



Fulfilling the Right to Participate

IHRFG Semi-Annual Meeting, San Francisco, California
Monday, January 25, 2010, 1:30 – 3:00 pm

Facilitator: **Daniel Lee**, Levi Strauss Foundation

Speakers: **Diana Samarasan**, Disability Rights Fund; **David Barr**, The Collaborative Fund for HIV Treatment and Preparedness (c/o The Tides Foundation)

Sponsor: Disability Rights Fund

Daniel Lee gave an introduction to the session and pointed out that the right to participate often gets short stretched in hierarchies of human rights organizations. However, there is a spectrum of ways in which communities being affected by human rights grantmaking can participate. The panelists represent funds that do this really well. He asked the panelists to share what mechanisms they put into place to get communities involved in their grantmaking process.

David Barr provided a background of the Collaborative Fund for HIV Treatment. Formed in 2003, the fund needed community based organizations to develop programs and make funding streams effective and for donors to work directly with communities/community members, rather than leaving them to the mercy of donors, without control over funding streams. They fund projects relating to health, literacy, nutrition, transportation, advocacy (stigma in accessing care). Their goals were 2-fold:

- Identify emerging grassroots organizations and help them build capacity.
- Build international preparedness coalition – using community driven grantmaking process at local and national level.

They set up the model as follows:

- Regional and Demographic model whereby constituents select their regional coordinator/governance.
- They developed an RFP process.
- Community review panel reviews the applications and makes funding decisions.

David also pointed out that it is an interesting time for the Fund and for the HIV advocacy field because donors are realizing that public health programs are very expensive and there is no end in sight. This is making human rights advocates nervous because money is needed to continue to develop programs that combine treatment (which is the best prevention tool) and prevention, and these programs are expensive.

Diana Samarasan discussed the philosophical base and history of the Disability Rights Fund (DRF). Convention on the Rights of Persons with Disabilities (CRPD) drafting process included persons with disabilities, which is a model for including marginalized populations in the decision-making process on a

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national level. In creating the DRF, it was decided that there would be a dialogue between donors and members of disability community. A global advisory panel was created to set out criteria for funding. A steering committee comprised of 4 advisors and representatives from disability community makes guidelines and recommendations. The majority of grantmaking focuses on movement building for rights advocacy.

Questions and Answers:

Q: What processes had to be put into place to create a participatory model?

DB: First it is important to set up a minimal structure and get the money out, then second stage is to work on improving the structure, making sure governing process is transparent, there are strict term limits, and defining what technical assistance means to this process.

DS: There was lack of trust in international disability community when they were asked to nominate advisors. Therefore, each member was asked to nominate 3 advisors each. Then 3 people were selected who were internationally credible, with a lot of disability experience. Gaps still existed because all nominees were over 40 years of age and youth with disabilities were not involved on national levels. We had to go outside of the nomination process to get youth with disabilities on the panel as well to be truly inclusive.

Q: What is the best advice you received at the onset of the project?

DB: Crisis of faith is the difficult part. It is important to trust the people you are working with and believe in your own rhetoric and keep process moving; do not get in the way of the agenda. Also, utilize the community expertise to get to people who have no other access to a group of donors. This type of mechanism really works at grassroots levels. The pay-off is that you develop leadership that will sit on national aid communities' boards and UN Bodies, and feed their knowledge to right places.

DS: Understand that the process is also the end goal. Democracy is about dialogue – hearing peoples' voices and allowing people to express their opinions in the decision making process. Without dialogue, there is a rights deficit and lack of credibility as a human rights grantmaker.

Q: How should knowledge of this model be imparted to donors?

DS: Monitor evaluation practices, and turn into documentation that can be used by others, also keep notes and document the process at meetings.

Q: Is there really a right to participate? There is a lot of progress in areas where donors are giving outside of their realm of knowledge and understanding. This puts burden on grantmakers and resources that could limit philanthropy.

DS: In the disability rights world, the model has always been to do things without people from disability community. New model is to educate donors and disability community about grantmaking. Maybe find

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a place in the middle where there is some participation but not too burdensome. There should be a mechanism to hear from the ground level, perhaps by surveys of grantees and applicants.

Q: How to deal with conflict of interest issues in this model?

DB: Make sure every region has conflict of interest policy in place and term limits.

Conclusion: Inclusion of affected communities helps with movement building and advocacy.