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THE STATE OF INTERSEX ORGANIZING (2ND EDITION)

Understanding the Needs and Priorities of a Growing but Under-Resourced Movement

In 2016, American Jewish World Service (AJWS), Astraea Lesbian Foundation for Justice (Astraea) and Global Action for Trans* Equality (GATE) surveyed 54 groups from across the globe working on intersex issues.¹ The results provide a unique snapshot of the funding and organizational needs and experiences of those at the front line of addressing the significant human rights challenges facing intersex people. While funding for intersex work has improved modestly in recent years, the intersex movement remains deeply underfunded. Further, intersex groups face unique barriers to reaching donors and accessing funds. *The State of Intersex Organizing*² intends to provoke dialogue among activists and donors, and serve as a call to action to donors to increase the amount and quality of resources flowing to the growing, dynamic, but under-resourced global intersex movement.



KEY FINDINGS

Around the world, intersex people experience stigma, shame, discrimination and violence because their bodies do not fit within societal expectations of “male” and “female.”

Widely held assumptions about sex and gender—rooted in social and cultural norms—fail to recognize the bodily diversity that exists among us. This means that intersex people face a range of human rights violations, starting with the violation of their rights to make autonomous and informed decisions about their own bodies, to be free from torture, to obtain identity documents, to enjoy sexual and reproductive freedoms, and to access health care, education and employment.

Many of the human rights abuses that intersex people face stem from the pathologization of intersex variations. Within many medical classifications, those bodies falling outside the rigid stereotypes of male and female are categorized as disordered or pathological. This is used to justify “normalizing” interventions, such as genital surgeries and hormonal treatments, which are performed routinely in medical settings. Often conducted in infancy, childhood and adolescence, these procedures—identified by activists as intersex genital mutilation (IGM)—are medically unnecessary, irreversible, and can have serious and life-long impacts.

Intersex people who are not subjected to these procedures can also face violence, social rejection and discrimination in many parts of the world. As a result of such stigma and discrimination, intersex people encounter a range of health, economic and social inequities.

Intersex groups are fighting back: advocating for their rights in their communities and countries, and building a global intersex movement.

Though intersex issues may be new to many people, intersex activists have been organizing and advocating for their human rights for more than 30 years. This growing global movement has expanded rapidly over the past decade and the increasing visibility of intersex rights activism has encouraged and enabled more intersex individuals to step forward.

This report uses the UN Free & Equal definition for intersex: “Intersex people are born with sex characteristics (including genitals, gonads and/or chromosome patterns) that vary from typical binary notions of male or female bodies. Intersex is an umbrella term used to describe a wide range of natural bodily variations.”

Working across local, national, regional and international levels, intersex-led groups around the world are utilizing a variety of strategies to build community, raise awareness and defend intersex people’s rights to self-determination, bodily autonomy and physical integrity. Activists have forged alliances with organizations and movements working on the rights of children, patients, women, LGBTQ people and people with disabilities. They are breaking through silence and stigma to connect intersex people and the parents of intersex children with one another. They are contesting the pathologization of intersex bodies and are promoting a more inclusive and celebratory understanding of bodily diversity. And they are making groundbreaking gains in legal protections and demanding justice for human rights abuses.³

However, intersex groups are doing this critical work to address human rights violations with very little funding.

In 2016, just under half (49.0%) of intersex groups surveyed had annual budgets of US\$5,000 or less and more than three-quarters (76.5%) had budgets of less than US\$10,000. Only about one in five (19.1%) intersex groups received US\$10,000 or more in external funding in 2016.

Intersex groups are deeply understaffed and rely on volunteers to do their work.

While nine in ten (90.0%) intersex groups that responded to the survey had volunteers, just one-third (32.0%) had paid staff. Further, given the very low budget sizes of intersex groups, those groups with paid staff may not be able to pay a living wage in most parts of the world. This suggests that activists working in the intersex movement are also often working other jobs and are at high risk for burnout. The related factors of few paid staff and low budgets compromise the work of intersex groups, hindering them from responding to the many needs and opportunities they encounter.

Intersex groups are largely autonomous and led by intersex people. Many are unregistered.

The intersex movement is predominantly led by intersex people. More than nine in ten groups (90.7%) surveyed were autonomous or independent, meaning that the group was not part of a larger organization. Two thirds of intersex groups (62.5%) reported that financial decisions were made entirely by intersex people in their group. In terms of legal structure, only half (50.0%) of intersex groups were registered with their governments.

Intersex activists work at multiple levels, with a high number engaging internationally.

More than half (56.6%) of intersex groups surveyed reported working at the national level in their own country, while two in five (39.6%) reported working at the international level. The frequency with which intersex activists across the globe are doing work at the international level suggests a movement simultaneously pursuing multiple avenues for change, with a high level of involvement in international human rights issues. When asked what work they would like to do but are precluded from doing for lack of resources, intersex groups most wanted to expand their work at local and national levels.

Intersex activists use a variety of strategies to benefit their constituents, with the largest numbers focusing on advocacy, education, social service provision and safety and anti-violence work.

More than eight in ten (85.4%) intersex groups surveyed did



Intersex Danmark/
Credit: Intersex Danmark

advocacy, community organizing or health provider education activities and almost three-quarters (73.2%) provided social services or peer support, or did individual-level advocacy. Groups were most likely to be precluded from doing more community organizing (34.1%), campaigning (26.8%) and base-building activities (26.8%) due to lack of resources.

Intersex activists have a wide variety of organizational development needs.

Intersex groups reported high levels of capacity-building needs related to organizational development, including fundraising and grant writing (79.4%), budgeting and financial management (76.5%), monitoring and evaluation (71.0%) and developing effective programs and services (71.0%). While groups are receiving non-financial support such as donated space (51.2%) and access to international gatherings (55.9%), they have less access to targeted organizational support.

Intersex activists are overstretched and need capacity-building support to prevent burnout.

Nearly three-quarters (74.3%) of intersex groups reported that they need support in healing, anti-trauma resources or burnout prevention for staff. This was the most common need reported among all measured capacity-building needs for intersex activists. While the survey did not measure the levels of burnout or trauma in individuals or organizations, this suggests that the lack of support in this area is a major threat to the health of the intersex movement. This is unsurprising given the high rates of volunteering, low numbers of paid staff and the personal trauma that many intersex leaders face.

Intersex groups mobilize community resources to support their work, including self-financing their activities.

The most common sources of community funding for intersex groups include cash or in-kind donations from individuals, a founder or founder's family member's savings or contribution, community fundraisers (e.g., sales of books, t-shirts, etc.) or events. Just over a third (36.6%) of intersex groups reported that a founder or founder's family member contributed funds to support their work.

Intersex groups face barriers to accessing new funding sources.

Intersex groups face a variety of problems that impact their ability to find and apply for grants. Nearly six in ten (59.5%) intersex groups reported that one barrier to finding funding was that most funders' websites or open calls for funding did not state an interest in funding intersex groups. Write-in responses indicated that intersex groups lacked the time and capacity to apply for funding opportunities.

Intersex issues are not a priority for many donors.

Among those intersex groups that applied for funding unsuccessfully, about half (52.8%) reported that donors told them that intersex people were not a key population for their work and a similar number (47.2%) reported that donors responded that intersex needs are not adequately documented in research. Notably, despite the natural intersections of intersex issues with many human rights issues, the most common feedback received from donors was that intersex issues did not fit with their priorities or that donors lacked information on intersex needs.

Intersex groups are most likely to receive intersex or LGBT-specific funding from foundations and larger NGOs as sub-grants. They receive almost no government funding.

Of the nearly two-thirds (64.3%) of intersex groups that received any external funding, a total of twenty-seven groups, the most common sources were foundation funding (55.6%) and sub-grants from larger NGOs (29.6%). Very few groups applied for or received any form of government funding. Intersex groups were most likely to receive intersex (64.9%) or LGBT-specific (44.8%) funding, with fewer receiving funding in areas related to women's rights (17.9%) or human rights (17.9%). This may indicate that donors outside of the LGBT field are less likely to fund intersex groups, which may be an opportunity to persuade donors in allied fields to consider support for intersex groups.

1 In 2013, AJWS and GATE did an initial survey of 340 trans and intersex groups, which yielded the first systematic data from trans activists and intersex groups about their work, leadership, funding, obstacles in accessing funding and capacity-building needs. The findings of this survey can be found in *The State of Trans* and Intersex Organizing: A Case for Increased Support for Growing but Under-Funded Movements for Human Rights*.

2 This brief is an executive summary of the full report: Howe, E, Frazer, MS, Dumont, M, and Zomorodi, G. (2017). *The State of Intersex Organizing (2nd Edition): Understanding the Needs and Priorities of a Growing but Under-resourced Movement*. New York: American Jewish World Service, Astraea Lesbian Foundation for Justice and Global Action for Trans Equality.

3 For more information about intersex activism, see Astraea's *We Are Real: The Growing Movement Advancing the Human Rights of Intersex People*.

4 In 2015, Astraea founded the Intersex Human Rights Fund to provide grants and other resources to intersex activists working to ensure the human rights, bodily autonomy, physical integrity and self-determination of intersex people. Astraea's Intersex Fund currently supports 37 intersex-led groups across the globe with grants of US \$5,000–\$10,000. The Intersex Fund is supported by Kobi Conaway and Andrew Owen, the Arcus Foundation, the Global Equality Fund, Open Society Foundations and Anonymous.

KEY RECOMMENDATIONS FOR FUNDERS

Based on the findings of this study, funders should:

Fund work led by intersex people.

Intersex groups are largely autonomous, with intersex people making the majority of decisions. Funders who prioritize self-led organizations should consider inclusion of intersex groups in their related portfolios, and support the intersex movement to grow and expand its leadership.

Provide flexible and stable funding to intersex groups.

Intersex groups are engaged in a wide range of activities but are held back from making progress with such little funding at their disposal. New investments of flexible and long-term resources will significantly and positively impact this small and growing movement.

InterACT/Credit: InterACT



Provide sufficient funding for paid staff.

Given the combination of a paucity of paid staff, very small annual budgets and high levels of requests for resources to prevent burnout and trauma, intersex activists may be at high risk of leaving the movement due to excessive demands on their time, resources and psyches. It is critical for the sustainability of the movement—and the activists personally—that intersex groups receive enough funding to employ staff and adequately compensate them.

Invest in anti-trauma resources and burnout prevention.

Many intersex activists have personal histories of trauma from being subjected to human rights violations. Intersex activists need not only more paid positions to support their work, but also dedicated resources for anti-trauma management, healing and wellness, and burnout prevention.

Invest in the organizational strengthening of intersex groups.

Intersex organizations need the capacity-development and non-financial support they are already receiving, such as donated space and access to international gatherings, and these should continue. However, there are neglected areas of capacity-building needs such as grant writing and fundraising, monitoring and evaluation, and financial management. Intersex groups want to build these organizational development skills, but they lack the capacity building and financial support to do so.

Support intersex activists to build community and national-level work, while they continue to advance work at the international level.

With their limited resources and capacity, intersex groups are working on multiple priorities at multiple levels. However, many groups are precluded from doing the community organizing work at the local and national level that they would like to do due to lack of resources. Intersex groups will need support for these activities from donors and sufficient capacity to work sustainably at multiple levels.

Educate your funding institution and your peers about intersex issues.

Intersex groups experience many donors as uninterested or uninformed about intersex issues despite the natural connections with the human rights issues they fund. Donors should seize opportunities to engage peers in allied fields to educate them about intersex issues and how they intersect with the donors' focus areas, including women's rights, child rights, disability justice, health and human rights, among others.

Decrease the barriers preventing intersex groups from finding and applying for funding, particularly by explicitly targeting calls for proposals to intersex groups and funding unregistered groups using intermediaries.

Intersex groups face a variety of problems that impact their ability to find and successfully apply for grants. By making an intention to support intersex groups (instead of or in addition to "LGBTI") explicit in their open calls and doing direct outreach to intersex groups, donors can make it easier for intersex groups to find funding opportunities relevant to them. Simplifying applications would also make applying for funding more accessible for over-stretched intersex groups. Finally, funders can contribute to pooled funds or to intermediaries such as the Intersex Human Rights Fund⁴ that can fund unregistered and small organizations.

For a copy of the full *The State of Intersex Organizing (2nd Edition)* report, please visit www.ajws.org, www.astraeafoundation.org or www.transactivists.org.

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We are grateful to the 54 intersex groups who took time out from their important work to respond to this survey and share detailed information about their work with us. We hope this report will serve and advance the struggle for intersex human rights, as well as be a tool to mobilize additional needed resources. We also thank the donors who provided project support for the production and dissemination of this report: American Jewish World Service and Open Society Foundations.