

**EXECUTIVE
SUMMARY**

THE STATE OF INTERSEX ORGANIZING

3RD EDITION

2024



GLOBAL
PHILANTHROPY
PROJECT



**EXECUTIVE
SUMMARY**

THE STATE OF INTERSEX ORGANIZING

3RD EDITION

2024



ACKNOWLEDGEMENTS, CREDITS, AND SUGGESTED CITATION

Report Authors Julia Lukomnik, VAPA Consulting
Somjen Frazer, Strength in Numbers Consulting Group
Mauro Cabral Grinspan, Global Philanthropy Project
Ezra Nepon, Global Philanthropy Project

The State of Intersex Funding
(Appendix I) Mauro Cabral Grinspan
Ezra Nepon

Conclusion Mauro Cabral Grinspan
Case Studies
(Appendix II)

GPP Review and Input Matthew Hart
Jay Postic

When referencing this report, we recommend the following citation:

Lukomnik, J., Frazer, S., Cabral Grinspan, M., and Nepon, E. (2024). *The State of Intersex Organizing* (3rd Edition). Global Philanthropy Project.

Advisory Committee Claudia Bollwinkel, Dreilinden
Morgan Carpenter, Intersex Human Rights Australia
Erika Castellanos, GATE
Adrian Coman, Arcus Foundation
Julia Ehrt, ILGA World
Felix Endara, Foundation for a Just Society
Julius Kaggwa, Intersex Human Rights Fund
Cathy Kapua, Trans Justice Funding Project
Siri May, Wellspring Philanthropic Fund
Jabulani Pereira, American Jewish World Service
Cianán Russell
Viviane Vergueiro Simakawa, International Trans Fund
Kimberly Zieselman, Outright International

Survey Design/Analysis Somjen Frazer, Erin Howe, Laura Laderman, Beksahn Jang, and Abby El-Shafei of Strength in Numbers Consulting Group designed the survey, conducted data analysis, checked the data, and provided written text. Julia Lukomnik of VAPA Consulting designed the survey security protocol, coordinated outreach, and provided written text.

Copyediting MaxZine Weinstein

Graphic and layout design Lukas Berredo

We are grateful to the 151 intersex organizations that took the time to respond to this survey and share detailed information about their work with us. We would also like to thank those organizations that provided information for the case studies featured in the report.

We also thank the donors who provided project support for the production and distribution of this report: American Jewish World Service, Astraea Lesbian Foundation for Justice, Dreilinden, and International Trans Fund.

REPORT PRODUCTION



RESEARCH PARTNERS



DONOR PARTNERS



EXECUTIVE SUMMARY

The third edition of *The State of Intersex Organizing* survey was launched in October 2023 and received participation from 151 intersex respondents worldwide. The results provide illuminating insight into the priorities, activities, needs, and experiences within the intersex movement.¹ The survey results also document their funding sources, budget sizes, and other elements related to movement sustainability and their capacity to serve intersex people.²

This survey documents a period (2020–2023) with simultaneous surges of movement growth and oppositional attack, all in the context of broader upheavals impacting intersex communities around the world—including wars, forced migration, and the COVID-19 pandemic.

The survey findings identify key ongoing and emergent themes:

- ¹ In this report, “intersex movement” refers to the entire universe of activists, organizations, networks, and initiatives focused on defending, promoting, and advancing intersex people’s human rights. The use of the word in singular does not assume, by any means, homogeneity, unity, or simplicity within that universe, whose diversity is reflected throughout the report.
- ² Intersex people are individuals born with sex characteristics that vary from those considered to be typical of male and female bodies. Conversely, endosex people are those born with the sex characteristics commonly associated with male and female bodies. Sex characteristics are the physical features of sex, such as genitals, gonads, and chromosomes. For more information, see the OHCHR fact sheet at tinyurl.com/ochrfactsheet
- ³ In this report, the expression “organization” refers to both autonomous (independent) groups (whether registered or unregistered) that were not part of any other group and intersex-focused programs that are part of broader organizations with issue area focuses that are not exclusively intersex. Where the report specifically refers to autonomous organizations or programs of broader organizations, it uses these phrases.

Intersex organizations³ are strongly focused on human rights advocacy, particularly on bodily integrity, decisional autonomy, and protection against abuses in medical settings. When asked what work they are doing most urgently needs additional resources, the most frequent responses by far were “advocacy against formal or informal practices of performing surgery or other medically unnecessary, non-consensual, and irreversible medical interventions on intersex babies and children” and “advocacy for human rights of intersex people.”

The intersex movement is under attack worldwide. Survey responses demonstrate the dire conditions of intersex organizations and activists facing attacks and harassment, discrimination, stigma, and marginalization. Organizations face both physical and online threats. More than one-quarter (28%) reported experiencing physical violence against their leadership, with about one in five (21%) reporting vandalism of their physical building, space, events, or other infrastructure. Almost 7 in 10 (69%) reported responding to external threats from opposition groups or individuals as challenges. Two-thirds of organizations experienced anti-intersex threats to their communities, while nearly half (47%) experienced threats to their organization’s leadership.

This is a critical time for the intersex movement, yet intersex movements worldwide are outrageously underfunded. Decades of organizing have led to campaign wins, including key international declarations, as well as several exemplary national laws protecting the human rights of intersex people. At the same time, the intersex movement plays a key role in providing support to community members. Still, survey results show that about half of intersex organizations had annual budgets under \$20,000, and 13% had no budget at all. While the percentage of organizations with budgets over \$50,000 has more than doubled from 12% in 2016 to 26% in 2023, 35% of organizations responding to the survey in 2023 received no external funding.⁴ There is an urgent need for not only more funding but more donors of all types to include intersex issues and populations in their funding strategies.⁵

Building safety and reducing burnout are strong needs within the intersex movement. In addition to the serious physical and mental health impacts of violence and ongoing threats, almost three-quarters (73%) of organizations cite responding to misinformation about intersex people as a significant source of strain or burnout.

The intersex movement remains a largely self-led and autonomous movement. Of the organizations surveyed, about 9 in 10 were autonomous (88%).⁶ A majority of decisions within intersex organizations were made by intersex leaders. Two in three (66%) organizations had more than half intersex decision makers, and just under one in two organizations (49%) had more than three-quarters intersex decision makers.

Even with extremely limited funding, the intersex movement is bigger, more diverse, and more formalized than at any previous point. In the past five years, many organizations were founded across the world, increasing the size and geographic diversity of the movement. These organizations need specific types of support as they continue to mature. As it grows, the intersex movement is increasingly formalizing. In 2023, 71% of organizations surveyed were registered with their governments, a significant increase from the 2017 report.

⁴ External funding refers to sources that include government and foundation funding and exclude membership fees, community fundraisers, events, and individual contributions from founders or their family members. It is a measure of the combined support intersex groups receive from government and private and public donors.

⁵ These findings are further affirmed by *The State of Intersex Funding* analysis in Appendix I.

⁶ Throughout the report, the phrase “autonomous” is used to describe an organization, whether registered or unregistered, that is not part of any other organization.

Recommendations

The findings of this report are a call to action to support intersex organizing around the world. As the report clearly shows, **there has been meaningful progress** since the last *The State of Intersex Organizing* report, **but there is much need for increased and diversified support.**

Building, sustaining, and expanding support for intersex organizing requires an **entire ecosystem** of committed stakeholders—including private and public foundations, donor governments, individual donors, corporations, and civil society organizations acting as regrating intermediaries.

While adequate philanthropic responses are key to supporting the intersex movement, responses from other stakeholders are also extremely important for the success of that ecosystem. That is the case, for example, of agencies monitoring and evaluating the implementation of humanitarian and development programs and institutions creating and applying inclusion indexes, research agendas, training curricula, and strategies for change. In a global context characterized by the demonization of movements working in the field of sexual and reproductive rights, a truly supportive ecosystem for intersex organizing requires not only providing access to effective support and protection; it also requires, more than ever, fully acknowledging intersex expertise and leadership in meaningful and transformative ways.

Increase resources for intersex organizations and activists.

Intersex organizations need more funding, larger grant sizes, support from a broader number of donors, and more sustainable types of funding, including multiyear and core funding. Access to unrestricted support is a key component of strong, resilient, and flexible movements capable of addressing emergencies, reacting effectively to sudden challenges and opportunities, and building reserves to ensure sustainability.

Join efforts to mobilize, activate, and defend global intersex

funding. Strong movements need diverse funders, and at this time, the intersex movement relies on a limited number of them. While no single institution or program can support the intersex movement as a whole, the addition of new financial or technical resources can make a truly decisive contribution to the entire field. Grantmakers are encouraged to join in efforts to mobilize and expand funding for the intersex movement, including GPP's Trans and Intersex Funding Task Force⁷ and the Donor Coordination Working Group at the Equal Rights Coalition.

7 globalphilanthropyproject.org/initiatives/trans-and-intersex-funding

Recognize the diversity within the intersex movement and ensure funding for the entire ecosystem. The intersex movement contains all kinds of organizations, from very small to very large and from old to new. Providing appropriate support to the movement requires responding to the challenges, needs, and opportunities they all face. For example, it requires providing the financial and technical resources needed by newer organizations to flourish, the resources needed for middle-size organizations to thrive, and the resources needed for international initiatives to succeed.

Provide real opportunities for growth. Fund to accompany an ever-growing movement, providing opportunities to develop institutional capacities, increase budgets, expand paid positions, and attract top candidates for those positions.

Provide resources to address the threats and burnout that intersex activists face. As intersex activists face significant online and real-world threats, ensuring their access to key resources to address those issues should be a priority, including, for example, access to top-up funding for legal funds, sabbaticals, and connections to and funding for security experts. Be proactive in providing support to address threats and burnout preemptively.

Support intersex work on multiple issues and at all levels. The intersex movement serves an extremely diverse population, including infants, children, teenagers, and adults; individuals and families; patients and ex-patients; citizens, refugees, and asylum-seekers; and people with all kinds of gender identities and sexual orientations. The same movement that provides personal support also trains health practitioners, reports to human rights institutions, drafts law bills, advocates for them to be passed, and monitors their implementation. In many cases, the same intersex activists and organizations work locally and nationally, regionally and internationally.

Support long-term advocacy work. Intersex organizations have made impressive strides in national, regional, and international advocacy, shaking seemingly unmovable structures of power, injustice, and oppression. That is precisely the kind of work that requires designing, developing, and implementing long-term strategies. Access to increased support spread over multiple years is key to ensuring the continuity and, ultimately, the success of the intersex movement.

Support organizations, but also individuals. Intersex organizations often grow out of the activities of individual activists. Individual grant programs, research and activism fellowships, and monetary awards in recognition of individual activists' achievements are key ways to fund individual intersex activists.

Become an advocate. Human rights violations against intersex people are an ongoing reality, and individual advocates are key to driving impactful ecosystem responses. Ask intersex activists how you and/or your institution can support their work; encourage your colleagues and allies to do the same. Share your interest, knowledge, and commitment; advocate for intersex people and intersex issues to be fully included in your field.

