



Reflecting a Movement's Principles in Grantmaking Structure:

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



November 2021



Acknowledgements

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The researchers would like to acknowledge the significant contributions of the members of the project's Research Board, who provided leadership and guidance on this project: Lisa Adams, consultant focused on disability and gender justice and former DRF/DRAF Program Director; Bhargavi Davar, founding DRF/DRAF Global Advisory Panel member and founder of Transforming Communities for Inclusion (global network of persons with psychosocial disabilities); Hannah Paterson, Winston Churchill Fellow (2019) on participatory grantmaking; Diana Samarasan, DRF/DRAF Founding Executive Director; and Alberto Vasquez, Senior Advisor at the Center for Inclusive Policy (CIP), President of SODIS (an organization of persons with disabilities in Peru and former DRF/DRAF grantee), former DRF/DRAF Global Advisory Panel member and Grantmaking Committee member, and DRF/DRAF Board member.

The researchers would also like to thank the participants in this project, who contributed their time, insights, and experience through one-on-one interviews and feedback on drafts of this report. The interviewees in this project included grantees, past and present staff members of the DRF/DRAF team, donor representatives, and global advisors who are disability activists. They collectively represent the community of people who helped build and iterate on the approach of the first and only global grantmaker exclusively focused on disability rights. We are grateful for their many years of dedication—sometimes at great cost—to broader efforts to support the rights of persons with disabilities.

A particular thanks to the DRF/DRAF Founding Executive Director, Diana Samarasan, for her steady feedback and grounding throughout this project. Diana trailblazed much of the approach outlined in this report as she advocated tirelessly with and for the most marginalized persons with disabilities and their communities. The researchers also appreciate Jen Bokoff, DRF/DRAF Director of Development, who provided insights into the report based on her own contributions to the participatory grantmaking literature.

This research was made possible through the support of the Ford Foundation.



Photo: DRF/DRAF staff interviewing a representative from Union des Femmes à Mobilité Réduite d'Haïti (Haitian grantee) during a Grantmaking Committee Meeting.

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Photo: Women with disabilities attending the Association of Women's Rights in Development Forum in Brazil.

Key Terms and Definitions

Participatory grantmaking – Ceding 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.)

Persons with disabilities – This term, as described in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), applies to persons who have “long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others.” Those negotiating the Convention—including, importantly, members of the International Disability Caucus—came to a consensus that “disability should be seen as the result of the interaction between a person and his or her environment. Disability is not something that resides in the individual as the result of some impairment.” (United Nations Enable, Frequently Asked Questions, <https://www.un.org/esa/socdev/enable/faqs.htm>, accessed August 11, 2021.)

However, there is no global consensus on terminology, even within the disability community. Some individuals or national movements may prefer to use *disabled persons* or other terms. (WeCapable, <https://wecapable.com/persons-with-disabilities-definition-rights-states-and-more/>, accessed August 11, 2021.) DRF/DRAF uses the term *persons with disabilities* to reflect the organizations' mandate to support organizations of persons with disabilities to advocate for advancement of the CRPD. Both terms (*disabled persons* and *persons with disabilities*) acknowledge that the stigma and discrimination people experience are due not to who they are, but rather to attitudinal, environmental, and social barriers in society.

Models of disability – Disability studies theorists have identified at least 9 different models of disability. The following models are most relevant to the work of DRF/DRAF:

- **Medical model** – This model of disability arose as early significant scientific medical advances took place in the mid-1800s in Europe, Australia, and the United States. Under this perspective, disability is seen as a medical problem that resides in an individual who is seen as outside the boundaries of “normal.” The goal is to cure or rehabilitate them through a variety of services so that they adjust to their surrounding conditions and environment instead of vice versa. The individual is in the role of patient or learner. (Cited in Retief, M. & Letšosa, R., 2018, ‘Models of disability: A brief overview’, *HTS Teologiese Studies/ Theological Studies*, 74(1). For more see Olkin, R., 1999, *What psychotherapists should know about disability*, Guilford Press, New York.)
- **Social model** – This model of disability provides a significant shift away from disability as a medical diagnosis. This model clarifies that it is societal barriers that are disabling and prevent people from exercising their rights and fully participating in society, and not impairment itself. The onus for participation moves from the individual to society as a whole to adapt and become inclusive. (For more, see what many consider to be the seminal scholarship on this term, Oliver, M. 1981, “A New Model of the Social Work Role in Relation to Disability,” in *The Handicapped Person: A New Perspective for Social Workers?*, Radar Publishing. For critiques of the social model, see Shakespeare, T., 2004, “Social models of disability and other life Strategies,” *Scandinavian Journal of Disability Research*, 6(1).)
- **Human rights model** – This model of disability emphasizes the human dignity of persons with disabilities and incorporates human, civil, political, economic, social, and cultural rights. The human rights model provides a space for the intersection of the various identities of persons with disabilities. The model also offers constructive proposals for improving the life situation of persons with disabilities and recognizes that medical and social interventions, properly formulated, involve the protection of one’s human rights. (Degener, T., 2017, ‘A new human rights model of disability’, *The United Nations convention on the rights of persons with disabilities: A commentary*, 41-60, Springer, Cham, Switzerland.)

To gain additional context on how these models relate to the history of the disability rights movement, more information is available through the Disability & Philanthropy Forum: <https://disabilityphilanthropy.org/topics/disability-history-culture-and-community/>.

Reasonable accommodations – Necessary and appropriate modifications and adjustments which do not impose a disproportionate or undue burden and which are needed in a particular case to ensure persons with disabilities enjoy and/or exercise all human rights and fundamental freedoms on an equal basis with others. (Article 2 - Definitions, United Nations Convention on the Rights of Persons with Disabilities.)

Effective – The extent to which the intervention achieved, or is expected to achieve, its objectives, and its results related to, for the purpose of this research, the achievement of rights outlined in the CRPD, including any differential results across groups. (Organization for Economic Co-operation and Development/Development Assistance Committee (OECD/DAC) Network on Development Evaluation. *Better Criteria for Better Evaluation: Revised Evaluation Criteria – Definitions and Principles for Use*. 2019.)

Relevant – The extent to which the intervention's objectives and design respond to beneficiaries', global, country, and partner/institution needs, policies, and priorities, and continue to do so even if circumstances change. For the purpose of this research, this is related to achievement of the rights outlined in the CRPD. (OECD/DAC Network on Development Evaluation. *Better Criteria for Better Evaluation: Revised Evaluation Criteria – Definitions and Principles for Use*. 2019.)

Responsive – The objectives and design of the intervention aimed to achieve the rights outlined in the CRPD are sensitive to the economic, environmental, equity, social, political economy, and capacity conditions in which it takes place. (OECD/DAC Network on Development Evaluation. *Better Criteria for Better Evaluation: Revised Evaluation Criteria – Definitions and Principles for Use*. 2019.)

Acronyms

COSP – Conference of States Parties

CRPD – Convention on the Rights of Persons with Disabilities

DRF/DRAF – Disability Rights Fund/Disability Rights Advocacy Fund

IDA – International Disability Alliance

OPDs – Organizations of Persons with Disabilities

UN – United Nations



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.



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

Introduction

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. As defined in the GrantCraft report on participatory grantmaking entitled *Deciding Together*, “participatory grantmaking cedes decision-making power about funding—including the strategy and criteria behind those decisions—to the communities that funders aim to serve.”⁴ The DRF and its sister organization, the Disability Rights Advocacy Fund (DRAF)—collectively referred to as the Funds—have used a participatory grantmaking model since inception, and were early practitioners of what is now known as the representative model of participatory grantmaking.⁵

For the vast majority of DRF/DRAF funding, final grant decisions are made by a Grantmaking Committee of the Boards, which comprises a majority of representatives/activists from the global disability movement as well as donor representatives.⁶ However, at the Funds, participation does not only occur in final decisions about grants. Persons with disabilities participate at *all* levels of Fund operations and are in the majority in the Board, the Grantmaking Committee, and among staff. This is because DRF/DRAF were designed to model the mandate for participation of persons with disabilities that is at the base of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD).

4 Gibson, C. (2018) *Deciding Together: Shifting Power and Resources through Participatory Grantmaking*, p. 7. http://grantcraft.org/wp-content/uploads/sites/2/2018/12/DecidingTogether_Final_20181002.pdf, accessed on January 15, 2020.

5 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.

6 The term donor representative indicates an individual employed by an institutional donor that supports DRF/DRAF.

Over time, DRF/DRAF have continued to iterate their participatory practices. A key change in recent years that has deepened the participatory grantmaking model has been the hire of activists with disabilities from DRF/DRAF target countries to manage grantmaking portfolios in their respective countries of origin.

This research documents the evolution of the DRF/DRAF participatory grantmaking model, the benefits and challenges of this model as experienced by stakeholders involved in grantmaking processes,⁷ and recommendations for other funders aiming to use a similar approach.

History of the Disability Rights Movement and DRF/DRAF

We first start with a brief history of the disability rights movement and DRF/DRAF to set the context for the subsequent sections on research findings.

Disability Activism

In the 1960s and 1970s, disability activists started to collectively mobilize and demand rights across the globe. It was during this time that South African disability activists coined a phrase that the international disability community would eventually adopt: *"Nothing About Us Without Us."*⁸ As collective mobilization grew, disability activists began to see global success starting with the passage of the first rights-based international instrument on disability: the 1975 UN Declaration on the Rights of Disabled Persons. Over the next 25 years, disability activists, academics, and legal experts continued to advance the rights of persons with disabilities through the declaration of the International Year of Disabled Persons in 1981, the establishment of the World Programme of Action Concerning Disabled Persons in 1982, the UN Decade of Disabled Persons in 1983, the adoption of the UN General Assembly Standard Rules on the Equalization of Opportunities for Persons with Disabilities in 1993, and the adoption of a General Comment on persons with disabilities by the Committee on Economic, Social and Cultural Rights in 1994.⁹

Adoption of the CRPD

By 2001, conversations and advocacy were well underway towards the development of what became known as the UN CRPD. The process leading up to the adoption of the CRPD was the most participatory process to date at the UN, with one-third of the working group who drafted treaty text reserved for civil society representatives (who formed the International Disability Caucus to jointly develop and present recommendations across different impairment groups and geographies). The CRPD, adopted by the UN General Assembly in December 2006,

7 For the purposes of this report, we are defining grantmaking processes as both participatory grantmaking, in which the majority of seats on the Grantmaking Committee are held by persons with disabilities, and the broader application, grant recommendation, and monitoring process by DRF/DRAF Program Officers, the majority of whom are persons with disabilities from DRF/DRAF target countries.

8 Sabatello, M. (2013). Chapter one: A short history of the international disability rights movement, *Human Rights and Disability Advocacy*, p. 13.

9 Ibid., pp. 14-15.

cemented a paradigm shift—from seeing persons with disabilities as “objects” for treatment and charity whose identities were based on medical diagnoses, toward an understanding of persons with disabilities as rights holders and active citizens, and an understanding of disability as a part of human diversity. The CRPD brought international consensus to disability activists’ assertion that persons with disabilities are capable of claiming their rights, being active members of society, and making decisions based on free and informed consent.¹⁰ When the CRPD opened for signature on March 30, 2007, it had more signatories than any other convention on its opening date. It became legally binding for States parties in May 2008. Since adoption, the CRPD has had the fastest rate of ratification of any UN treaty.¹¹

Disability within the Field of Philanthropy and the Launch of DRF/DRAF

Despite this trajectory of increasing international legal frameworks, significant structural and social challenges still prevent persons with disabilities everywhere from fully participating in society and achieving fulfillment of their rights. Efforts of persons with disabilities to advance rights are also underfunded in international development and within philanthropy; the majority of funds dedicated to disability goes to services, health, rehabilitation, and charity. Though accurate global data does not exist on the prevalence of disability in many countries, the World Health Organization and the World Bank estimate more than 1 billion people, or 15% of the global population, have a disability.¹² Yet, persons with disabilities receive only 2% of foundation human rights funding and 3% of bilateral and multilateral human rights funding.¹³ Within the philanthropic field, persons with disabilities are also underrepresented and marginalized. For example, a survey of almost 1,000 people working in nonprofits and foundations found that bias against persons with disabilities prevents full inclusion and meaningful participation.¹⁴ An additional study by the Council on Foundations found that less than 1% of more than 700 foundations in the United States reported employing full-time staff members with disabilities.¹⁵

In early 2008, as the CRPD was about to become legally binding, DRF/DRAF were launched under the fiscal sponsorship of the Tides Foundation to channel resources to the disability movement in the Global South to advance the ratification and implementation of the CRPD.

10 United Nations Department of Economic and Social Affairs, Convention on the Rights of Persons with Disabilities, Information on the UN Convention on the Rights of Persons with Disabilities. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>, accessed on January 15, 2020.

11 United Nations Department of Economic and Social Affairs, Convention on the Rights of Persons with Disabilities, Information on the UN Convention on the Rights of Persons with Disabilities. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>, accessed on January 15, 2020.

12 World Health Organization & World Bank. (2011). *World Report on Disability*. WHO, Geneva.

13 Candid & the Human Rights Funders Network. Advancing Human Rights: 2017 Annual Review of Global Foundation Grantmaking, pg. 9 and <https://humanrightsfunding.org/populations/disabilities/>, accessed April 14, 2021.

14 For more on the scope and breadth of barriers that persons with disabilities face in philanthropy serving institutions and recommendations on greater disability-inclusion, see RespectAbility. (2019). *Disability in Philanthropy & Nonprofits: A Study on the Inclusion and Exclusion of the 1-in-5 People Who Live with a Disability and What You Can Do to Make Things Better*.

15 Council on Foundations. *2020 Grantmaker Salary and Benefits Report*.

The DRF/DRAF framework—developed through a broad consultative process led by the Founding Executive Director, Diana Samarasan—set out a structure which envisioned engagement of persons with disabilities at all levels of decision making in the Fund (governance, advisory, and staffing) to reflect the call of the international disability movement for “*Nothing About Us Without Us*” and the CRPD mandate for the participation of persons with disabilities and organizations of persons with disabilities (OPDs) in the achievement of rights. This included involvement of persons with disabilities in decision making regarding funding and the strategy behind that funding.

It is often asserted that decision-making by target communities adheres to a human rights-based approach and may result in more effective and relevant philanthropic outcomes.¹⁶ This was certainly the premise of DRF/DRAF’s participatory grantmaking structure: that having persons with disabilities in decision-making roles within the organization would be a significant enabling factor in helping DRF/DRAF effectively support persons with disabilities to make progress towards the achievement of rights. The first meeting of the Global Advisory Panel and Steering Committee in early 2008 underlined this premise.

About DRF/DRAF

The DRF mission, as presently expressed, is to support persons with disabilities around the world to build diverse movements, ensure inclusive development agendas, and achieve equal rights and opportunity for all. The DRAF mission is to support persons with disabilities around the world to build diverse movements, ensure inclusive development agendas, and achieve equal rights and opportunity for all. As of mid-2021, DRF/DRAF have given more than 40 million USD through more than 1,400 grants to OPDs across low- and middle-income countries—primarily in Africa, Asia, the Pacific Island countries, and the Caribbean—to participate in ratification, implementation, and monitoring of the CRPD (including through advancement of the Sustainable Development Goals).

The DRF/DRAF model has been shown to be effective, efficient, a good value for the money, responsive, sustainable, and impactful (OECD-DAC evaluation criteria) in 4 different external independent evaluations completed between 2012 and 2019.¹⁷

¹⁶ United Kingdom Department for International Development representative at the 2019 Buenos Aires Global Disability Summit, June 6 – 8, 2019.

¹⁷ For more on the external independent evaluations, see the Disability Rights Fund evaluation page: <https://disabilityrightsfund.org/our-impact/evaluation/>.



Photo: DRF/DRAF staff person speaking with a Global Advisory Panel Bridge Advisor.

Methodology

Research Focus

The main objective of this research was to provide evidence of the benefits of engaging persons with disabilities in decision-making roles about grants within DRF/DRAF. The research had 2 components:

- Document in detail the DRF/DRAF participatory grantmaking model.
- Gather key stakeholder perceptions about how the DRF/DRAF participatory grantmaking model affects its relevance and effectiveness.¹⁸

Given DRF/DRAF's extensive experience with participatory grantmaking—particularly with marginalized groups—this research aimed to explore why this approach matters.

Research Methodology

To document the evolution of the DRF/DRAF participatory grantmaking model and examine the link between the model and its relevance and effectiveness for grantees, the research consisted of 4 steps:¹⁹

¹⁸ Evaluation methods for participatory grantmaking are evolving as the field of participatory grantmaking expands. For more on methodological considerations to explore as well as a brief discussion on the use of outcome mapping, see Hutton, C. (2016) "Monitoring and Evaluating Participatory Grantmaking" or the Evaluating Participatory Grantmaking section in Patterson, H. (2018) *Grassroots Grantmaking: Embedding Participatory Approaches in Funding*, p. 42-46.

¹⁹ More detailed information about the research methodology can be found in Annex 1.

1. **Literature review** – The research team completed a desk review of 19 published blogs, articles, literature, and academic research on participatory grantmaking to form a basis of understanding of participatory grantmaking as it is practiced in a variety of contexts.
2. **Evaluation reviews** – The research team reviewed the 3 previous DRF/DRAF independent evaluations (the 2010-2013 global evaluation, the 2013-2015 global evaluation, and the 2017-2019 Pacific evaluation) and analyzed them in light of the findings of the 2017-2019 global evaluation. Particular attention was given to portions of the evaluations that addressed the DRF/DRAF participatory grantmaking model and the effectiveness and relevance of DRF/DRAF to grantees. Synthesized findings informed the primary data collection approaches of this research and portions of this report.
3. **Interviews** – The research team conducted interviews with the following key stakeholders:
 - *Grantees:* The research team interviewed past and current DRF/DRAF grantees, who were asked about the DRF/DRAF participatory grantmaking model from their perspectives compared to other organizations' grantmaking processes (participatory or not). Nine DRF/DRAF grantees from 4 countries were interviewed.
 - *DRF/DRAF staff:* This included staff members who were a part of the organization at the start of the Fund, as well as a representative sample of current DRF/DRAF leadership. They answered questions arising from the literature review related to the effectiveness of the DRF/DRAF participatory grantmaking model. Ten current and previous staff and Board members from 5 countries were interviewed.
 - *Stakeholders, particularly persons with disabilities, involved in DRF/DRAF participatory grantmaking and the development of its Pathway to Change:* This group of interviewees included a wide representation of persons with disabilities who have played key leadership roles in the DRF/DRAF participatory grantmaking model, such as Grantmaking Committee members and Board members. Interviewees were selected after the initial literature review and documentation of DRF/DRAF grantmaking processes was completed. Seven Grantmaking Committee and Board members from 5 countries were interviewed.
4. **Sensemaking workshop** – The research team held a virtual sensemaking workshop with the Research Board to review the findings from the literature review, evaluation review, and interviews, and to reflect on questions that emerged from them.²⁰ The workshop enabled the research team to share and validate early findings, while also collecting additional information.

20 For a description of the Research Board, see Annex 1.

Limitations

While our overall interview sample of 26 interviewees was large enough to produce credible findings, our stratified samples—in which we explored the perspectives of Board and staff members, Grantmaking Committee members (both activists and donors), and grantees—were not. We asked each of these smaller samples different questions about participatory grantmaking to get their reflections from different angles, and as a result, often no more than 1 or 2 interviewees expressed a particular point. This meant that drawing out findings was challenging. We have been careful, therefore, in our analysis and reporting to only share findings that we are confident reflect the perspective of the majority of the sample.

For this research, the research team brought our own lenses and experiences to bear, both personally and having worked with multiple organizations engaging in similar endeavors through our project work. As researchers, we are often assumed to be neutral and objective purveyors of information. We do not think objectivity is possible, as everyone interprets information through their own racial and cultural lens, and we do not think neutrality is helpful, particularly when it comes to issues of equity and power. Thus, we acknowledged our biases and addressed them directly as a team primarily during our design, analysis, and report drafting processes.



Photo: DRF/DRAF Global Advisor (and Sign Language Interpreter) speaking with a DRF/DRAF donor representative at a Grantmaking Committee meeting.

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 UN CRPD for the full inclusion of persons with disabilities in decision making.

The Iteration Inherent in a Rights-Based Participatory Approach

Origins of the Funds’ Rights-Based Structure

In 2007 when the Funds launched, “participatory grantmaking” was not a formally defined or discussed philanthropic practice.²¹ There wasn’t a community of practice, and there was little attention in philanthropic discourse to the few foundations that were using it. Moreover, the mainstream philanthropic field had yet to fully understand the history of centuries-old community practices—such as African-American mutual aid benefit societies or Chinese benevolence societies—as participatory grantmaking approaches or precursors. These mutual aid benefit societies or benevolence societies, which placed funding decision making into the hands of their focus communities, began after the American Civil War and the influx

²¹ At the time of this report’s publishing, there is a participatory grantmaking community of practice founded by Hannah Patterson with more than 500 members. For more information, visit www.participatorygrantmaking.org.

of Chinese immigration to the United States in the middle of the 18th century.²² In these instances and others where a form of participatory grantmaking was practiced, community-focused philanthropy tended to focus on critical community needs, such as education, social justice, or economic development.²³ The concept of including persons with disabilities in decision making at a global level to advance the rights of persons with disabilities had not been applied before the establishment of DRF/DRAF.

Participation of persons with disabilities in decision-making roles was a fundamental principle and value of DRF/DRAF from the beginning. This was of critical importance, as DRF/DRAF was structured by the Founding Executive Director to meet the mandate of the CRPD: that persons with disabilities participate in the achievement of rights. The CRPD is based on the key principle of self-representation by persons with disabilities. One interviewee remarked how significant a shift this was:

“For far too long persons with disabilities were separated from their communities and the medical and charity approach were prevalent. In light of CRPD, [we] needed to shift 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.”

The Founding Executive Director held almost a year of dialogue with activists and funders as she developed the participatory grantmaking model of DRF/DRAF, making sure it was in tune with the well-known slogan, “*Nothing About Us Without Us*.”²⁴ The work of the Founding Executive Director to develop a participatory framework, raise initial funding, and develop a temporary legal seat at the Tides Foundation led to the launch of DRF and DRAF in early 2008. The first main activity was the February convening and meeting of a Global Advisory Panel of activists with disabilities to begin to outline where the Funds would work, what the grantmaking priorities would be, what range of grants the Funds would make, and how to outreach to and best serve the global disability movement accessibly.

22 Examples of scholarship on philanthropy and community giving include work by Dr. T. McKinley Freeman, Y. M. Brake’s unit on Black Philanthropy on [Learning to Give](#), or H. Mark Lai’s chapter “Historical Development of the Chinese Consolidated Benevolent Association” in *Chinese America: History and Perspectives*, 1987.

23 For more on the roots of participatory practice in community organizing and deliberative democracy, see C. Gibson (2019) *The Historical Case for Participatory Grantmaking*.

24 DRF/DRAF original funders include the American Jewish World Service, Sigrid Rausing Trust, Open Society Foundations, and Wellspring Advisors, LLC (predecessor of the existing Wellspring Philanthropic Fund).

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.²⁵ The 12-member Global Advisory Panel consisted of 9 disability activists with diverse backgrounds (diversity of impairments, gender, age, geography) and 3 bridge builders from other human rights movements (women's rights, Indigenous Peoples' rights, and economic social cultural rights) for the purpose of cross-movement learning and increasing inclusion within other movements. The Global Advisory Panel 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.

Given the low level of familiarity and few existing opportunities for engagement between donors and activists with disabilities, the Funds initially designed the Steering Committee (now called the Grantmaking Committee)—to comprise equal numbers of donors and disability activists. The 8-member Steering Committee consisted of the 4 founding donor representatives and 4 Global Advisory Panel disability activist members selected by their peers. DRF/DRAF intentionally included donors and Global Advisory Panel members together on the Steering Committee. According to one interviewee:

"When we first started out, very few donors knew anything about the disability rights movement in the Global South: who the organizations of persons with disabilities were, size, what they were doing, advocacy roles, whether national or local, about making grantmaking accessible. It seemed really important to have a learning mechanism so that donors could learn from activists about all of these questions. The fact that most OPDs had never received donor funding told us that there was much learning required on the activist side as well. Who are donors? Building that relationship was key. It still is. While the number of donors involved in disability rights and disability-inclusive development has grown, there are still very few."

It was through interactions with persons with disabilities that founding donor representatives were convinced of the value of including persons with disabilities in grants decision making and in the Steering Committee. Following a couple of days of meetings to hash out key questions, several Global Advisory Panel members with disabilities presented recommendations to founding donors regarding countries of focus, grant priority areas and size, and key accessibility measures, as well as their analysis of the capacities of OPDs.

²⁵ 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.

The donors were impressed, and recognized that they did not have the Global Advisory Panel members' depth of knowledge about the disability movements the Funds would need to reach. Because of this, donors agreed to equal decision making in a joint Steering Committee. One interviewee noted the evolution of engagement between donors and activists over time:

"While I have always seen donor representatives being passionate about disability rights, [at the beginning] it did look like it was still an 'us and them' matter. It seemed donor representatives sat on one side, talked with fellow donor representatives while the activists with disabilities would often talk with each other such as during breaks/lunch. Now, donor reps are very engaged and eager to talk to activists with disabilities to tap into their knowledge wealth. I also see donor reps more happy to defer to the activists with disabilities to have the higher hand in making the final decision."

Origins of the Funds' Grantmaking Structure

At the first meeting of the Global Advisory Panel, members gave input on what would evolve into grantmaking guidelines and a Request For Proposals. As previously outlined, decisions were also made about which Global Advisory Panel members would be the first 4 activists to join the Steering Committee.

DRF/DRAF adopted what would later be termed a representative model of participatory grantmaking. This model of participatory grantmaking "involves bringing in practitioners, sector experts or individuals with lived experience to add depth and knowledge to discussions and decisions."²⁶ This is operationalized at DRF/DRAF through representative participation of the Global South community of persons with disabilities in strategy and funding decisions. The main areas where those decisions take place is in the grantmaking process and in the development of:

- Global strategy as outlined in the Funds' strategic plan
- Country-level strategies
- Annual grantmaking guidelines
- Grantmaking procedures, including grantmaking decisions

²⁶ Original term described by Evans, L (2015) *Participatory Philanthropy*, p.7 and outlined in Patterson, H. (2018) *Grassroots Grantmaking: Embedding Participatory Approaches in Funding*, p. 19.

Deepening of the Funds' Participatory Structure

The Founding Executive Director and a representative from Wellspring Advisors, LLC worked hard to ensure that Global Advisory Panel members represented the diversity of the disability rights community. Within all social movements, hierarchies exist; intersectional identities can exacerbate marginalization. This is also true within the disability movement. A person with disability can be further marginalized by their type of impairment (such as visible versus invisible disability or more stigmatized disability), age, gender, sexual orientation, sexual characteristics, ethnicity, or Indigeneity. To address this reality, the Founding Executive Director and the Wellspring Advisors, LLC representative created diversity criteria to make sure different identities were represented on the Global Advisory Panel. To ensure a structure that was broadly representative of the disability movement, DRF/DRAF partnered with IDA to recommend potential Global Advisory Panel members based on diversity criteria set out by the Funds.

Participation was not just designed into the governance structures of the Funds; the Founding Executive Director also intentionally hired persons with disabilities in staff roles, and especially as Program Officers, to be liaisons to disability communities in the countries where DRF/DRAF operates. One interviewee noted the “*absolute importance*” of having Program Officers who self-identify as persons with disabilities:

“One of the reasons is to show donors – most of who[m] were not persons with disabilities – that people with disabilities have the capacity to do things just like everyone else.”

As DRF/DRAF grew, the Program Officer role evolved from persons with disabilities who worked (primarily) in the Global North and were responsible for oversight of a number of countries or regions to persons with disabilities hired in and responsible for grantmaking in the country where they are based. Program Officers play a critical role in having a direct relationship with the disability movements, applicants, and grantees, and in getting OPD input on country-level strategies and objectives for funding. One interviewee said this about the evolution of DRF/DRAF grantmaking decisions over time:

“Certainly, in the first five to seven years, DRF was constantly revisiting its model of participatory grantmaking – that kind of ethos makes it far easier to interrogate your structure. And that allowed for changes more naturally. Scale shifts things – staffing – it is important think about how the grantmaking decisions [happened] when every single grant was looked at by the Grantmaking Committee. We had to shift what the participation looked like as the staff reflected more and more community.”

When DRF/DRAF launched as independent nonprofits in 2011 and were no longer under the fiscal sponsorship of the Tides Foundation, there was a major evolution in the structure that deepened the participatory grantmaking model. DRF/DRAF set up their own Boards of Directors after achieving non-profit tax status and 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 disability. The initial Boards drew some donor and activist members from the Steering Committee. The Steering Committee then became the Grantmaking Committee, a Board committee comprised of 4 donors and 4 Global Advisory Panel members. Initially, there was some membership overlap between the Board and the Grantmaking Committee, although that was later changed. The Grantmaking Committee's role was to review the DRF/DRAF country strategies and to make grants recommendations to the Boards regarding proposals submitted to the pooled fund, with the Boards making final grants decisions. The Global Advisory Panel continued to advise DRF/DRAF on strategy. Because 4 Global Advisory Panel members were part of the Grantmaking Committee, they were able to bring forward the Global Advisory Panel's strategic recommendations.

In 2018, DRF/DRAF further evolved the participatory grantmaking model by giving the Grantmaking Committee full decision-making power to approve pooled fund grants.

This made sense, since the Grantmaking Committee's role was to discuss grant proposals. Additionally, with a growing staff that was more often from focus country (or region) disability movements, the Global Advisory Panel's role began to overlap with that of DRF/DRAF staff. Moreover, DRF/DRAF leadership wanted a continued evolution of structure such that the role of persons with disabilities moved from advisory to decision-making. As a result, DRF/DRAF dissolved the Global Advisory Panel and increased the number of disability activists on the Grantmaking Committee (from 4 to 6) and the Boards to ensure majority. At the time of this report, the Board has a majority of persons with disabilities.²⁷ The role of IDA role in providing nominations shifted from the Global Advisory Panel to the Grantmaking Committee.

²⁷ For the most recent information on DRF/DRAF leadership composition, visit the Funds' GuideStar profile: <https://www.guidestar.org/profile/27-5026293>.

Facilitating Activist Participation in the Grantmaking Committee

As previously noted, **DRF/DRAF intentionally include disability activists from a diversity of impairment groups, geographies, ages, ethnicities/Indigenous identities, and gender identities in the Grantmaking Committee.** Donor representative interviewees on the Grantmaking Committee recognized the challenge of ensuring representation of a broad range of groups, while at the same time maintaining a relatively small and workable Committee. To address this representational diversity challenge—initially within the Global Advisory Panel and subsequently, the Grantmaking Committee—the Founding Executive Director took a number of steps:

- Setting clear and staggered term limits to ensure a variety of voices over time while keeping experience in the Grantmaking Committee intact.
- Developing a template for activist nominations from IDA which sets out diversity criteria for activist nomination (DRF/DRAF develops these criteria based on the geographies and diverse identities missing on the Grantmaking Committee).
- Clarifying the recruitment process and the Grantmaking Committee role document that Grantmaking Committee activists represent the interests of the broader disability community, not themselves, their organizations, or their networks.

DRF/DRAF facilitate activists' participation in a number of ways. DRF/DRAF provided, and continue to provide, an honorarium to each Global Advisory Panel and now Grantmaking Committee member, and cover costs related to travel, accessibility, and reasonable accommodations, such as accessible hotels/meeting venues, Braille documents, Sign Language interpreters, a professional captioner, and personal assistants. Ensuring reasonable accommodations so that meetings are accessible for all attendees is a basic right and principle of inclusion that should be met in any setting.

When Grantmaking Committee meetings occur in Boston, DRF/DRAF bring in activists an additional day prior to the start of the meetings so they can further prepare. This is especially important for those activists who need additional support in understanding the documents and preparing interventions, such as activists with intellectual disabilities. This preparation may include DRF/DRAF staff going over documents with Grantmaking Committee members.

A staff person, whose job responsibilities touch on accessibility across the organization, explained the difference between accessibility and inclusion:

"You can have accessibility but that is not inclusion. You can have a sign language interpreter for a person who is Deaf - that is accessibility. But that does not create inclusion if people do not sit next to the person and engage in conversation. You could have provided Braille or a Powerpoint ahead of time for someone who is visually impaired [to review] - that is accessibility. But if you do not describe what's happening in the room, or what's up on the Powerpoint while it is being shown, that's a lack of inclusion. . . Our team internally gets training and guides on appropriate language, how to create inclusive and accessible social media. DRF/DRAF over the years have understood that inclusion needs to be a team effort and not simply the responsibility of one person. When that happens, you see a more inclusive Grantmaking Committee and Board meeting."

Finally, DRF/DRAF have always scheduled the main in-person (or virtual) Grantmaking Committee meeting just before each annual session of the Conference of States Parties (COSP) to the CRPD to make it easy for activists to attend COSP. One interviewee said this:

"DRF was always taking care of me to give me 2 interpreters so I could participate. In my country, the cost of interpreters was not covered. DRF always covered this. I needed 24/7 interpreter. Plus, during the meeting, when I was there, they also enabled me to use their technologies - tablets. Kerry had typewriting and provided me with all the technicalities. So, it was easy for me. . . I had 2 resources [a human interpreter and the captioning]. I really liked that. In that way, I can feel that I am equal."

Lessons from the DRF/DRAF Participatory Grantmaking Model and Broader Participatory Approach

Summary of Key Findings

The research highlights several ways that the participatory grantmaking model advances the missions of DRF/DRAF.

It matters to persons with disabilities. This was unanimously agreed by staff, Board members, Grantmaking Committee members, and grantees. 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.

Through the DRF/DRAF participatory grantmaking model, persons with disabilities bring critical perspectives to the grants decision-making process. These perspectives are grounded in the realities of OPDs and the disability community, which is important according to interviewees.

It helps grantees trust DRF/DRAF. According to grantees, 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.”

Grantees gain great value from broader DRF/DRAF participatory processes, especially from their interactions with DRF/DRAF Program Officers, according to DRF/DRAF staff and Grantmaking Committee members interviewed. DRF/DRAF Program Officers, the majority of whom are persons with disability, are now country-based (or in the case of the Pacific Island countries, region-based) and come from the national disability movements. They do outreach into disability communities, work closely with grantees to support their proposal development, and summarize proposals in grant recommendations that are then submitted to the Grantmaking Committee for review and (most often) approval. Through this process as well as in grants oversight, Program Officers build essential knowledge of and trust with grantees. Because of this, grantees interviewed for this research note that some of the greatest value they currently gain from the DRF/DRAF's participatory approach model derives from their interaction with DRF/DRAF's Program Officers.

Over the years, the Grantmaking Committee has shifted more grants decision-making authority to Program Officers. The Grantmaking Committee members no longer review every grant application. Rather, they make decisions on proposals that Program Officers put forward for anticipated approval, with the option of raising concerns about proposals that are then discussed in the meeting. Recognizing that the majority of Program Officers are persons with disabilities who are hired and responsible for grantmaking in the countries where they are based, and that they therefore have deep understanding of their contexts and national disability movements, the Grantmaking Committee gave Program Officers

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. As evidence of Program Officers' important role in the DRF/DRAF grantmaking, Program Officers now send grant recommendations to the Grantmaking Committee that have already been included in their DRF/DRAF country budgets and are being put forward for anticipated approval.

Several Grantmaking Committee and Board members interviewed talked about this as a deepening of trust for the role of Program Officers, who come from national disability movements themselves. One interviewee talked about their level of lived experience and knowledge:

"There are other forms of proximity – you could have other structures where you have 100% persons of disabilities but all from North America or they did a two-week trip – but what is effective to dismantle that stigma? I think that representation [from focus communities] is as important as the proximity piece is important. Which is why staff is important. To me that is more important than the risk [inherent related to providing any grant], how do you even know what risk is if you don't even have a sense of the context?"

Another interviewee shared that it mattered to a grantee that Fund staff are persons with disabilities:

"I remember in India, meeting someone/a grantee who is blind. One of the first questions he asked me, what's your disability. For him, he wanted to know if he was speaking with someone who had a disability or not. And that made a difference in our communication."²⁸

While the vast majority of persons with disabilities might not appreciate a direct question about one's impairment or disability status, this question indicates that this person, like many others, wanted to be represented and to see their identity reflected in the donor agency.

²⁸ This interviewee appreciated another person with a disability asking about the interviewee's experience with disability. However, we recommend people voluntarily self-identify as a person with disabilities.

For the Grantmaking Committee to have more proximity to prospective grantees, one interviewee suggested possibly replicating it at the country level and/or bringing members in earlier in the grant development process. This latter option would revert to the Grantmaking Committee's earlier practice of carefully reviewing all proposals and all activities and budget line items within them—responsibilities that the Grantmaking Committee has now ceded to Program Officers.

Benefits of the DRF/DRAF Participatory Grantmaking Model and Broader Participatory Approach

The research surfaced the benefits of the Funds' broader commitment to a participatory grantmaking model, as well as to a broader participatory approach.

Benefits for DRF/DRAF and Grantees

It increases the Funds' credibility with OPDs, other disability rights activists, donors, and others in the global disability movement. According to many interviewees, the model demonstrates that DRF/DRAF take *"Nothing About Us Without Us"* seriously. Having persons with disabilities involved in deciding which OPDs should receive DRF/DRAF grants increases confidence in the relevance and appropriateness of DRF/DRAF funding decisions.

It may have helped the Funds further diversify their grants portfolios by increasing the incorporation of perspectives of people with a diverse range of impairments and more marginalized impairment groups. Activists on the Grantmaking Committee report that they provide helpful guidance to DRF/DRAF on the diverse range of experiences among persons with disabilities. For example, DRF/DRAF developed multiple funding streams (small grants, national coalition grants, and so forth) because activists on the Grantmaking Committee pointed out the need for grants of different sizes with different purposes to go to OPDs with varying experience. Different types and sizes of grants helps OPDs representing people with a diverse range of impairments, and often more marginalized persons with disabilities, to receive DRF/DRAF support.²⁹

Over time, according to Grantmaking Committee activists and DRF/DRAF staff members, DRF/DRAF have made more and better grants to OPDs representing specific marginalized groups as a result of this influence, including to persons who are deafblind as well as persons with psychosocial disabilities. According to one interviewee:

²⁹ For another example of how more participatory grantmaking and more open and discursive processes helped overcome bias against small organizations, see Wojcik, O., Ford, L., Hanson, K., Boyd, C., & Ashley, S. (2020). "Participatory Grantmaking: A Test of Rubric Scoring Versus Popular Voting Selection in a Blinded Grantmaking Process." *The Foundation Review*, 12(1). This research provides interesting insights, however its use of the term "blinded" in describing anonymous grantmaking is problematic in its perpetuation of using ableist language.

"By having diverse representation of activists with disabilities on the Grantmaking Committee and Board we have seen how their recommendations and expertise has helped us do more, such as defining what is considered to be marginalized. In creating a specific definition of marginalization, we are seeing more grant applications from these populations, as well as more collaborations between different OPDs of different disability types and also more collaborations with [civil society organizations/ non-profit organizations]. The Program Officers have listened to the Grantmaking Committee and Global Advisory Panel members and try to help raise awareness of including them."

Benefits for Grantmaking Committee Members

It increases knowledge and understanding between activists and donors. Those who are part of the Boards or the Grantmaking Committee report that they have valued learning from each other. Most interviewees valued the different perspectives brought to Grantmaking Committee and Board discussions. Half highlighted the benefit of having activists and donors learn from each other in the Grantmaking Committee. As a result of discussions in the Grantmaking Committee, donors remarked that they better understand the experiences and perspectives of persons with disabilities, while activists said they better understand how donors think and operate. Both groups reported increasing their knowledge of what is happening with the disability community in more countries.

It helps activists increase their visibility, including activists building relationships with other activists and donors. In addition, activists often have opportunities to share their experiences in regional and global venues, such as the COSP to the CRPD.

It increases networking between activists and donors. Activists value networking with each other and with donors, and donors value connecting with activists from disability movements they may not have known before. In some cases, these connections have led to increased donor funding for activists' work within the movement and greater advocacy collaboration at a global or national level. For instance, one donor representative recalled meeting the newly appointed UN Special Rapporteur on the Rights of Persons with Disabilities at a Grantmaking Committee meeting and deciding to provide needed funds to support the Special Rapporteur's work. The interviewee recapped the meeting like this:

Challenges Related to the DRF/DRAF Participatory Grantmaking Model

The interviews surfaced a number of challenges in the DRF/DRAF participatory grantmaking model. These also surfaced in our literature review as common challenges that many participatory grantmakers³⁰ grapple with—and that ultimately strengthen approaches when actively acknowledged.

Balancing the need for a diverse Grantmaking Committee while maintaining a manageably sized decision-making body. Having a Grantmaking Committee that is both diverse and right-sized for budget and decision making is a challenge. DRF/DRAF want to maximize representation of impairment groups, geographies, and other demographic characteristics among Grantmaking Committee activist members. At the same time, DRF/DRAF value having a small enough Grantmaking Committee in which members can have a strong sense of belonging, ownership, and responsibility. DRF/DRAF also hope that a small committee size will foster relationship and trust building and learning among members. DRF/DRAF have addressed this challenge by carefully designing a nomination and selection process, as well as role and term clarity, as previously discussed.

Balancing participatory processes against the time and resources associated with them.

Interviewees noted that including more people in decision-making processes inevitably requires more time and resources. Those who engage in these processes believe that the benefits are greater than the cost involved, because involving people with relevant lived experience in grants decision-making processes leads to more relevant, effective, and impactful grantmaking. However, more research is required to test this hypothesis.³¹

Considering when the Grantmaking Committee is brought into grants decision-making and what this means for their influence. Once the Grantmaking Committee recognized the expertise of Program Officers and ceded most proposal review responsibilities to them, the Committee's role with proposals became more of a *"rubber stamp"* function, as described by one interviewee who went on to say, *"I think that is a good thing. [National] staff [largely from the disability movement] make the recommendations based on their knowledge of the context and the budget."* The Grantmaking Committee meetings now focus on overarching strategic issues.

Power dynamics within the Grantmaking Committee. The Founding Executive Director purposefully designed the Committee so that activists could educate donors about disability rights and also learn from donor perspectives and practices. However, this pairing inevitably

30 In addition to previously cited works, such as Hutton's *Monitoring and Evaluation Participatory Grantmaking*, Gibson's *Deciding Together*, or Patterson's *Grassroots Grantmaking*, see Smith, T. and Love, K (2020) "Exploring Participatory Grantmaking with Grants Managers."

31 While more research is still needed on the benefits of participatory grantmaking, a growing body of research has started to explore this area of work. See, for example, "Who Decides: How Participatory Grantmaking Benefits Donors, Communities and Movements," (2014), The Lafayette Practice and Hutton, C. (2016) *Monitoring and Evaluation for Participatory Grantmaking*, which includes a brief discussion on participatory grantmaking and increased value for money.

comes with an unequal power dynamic. To address this, DRF/DRAF shifted the grants decision-making process from an open discussion of all grants to a pre-meeting confidential survey that each member completes with their decisions and comments on each grant. This allows Grantmaking Committee members to decide on grants without others knowing how they decided. Members then use the meeting to discuss overarching strategic issues, as well as any grant recommendation that any Grantmaking Committee member did not approve. While this shift has mitigated some of the power dynamics, Grantmaking Committee members stated that some power dynamics remain.

Interviewees described the power dynamic as resulting from a number of factors, some of which are related to position (donor representative vs. activist), gender, and race. Interviewees also noted that some dynamics may be related to culture, with some donors coming from cultures where people are more likely to speak up in a public setting, and some activists coming from cultures where people are expected to be quiet and defer to others. A few DRF/DRAF staff members and Grantmaking Committee members noted the importance of expert meeting facilitation to help address these dynamics.

Other factors included level of familiarity with the Grantmaking Committee, with those who are more familiar with its dynamics and processes more willing to speak up, while those less familiar might prefer to listen. One Grantmaking Committee member suggested that greater continuity of membership could help address this challenge. However, longer membership terms must be balanced with the need for diversity and new voices over time among members.

Finally, many interviewees pointed to a power dynamic created by the time required to prepare for grants decisions and meetings. Many members mentioned the large amount of reading, which includes country contextual documents and recommendations for each grant under review. Interviewees noted that, while donor representatives have larger teams available to help them digest the documents, activists do not. As a result, donor representatives may arrive at Grantmaking Committee meetings better prepared to participate, and therefore, more likely to comment and raise questions. To address this problem, activists and some donor representatives suggested more time to review the documents, and activists also welcomed more support from DRF/DRAF, including via provision of more simplified information.



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

Conclusion

DRF/DRAF have used a participatory grantmaking model since inception and have continued to iterate on and strengthen it over time. The Grantmaking Committee is now majority comprised of persons with disabilities and makes final decisions on grants from the pooled fund. DRF/DRAF Program Officers, who work closely with OPDs throughout the grantmaking process, are now country-based (or in the case of the Pacific Island countries, region-based), and the majority are activists from those disability movements.

DRF/DRAF grantees, Grantmaking Committee members (both activists and donors), staff, and Board members all value participation by persons with disabilities in the Funds and the participatory grantmaking model itself. They note that it aligns with the disability movement's slogan, *"Nothing About Us Without Us."* Grantees interviewed appreciate that they are well represented throughout the Fund and in decisions regarding DRF/DRAF grantmaking.

Participatory grantmaking is a relatively new model for global grantmakers and, as such, is changing with constant learning, reflection, and revision.³² Challenges remain in determining which members of a global community to include in grantmaking decision processes and when and how to best include them. Ongoing community and staff feedback can help inform these choices, which will continue to evolve over time.

³² For more on the formative learning approach at DRF/DRAF, see Patterson, H. (2018) *Grassroots Grantmaking: Embedding Participatory Approaches in Funding*, p. 47-48.

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. This model of grantmaking fits with the CRPD and the values of the disability movement and broader human rights movement, which state that persons with disabilities have the right and the capacity to make decisions about their own lives. For funders considering adopting a representative participatory grantmaking approach and/or a broader participatory approach, the progressively more participatory model from DRF/DRAF offers valuable insights.

Recognize 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. While outsiders might have important technical knowledge to contribute, members of a focus community best understand a community's culture, needs, priorities, and the kinds of interventions that are best designed to respond to them. This ethos is critical to understand and strive for in designing a representative model of participatory grantmaking. Include members of a focus community among grants decision makers to ensure that their perspectives are taken into account and that they will find any initiatives funded relevant and appropriate to their lives.³³

Make the goals of the participatory grantmaking model—not only the funding decisions—explicit to better illustrate the benefits of a participatory process. The DRF/DRAF model, which includes a Grantmaking Committee comprised of both donors and activists, was designed for mutual learning and networking, in addition to grantmaking. This mix has also helped to raise the profile of some of the activist members involved, potentially contributing to leadership development. These kinds of goals are important to articulate to better share the results of a participatory grantmaking approach.

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. This transparency will help ensure that committee members represent their communities well and simultaneously strengthen community members' trust in the process. Members should represent the diversity within their community and/or be known, through the positions they hold and the groups within which they are active, to represent the community as a whole, not just their interest group. If possible, grantmakers should partner with a broadly representative

³³ A staff member noted that when a donor chooses not to include members of a focus community among grants decision makers, they can support regranteeing through organizations that are more participatory. For an example of one foundation's journey into greater proximity and participatory grantmaking, see Randell, N.G. and MacDavey, M. (2020). "Human-Centered Design and Foundation Staff: A Case Study in Engaging Grant Beneficiaries." *The Foundation Review*, 12(1).

body, as DRF/DRAF does with IDA, to receive nominations for grant review committee membership. This may contribute to the maturation of a movement and its internal dynamics. Setting term limits on committee membership also allows a critical rotation of members and, over time, representation from different sub-groups within a community.

Value the time that community members spend on the grant review and decision-making process to ensure a commitment to participation. This might include covering travel costs, offering a stipend to cover their time spent engaged in committee activities (including reviewing materials in preparation for their participation), providing preparatory materials that are simple to digest, ensuring they are familiar with committee expectations and procedures, and/or briefing them ahead of a committee meeting.

Offer additional information to help all grant review committee members fully understand information related to the collective decisions that will be made. This might include in-person visits/or webinars with current grantees, discussions with staff members, the provision of relevant—but not too lengthy—reading materials, and educating community members about grantmaking and donors' priorities and perspectives.

Build in a variety of review and feedback processes to mitigate power dynamics within the grant review committee. These processes should be reflective of members' different backgrounds, communication styles, languages, impairments, etc. to facilitate all members' equal participation. Any facilitator should also take power dynamics and these differences into account.

Offer grant review committee members opportunities for networking and increasing their visibility to strengthen leadership of the focus community in new contexts. Facilitating introductions with other community members, donors, and others working to advance human rights, and offering opportunities to speak in relevant forums can help committee members strengthen their own work and influence. While some committee members will already be established leaders, for others, this can serve as an opportunity to strengthen their leadership skills and networks. Even for established leaders, being affiliated with the grantmaking process may strengthen their existing connections and positioning within the focus community.

Hire staff from focus communities to enhance the relevance and effectiveness of funding decisions. Staff drawn from focus communities are well positioned to understand the community's culture, priorities, strengths, and challenges, which in turn may increase donor confidence in shifting decision-making power to persons with lived experience. Donors also need to be aware of community dynamics in order to select staff members who will represent a community as a whole and avoid favoring any sub-group. Additional research needs to be done to examine the benefits of hiring staff from the communities with which donors seek to partner.

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 on the following:

- How individual benefits experienced by Grantmaking Committee members contribute to wider social movements
- How the impact of participatory grantmaking on social movements compares with the impact of more traditional philanthropy on social movements
- How strong the link may be between participatory grantmaking and better responsiveness to marginalized groups
- How strong the link may be between participatory grantmaking and increased effectiveness

Annex 1: Methodology

The main objective of this research was to provide evidence of the benefits of engaging persons with disabilities in decision-making roles about DRF/DRAF grants. The focus of this research had 2 components.

The first component was to document in detail the DRF/DRAF participatory grantmaking model. This was explored by answering the following questions:

- What are these processes?
- Who is involved? (noting where persons with disabilities are involved or not, with explanation)
- How are decisions made?
- How are persons with disabilities involved in each? (Program Officers, Grantmaking Committee members, Board members, OPD representatives)
- What type of input do persons with disabilities provide?

The second component was to gather key stakeholder perceptions about how the DRF/DRAF participatory grantmaking model affects the relevance and effectiveness of DRF/DRAF. To do this, the following questions were examined:

- In what ways, if at all, does the involvement of persons with disabilities in the DRF/DRAF participatory grantmaking processes affect DRF/DRAF's responsiveness to the advocacy priorities of the disability movement?
- In what ways, if at all, does the involvement of persons with disabilities in the DRF/DRAF participatory grantmaking processes affect DRF/DRAF's capacity to fund advocacy-related projects based on the advocacy priorities of the disability movement?
- In what ways, if at all, does the involvement of persons with disabilities in the DRF/DRAF participatory grantmaking processes affect DRF/DRAF's effectiveness as a funder? That is, what is DRF/DRAF's capacity to effectively support grantees in making progress toward their objectives?

Intended Use and Users of the Research

The primary intended users of this research are private United States donors, peer philanthropic and grantmaking organizations of the Ford Foundation, and philanthropists and grantmakers who have been using traditional models of decision and strategy making to determine their philanthropic investments and who are considering adopting participatory grantmaking approaches. Other funders who utilize participatory grantmaking approaches may also benefit from this research for peer learning purposes.

Secondary users of the research findings also include those communities who are affected by traditional models of grantmaking and want to increase their involvement in grantmaking for more relevant and effective community outcomes and outputs.

The research may serve as a guide on participatory grantmaking strategies and approaches for the promotion of disability rights.

Research Team

The research team included Carlisle Levine, President & CEO of BLE Solutions, an independent research and evaluation firm; and Melanie Kawano-Chiu, Evaluation and Learning Manager at DRF/DRAF.

The Research Board's role was to provide guidance and leadership on the research. This representative body included persons with disabilities, former and current DRF/DRAF grantees, former DRF/DRAF staff and Global Advisory Panel members, and a participatory grantmaking researcher. Research Board members include Lisa Adams, a consultant focused on disability and gender justice and former DRF/DRAF Program Director; Bhargavi Davar, founder of Transforming Communities for Inclusion (global network of persons with psychosocial disabilities); Hannah Paterson, Winston Churchill Fellow (2019) on participatory grantmaking; Diana Samarasan, DRF/DRAF Founding Executive Director; and Alberto Vasquez, Research Coordinator of the UN Special Rapporteur on the Rights of Persons with Disabilities, President of SODIS (an OPD in Peru and former DRF/DRAF grantee), former DRF/DRAF Global Advisory Panel member and Grantmaking Committee member, and DRF/DRAF Board member.

Research Approach and Principles

The research team applied research approaches that are similar to the evaluation approaches that have been applied to the previous independent DRF/DRAF evaluations:

- The **utilization-focused approach** aims to make the research findings relevant and useable for the intended users of the research.
- The **participatory approach** aims to ensure that the perspectives and insights of all identified key stakeholders (DRF, grantees, donors, and governments) are reflected in our research findings.
- The **human rights-based approach** aims to ensure that the research is voluntary, inclusive, and respectful of the participants of the project.

In addition, this research adhered to the following principles, reflecting the DRF/DRAF evaluation and learning principles:

- **Commitment to a rights-based approach:** In addition to ensuring that the research is voluntary, inclusive, and respectful of participants, this approach includes conducting the research from a strengths-based approach when engaging with persons with disabilities and representing OPD-led accomplishments in disability rights advocacy.³⁴
- **Long-term capacity development of the disability movement and its link to rights realization:** Recognizing that persons with disabilities should be involved from the start of the process, not just as a point of data collection, the research team will include persons with disabilities in the research design and implementation and seek to translate relevant findings into easy-to-read and multiple language formats for OPDs and DRF/DRAF grantees.
- **Inclusiveness and recognition of the diversity of the disability movement:** The disability community is not homogenous, and marginalization and inequality exist among disability groups based on characteristics such as gender, age, type of impairment, ethnicity, geographic location, or poverty. This research project will be designed, implemented, and shared with this diversity in mind.
- **Mutual benefit to DRF/DRAF and the disability movement:** It is essential that the research findings are valuable to grantees as well as to DRF/DRAF. The research team will seek to minimize the burden of participation in this project on DPOs, while maximizing the benefits of the research findings for OPDs and persons with disabilities.

34 For a detailed description of the human rights-based approach described here, see the UN Office of the High Commissioner on Human Rights Guidance Note to Data Collection and Disaggregation: *A Human Rights Based Approach to Data - Leaving No One Behind in the 2030 Agenda for Sustainable Development*.

Minimizing Research Bias

The research team sought to minimize various types of bias through the following methods:

Stage of Research	Type of Bias	Minimization Tactics
Design	Method/flawed study design	Clearly defined research objective and validated methods with standardized data collection and inclusive practices
	Selection bias	Clearly defined criteria for interviewee selection, agreed with the Research Board
Data Collection	Interviewer bias	Standardize interviewer's interactions with interviewees using interview protocols Common understanding between interviewers of the utilization of follow-up questions
	Response and reporting bias	Triangulation of interviewees' responses Intentional assignment of interviewer to interviewee
Data Analysis	Researcher bias	Use of a sensemaking workshop to bring in other perspectives to help make sense of research findings Research Board review of analysis

The research team and Research Board considered response bias (acknowledging that interviewees may perceive incentives to positively portray the overall impact of participatory grantmaking in DRF/DRAF grantmaking) and knowledge bias (acknowledging that various interviewees may not be aware of the various participatory grantmaking procedures) as the most likely types of biases to influence the research findings. However, both DRF/DRAF staff and the independent evaluation team of BLE Solutions have received honest feedback regarding DRF/DRAF operations and programs from a variety of partners in the past via conversation, surveys, and interviews during previous evaluations. This is an indication that in the area of response bias, partners can provide at least partially open and transparent feedback. Triangulating interviewer findings, as well as the information provided by interviewees, further helped the research team address response bias.

Data Analysis

The research team used the following methods to analyze the data collected:

- **Descriptive analysis:** This allowed for understanding the context in which DRF/DRAF participatory grantmaking takes place, as well as the structures and processes used to implement it.
- **Content and narrative analysis:** This was the core method for the qualitative analysis of the influence of participatory grantmaking on the relevance and effectiveness of DRF/DRAF. Documents and interview notes were used to identify patterns and to flag diverging views and opposing trends.
- **Participatory analysis:** Through the virtual sensemaking workshop, the research team elicited participants' insights into the meaning of key findings and their significance within the context of the research objectives. The evaluation team synthesized workshop outcomes in the findings and data analysis.

Cover photo: Collage of DRF/
DRAF Steering Committee,
Global Advisory Panel, grantees,
and staff during in-person
meetings between 2008 to 2019.

