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THE STATE OF INTERSEX ORGANIZING (2ND EDITION)

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



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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. In particular, we would like to thank the organizations who provided information for the case studies featured in the report. 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.



When referencing this report, we recommend the following citation:

Howe, E., Frazer, S., 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.

About American Jewish World Service: American Jewish World Service (AJWS) is the first and only Jewish organization dedicated solely to ending poverty and promoting human rights in the developing world. AJWS advances the health and rights of women, girls and LGBTI people; promotes recovery from conflict, disasters and oppression; and defends access to food, land and livelihoods. We pursue lasting change by supporting grassroots and global human rights organizations in Africa, Asia, Latin America and the Caribbean, and by mobilizing our community in the U.S. to advocate for global justice.

About Astraea Lesbian Foundation for Justice: The Astraea Lesbian Foundation for Justice is the only philanthropic organization working exclusively to advance LGBTQI rights around the globe. Through grantmaking, capacity building and leadership development, philanthropic advocacy and media and communications, we support hundreds of brilliant and brave grantee partners in the U.S. and internationally who challenge oppression and seed social change. We work for racial, economic, social and gender justice, because we all deserve to live our lives freely, without fear and with profound dignity. Astraea launched the Intersex Human Rights Fund as a core program in 2015 and serves as the fiscal host for the International Trans Fund.

About Global Action for Trans Equality: Global Action for Trans Equality (GATE) is a civil society organization working internationally on gender identity, gender expression and bodily diversity issues by defending human rights, making available critical knowledge and supporting political organizing worldwide. Our areas of work include depathologization and human rights, trans and gender diverse issues in the international HIV response, movement building and socioeconomic justice, and trans, gender diverse and intersex advocacy at the United Nations.

About Strength in Numbers Consulting Group: Strength in Numbers Consulting Group (SiNCG) is a woman-owned, LGBTQ-led research and evaluation group started in 2010. SiNCG provides services related to research, evaluation, capacity building and philanthropic strategy to nonprofit organizations, foundations and government agencies. We are committed to combining rigorous social scientific and participatory methods to improve services, advocacy and outcomes for marginalized people locally, nationally and internationally.

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INTERSEX ISSUES LIE AT THE HEART OF HUMAN RIGHTS VALUES, INCLUDING BODILY integrity, autonomy and self-determination. Many of the rights violations that intersex people face relate to the ways that their bodies do not conform to medical and societal expectations about sex and gender. As babies and children, intersex people face surgeries and other medically unnecessary, nonconsensual and irreversible medical interventions. As adults, intersex people experience stigma, discrimination and violence that impacts their well-being and access to education, health care, employment and public services. Although many people may not be familiar with intersex people and issues, activists and donors have been working for years to highlight the discrimination, stigma and human rights violations faced by intersex people.



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Global Action for Trans Equality (GATE), American Jewish World Service (AJWS) and the Astraea Lesbian Foundation for Justice (Astraea) all work with intersex activists and support intersex groups. We see that the intersex movement—which has been fighting for the human rights of intersex people since the 1990s—is growing rapidly, yet it is vastly underfunded. From global LGBTI resource tracking efforts, we know that projects that explicitly served the needs of intersex communities received less than one percent of the total amount awarded for global LGBTI issues in 2013 and 2014.ⁱ In the Astraea report, *We Are Real: The Growing Movement Advancing the Human Rights of Intersex People*, we learned from intersex activists how donors can better support intersex groups including providing flexible funding, investing in capacity strengthening and movement building, and encouraging other donors to understand and support intersex issues. However, we realized that a lot of what we know about intersex groups is anecdotal and we needed to gain a more comprehensive—and evidence-based—understanding about the work and funding of this movement.

There are very few funding opportunities explicitly available for intersex groups. In 2015, Astraea founded the Intersex Human Rights Fund to provide grants and other resources to organizations, projects and timely campaigns led by 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. While this dedicated funding is critical, the amount of funding available to the intersex movement continues to pale in comparison to the need. The budgets of intersex groups remain very small and activists continue to face challenges accessing funding.

In response to these experiences, Astraea, AJWS and GATE set out to learn more about intersex groups worldwide, as a foundation for growing support for the movement and to quantify some of the anecdotal experiences articulated by intersex activists and witnessed by donors. The project aims to assess how best to support intersex leadership, promote the

sustainability of an active and stretched movement, and better address the capacity needs of intersex groups.

This report describes the findings of a survey of 54 groups that exist specifically and primarily to work with intersex people or on intersex issues. It builds on a 2013 effort by GATE and AJWS to assess the organizational and funding landscape for transgender and intersex groups, which resulted in the report *The State of Trans* and Intersex Organizing: A Case for Increased Support for Growing but Under-Funded Movements for Human Rights*.ⁱⁱ At that time, there were too

This report uses the United Nations 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.”

few intersex respondents to disaggregate the data, so the needs and experiences of intersex and transgender groups were presented together. In recognition that the intersex movement and the trans movement are separate and distinct movements, the 2016 survey and corresponding report were designed and written explicitly with intersex groups in mind.

By creating knowledge about the state of the intersex movement and highlighting funding needs and opportunities, we hope that this report will contribute to growing the resources available for intersex activists’ critical, transformative and life-saving work. We call upon donors to join us in this effort.

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.



StopIGM.org/
Credit: Roger Schmid

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. 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 children’s rights, patients’ rights, feminist, LGBTQ and disability rights organizations and movements. 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 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.ⁱⁱⁱ

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, service provision and safety and anti-violence work. More than eight in ten (85.4%) intersex groups surveyed did

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 organizers. 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; they didn't believe their application would be successful or they simply did not have the time amidst other activities.

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

*The Astraea Lesbian Foundation for Justice launched the **Intersex Human Rights Fund** in 2015 to support organizations, projects and timely campaigns led by intersex activists working to ensure the human rights, bodily autonomy, physical integrity and self-determination of intersex people. Working with an international board of intersex activist advisors, the Fund makes grants to intersex-led groups fighting human rights violations; strengthens the capacity of intersex activists and supports movement building; and mobilizes philanthropic resources through donor education and engagement. The Intersex Fund is supported by Kobi Conaway and Andrew Owen, the Arcus Foundation, the Global Equality Fund, the Open Society Foundations and Anonymus.*

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.

KEY RECOMMENDATIONS FOR FUNDERS

- Fund work led by intersex people.
- Provide flexible and stable funding to intersex groups.
- Provide sufficient funding for paid staff, and invest in anti-trauma work and burnout prevention.
- Invest in the organizational strengthening of intersex groups.
- Support intersex activists to build community and national-level work, while they continue to advance work at the international level.
- Educate your funding institution and your peers about intersex issues.
- Decrease the barriers for intersex groups in finding and applying for funding, particularly by explicitly addressing calls for proposals to intersex groups and funding unregistered groups through intermediaries.

HUMAN RIGHTS VIOLATIONS AGAINST INTERSEX PEOPLE

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 right to make autonomous and informed decisions about their own bodies, to be free from torture, to obtain identity documents, to enjoy sexual and reproductive rights, and to access health care, education and employment.

MEDICALIZATION, PATHOLOGIZATION AND LACK OF CONSENT

Many of the rights abuses that intersex people face stem from the pathologization of intersex variations. Within medical classifications (such as the International Classification of Diseases, a diagnostic tool used globally), those bodies falling outside the rigid stereotypes of male and female are categorized as intrinsically disordered or pathological. This hierarchical distinction between normal and abnormal bodily variations 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 are medically unnecessary and irreversible.^{iv} They can have serious and lasting impacts such as loss of sexual sensation, impaired sexual function, sterility, chronic pain and

typically occur in infancy, childhood and adolescence, they are performed without the full, free and informed consent of the person concerned. As such, they disregard children’s rights to protection, to express their views on matters that affect them and to preserve their own identity. Juan E. Mendez, the United Nations (UN) Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, issued a statement in 2013 condemning non-consensual surgical interventions on intersex people as a form of torture.^{viii} Because of the secrecy and shame propagated in the quest to “normalize” intersex bodies, there is little comprehensive data on the prevalence of these interventions; however, recent reports from Europe, for example, indicate that surgeries on intersex infants and children are still performed in 21 European Union countries and that the frequency of such surgeries has remained steady.^{ix}

Thanks to the international advocacy of intersex activists, these practices have come under increasing scrutiny by various human rights bodies. In 2016, UN human rights experts and agencies (including the UN Committee against Torture, Committee on the Rights of the Child, Committee on the Rights of People with Disabilities, and Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment) as well as the Inter-American Commission on Human Rights and representatives from the Council of Europe and the African Commission on Human and Peoples’ Rights called for an end to violence and harmful medical practices on intersex children and adults in a joint statement.^x Treaty bodies have issued more than 25 recommendations to various countries, stating that non-consensual medical interventions on intersex children are human rights violations and demanding that governments bring an end to them.^{xi} In 2017, the European Union (EU) Parliament passed a groundbreaking resolution recognizing that genital mutilation impacts the physical, psychological, and sexual and reproductive health of intersex individuals and calling on member states to prevent, ban and prosecute genital mutilation affecting intersex people.^{xii}

In 2015, Malta became the only country in the world to ban medically unnecessary surgeries on intersex infants and children. That same year, Chile’s Ministry of Health issued a moratorium on unnecessary “normalizing” treatments on intersex children until they are old enough to make decisions about their bodies. While several other governments are considering taking steps in this direction, there is much work to be done to increase state accountability to protect intersex people from these violations.



AIS Support Group Australia/
Credit: AIS Support Group Australia

infection, scarring, bleeding, osteoporosis, and psychological trauma.^v Those interventions have been identified as intersex genital mutilation (IGM).^{vi}

The push to “normalize” can begin before the moment of birth. In some cases, fetuses with intersex traits are exposed to prenatal treatments or selected for abortion. Through pre-implantation genetic diagnosis, parents can choose—and may be encouraged—to avoid embryos with intersex traits.^{vii}

These medical practices violate the autonomy and bodily integrity of intersex individuals. Because “normalizing” surgeries

BARRIERS IN ACCESS TO HEALTH CARE

Despite the invasive surgeries and other procedures that many intersex people undergo, there is a general lack of follow-up care and attention to how intersex people's quality of life may be impacted by such interventions. Many national health systems and insurance companies do not cover the cost of follow-up care or the expenses of repairing the damage from earlier surgeries. Simply recovering their own medical history can be a challenge; intersex individuals report being given incomplete or false information by doctors or being denied access to their medical records.^{xvi}

For many intersex individuals, even if they have not been subject to "normalizing" treatments, accessing health care can be a fraught experience. In seeking routine or emergency care, they risk ridicule, harassment and breaches of medical privacy. Many have experienced intrusive and unnecessary examinations or report being asked inappropriate questions by health care providers.^{xvii} In addition, medical professionals lack the knowledge and training to respond to their specific health needs.^{xviii} This extends to mental health care as well.^{xix}

CASE STUDY

Setting Legal Standards: Malta's Gender Identity, Gender Expression and Sex Characteristics Act

In countries across the globe, intersex activists are educating policy makers and promoting laws and policies that uphold the human rights of intersex people. In 2015, Malta's parliament unanimously passed the **Gender Identity, Gender Expression and Sex Characteristics Act**, a groundbreaking law that encompasses many of the legislative priorities of the global intersex movement and has become a touchstone for intersex advocacy efforts. The act creates a protected right to bodily integrity and physical autonomy for all people as well as a right to gender identity, including the ability to legally change gender based on self-determination. It requires informed consent for any medical intervention on an individual's sex characteristics and mandates access to psychosocial and medical support, establishing a working group to align treatment protocols with human rights standards and medical best practices. It also prohibits discrimination on the basis of sexual orientation, gender identity, gender expression and sex characteristics.

How did Malta come to be a standard bearer? In 2013, ILGA and ILGA-Europe^{xiii} hosted the Third International Intersex Forum in this tiny Mediterranean country, bringing together activists from 30 intersex organizations.^{xiv} After 25 years of conservative rule, Malta had elected a new Labour-led government which created an LGBT-friendly Ministry for Civil Liberties. Activists invited the new minister, Dr. Helena Dalli, to meet with them and set in motion the chain of events that led to this

precedent-setting law. The meeting opened the minister's eyes to the experiences of intersex people and the harmful practices that, as in most countries, were being perpetrated in Malta. She asked what she could do.

At the time, there were no intersex-inclusive organizations and no visible intersex activists in Malta. International intersex activists helped to fill the gap and worked collaboratively with local LGBT groups, medical professionals and government officials to draft the legislation. They were especially instrumental in framing "sex characteristics" as an inclusive and human rights-based terminology. Ruth Baldacchino (Program Officer for the Intersex Human Rights Fund at Astraea, ILGA World Co-Secretary General, and Maltese citizen) explains, "This emerged from discussion with international intersex activists who had the experience of working with human rights mechanisms where we talk about sexual orientation and gender identity and expression. We wanted to find and use something similarly encompassing."

Since its passage in 2015, the Gender Identity, Gender Expression and Sex Characteristics Act has had profound impacts in Malta and beyond. Malta's Ministry for Education developed a supportive policy for trans and intersex students which is now being implemented



Third International Intersex Forum in Malta/Credit: Betsy Driver

country-wide. Local LGBT groups have seen an increase in intersex people and their parents seeking psychosocial support. Intersex youth are showing an interest in activism. And excitingly for the international movement, political leaders and intersex activists in other countries are building upon this success. Governmental delegations from Belgium and Greece visited Malta to learn from the country's experience and inform changes to their own laws. Intersex activists in Iceland and Argentina are drafting new laws in their countries, based upon Malta's law. More broadly, activists are increasingly and successfully using the language of sex characteristics in their advocacy to expand anti-discrimination protections. For example, Bosnia-Herzegovina amended its anti-discrimination law in 2016 to explicitly prohibit discrimination on the ground of sex characteristics and to provide protections for intersex people in all spheres of life.^{xv}

Generally, health care schemes fail to recognize the needs of intersex people, which may result in denial of access to services, medication or insurance coverage. Policies that make certain treatments available on the basis of sex (e.g., prostate examinations or breast cancer screening) mean that an individual registered as the “wrong” sex may not be able to access them.^{xx} All of these barriers violate the right to the highest attainable standard of health.

Some gains have been made in recognizing the need to improve health care. For example, a 2017 EU Parliament resolution called on member states to provide mental health support along with physical care to victims of genital mutilation and those likely to be targeted. In its recommendations to several countries, the UN Committee on the Elimination of Discrimination against Women (CEDAW) urged them to put in place rights-based health-care protocols for intersex children.^{xxi}

ACCESS TO IDENTITY DOCUMENTS

For intersex people who do not identify with the sex assigned to them at birth or who feel that the categories of male and female do not describe them, changing their legally registered sex or gender marker can be challenging, if not impossible. In many countries, the barriers intersex individuals face are similar to those that trans people encounter when trying to amend their legal sex/gender identification. This includes burdensome and discriminatory requirements like a court order, psychological or medical examination, or a “real-life test” showing they have lived for a period of time in the gender role corresponding to the sex marker they are seeking. Some requirements promote “normalizing” procedures; in Vietnam and Thailand, for example, only intersex individuals who have undergone sex-reassignment surgery are able to change their civil registration records.^{xxii}

Sometimes the requirements for changing legal identification exclude intersex individuals because they are specific to trans people (such as a mental health diagnosis or particular surgical and hormonal interventions) or because they do not explicitly apply to intersex people. The United Kingdom’s Gender Recognition Act 2004, for example, requires an applicant to have been diagnosed with “gender dysphoria.”^{xxiii} Gender dysphoria is described in the widely used Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) as a mismatch between a person’s gender assigned at birth and their experienced and/or expressed gender. In addition to its characterization of this situation as a pathology, requiring such a diagnosis is problematic because an intersex person may or may not identify with the gender they were assigned at birth.

Further, in many countries, the only legal gender categories are male and female. This means there is no option for intersex individuals who identify as between male and female, as both, or with neither category.

As with medical records, intersex people may have difficulty accessing their original birth certificates because doctors and others may hide or change records to prevent disclosure of an intersex variation or proof of non-consensual interventions

from the person concerned. In one sign of legal progress, in 2014, a ruling by Kenya’s High Court in the case of the intersex Baby “A” affirmed the right of every child to legal recognition and identity through the issuance of a birth certificate.

The Malta Declaration, a guiding document of the intersex rights movement, states that individuals should be able to amend their sex or gender classifications through a simple administrative procedure. However, currently only a handful of countries—Argentina, Denmark, Malta and Ireland—allow any adult to change their legal gender without proof of genital surgery, hormonal therapies, or psychosocial or medical treatment.



VIOLENCE AND DISCRIMINATION

Intersex people around the world face stigma and discrimination fueled by stereotypes of what it means to be “male” or “female.” An inability to access identity documents or a perceived “mismatch” between a person’s legal identity and sex characteristics can perpetuate this discrimination and have multiple effects on intersex individuals’ rights. For example, intersex people may confront barriers to marriage or adoption of children, in violation of the right to marry and form a family. They may face harassment or difficulties when enrolling in school or seeking employment, in violation of the rights to education and equal opportunity. Yet while access to legal documents that reflect an individual’s identity is crucial and may mitigate the stigma that intersex people experience, the recognition of any person’s human rights should not be dependent upon this.

As a result of stigma and discrimination, intersex people encounter a range of health, economic and social inequities. A 2015 survey of intersex people in Australia revealed high rates of poverty—more than 40 percent of respondents earned less than US\$20,000 a year—and showed how bullying and medical treatment during puberty is linked to higher dropout rates in secondary school.^{xxiv} In some places, intersex individuals and their families may face extreme social rejection and violence, including infanticide. Activists in Uganda, South Africa and China report that parents may mutilate or kill their intersex babies out of fear for their own safety if they are discovered to be violating taboos by raising an intersex child.^{xxv}

A limited but growing number of countries provide explicit protection from discrimination for intersex people. In 2005, South Africa added “intersex” to its equality law as part of an existing prohibition on discrimination on the ground of “sex.”^{xxvi} Australia became the first country to include “intersex status” as a stand-alone attribute protected from discrimination in 2013.^{xxvii} Malta’s 2015 law was the first to specify “sex characteristics” as a protected ground. Since then, Bosnia-Herzegovina and Greece have included sex characteristics in laws prohibiting discrimination and hate crimes.^{xxviii} While these are positive developments, a lot more work is needed for intersex people to see changes in their lived experiences and to access adequate reparations for the suffering and injustice they have endured.

Greater resources and support will enable intersex groups to sustain their work and increase their impact. As Wiktor Dynarski, a program officer with the Open Society Foundations, highlights, “It is crucial that donors support the intersex movement in all of its shapes—from smaller groups and initiatives just establishing themselves in their local context, to organized and registered associations working in regions and with international human rights bodies, to funding mechanisms like the Intersex Human Rights Fund which can help leverage funding for those who we couldn’t reach otherwise. We have to help maintain the movement’s growth—both from a financial and a networking perspective. In places where we cannot fund, we should encourage other colleagues who can and help other funders who work on bodily autonomy and reproductive rights to understand that this is a complex and important issue that needs our urgent support.”

have agreed that the group they represented works “specifically and primarily with intersex people or on intersex issues,” consented to take the survey and provided, at minimum, information about the country location of their group.³ Survey respondents were provided with the opportunity to request a copy of the report and to take part in the case studies; in order to preserve anonymity, these data were collected on a separate platform from the survey and cannot be linked to survey responses.

Primary channels of survey outreach included the grantees of and past applicants to the Intersex Human Rights Fund at Astraea, as well as activists on the GATE listserv. All outreach materials were translated into the languages offered for the survey. GATE, Astraea and AJWS also promoted the survey at relevant activist and donor conferences.

METHODS

The data for this report come from an international survey for groups¹ that specifically and primarily work with intersex people or on intersex issues. The survey was distributed by the three organizations that commissioned the report and their partners, including donors, grantees, advisors and other civil society organizations. The survey used Qualtrics software and was available online (survey participants were given the opportunity to take the survey via phone with assistance from trained research staff; however, none elected to use this option). It was anonymous and confidential, and was offered in five languages: English, Spanish, French, Russian and Simplified Chinese. All respondents were asked about their group’s location, founding year and organizational structure, as well as the percent of intersex people represented on staff, in leadership and in decision-making bodies and roles. They were also asked about the amount and types of funding they received, barriers to funding, the types of work they did and wanted to do, their constituents and the types of training and capacity building they received and needed.²

The survey was available online from August 24, 2016 until October 16, 2016. There were 54 valid responses. In order to be included in the final dataset, survey respondents must

Strength in Numbers, the consulting group retained for this project, performed data analysis in Stata statistical programming software. Percentages were not reported for questions that had fewer than 5 respondents in the numerator or 20 in the denominator. This policy protects the respondents from being identified and decreases the likelihood that findings are artifacts of a small sample. Individual survey questions were calculated as percentages of valid totals; if a survey respondent skipped a question, this group was not included in the denominator of that specific question. With the exception of geographic location, no data were imputed and thus the statistics may not match other analyses in which imputation was performed. Due to rounding, some categories may add up to slightly more or slightly less than 100%.

The survey development, outreach and interpretation of the data were done in close collaboration with representatives from GATE, Astraea and AJWS. Astraea worked closely with members of the Intersex Fund Advisory Board^{xxix} to gather stakeholder feedback throughout the survey development, fielding and writing of this report. For any other inquiries about the methods for this survey, please contact the authors of this report.

1 Throughout the survey, the word “group” was used to describe an autonomous (independent) group, whether registered or unregistered, that was not part of any other group. The word “program” was used to describe those that are part of or are housed within other groups. While the word “organization” may be more specific and appropriate in English, in some place intersex groups associate the word “organization” with a formal, registered group and thus the less specific term was preferred.

2 The survey also asked about the percentage of intersex people that groups work with directly, such as direct beneficiaries or service recipients, and the percentage of the people they represent, also known as indirect beneficiaries. These data are not reported here.

3 In rare cases, groups with otherwise complete or nearly complete data who did not include their country names had country names imputed using the latitude and longitude of the survey taker’s location when completing the survey.



Brújula
Intersexual/
Credit:
Morgan
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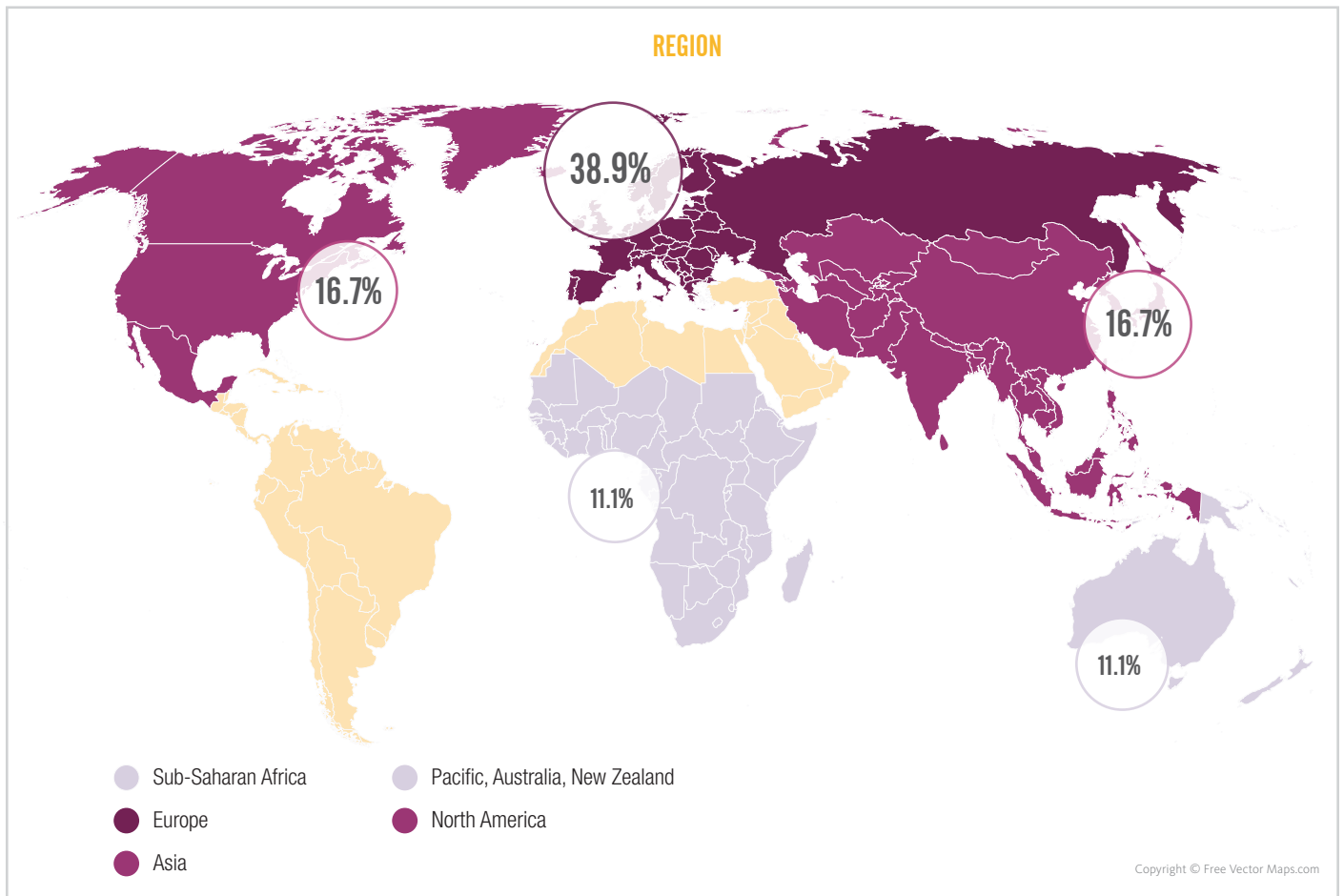
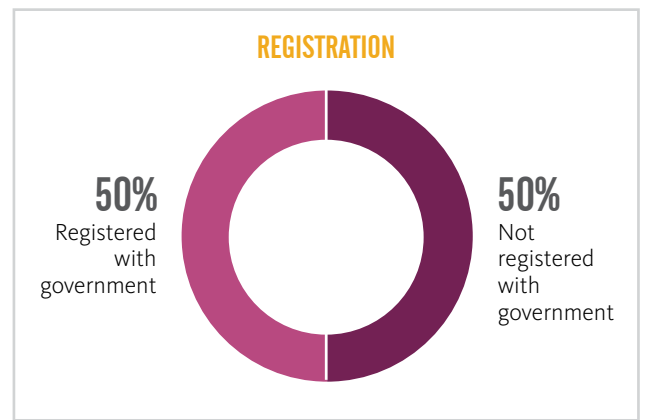
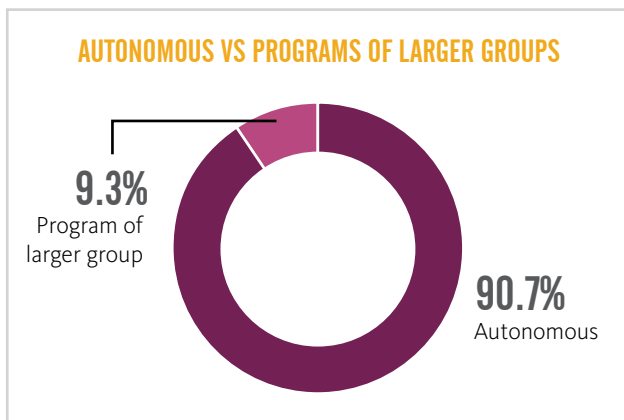
REGISTRATION, AUTONOMY AND LOCATION

THE INTERSEX MOVEMENT IS GLOBAL, GROWING RAPIDLY AND NOTABLY SELF-LED.

This section describes the legal and organizational status of the intersex groups who responded to the survey, including the year they were founded, where they are located, the level(s) at which they work, their registration status, and whether they were autonomous or a program of a larger organization.

Representing a growing movement, the majority (62.3%) of intersex groups were founded in or after 2009. Just under one-third (30.2%) were founded in or after 2014. Fewer than one in five (18.9%) intersex groups were founded in 2001 or prior.

Intersex groups are notably self-led. More than nine in ten (90.7%) intersex groups responding to this survey were autonomous or independent, leaving fewer than one in ten (9.3%) that were programs of larger organizations.



Half (50.0%) of the groups were registered with the government of the country or state where they are located, while the rest were not.

Intersex groups are working across the world.⁴ Two in five (38.9%) intersex groups in this sample were from Europe, with just over one in six (16.7%) from Asia and the same number from North America. Just over one in ten (11.1%) intersex groups were from Sub-Saharan Africa and the same number were from the Pacific Islands, Australia and New Zealand. There were too few respondents from the Middle East and North Africa, and from Central and South America and the Caribbean to report separately.

Just under two in five (39.6%) intersex groups worked at the international level, while more than half (56.6%) reported working at the national level in their own countries. Just under one-third (30.2%) worked at the city or municipal level.

ORGANIZATIONAL STRUCTURES

Intersex groups operate largely via the labor of unpaid volunteers and few have the resources to hire paid staff.

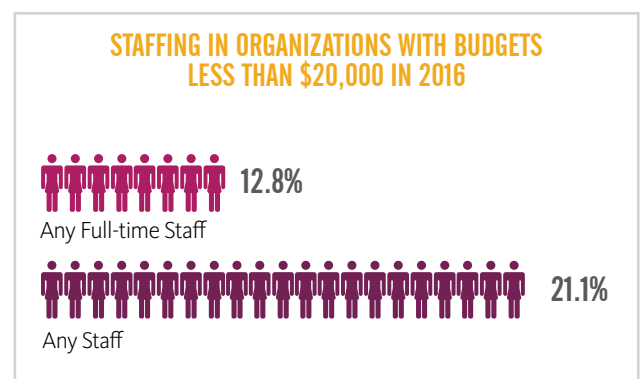
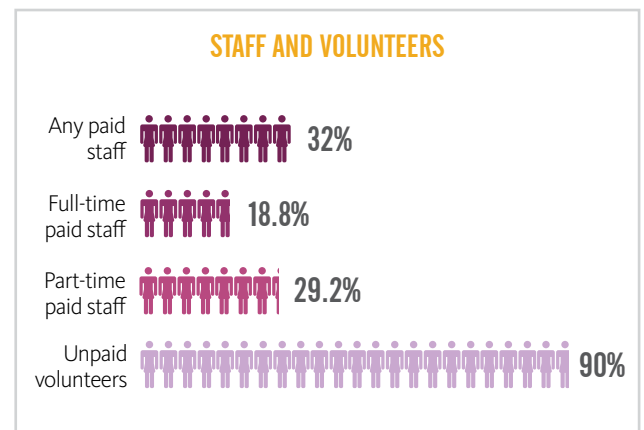
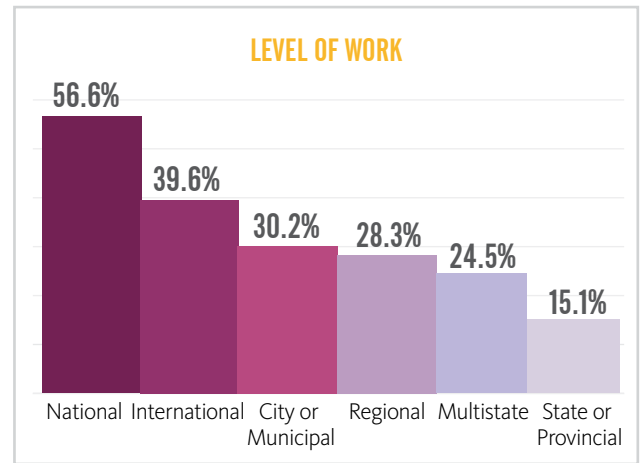
This section describes the structures and leadership of intersex groups who responded to the survey, including their staff, volunteers and leadership bodies, and the degree to which intersex people are represented in those structures. The intention of this section is to better understand the organizational structures of intersex groups, including how/whether staff and leadership include intersex people and if or how activists working with these groups are compensated for their work.

Regarding leadership structures, just over six in ten (60.4%) intersex groups reported having a sole coordinator, director or chair. Almost half (47.9%) have some sort of leadership body, such as a board of directors.⁵ Almost two in five (37.5%) intersex groups have more than one coordinator, director or chair, and just under one in five (18.8%) have a collective structure.

The majority of intersex groups (68.0%), 34 groups, reported no paid staff at all. Only (18.8%), nine groups, have full-time staff.^{6,7} With few groups having paid staff, most are comprised of volunteers. Nine out of ten (90.0%) of intersex groups, 45 groups, have unpaid volunteers.

Intersex groups report having some paid staff, despite having very small annual budgets (less than US\$20,000).

More than one in five (21.1%) intersex groups with budgets of less than US\$20,000 in 2016 reported having any paid



staff. More than one in ten (12.8%) intersex groups in this budget category also reported having at least one full-time paid staff person. There are several possible conclusions to be drawn from this, including (1) intersex groups may not be able to pay staff amounts that would be commiserate with a living wage in most (if not all) regions of the world and still have resources to implement their program activities; (2) staff of intersex groups may be working more hours than they're paid for (e.g., they are paid a stipend for full-time

4 Intersex groups responding to this survey were asked about the country where they are located. Countries were aggregated into the United Nations world regions to ensure the sample size was sufficient to protect the confidentiality of individual intersex groups. United Nations world regions can be found here: <http://unstats.un.org/unsd/methods/m49/m49regin.htm>.

5 Due to sample size constraints, the different leadership bodies (i.e., advisory council, administrative council, board of directors and/or steering committees) have been combined into one category.

6 Data on paid staff include both autonomous groups and programs of larger organizations. There were too few programs of larger organizations to disaggregate the data.

7 Full-time staff are defined as those who work more than 35 hours per week.

work, as opposed to a salary based on time spent). Regardless, the related factors of few paid staff and low budgets compromise the work of intersex groups. The interpretation of these findings merits more research. For more information on the budgets of intersex groups, see *Budgets and External Funding* on page 18.

Intersex groups are largely intersex-led, though intersex people are less represented as paid staff.

Intersex groups reported the percent of people among their staff, volunteers and leadership bodies who are intersex. Data are presented as the average percent of intersex people for each category (see figure on top of page 15).

Intersex groups were likely to be led by intersex people. More than eighty percent (82.8%) of intersex groups with one leader (i.e., coordinator, director or chair) said that leader was intersex. For groups with more than one leader, an average of just over two-thirds (67.5%) of these leaders were intersex. On average, just over half (56.5%) of the members of leadership bodies for intersex groups were intersex people, compared to nearly two-thirds of collectives (64.1%).

For intersex groups with paid staff, an average of just under two in five (38.6%) of those staff were intersex. Lower proportions of intersex people amongst paid staff require

CASE STUDY

Breaking Silence and Bringing Visibility

The stigma and secrecy long surrounding intersex issues has had powerful effects: isolating intersex people from one another, silencing their voices and perpetuating human rights abuses. Intersex activists are using a variety of creative means to overcome these challenges, often through multimedia strategies that enable people to connect and create awareness. Through this work, activists are countering misperceptions about intersex people, exposing rights violations, sharing stories and celebrating intersex lives.

The **Intersex Day Project** was started by Morgan Carpenter and Laura Inter, activists living in Australia and Mexico respectively. The project promotes events for two long-standing global days of action—Intersex Awareness Day and Intersex Day of Solidarity—and serves as a valuable online forum for intersex people around the world to reflect on a diversity of regional issues, histories and personal experiences. Laura Inter is also the driving force behind **Brújula Intersexual**, a project that provides support and guidance to intersex people and their families, and a space for intersex people to connect and find community through its website. Responding to the lack of information available in Spanish, Brújula Intersexual translates articles, videos and radio programs about intersex issues, giving priority to the perspectives of intersex people and materials created by intersex organizations. As Laura

explains, “It took years of research and work to find reliable information about intersex issues written by intersex people. When I found it, it was usually in English. The circulation of information in multiple languages strengthens the intersex movement by creating dialogue about what happens in different latitudes and cultures, highlighting the intersex movement demands that we have in common and the particularities of each country or region. In the same way, the Intersex Day Project

for intersex issues in their own languages. In the short time that InterVisibility has existed, more than 15,000 individuals have visited the website.

In the U.S., **interACT**, a national organization that raises intersex visibility, empowers young intersex activists and promotes laws and policies that protect intersex youth, advised on the portrayal of the first intersex main character on television for the popular MTV show “Faking It.” Their involvement ensured that the show’s writers and cast heard directly from intersex teenagers and young adults about their experiences; one of interACT’s youth members appeared in an episode, becoming the first intersex character played by an openly intersex person on U.S. television.

As the profile of intersex activism grows, invisibility and isolation shrink. These projects, and many others led by intersex activists, are increasing awareness and understanding of intersex issues and lived realities—both among intersex people and more broadly. More intersex people are realizing that they are not alone and are learning how to find information and support from other intersex individuals. By sharing their personal histories, intersex activists are encouraging more people to disclose their status, talk about their own experiences and recognize their resilience. These efforts are building community, strengthening activism and contributing to the expanding narratives of the global intersex movement.



“Faking It” photo shoot/Credit: InterACT

allows for the exchange of experiences, strategies and achievements generated in different contexts.”

Similarly, **InterVisibility: European Intersex Visibility Works!**, a project of **OII Europe**, provides information in 30 languages about who intersex people are and the human rights abuses they face. The project represents the first time non-pathologizing information on intersex has become available in a number of these languages. In several cases, through this project, activists coined terminology

further qualitative investigation, but may be due to the involvement of family members and allies in the work of intersex organizations. On average, about half (48.8%) of volunteers for intersex groups were intersex.

DECISION MAKING AND REPRESENTATION

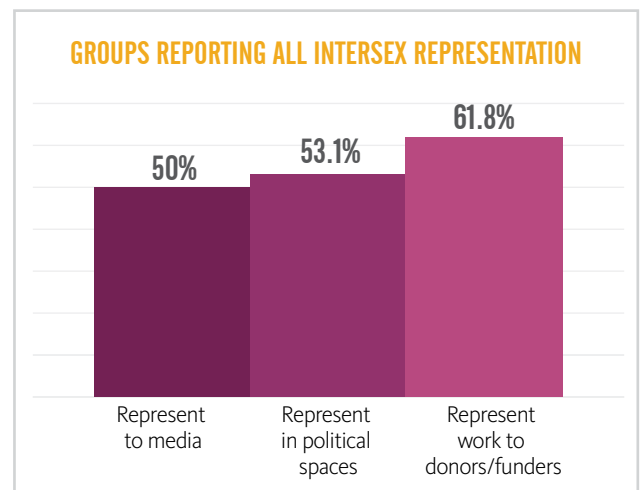
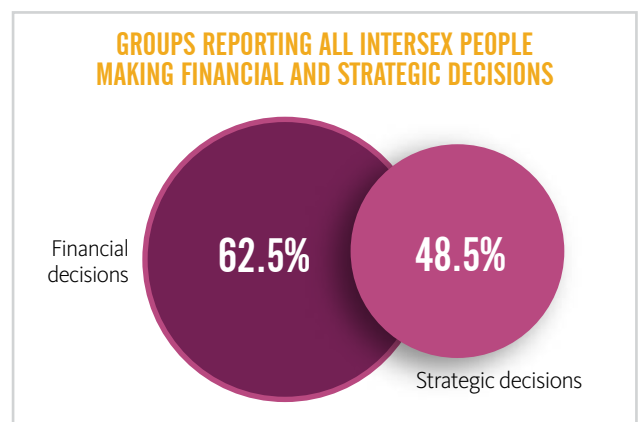
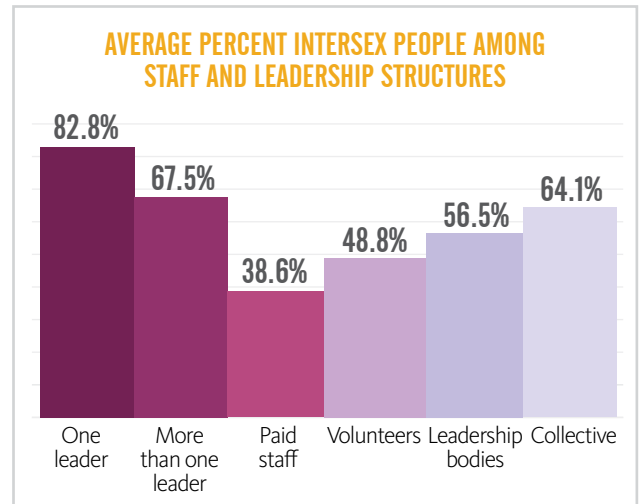
Financial decisions in intersex groups are made entirely by intersex people for a majority of groups. However, for representation, the picture is somewhat mixed, with intersex people more likely to represent their group to donors and funders than to the media or in political spaces.

This section describes intersex leadership. Decision making and representation were the core components of leadership, broken down by representation to different audiences (i.e., the media, in political spaces and to donors and funders) and types of decisions intersex groups make (i.e., strategic, financial). Separating the different dimensions of leadership provided an opportunity to learn more about how leadership is expressed in intersex groups and how donors can better assess and support intersex leadership. Dimensions of leadership were defined in dialogue with activists and donors involved in or supporting intersex and trans movements.

Intersex groups were asked who in their group was involved in each facet of leadership. Groups could select the individual leader(s) (e.g., coordinators, executive directors or chairs) or a leadership body (e.g., board of directors, advisory council, etc.). Data were also collected about whether intersex people hold these positions.⁸

Nearly two-thirds of groups reported all intersex people made financial decisions (62.5%), while almost half of groups reported all intersex people made strategic decisions (48.5%). A smaller number of groups have very few intersex people making financial and strategic decisions. While many groups reported a large amount of decision-making by intersex people, one-third (31.3%) of intersex groups said fewer than half of those making financial decisions are intersex and 45.5% of intersex groups said fewer than half of those making strategic decisions are intersex. Overall, strategic decisions are less likely to be made by intersex people than are financial decisions.

Nearly two-thirds of groups reported that only intersex people represented their group's work to donors/funders (61.8%); about half of groups had all intersex people representing them in political spaces (53.1%) and to the media (50.0%). At the same time, a smaller number of groups reported very few intersex people represented the group and its work. About one-third (32.4%) of intersex groups said fewer than half of those representing their work to donors/funders were intersex, while more than two in five intersex groups said fewer than half of those representing their work in political spaces (43.8%) and to the media (44.1%) were



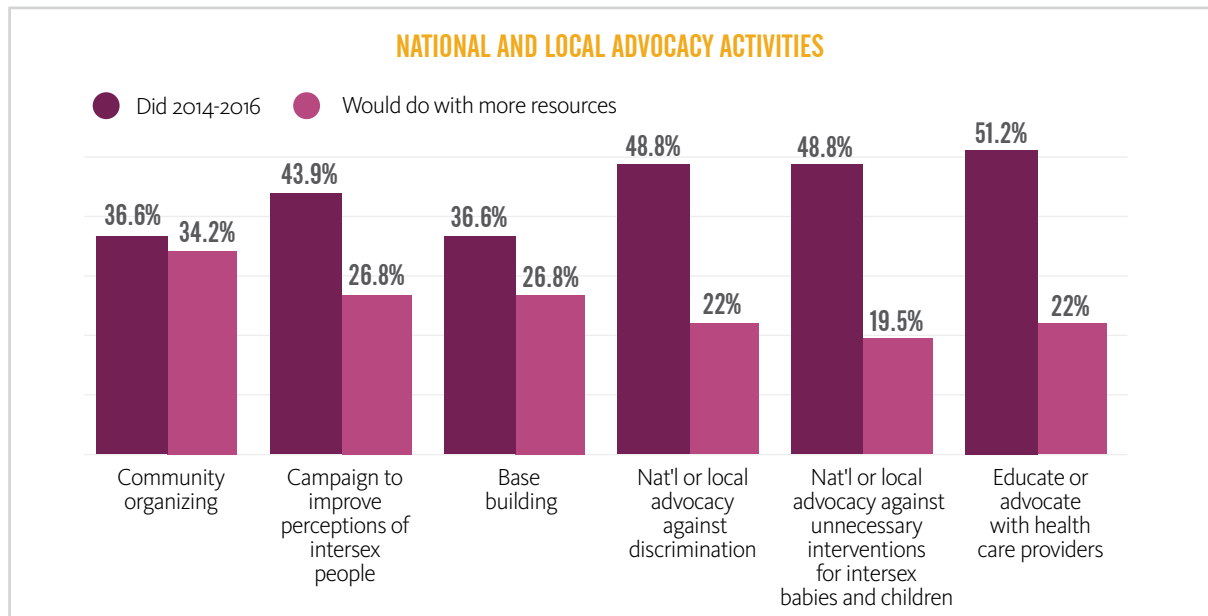
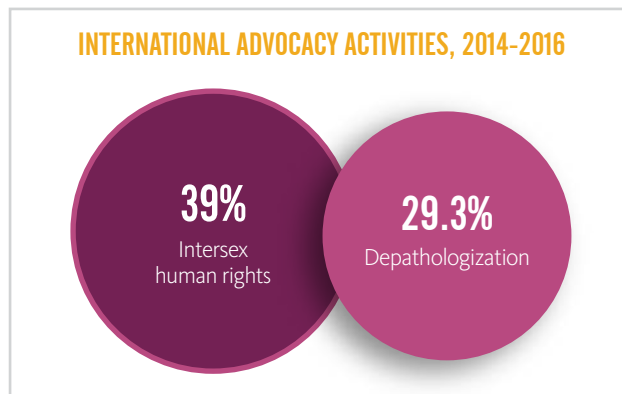
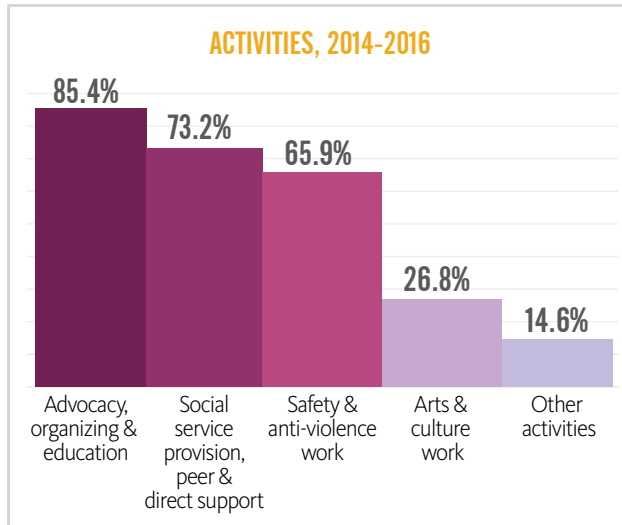
intersex. Overall, intersex people are more likely to represent their groups to donors/funders than in political spaces or to the media.

Together, these findings require further qualitative research to better understand the dynamics of decision making and representation within intersex groups.

⁸ Survey respondents could also indicate that some other person in their group was involved in this type of leadership and were then asked follow-up questions about whether this other person was intersex (or the percentage of this group of people who were intersex). In the case of more than one decision-maker, they were asked to report the percentage of decision-makers who were intersex on a scale from 0% to 100%.

ACTIVITIES

Intersex groups are doing a wide variety of activities, from advocacy and service provision to arts and anti-violence work.



This section describes the different types of activities intersex groups reported doing in the years 2014 to 2016, as well as those they reported wanting to do, but which have been precluded due to lack of funding or resources. The groups were asked about activities in the following categories: (1) advocacy, community organizing and/or provider education; (2) social service provision, peer support or individual-level advocacy with intersex people; (3) safety and anti-violence work, including documentation of human rights violations; and (4) arts and culture work. Groups were also allowed to write in activities not mentioned in the checklist. The purpose of this section is to better understand the types of work intersex groups are doing and what they would like to do if more resources were available. It is important to note that though intersex groups reported doing a type of work, they may have resourced that activity without the support of external funding.

The largest number (85.4%) of intersex groups reported doing advocacy, community organizing and/or provider education. Nearly three quarters (73.2%) reported doing social service provision, peer support or individual advocacy with intersex people. Just under two-thirds (65.9%) reported safety and anti-violence work and just over one in four (26.8%), arts and culture work. Several groups also mentioned the translation of relevant research and publications from English into other languages as another key activity.

Several of the activities described above have subcategories, which were only asked of intersex groups who said they do this type of work.⁹

In the area of international advocacy, almost two in five (39.0%) intersex groups reported working to influence an international or regional decision-making body to improve the human rights of intersex people, while nearly three in ten (29.3%) worked to

⁹ All subcategory frequencies reported are among the forty-one groups those who answered any questions about the types of work they did. Subcategory responses are reported only for the questions for which sample size was sufficient.

influence an international decision-making body to advance the depathologization of intersex people.

Common types of advocacy reported by intersex groups at the national and local levels include education or advocacy with health care providers (51.2%), national or local advocacy against unnecessary interventions for intersex babies and children (48.8%), advocacy for laws or policies that protect intersex people from discrimination (48.8%) and campaigns related to improving the public perception of intersex people (43.9%). Only just over one-third of intersex groups reported doing community organizing or building community capacity to

work towards a common, specific target or goal (36.6%) or base building or growing the membership or their organization or campaign (36.6%) in 2014–2016.

Intersex groups need more resources to do community organizing, base building and local advocacy, and to provide services to intersex people and family members.

Intersex groups were also asked about activities they wanted to do at the time they took the survey, but had been precluded from doing due to lack of funding or resources. The most common national and local advocacy activities intersex groups wanted to do but could not were community organizing (34.2%), running a

CASE STUDY

Leveraging International Human Rights Mechanisms

Over the past few years, intersex activists and organizations have been particularly strategic in using a variety of international human rights mechanisms to bring attention to the concerns of intersex people, gain recognition of rights violations and pressure their national governments to take action. As the United Nations High Commissioner for Human Rights Zeid Ra'ad Al Hussein pointed out, “[Intersex] violations are rarely discussed and even more rarely investigated or prosecuted. The result is impunity for the perpetrators; lack of remedy for victims; and a perpetuating cycle of ignorance and abuse. But there are signs that the tide may at last be turning, thanks to the tireless work of intersex organizations and human rights defenders, over many decades. There have been clear recommendations by several human rights mechanisms urging states to take steps to address these violations.”^{xxx}

The Swiss intersex group **Zwischengeslecht.org** (also called StopIGM.org) has played a lead role in leveraging opportunities within the UN system through country reviews by UN treaty bodies. The organization has authored and co-authored dozens of NGO reports with intersex activists and organizations in those countries, resulting in more than 25 condemnations by UN treaty bodies of non-consensual, medically unnecessary surgeries and treatments, particularly in relation to intersex children. In the past four years, the Committee on the Rights of the Child (CRC) and the Committee on the Elimination of Discrimination against Women (CEDAW) have recognized such interventions as a harmful practice and as intersex genital mutilation; the CRC further called it violence

against children. In addition, the Committee on the Rights of Persons with Disabilities (CRPD) has reprimanded several countries for failing to uphold the bodily integrity of intersex children. In 2017, for the first time, the Committee on Economic, Social and Cultural Rights included intersex issues in a Concluding Observation. **Zwischengeslecht.org's** Daniela Truffer emphasizes, “Increasing the pressure on perpetrators and complicit states by naming and shaming, non-violent confrontation, and using UN human rights mechanisms is crucial to end IGM.”

Similarly, a 2015 submission by Hong Kong-based organization **Beyond the Boundary - Knowing and Concerns Intersex** to the UN Committee Against Torture (CAT) resulted in recommendations calling on Hong Kong and China to take legal measures to ensure respect for the autonomy and physical and psychological integrity of intersex people; to guarantee the postponement of non-urgent, irreversible medical interventions until intersex children are old enough to give full, free and informed consent; and to provide redress for the suffering caused by non-consensual medical practices.

Advocacy efforts led by **activists from Argentina and Costa Rica** have spurred the Inter-American Commission on Human



Beyond the Boundary/Credit: Beyond the Boundary

Rights (IACHR) to action. In a 2015 report, the IACHR called for legal prohibition on surgeries and other unnecessary medical interventions on intersex people without their informed consent and urged states to collect data on human rights violations of intersex people, including the prevalence of medical treatment and surgical interventions. It also recommended that states adopt measures to eradicate social stigma and conduct educational campaigns to address stereotypes and invisibility.^{xxxi}

Through these regional and international human rights spaces, activists have been able to make progress when doors at the national level are closed. Their advocacy efforts are creating a new level of visibility of the rights violations that intersex people experience. Activists' testimony and reports—and the resulting recommendations and statements by international human rights bodies—have established a growing body of evidence that can be used to further advance the rights of intersex people.

campaign to improve public perception of intersex people (26.8%) and base building or growing the membership of their organization or campaign (26.8%)—notably, all activities intended to build community and power among intersex people.

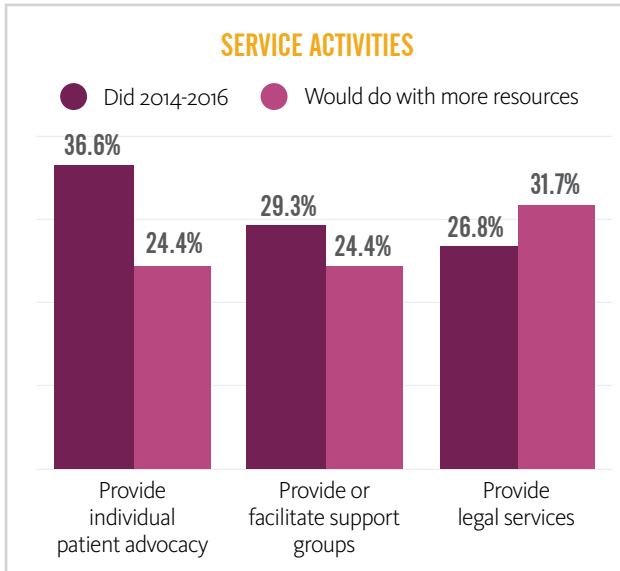
In the area of service provision, intersex groups were most likely to report legal services or advocacy (31.7%), facilitating support

groups (24.4%) and individual patient advocacy (24.4%) as activities they wanted to do but couldn't due to lack of resources.

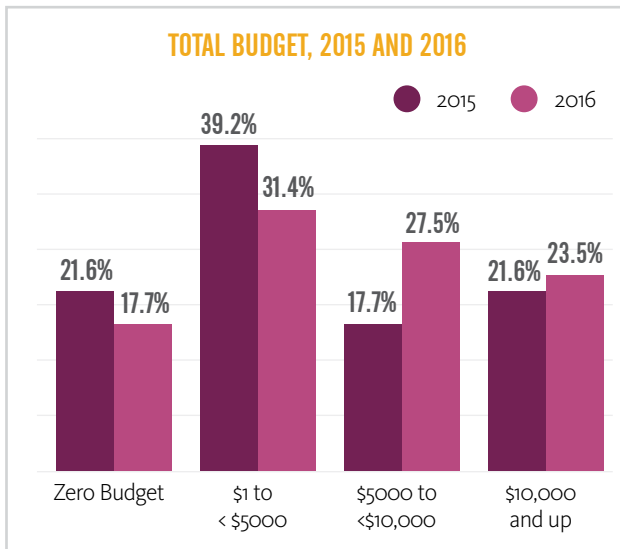
BUDGETS AND EXTERNAL FUNDING

Intersex groups operate with very low budgets and with limited access to external funding.

This section describes the annual budgets, funding sources, nonfinancial support and financial health reported by intersex groups in 2015 and 2016. The intention of this section is to understand the funding levels, trends and sources for intersex groups, as well as their financial stability, access to nonfinancial support and their experiences applying for different types of funding.

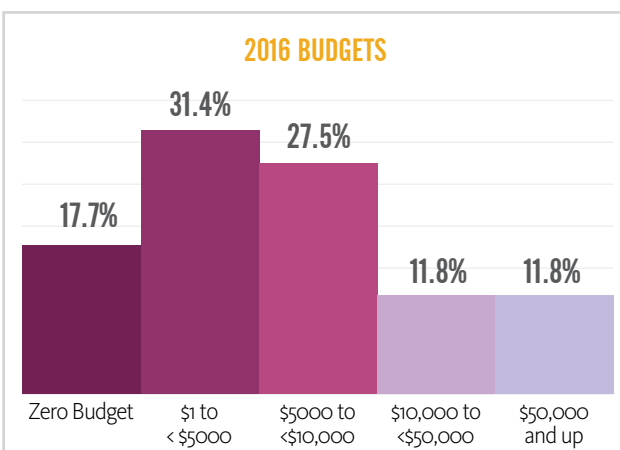


Budget was defined as the cost to run the group for a year (in contrast to external funding, which was defined as the amount taken in from external sources in a year, see below). Collecting budget data from the same organizations for a two-year period provided the opportunity to assess whether budgets grew during this period. Overall, the percentage of intersex groups with an annual budget of US\$5,000 or less decreased between 2015 and 2016, while the percentage of intersex groups with US\$5,000 or more increased. In 2015, more than one in five (21.6%) intersex groups had zero budgets, while in 2016, just over one in six (17.7%) had zero budgets.



Although this is a positive trend in funding for intersex groups between 2015 and 2016, increases in annual budgets are modest and actual budget amounts remain small. In 2016, just under half (49.1%) of intersex groups reported annual budgets of less than US\$5,000 and more than three-quarters (76.6%) had annual budgets of less than US\$10,000. Conversely, less than a quarter (23.5%) of intersex groups had budgets of US\$10,000 or more in 2016.

A further breakdown of 2016 budgets of intersex groups shows the proportion with budgets from US\$10,000 to less than US\$50,000 and US\$50,000 or more. Note that the categories are not divided evenly. Just over one in ten (11.8%), a total of six intersex groups, had a budget of US\$50,000 or more in 2016.



Intersex groups were also asked about the external funding they received in 2015 and 2016.¹⁰ Trends in external funding are similar to those in the annual budgets of groups. Overall, the percentage of intersex groups with external funding of less than US\$5,000 decreased between 2015 and 2016, while the percentage of intersex groups with US\$5,000 or more increased. However, more than one-third (35.7%) of intersex groups still had no external funding in 2016. **Only about one in five (19.0%) intersex groups reported receiving US\$10,000 or more in external funding in 2016.**

Groups operating in Asia, Sub-Saharan Africa, and the Caribbean, Central and South America reported that they had no external funding nearly three times as often as those in Europe, North America and the Pacific, Australia and New Zealand (60.0% vs. 22.2%). Data suggest that groups in the Global South and East regions are much less likely to have external funding than those in the Global North.

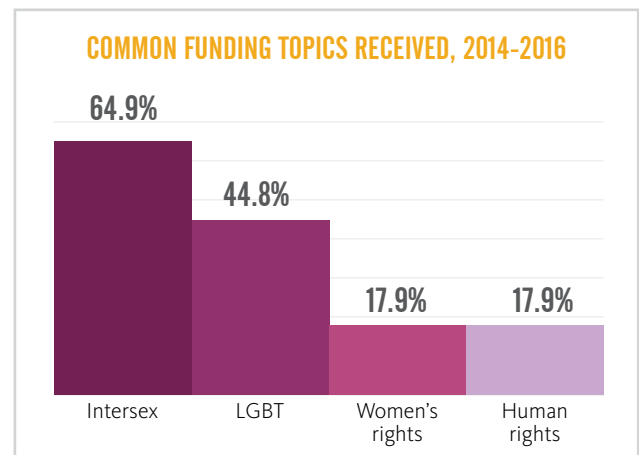
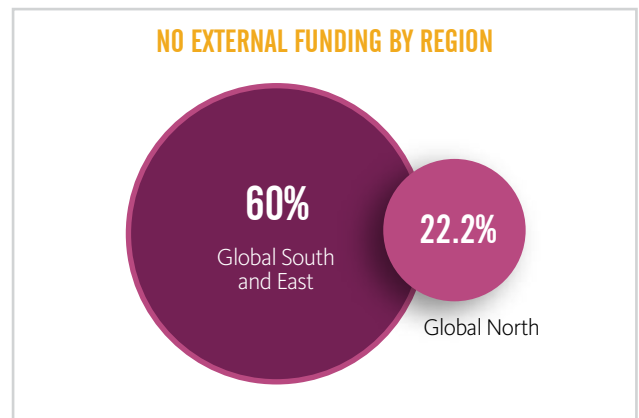
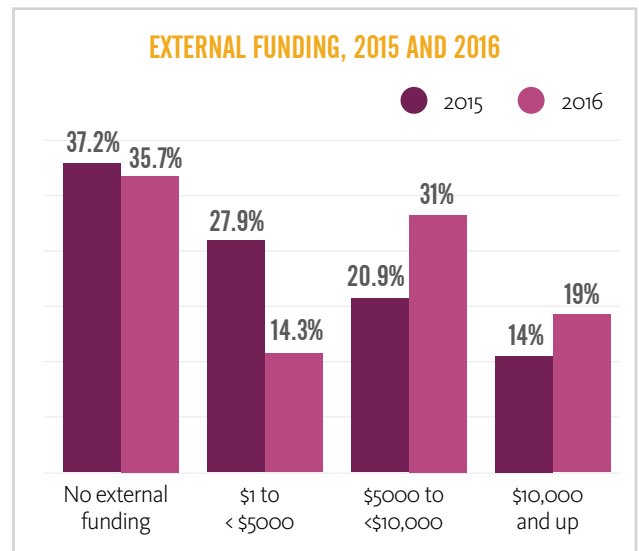
Intersex groups are getting almost no support from governments. Foundations and NGO sub-grants are the most common sources of funding.

The most common sources of external funding were foundations and sub-grants from an NGO.¹¹ Of the nearly two-thirds (64.3%) of intersex groups that received any external funding, a total of 27 groups, more than half (55.6%), 15 groups, received foundation funding and just over one quarter (29.6%), eight groups, received a sub-grant from an NGO. Of the intersex groups that had foundation funding, almost two-thirds (63.2%) said that some of this funding was multi-year and just under half (47.4%) said fifty percent or more of that funding was general operating support. The number of intersex groups receiving government funding was too few to report, even when all government categories were combined, meaning that intersex groups surveyed were getting almost no support from governments. A few intersex groups also wrote in other types of external funding; the most common of these was financial support or scholarships to attend a conference or meeting from a regional or national NGO.¹²

Intersex groups were most likely to receive funding¹³ that was explicitly targeted towards intersex issues (64.9%). Other common themes for intersex groups to receive funding were LGBT (44.8%), women’s rights (17.9%) and human rights (17.9%).¹⁴

Many intersex groups are mobilizing their own resources to supplement their low levels of funding.

In addition to receiving external funds, intersex groups reported raising funds from community sources. The most common sources of community funding included cash or in-kind donations from individuals (46.3%), a founder or founder’s family member’s savings or contribution (36.6%), community fundraisers (e.g., sales of books, t-shirts, etc.) or events (26.8%), membership fees (19.5%) and cash or in-kind donations from businesses (12.2%). Only one in five (19.5%) reported no community funding sources, suggesting that the majority of intersex groups are mobilizing their own resources to supplement their low levels of external funding. In the “other” section of this question, several intersex groups raised the issue that the time key staff or volunteers invested in the work was significant and largely uncompensated, and although not monetary, could be considered a community funding source.



10 External funding includes government and foundation funding and excludes membership fees, community fundraisers, events and individual contributions from founders or their family members. It is an important measure of the combined support intersex groups receive from government, private and public donors.

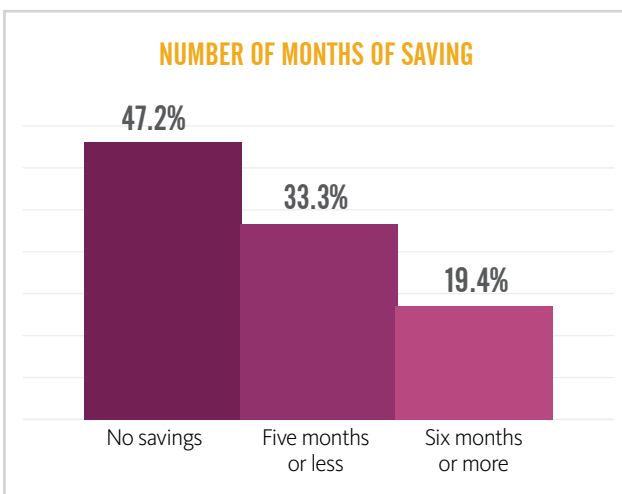
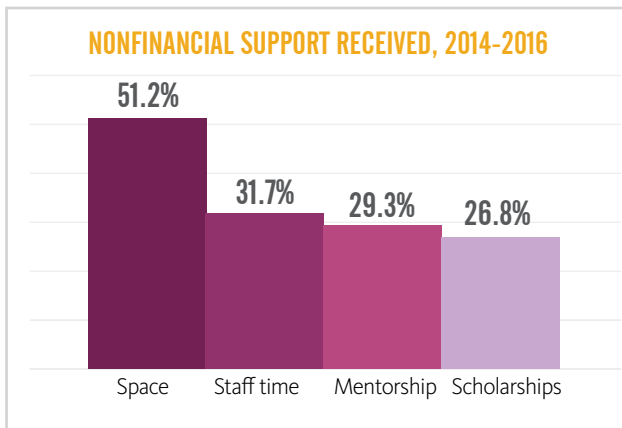
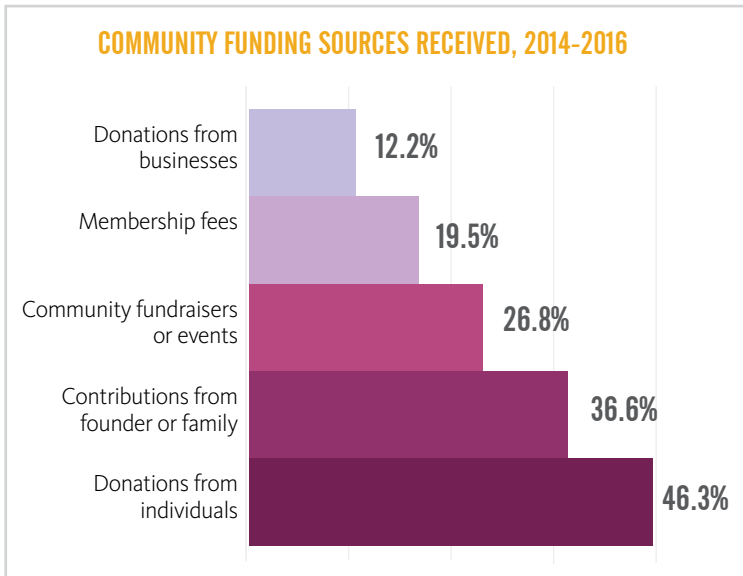
11 External funding sources included on this survey were the national, state and/or municipal/city government where the group was located, foundation donors, an embassy of a country other than the one where the group was located, a government of a country other than the one where the group was located (not the embassy, sometimes referred to as bilateral funding) and a sub-grant of a non-governmental organization (NGO). Groups receive sub-grants to do a part of a larger scope of work from a grant received by another organization.

12 In addition to asking what funding intersex groups had received, groups were asked to report on which types of funding they had applied for and not received. There were few instances of this experience across most funding types; the exception was that about one in five (19.0%) intersex groups reported applying unsuccessfully for funding from their own government at the country, state and/or municipal level.

13 Many donors fund by thematic areas or portfolios, such as intersex, LGBT, women’s rights, human rights, disability, children, youth or adolescents, HIV/AIDS and health.

14 Intersex groups were most likely to apply unsuccessfully for funding related to women’s rights, health and human rights (data not shown due to small sample size).

Intersex groups received a range of nonfinancial forms of support, the most common of which was donated space. More than half (51.2%) of intersex groups received space as a form of nonfinancial support. Other common forms of nonfinancial support included donated staff time from staff of another organization (31.7%), mentorship (29.3%) and scholarships (26.8%).



A few intersex groups wrote in examples of mentorship they received, including facilitation of a strategic planning workshop and legal support.

Savings can be an important indicator of financial stability. Non-profits are recommended to have between two and six months of savings in reserve for unforeseen expenses, cash shortfalls, replacement or repair of equipment or property or unexpected opportunities.^{xxxiii} Almost half (47.2%) of intersex groups said they had no savings¹⁵ and one-third (33.3%) reported five months or less of savings. Only just under one in five (19.4%) intersex groups had six months or more of savings.

FUNDING CHALLENGES

From the perspective of intersex groups, funders appear uninterested in supporting their work and often give feedback that their work does not align with donor priorities. Along with low staff capacity and heavy reliance on volunteers, this is the largest barrier groups face to resourcing their work.

This section describes challenges intersex groups face finding and accessing funding, the feedback they receive from donors when funding requests are denied, as well as difficulties implementing grants once received. The intention of this section is twofold: (1) to better understand the challenges intersex groups face related to funding, so actions can be taken to lower barriers; and (2) to understand the reasons that donors may not fund intersex groups, so donors supporting this work can address them.

The survey measured barriers to finding funding opportunities, applying for funding and implementing grants from 2014–2016, and reasons that donors might have turned down funding requests. As well, the survey gave respondents the opportunity to write in additional barriers. A complete list of measured barriers is available from the researchers on request. Respondents could report multiple barriers. Only the most frequently reported barriers are discussed here.

The most common problems intersex groups reported among the barriers to finding funding included funders' websites or open calls for funding not explicitly stating an interest in funding intersex groups (59.5%), lack of staff or volunteers who knew how or where to look for funding (35.7%), uncertainty around whether their intersex group was a good candidate for funding opportunities (35.7%), and lack of knowledge on how to apply despite awareness of donors (23.8%). Many also wrote in that a significant barrier to finding and applying for funding was that they had "no time to apply" (14.3%). Intersex groups wrote in a variety of reasons that they lacked time to apply, including they did not think it was a worthwhile investment to apply for funding because they were unlikely to get it, and staff and volunteers did not have time to find funding opportunities because they were too busy, overstretched or burned out.

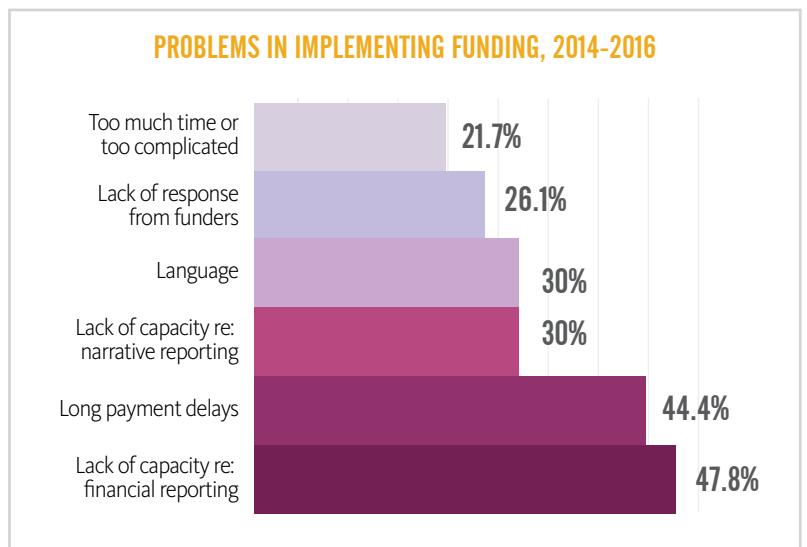
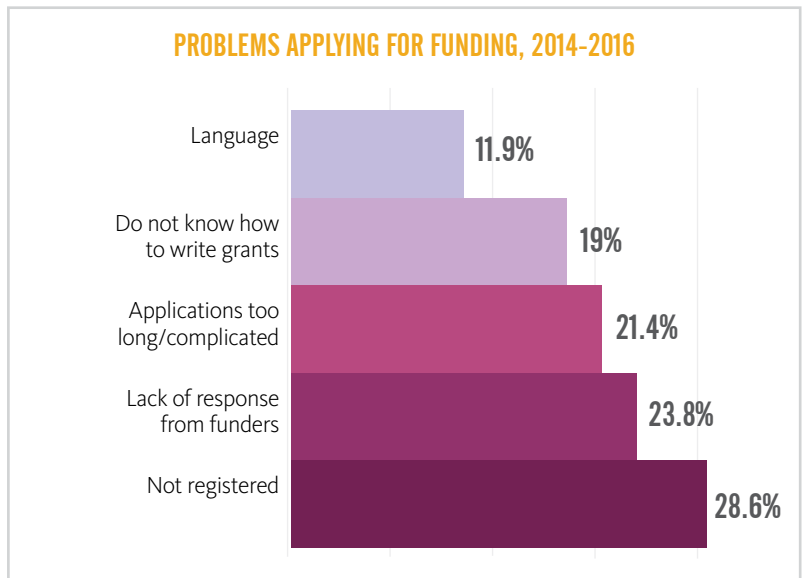
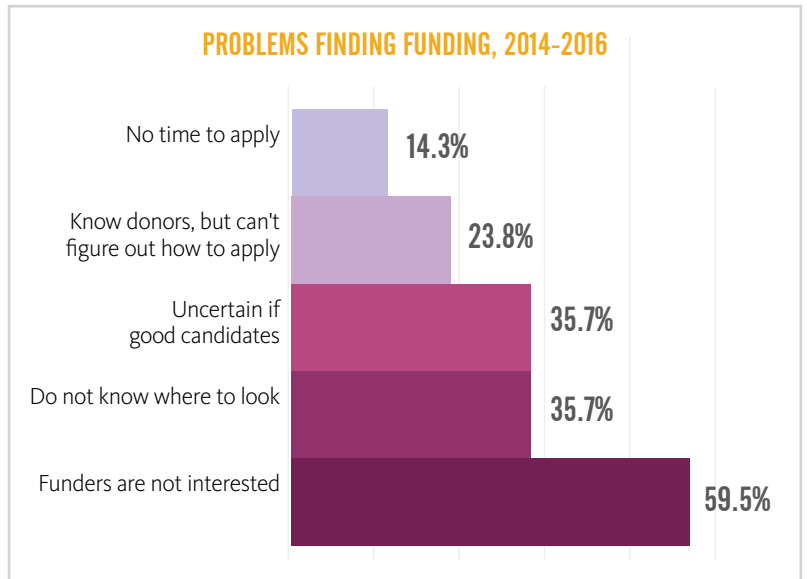
¹⁵ Months of savings was defined as the number of months your group could operate on savings if you suddenly stopped receiving any money from external sources and grassroots fundraising.

Intersex groups also reported problems applying for funding. The most common problems included lack of legal registration, which rendered the group ineligible (28.6%), lack of response from funders when the group submitted applications (23.8%), and complicated or long application forms (21.4%).

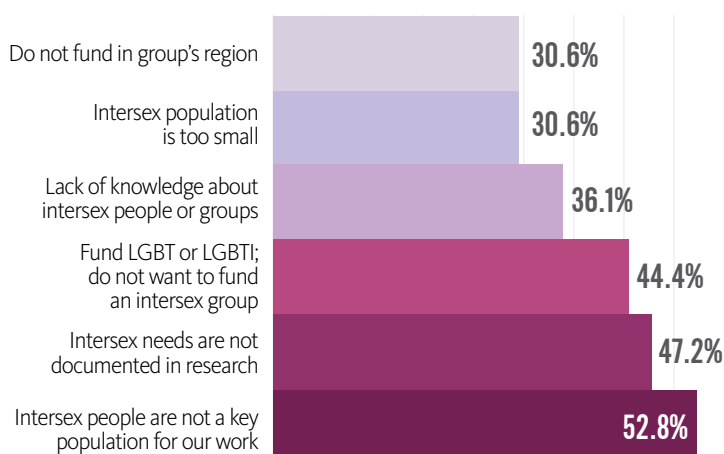
Intersex groups also reported challenges related to receiving and managing the funding they had been awarded. During grant implementation, the most common problems experienced by intersex groups were lack of staff/volunteers who knew how to complete financial reporting requirements (47.8%), long delays in payment (primarily the initial payment) (44.4%), lack of staff/volunteers who knew how to complete narrative reporting requirements (30.0%) and language requirements for reports, as the language was difficult for the group (30.0%). A few intersex groups also wrote in that they found reporting processes to be too long and complicated and that they lacked time and resources to write reports.

Intersex groups were also asked about feedback from donors that had declined their funding requests (see figure on top of page 22). Notably, the most common feedback was about intersex issues not fitting with the donor's strategy or priorities, or lacking information about intersex needs, as opposed to anything about the organizational capacity of intersex groups. Intersex groups were most likely to receive the following types of feedback: intersex people are not a key population for our work (52.8%), intersex needs are not adequately documented in research (47.2%) and this funder or donor funds LGBT or LGBTI organizations but does not want to fund an intersex-specific group (44.4%). Other common donor feedback included not knowing enough about intersex people or groups to fund this work (36.1%), the intersex population is too small (30.6%) and the funder or donor does not fund in the region where the intersex group works (30.6%).

Feedback from donors that intersex issues are not a priority for their work, that intersex needs are not well-documented in research and that LGBT or LGBTI donors do not want to fund an intersex-specific group may discourage groups from applying for funding in the future. Additionally, intersex groups reported a reluctance to apply for funding when they are unsure if they will be successful. Groups have small budgets and very little paid staff time to dedicate to fundraising



DONOR FEEDBACK RECEIVED, 2014-2016



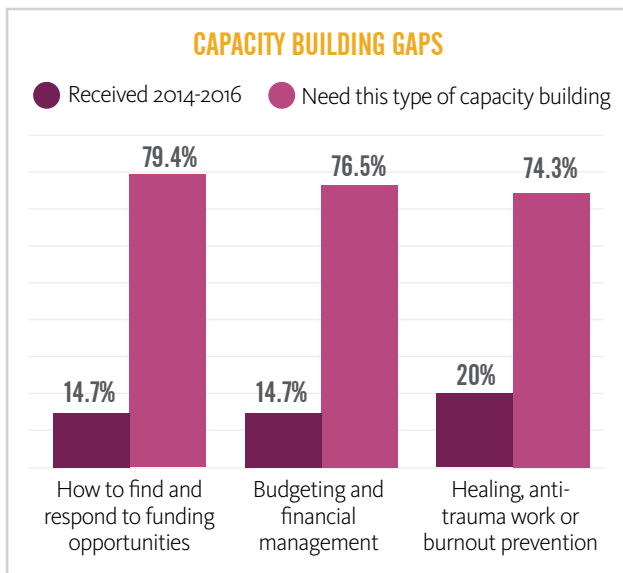
and grant writing, particularly given the wide range of programmatic work they are engaged in with the limited resources at their disposal.

TRAINING AND CAPACITY BUILDING

Intersex groups report they have a variety of capacity-building needs, with significantly high interest in healing, anti-trauma and burnout prevention.

This section describes the training and capacity building that intersex groups received or needed, including the types and topics of capacity building. The intention is to understand the capacity-building support intersex groups received between 2014 and 2016 and what they continue to need, so capacity-building opportunities can be found or developed to meet those needs.

CAPACITY BUILDING GAPS

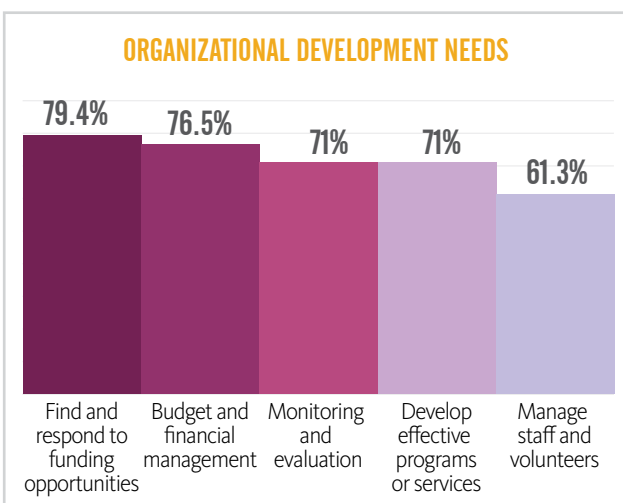


The capacity-building needs of intersex groups responding to this survey exceeded the capacity building they received between 2014 and 2016 in the areas of advocacy and community organizing, organizational development, media training, and mentorship and leadership development. The largest gaps between types of capacity building received and capacity-building needs were in the areas of finding and responding to funding opportunities (14.7% vs. 79.4%), budgeting and financial management (14.7% vs. 76.5%) and healing, anti-trauma work or burnout prevention (20.0% vs. 74.3%).

Overall, capacity-building needs were high in areas 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%).¹⁶

Other types of training needed or received by intersex groups included advocacy, community organizing and media. More than half of intersex groups reported needing capacity building to work with traditional media (60.0%), use social media (59.4%), do community organizing (58.6%) and do legal and policy advocacy (58.1%).

ORGANIZATIONAL DEVELOPMENT NEEDS



In addition to training, intersex groups reported on their access to and needs for gatherings, leadership development and mentorship. More than half (55.9%) of intersex groups responding to this survey reported attending an international gathering about intersex topics as a form of capacity building. Similar numbers reported attending national gatherings (data not shown). Attending gatherings was the single most common form of capacity building received by intersex groups. However, the gap between the number of groups who wanted this type of capacity building and who received it was very small, suggesting that although many groups received this type of support, a similar number of groups would like these opportunities.

16 The number of intersex groups receiving organizational development training was too small to report for many of the categories, compared to the high level of need in this area. The types of organizational development training intersex groups were most likely to receive included developing effective programs or services (22.6%), budgeting and financial management (14.7%) and finding and responding to funding opportunities (14.7%) (data not shown).

In addition to training and attending gatherings, intersex groups were also asked about access to mentorship and leadership development support. Nearly two in five (44.1%) intersex groups received some form of mentorship from another organization; second to attending gatherings, this was the most common form of capacity building intersex groups received between 2014 and 2016. Intersex groups were more likely to need (62.5%) and less likely to receive (28.1%) access to leadership development, when compared with need (52.9%) and receipt of (44.1%) mentorship support.



CASE STUDY

Building Regional Networks

While the number and visibility of intersex groups continue to grow, the total number of intersex activists in the world remains relatively small. Most groups are the only intersex-led organization in their country. With support from allies like the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) and Transgender Europe (TGEU), and increasing recognition by funders of the importance of movement building, intersex activists and groups are finding ways to support one another, develop shared priorities and advance their advocacy goals at the regional level. As Rebecca Fox, senior program officer at Wellspring Advisors, observes, “It’s so important for donors to provide funds for intersex activists to come together. It enables them to support one another and to build strong networks and organizations, leading to concrete changes in policies and medical practices.”

Founded in 2012 during the Second International Intersex Forum, **Oii Europe** is the first and only intersex-led pan-European organization. What began with four organizations has grown into a vibrant network of 15 member organizations and individuals working collectively for the human rights of intersex people. With members from every region of Europe, the network plays a unique role in engaging governments and human rights institutions, particularly through the European Commission, European Parliament and the Council of Europe. It also provides a space for European intersex activists to receive advice and support from peers to advance their work on the national level. “It is important for us as

a national organization to be a member of a European umbrella organization,” adds Alessandro Comeni, founder of Oii Italy and member of the Oii Europe Steering Board. “This gives us the opportunity to share knowledge and to exchange strategies and approaches. It can feel very isolated working on a national level, as a lot of European countries still do not even acknowledge the existence of intersex people.”

In the vast Asia region, intersex activists can easily feel isolated. In 2015, **Oii-Chinese** organized the first-ever pan-Asia intersex gathering as a pre-conference to the ILGA-Asia conference in Taiwan. Eight activists from China, Hong Kong, Indonesia, Nepal, Thailand, the Philippines and the UK came together to share experiences and raise awareness about intersex people in the region. This gathering spurred a significant increase in attention to and support for intersex activism in Asia. In 2016, UNDP supported intersex activist Esan Regmi to hold the first national intersex conference in Nepal and publish the personal stories of participants. New intersex activists, notably in Myanmar and Pakistan, are emerging. Six intersex activists from Asia—a record number from the region—took part in the Fourth International Intersex Forum in Amsterdam in 2017. As Oii-Chinese founder and ILGA-Asia co-chair Hiker Chiu notes, “Building connections among intersex activists in Asia means we are not alone and we can work together for the improvement of our issues and human rights grounded in the Asian context. We need to incubate Asian intersex

activists to help each other—to eliminate the loneliness, to empower each other, to improve our lives and to join the international intersex family.”

In March 2017, over 20 intersex advocates representing Australian and Aotearoa/New Zealand intersex organizations (**AIS Support Group Australia, ITANZ, and Oii Australia**), along with other independent activists, gathered for a two-day retreat. It was the first of its kind in the Oceania region. The meeting provided an important space for activists to discuss their priorities, and the resulting **Darlington Statement** represents the first comprehensive policy platform for intersex people in Australia and Aotearoa/New Zealand.^{xxxiii} As Bonnie Hart, president of AIS Support Group Australia, stresses, “This statement is a powerful and directive message addressing the key issues currently affecting intersex people in our countries. The Darlington Statement has galvanized our community and the intersex movement generally.” The statement calls for legal reform to recognize the bodily autonomy of intersex people, specifically urging the criminal prohibition of deferrable and non-consensual medical interventions on infants and children, and demanding transparent, human rights-based standards of care. It emphasizes the importance of peer support and education efforts led by intersex organizations, outlining how allies can support these priorities. Enabling regional networking and movement building is a key strategy to support the intersex movement to continue to build knowledge, strength and power.

FUND WORK LED BY INTERSEX PEOPLE.

Intersex groups are largely autonomous, with intersex people making the majority of decisions. More than nine in ten groups are independent/not programs of larger organizations. 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.

The intersex movement operates using limited financial resources and with very little stability in funding. More than one-third of groups have no external funding and half have no savings; over three quarters have less than US\$10,000 budgets. Intersex groups are engaged in a wide range of activities, but are held back from making progress with such little funding at their disposal. Further, few intersex groups receive multi-year funding, which, combined with the lack of savings, puts them at risk of not being able to continue or expand their work. New investments of flexible and long-term resources will significantly and positively impact this small and growing movement.

Provide sufficient funding for paid staff, and invest in healing from trauma and burnout prevention.

Given the combination of low levels of paid staff and 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. Many intersex activists also have personal histories of trauma from being subjected to human rights violations. To address this, intersex activists need more paid positions to support their work, as well as resources for anti-trauma work, healing and wellness, and burnout prevention.

Invest in the organizational strengthening of intersex groups.

Intersex organizations need the capacity development support they are already receiving, such as mentorship and attendance at 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 lack the capacity building and financial support to do so. If resources do not increase for intersex groups, the combination of low levels of funding, high levels of burnout and organizational development capacity-building needs remain a serious threat to intersex organizing.

Groups who have accessed funding also report capacity issues with implementing and reporting on grants. Investing in capacity building in this area may reduce stress of grant implementation and increase groups' ability to manage progressively larger amounts of funding.

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. More than half of intersex groups work at the national level in their own countries, while almost two in five work at the international level. However, one-third of groups were precluded from doing the community-organizing work at the national and local level that they would like to do due to lack of resources. Over one in four were precluded from doing public campaigns and building their base. To do this work, 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. For example, intersex groups received responses from donors that indicated that intersex issues do not fit with their strategies or priorities or they lack information on intersex needs. More than half of intersex groups reported that donors told them that intersex people were not a key population for their work and nearly half reported the response that intersex needs are not adequately documented in research. There is a significant opportunity to engage donors in allied fields to educate them about intersex issues and how they intersect with their focus areas, including women's rights, child rights, disability justice, health and human rights, among others. Lowering these structural barriers that are unrelated to the activities or organizational capacity of intersex groups could make a big difference in how they are received when they apply for funding.



Decrease the barriers for intersex groups in finding and applying for funding, particularly by explicitly addressing calls for proposals to intersex groups and funding unregistered groups through intermediaries.

Intersex groups face a variety of problems that impact their ability to find and successfully apply for grants. A top barrier reported by groups is that funders' websites or open calls for funding do not state an interest in funding intersex groups. Donors may say they fund "LGBTI groups," but it is not clear if they intend to fund intersex groups. By making it 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 and providing application materials in more languages would also make applying for funding more accessible for over-stretched intersex groups.

Just half of the groups participating in this survey were registered with their governments, which can be another barrier to funding eligibility. To overcome this challenge, funders can contribute to pooled funds or to intermediaries such as the Intersex Human Rights Fund^{xxiv} that can fund unregistered organizations.

LIMITATIONS

The data in this report come from a convenience sample and may under-represent groups that do not have access to channels of dissemination that were used. The survey had too few responses from the Middle East and North Africa, Central and South America, and the Caribbean to report separately. The small sample of respondents overall precluded extensive subgroup and relational statistics. It is unknown whether more intersex groups are operating in these regions and did not participate in the survey or few groups are currently operating in these regions. Further, data are self-reported by individuals within groups and have not been checked with any objective measures (such as budget forms); this is particularly salient for identity measures, as in many cases the individual taking the survey may be reporting on the identity of other members of the group (e.g., the treasurer who took the survey may have estimated the percentage of leadership bodies who are intersex).

For any other inquiries about the methods or limitations of this survey, please contact the authors of this report.

GLOSSARY

ASSIGNED SEX: The sex recorded when a child's birth is registered. Usually the sex assigned at birth is also used in social interactions.

BIOLOGICAL SEX: One use of the term "sex" when referring to a person's biological characteristics. These may be genetic, hormonal or anatomical characteristics, and typically are used to categorize people into two distinct categories, as either male or female. The term "sex characteristics" is a more precise framing of biological sex.

BASE BUILDING: Growing the membership of your organization/group or campaign.

COMMUNITY ORGANIZING: Building community capacity to work towards a common, specific target or goal.

DEPATHOLOGIZATION: The aim of challenging the cultural understandings and medical classifications that view being intersex as a disorder, a defect or an illness. Depathologization is the political goal of many intersex activists who want the world to view intersex bodies and identities as examples of bodily diversity.

EXTERNAL FUNDING: Funding 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, private and public donors.

GENDER: The attitudes, feelings and behaviors that a given culture associates with a person's biological sex. Behavior that is compatible with cultural expectations is referred to as gender-normative; behaviors that are viewed as incompatible with these expectations constitute gender variance or gender non-conformity.

INTERSEX GROUP: A phrase used to describe an autonomous (independent) group, whether registered or unregistered, which was not part of any other group. The word "program" was used to describe those that are part of or are housed within other groups.

INTERSEX LEADERSHIP: For this survey, the following five aspects of leadership were measured: (1) financial decision making; (2) strategic decision making; (3) representation to the media; (4) representation in political spaces; and (5) representation of the group's work to donors and funders.

HUMAN RIGHTS VIOLATION: The violation of universal legal guarantees that protect individuals and groups against actions which interfere with fundamental freedoms and human dignity. Human rights violations may be civil, political, social, economic and/or cultural. For human rights violations facing intersex people see page 8.

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. The term intersex has been reclaimed by some intersex people as a part of their larger personal and political identities.

LGBT/LGBTI: Abbreviations in varying configurations for the words "lesbian," "gay," "bisexual," "trans/transgender" and "intersex."

SEX CHARACTERISTICS: A person's physical characteristics relating to sex, including genitalia, chromosomes or hormones and secondary sex characteristics that emerge at puberty.

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- ii Eisfeld, J, Gunther, S and Shlasko, D. (2013). *The State of Trans* and Intersex Organizing: A Case for Increased Support for Growing but Under-Funded Movements for Human Rights*. New York: Global Action for Trans* Equality and American Jewish World Service. Retrieved from https://ajws.org/wp-content/uploads/2015/05/ajws_trans-intersex-funding-report.pdf
- iii For more information about intersex-led activism, see Astraea Lesbian Foundation for Justice. (2016). *We Are Real: The Growing Movement Advancing the Human Rights of Intersex People*. New York: Astraea Lesbian Foundation for Justice. Retrieved from <http://astraeafoundation.org/wearereal/>
- iv Report of the United Nations High Commissioner for Human Rights. (2011, November 17). *Discriminatory Laws and Practices and Acts of Violence against Individuals Based on Their Sexual Orientation and Gender Identity*. Retrieved from http://www.ohchr.org/Documents/Issues/Discrimination/A.HRC.19.41_English.pdf; Ghattas, D (2013). *Human Rights between the Sexes – A Preliminary Study on The Life Situations of Inter* Individuals*. Berlin: Henrich-Böll-Stiftung. Retrieved from <http://www.boell.de/en/2013/10/21/human-rights-between-sexes>.
- v United Nations General Assembly, Human Rights Council (2013, February 1). *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (A/HRC/22/53)*. Retrieved from http://www.ohchr.org/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf; Global Action for Trans* Equality. (2014, September). *Intersex Issues in the International Classification of Diseases: A Revision*. Retrieved from <http://transactivists.org/2015/10/26/intersex-issues-in-the-internationalclassification-of-diseases-icd/>
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- vii Organisation Intersex International Australia Limited. (2015, September 13). *Submission on the Review of Part B of the Ethical Guidelines for the Use of Assisted Reproductive Technology in Clinical Practice and Research, 2007*. Retrieved from <https://oii.org.au/wp-content/uploads/2015/09/OII-Australia-PGT-2015.pdf>; Dreger, A., Feder, E., and Tamar-Mattis, A. (2012). Prenatal Dexamethasone for Congenital Adrenal Hyperplasia: An Ethics Canary in the Modern Medical Mine. *Journal of Bioethical Inquiry*, 9(3), 277–294. Retrieved from <http://link.springer.com/article/10.1007%2Fs11673-012-9384-9>; Parliamentary Assembly of the Council of Europe (PACE). (2011). Resolution 1829: “Prenatal sex selection.” Retrieved from <http://assembly.coe.int/nw/xml/XRef/Xref-XM-L2HTML-EN.asp?fileid=18020>
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- xi** See StopIGM.org's compilation at <http://stop.genitalmutilation.org/post/IAD-2016-Soon-20-UN-Reprimands-for-Intersex-Genital-Mutilations>
- xii** European Parliament. (2017). European Parliament Resolution on Promoting Gender Equality in Mental Health and Clinical Research, 2017. Retrieved from <http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P8-TA-2017-0028+0+DOC+XML+V0//EN>
- xiii** ILGA is the International Lesbian, Gay, Bisexual, Trans and Intersex Association; ILGA-Europe is focused on the European region.
- xiv** This convening notably produced the Malta Declaration, a key document which outlines demands to end discrimination against intersex people and ensure their rights of bodily integrity, physical autonomy and self-determination. The declaration is available at <https://oiiurope.org/malta-declaration/>.
- xv** Sarajevo Open Centre. (2016, July 14). Better protection of LGBTI persons through the amendments to the Anti-discrimination Law of BiH. Retrieved from <http://soc.ba/en/better-protection-of-lgbti-persons-through-the-amendments-to-the-anti-discrimination-law-of-bih/>
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xxxiv In 2015, Astraea founded the Intersex Human Rights Fund to provide grants and other resources to organizations, projects and timely campaigns led by 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.



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