Social Justice Funders SPOTLIGHT:

Disability Rights Fund

The genesis of The Disability Rights Fund (DRF) can be traced back to 1999 and a brief exchange that its founding former 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 <u>Convention on</u> the Rights of Persons with Disabilities or <u>CRPD</u> (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.

It would not be until 2007 and after the ratification of the CRPD, that the opportunity to create a fund dedicated solely to advancing the human rights of people with disabilities would arise. Through support of an anonymous donor Samarasan was hired as a consultant and, in collaboration with the broader disability community and donors, built the framework for the new fund. Samarasan left DRF in 2021. DRF Executive Director Catalina Devandas was appointed in August, 2022. Since its founding, DRF has significantly expanded its donor pool and grantmaking. In 2021, DRF provided \$4.5 million USD to 136 organizations advancing the rights of persons with disabilities.

In keeping with its inclusive philosophy and mission, the Fund practices "participatory grantmaking." The Fund's grantmaking committee includes four donor members and four leaders with disabilities from the regions where DRF works. This model 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. Meanwhile, program officers at DRF "work side-by-side with their fellow activists with disabilities, providing advocacy and technical support," explained Kerry Thompson, DRF's inclusion and accessibility development manager.

DRF has funded organizations of persons with disabilities (OPDs) working in 40 countries, which currently include Haiti, Ghana, Malawi, Nigeria, Rwanda, Uganda, Bangladesh, India, Indonesia, Nepal, and the Pacific Island Countries. 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. The fund also encourages cross-movement work involving women, indigenous and LGBTQ populations. Much of the current advocacy in these countries

revolves around ratification, implementation, and monitoring of the United Nations' Convention on the Rights of Persons with Disabilities (CRPD). This includes drawing upon the Convention's work to make the case for inclusion of people with disabilities in the implementation of the United Nations' global development framework, the Sustainable Development Goals adopted in 2015. The CRPD mandates participation of representative organizations of persons with disabilities in the implementation and monitoring of rights, including the right to development.

DRF typically convenes its grantees every two years, providing opportunities to develop skills, networks, and joint advocacy initiatives. DRF paused the convenings during the COVID-19 pandemic. In May, 2022, DRF cohosted its first first convening in nearly three years, bringing together grantees in Uganda for a week of technical training, feedback sessions, priority setting, and knowledge sharing.

Celebrating its 15th anniversary in 2023, Thompson, DRF's inclusion and accessibility manager, said she sees DRF continuing to raise awareness among other grantmakers about the importance of increasing funding for disability, which remains low relative to spending on other historically marginalized groups. Thompson is also looking forward to forging even stronger connections with other movements, including climate justice and the prevention of gender based violence.

"At DRF we embrace and celebrate human diversity," said DRF Executive Director Catalina Devandas. "We are excited to expand the reach of our participatory model beyond DRF, building powerful feminist partnerships for sustainable impact in the lives of persons with disabilities worldwide."

Disability Rights Fund GRANTEE SPOTLIGHT: OHANA

Yogyakarta Province, Indonesia

An Indonesian activist and lawyer named Risnawati (Risna) Utami, founded <u>OHANA</u> 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 dis-

tances 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 in Indonesia.

"People with disabilities have been stigmatized and discriminated against, we still have to struggle to be more equal with others in Indonesia," Utami, OHANA's executive director, explained. While seeking to unite all people with disabilities into a rights movement, OHANA places particular emphasis on empowering women and girls. In January,

2019, Utami became the first person from Indonesia to sit on the <u>United Nations Committee on the Rights of Per-</u> sons With Disabilities.

OHANA, Utami said, "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. Since 2019, OHANA has worked to eliminate gender-based violence against women and girls with disabilities in Yogyakarta Region by increasing disability awareness for service providers. The OHANA Circle uses an intersectional and human rightsbased approach supported by the UN Trust Fund.

In 2022, OHANA initiated the Gender and Disability Working Group at the Indonesia Civil Society 20 Summit, contributing to recommendations from the Indonesian Coalition to G20 Leaders.

Part of OHANA'S challenge, she said, is to shift the Indonesian government's view of people with disabilities as "charity cases" to one that sees people that deserve expanded rights and power. 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." Ohana is also developing a network of organizations throughout Indonesian provinces so as to connect local and regional efforts to the national regulations and policies related to "disability inclusive development" in the SDGs.

> "We are demanding a lot in many areas of development and at the policy level," Utami said. "We've never been active before in how to influence policy makers." Ohana also staffs a 2000 square foot community center, which provides people information about government services, hosts training for aspiring occupational and physical therapists and also provides and repairs wheelchairs for community members. DRF's funding enabled OHANA to expand its pool of funders and increase its outreach to marginalized identities, such as women with disabilities and migrant workers with disabilities.

Utami said she expects OHANA to "be around for a long time until individuals with disabilities enjoy full equality in this country." She continues planning for the future, both her own and that of the organization that she has devoted so much of her energy to shaping. OHANA participates in grantee meetings convened by DRF to discuss progress and share strategies. There, she is able to meet and network with other potential funders. OHANA aspires to increase the number of disability rights initiatives in cities and provinces across Indonesia, including in Bali, Central Java and the District of Temanggung. Meanwhile, Utami, who is in her 40s, 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."

The revised version of this spotlight was compiled by Susan Eaton, Johanna Wald and Brian Stanley. An earlier version of this spotlight was published in 2017.



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Risna Utami. A brownskinned woman wearing a pink hat and scarf, smiles in front of a microphone. (photo courtesy of Risna Utami)