBTQ populations. Much of the current advocacy within these countries revolves around ratification, implementation, and monitoring of the Convention on the Rights of Persons with Disabilities (CRPD), including utilizing the treaty to argue for inclusion of people with disabilities in the implementation of the new global development framework, the Sustainable Development Goals. The CRPD mandates participation of representative organizations of persons with disabilities in the implementation and monitoring of rights, including the right to development.

Every year, DRF convenes grantees in each country or region, where it brings in experts to train participants in movement building and strategies for effectively engaging with local and national governments. Samarasan feels bolstered by what the Fund has accomplished to date. It is, she says, “empowering to see activists with disabilities coming together to fight for rights in their own countries and globally.”

Disability Rights Fund

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GRANTEE SPOTLIGHT: OHANA

Yogyakarta Province, Indonesia

An Indonesian activist named Risnawati (Risna) Utami, founded OHANA in 2009 with some colleagues who, like her were alumnae of the Ford Foundation International Fellowship. Until she was 10 years old, Utami had gotten around using crutches for short distances and a wheelchair for long distances. The organization she helped found is dedicated to strengthening the rights of people with disabilities enhancing their political power and assuring access to educational opportunities.

“People with disabilities have been stigmatized and discriminated against, we still have to struggle to be more equal with others in Indonesia,” Otami explains. While seeking to unite all people with disabilities into a rights movement, OHANA places particular emphasis on empowering women and girls.

In Utami’s words, OHANA “works in several layers” and sees itself as a “bridge between local, national and global efforts.” Major activities include drafting legal regulations for provinces and for the national government, conducting policy advocacy related to disability rights, and offering workshops and trainings to develop knowledge and skills that benefit a rights movement of like-minded organizations across Indonesia. Currently OHANA is trying to push passage of a disability rights bill in Indonesia and to implement, within Indonesian provinces, the principles and tenets set forth by the United Nations Convention on the Rights of Persons with Disabilities. Despite the fact that the Indonesian House of Representatives ratified the CRPD in 2011, Utami explains that implementation at the local level has been a challenge.

Part of that challenge, she says, is because the Indonesian government was initially reluctant to change its approach from viewing people with disabilities as charity cases to people that deserve expanded rights and power.

“We are demanding a lot in many areas of development and at the policy level,” Utami says, adding, “We’ve never been active before in how to influence policy makers.” With training and education, the government has become more aware and open to this new paradigm, and OHANA now works closely with government officials not only to create regulations but also programs and policies aligned

with CRPD principles and Sustainable Development Goals (SDGs) that demonstrate “Leave No One Behind.”

As a result of OHANA’s advocacy, Utami sits on the Yogyakarta city planning council, where she aspires to increase the amount of accessible public space by 10%

every year for the next 10 years as is required by a local regulation on the protection and fulfillment of the rights of persons with disabilities of Yogyakarta Province. OHANA is also helping to develop a network of organizations throughout Indonesian provinces working to connect local and regional efforts to the national regulations and program policies related to “disability inclusive development” in the SDGs being formalized by the government.

Utami expects OHANA to “be around for a long time until individuals with disabilities enjoy full equality in this country.” Lately, she has been planning for the future—both her own and that of the organization she has devoted so much of her energy to shaping. OHANA participates in the annual grantee meeting convened by DRF to discuss progress and share strategies. There, she is able to meet and network with other potential funders who may be able to fill the gap created when DRF funding is eventually phased out.

Utami’s work is also moving into the international arena. She chairs the Indonesian National Consortium for Disability Rights (INCDR). The Indonesian government recently nominated her to a three-year term as a CRPD Committee member at the United Nations. Meanwhile, Utami, who is 44, thinks ahead: “I am trying to share the leadership with the younger generation, so once I get older then there are perfect successors to continue leading our disability rights movement in Indonesia.



Risna Utami at the United Nations. (photo courtesy of Risna Utami)

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