



Reflecting a Movement's Principles in Grantmaking Structure:

Evidence of the Benefits of Participation from the
Disability Rights Fund and Disability Rights Advocacy Fund



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Photo: DRF/DRAF's Steering Committee, Global Advisory Panel, and staff in Boston during in-person meetings.

Executive Summary

Research Overview

This research was funded by a grant from the Ford Foundation as part of a larger effort to better understand the impact of participatory grantmaking. The Disability Rights Fund (DRF) and its sister organization, the Disability Rights Advocacy Fund (DRAF), have used a participatory grantmaking¹ model since inception, and are known for their participatory approach.² This research documents the evolution of the DRF/DRAF participatory grantmaking model, the benefits and challenges of this model as experienced by stakeholders, and recommendations for other funders aiming to use a similar approach. Research methods included a literature review, evaluation reviews, interviews, and a sensemaking workshop.

Findings

The findings reveal deepening participation over time of persons with disabilities at *all* levels of DRF/DRAF operations—including at the Board, Grantmaking Committee, and staff levels. The research also shows an iterative approach that builds on the call of the international disability movement for “*Nothing About Us Without Us*” and the mandate of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) for the full inclusion of persons with disabilities in decision making.

1 As defined in Evans, L (2015) *Participatory Philanthropy*, a representative participation model involves bringing individuals with lived experience to add depth and knowledge to discussions and decisions.

2 Participatory grantmaking, in this research, is defined as the “ceding of decision-making power about funding—including the strategy and criteria behind those decisions—to the communities that funders aim to serve. Gibson, C. *Deciding Together: Shifting Power and Resources through Participatory Grantmaking*, 2018. Participatory approaches at DRF/DRAF refer to the ethos of the organization in having persons with disabilities in every part of the organization, including its Board and staff.

The Iteration Inherent in a Rights-Based Participatory Approach

In early 2008, as the CRPD was about to become legally binding, DRF/DRAF were launched under the fiscal sponsorship of the Tides Foundation. The goal was to channel resources to the disability movement in the Global South to advance the CRPD. The CRPD cemented a paradigm shift from persons with disabilities being seen as 'objects' for treatment or charity to rights holders and active citizens. DRF/DRAF Founding Executive Director Diana Samarasan set out a structure which envisioned engagement of persons with disabilities at all levels of decision making: governance, advisory, and staffing. This included involvement of persons with disabilities in grants decision making and the strategy behind that funding.

In the original DRF/DRAF framework document, the Funds' model consisted of a Global Advisory Panel and a Steering Committee with a majority of persons with disabilities across the 2 bodies.³ The 12-member Global Advisory Panel, comprised of 9 disability activists and 3 bridge builders from other human rights movements, provided DRF/DRAF with important advice about all aspects of the Funds' grantmaking, including country selection, priority areas for funding, size of grants, and how to make the application process accessible. Following the Global Advisory Panel's first meeting, presentations by members with disabilities on these topics convinced founding donor representatives of the value of including persons with disabilities in grants decision making and in the Steering Committee. As one interviewee noted:

"In light of CRPD, [we] needed to shift [from a medical] to a social model to disability in which the principle of participation was paramount. . . Persons with disabilities have the right and capacity to be involved. They are making good choices about what they need because they are experts in their situations and countries."

Over time, DRF/DRAF have continued to iterate their participatory practices. Importantly, when DRF/DRAF launched as independent nonprofits and set up their own Boards of Directors, they created by-laws stipulating that 50% of the Boards would be persons with disabilities and that 1 co-chair would always be a person with a disability. In 2018, DRF/DRAF further evolved the participatory grantmaking model: in addition to reviewing the DRF/DRAF country strategies and grant recommendations, the Grantmaking Committee (a further evolution of the Steering Committee) would have full decision-making power to approve pooled fund grants. In addition, DRF/DRAF increased the number of disability activists on the Grantmaking Committee and the Boards to ensure majority.

³ For more on the DRF/DRAF original framework, visit <https://disabilityrightsfund.org/about/more-drf-info/our-story/>. Since DRF/DRAF began under the fiscal sponsorship of the Tides Foundation, the governance mechanism was a Steering Committee, in lieu of a Board of Directors.

Further, DRF/DRAF moved from having international Program Officers with disabilities to Program Officers based in focus countries and belonging to or working closely with national disability movements. Given Program Officers' expertise and proximity to national disability movements, in addition to tasking them with managing national grantmaking portfolios, the Grantmaking Committee gave them authority to recommend for approval only those grants they believe will have the greatest impact on the rights of persons with disabilities in their countries. Grantees interviewed for this research note that some of the greatest value they currently gain from the DRF/DRAF participatory model derives from their interaction with these Program Officers.

DRF/DRAF participatory grantmaking and broader participatory approaches further their missions

The research highlights several ways that the participatory grantmaking model advances the missions of the Funds:

- **It matters to persons with disabilities.** The DRF/DRAF model gives persons with disabilities a voice in grants decision making, in line with the CRPD and *"Nothing About Us Without Us,"* and aligns with rights-based approaches and principles of inclusion. Persons with disabilities bring critical perspectives, which are grounded in the realities of the disability community, to the grants decision-making process.
- **It helps grantees trust DRF/DRAF.** According to grantees who were interviewed, DRF/DRAF Grantmaking Committee and Board members who are persons with disabilities "know our reality" and "represent us well". The fact that persons with disabilities provide input and make decisions on grants gives disability community members confidence in DRF/DRAF funding decisions. As described by one grantee:

"Without the Grantmaking Committee, it would not be the same.... It is important to include persons with disabilities in grantmaking decisions. Their voices are our voices. When someone with disabilities is part of the decision-making process, they express what we feel."

- **It fosters learning and expansion of networks.** Disability activists and donors on the Grantmaking Committee valued learning from each other and the different perspectives brought to discussions, and have increased networking in ways they may not have before. It has also increased visibility for activists, as they often have opportunities to share their experiences in regional and global venues.

- **It may have helped the Funds further diversify their grants portfolios.** Activists on the Grantmaking Committee report that they provide helpful guidance to DRF/DRAF on the diverse range of experiences among persons with disabilities. Over time, according to Committee members from specific marginalized groups, DRF/DRAF have made more and better grants to organizations of persons with disabilities representing these marginalized groups as a result of this influence.

In addition, the research surfaced the benefits of the Funds' broader commitment to a participatory model, particularly hiring persons with disabilities from focus communities as Program Officers. Grantees interviewed noted that DRF/DRAF Program Officers, the majority of whom are persons with disabilities and activists, work closely with grantees to support their proposal development. Program Officers then summarize proposals in grant recommendations that are submitted to the Grantmaking Committee for review and (most often) approval. Through this process, as well as via grants oversight, Program Officers build critical trusting relationships with grantees.

The research also surfaced a number of challenges in the DRF/DRAF participatory grantmaking model. Power dynamics, Grantmaking Committee composition, and optimization of time and resources were identified by interviewees as challenges that have been encountered as the DRF/DRAF participatory grantmaking model has evolved over time. Not surprisingly, these challenges also surfaced in our literature review as common challenges that many participatory grantmakers grapple with—and that ultimately strengthen approaches when actively acknowledged.

Recommendations for Funders Considering Participatory Grantmaking and Broader Participatory Approaches

As an early and ever-evolving practitioner of participatory grantmaking, DRF/DRAF and the many people interviewed are advocates for its use, particularly when funding human rights work. For donors considering adopting a representative participatory grantmaking approach and/or a broader participatory approach, the Funds' progressively more participatory model offers valuable insights. It shows that members of a focus community are most knowledgeable about how funding can benefit their community, and that they have the right to have a say in matters that affect their lives. This ethos is critical to understand and strive for in designing a representative model of participatory grantmaking.

Recommendations to other funders, based on the research, are to:

- Make the goals of the participatory grantmaking approach—not only the funding decisions—explicit to better illustrate the benefits of a participatory process.
- Establish clear criteria for the identification, selection, scope, and terms of members of a grant review committee (or whatever body is used for grantmaking decisions) to ensure diversity of experience and transparency in who is involved and what their role is.
- Value the time that community members spend on the grant review and decision-making process to ensure a commitment to participation.
- Offer additional information to help all grant review committee members fully understand information related to the collective decisions that will be made.
- Build in a variety of review and feedback processes to mitigate power dynamics within the grant review committee.
- Offer grant review committee members opportunities for networking and increasing their visibility as a way to strengthen leadership of the focus community in new contexts.
- Hire staff from focus communities to enhance the relevance and effectiveness of funding decisions.

Finally, the Funds' ever-evolving approach to this work is an important lesson in and of itself. The Funds' iterative approach to its participatory grantmaking and participatory practices have allowed DRF/DRAF to progressively deepen and expand their reach in supporting persons with disabilities, particularly among the most marginalized groups within the disability movement. The increasing involvement of persons with disabilities in the Funds' Boards, Grantmaking Committee, and staff has been critical to the Funds' ability to expand their reach—and potentially their impact and influence. The philanthropic field would benefit from additional research about how individual benefits experienced by Grantmaking Committee members contribute to wider social movements, how the impact of participatory grantmaking compares with the impact of more traditional philanthropy, how strong the link may be between participatory grantmaking and better responsiveness to marginalized groups, and how strong the link may be between participatory grantmaking and increased effectiveness.