

ANNEX H: CASE STUDIES

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SOUTH-SOUTH TECHNICAL ASSISTANCE TO ADVANCE INTERSEX RIGHTS IN THE AFRICAN REGION: THE CASE OF SIPD

BACKGROUND

Conservative and discriminatory attitudes towards people and bodies defying social norms of "normalcy" are pervasive in the East African Region. Hostility against intersex persons often results in violence, including infanticides or social ostracism justified on cultural or religious grounds. For those surviving, isolation, and lack of access to healthcare services or any meaningful form of livelihood is a common place. While lesbian and gay people in the region gained terrain in terms of movement building, and access to funding, intersex activists in Africa were left behind.

Since its founding in 2007, Support Initiative for People with Congenital Disorders (SIPD) in Uganda, has advocated for intersex people by "creating awareness and providing public education and capacity building for key stakeholders, and to mobilize allies and partners as a sustainable way of creating social change". SIPD is a pioneer organization in Uganda, developing expertise, resources, and organizational experience for advocacy, which have made it a point of reference on intersex issues in the region. With the continued support of the IHRF since 2015, SIPD has been able to create synergies to support the intersex organizing beyond Uganda, contributing to South-South knowledge sharing, and advocacy in the African region.

STRATEGIES

Regional Knowledge sharing, and capacity building with strategic allies

With the support of the IHRF, SIPD² funded innovative regional meetings that provided the opportunity to gather diverse African activists for the first time in order to get together and produce public statements to develop a collective voice on intersex issues. The Astraea's IHRF also provided funds for the Africa Intersex Movement (AIM) created in June 2019 to formalize a network of African intersex activists with the objective of consolidating sharing information, skills and resources itself and consolidate the regional movement's collective agenda.

¹SIPD approaches activism through various strategies; channeled through outreach programs, capacity building, and strengthening of alliances with communities, religious leadership, civil society, health and education sectors, government ministries, human rights commissions, and legislators. See more https://sipdug.org/about-us/

²The IHRF also continued to fund SIPD with general support, thus making it possible for SIPD to be flexible enough in enabling the movement of activists from their countries, particularly those coming from grassroots organizations which are not structured or registered.

SIPD created regional spaces for knowledge sharing, and capacity building among other civil society organizations to refine common grounds on theoretical, methodological, and documentation issues to address best practices to professionalize intersex activism. This strategy comprised exchange visits of intersex activists, as well as multiple African regional meetings to create a "critical mass of intersex allies".

"This approach and strategy has been and continues to be a real opportunity for Intersex activists to engage meaningfully, and form helpful and effective alliances with different actors within the movement, through strategic partnerships, and within their own governments to facilitate a regional advocacy agenda"

SIPD also invested in alliances including among multi-sector actors to co-develop, and strengthen key capabilities for the generation of evidence, and documentation for advocacy organizations on behalf of intersex communities. SIPD also generated resources to understand the needs, and current context of organizing of the intersex people in the region such as the Baseline Survey on Intersex Realities in East Africa (covering data of Uganda, Kenya, and Rwanda).³ At the regional level,⁴ SIPD collaborated with the Kenya National Human Human Rights Commission, the Kenya Intersex Taskforce, the Human Rights Center at the University of Pretoria (South Africa), Health Development Initiative in Rwanda, University of Dar-es-Salaam, Gender Minority Advoacy Trust in Kenya, as well as with medical practitioners in Uganda, Kenya, Zambia, Tanzania, and Rwanda.

Advancing advocacy across the region

The Kenya Intersex Task-force visited Uganda and was hosted by SIPD in order to engage, and complement its analysis on the reforms needed on the existing policy, institutional, legislative, medical and administrative structures and systems governing intersex persons. Established by the Attorney General, Honourable Githu Muigai, the Taskforce mandate was to produce research to advance intersex rights in Kenya. Furthermore, the task force was crucial to outline relevant reccommendations to advocate for equality in law and legal protection of intersex persons in Kenya.⁵

³Baseline Survey on Intersex Realities in East Africa. https://sipdug.org/wp-content/uploads/2019/03/SIPD-Baseline-Survey-on-Intersex-in-East-Africa.pdf

⁴ Among SIPD's local partners are: Human Rights Awarenss and Promotion Forum, World Vision, Reproductive Health Uganda, FARUG, Uganda Human Rights Commission, Society for Adolescent Health in Uganda, Makerere University Faculty of Law, and its Human Rights and Peace Center, African Center for Media Excellence, the Uganda Center for Domestic Violence Prevention, parents of intersex children, focal point persons, district leaders, and village health teams in 52 districts of Uganda.

<u>See Report of the Taskforce on Policy, Legal, Institutional and Administrative Reforms Regarding the Intersex Persons in Kenya. https://intersexkenya.org/wp-content/uploads/2019/08/2019-Abridged-INTERSEX-TASKFORCE-REPORT.pdf</u>

See also https://sipdug.org/the-intersex-task-force-kenya-in-uganda-sipd-ug/

"[In Africa] many intersex organizations are trying to develop leadership, [learning] how to integrate at the UN, ... the processes, and the language ... The Human Rights Commission in Kenya has come to Uganda to learn, [personnel of] the Ministry of Health, the Ministry of Education [have exchanged with us about] sexual and reproductive health and rights, also including intersex issues. With support from the Kenyan government, intersex counted in the recent census ... issues that they learned from here, what we told them, was how they did the replication from there, [after] the IHRF supporting Kenya activism- other funders have now come on board - Intersex Persons Society of Kenya, [activists from] Malawi, Zimbabwe, Zambia have all been here."

Despite COVID-related challenges, SIPD has continued to facilitate the growth of intersex advocacy voices in the region. Some of these include three Intersex advocacy groups operating in Kenya with capacity support from SIPD: Intersex Persons Society of Kenya (IPSK), the Intersex desk at Jinsiangu, and the Gender Advocacy Minority Advocacy Trust (GMAT).

SIPD continues to build the capacity of emerging intersex activists, and allies by exposing them to its model of advocacy and community engagement, in order to contribute to movement ownership and agency in the African Region. This has resulted in increased inclusion of young intersex activists in advocacy efforts.

"The learning visits were significant in building confidence and inspiration among the young African intersex leadership. This agency of young intersex leaders contributes to a strong African intersex movement. Stronger partnerships through sustained experience, and knowledge sharing have been essential in mitigating isolation, and providing a fundamental foundation for change and sustainable impact, and for strengthened leadership."

LESSONS LEARNED

- Resourcing the intersex movement to build capacity, including exchanges on practices, experiential learning, and tools for effective organizing, fosters the agency and skills of intersex leaders
- Evidence-based tools and approaches contextualized to the African context, were critical
 to public education, including consensus building on key strategies and a local definition
 of "advocacy"
- Guaranteeing access to traditionally excluded intersex groups in a South-South knowledge-exchange environment is a worthwhile investment for the identification, and refinement of common grounds on intersex issues
- Stronger partnerships with local, and regional actors have been essential in mitigating isolation and achieving sustainable impact
- Visible ownership, as well as strengthened voices of intersex activists in both local, and regional advocacy spaces in the Global South, provide opportunities to develop young intersex leadership which is crucial to sustain a strong intersex movement in the African continent



DECOLONIZING THE INTERSEX MOVEMENT: ASOCIACIÓN PERUANA DE PERSONAS INTERSEXUALES (PERU)

BACKGROUND

Thanks to support from the IHRF, intersex activists have been able to network between countries in the Global South in order to support the creation of new organizations led by intersex people. This is especially important in geographic areas where there are few or no existing intersex organizations. An example of this is the Asociación Peruana de Personas Intersexuales (Peruvian Association of Intersex People - IntersexPeru) in Peru, which was founded in 2020 with the support of the Mexican organization Brújula Intersexual, also an IHRF grantee. Since then, the Asociación Peruana de Personas Intersexuales has carried out different strategies of cultural activism and accompaniment of family members to inform, and raise awareness in Peruvian society about intersex experiences.

STRATEGIES

Cultural change, networking, and intersectionality

In 2018 Bea Is, founder and coordinator of the Peruvian Association of Intersex People, became aware of Brújula Intersexual through their website, and in an interview expressed being amazed by the information they provide about being intersex outside the medical and binary discourses.

Two years later, Bea Is traveled to Buenos Aires to attend La II Conferencia Interamericana y del Caribe de Personas Intersex (the II Inter-American and Caribbean Conference of Intersex People), the second meeting in the Latin American region, which was made possible primarly through IHRF funding. Attendees report that the meeting was a key moment to connect personally with other organizations and be inspired to imagine the creation of a respectful world for the intersex community.

"Meeting the people who promote Brújula Intersexual, I could say that it was like meeting myself. Finally, at 24 years old, I was able to find the reflection that I longed for [...] I confess that it is wonderful to meet someone who lives the same thing in my own flesh. To feel accompanied and know that I am not alone is a great satisfaction."

In 2020 and in the midst of the COVID-19 pandemic, Bea founded the first intersex leadorganization in Peru, the Peruvian Association of Intersex People, in order to support, promote visibility for the intersex community in the country, and provide information outside of pathologizing, binary, and heteronormative discourses. From its founding, the organization challenged binary colonial conceptions of gender and the body, as well as the lack of information and representation of intersex people.

⁶Buscándome por Bea Is, <u>https://brujulaintersexual.org/2019/04/20/buscandome-por-bea-is/</u>

Social networks and digital cultural activism have been key pieces for the organization's activities, for example, in the last two years they have promoted virtual encounters in collaboration with multiple intersex people and organizations. The Peruvian Association of Intersex People has participated in different digital meetings, podcasts and workshops on intersex issues along with various intersex organizations, as well as in alliance with other social movements, particularly LGBTIQ+. These spaces have been important to share experiences about being intersex, the diversity and intersections that surround an intersex person, such as functional diversity⁷, and to inform about the pathologizing consequences of intersex bodies. These meetings have allowed the building of alliances with different intersex activists, strengthening their support networks and exchanging perspectives and knowledge with other intersex organizations.

Currently, the Peruvian Association of Intersex People has participated in spaces such as El Campamento Lésbico Bisexual (the Lesbian Bisexual Camp) organized by Movimiento LESBIA (LESBIA Movement) in Arequipa, the second most populated city in Peru. During the camp, a talk on being intersex was given, informative material was distributed and infographics were filed in the LESBIA Library.

"We are very happy to be able to approach and get to know more closely such an important group as the LESBIA Movement, to whom we handed out informative material about our intersex collective."

On June 12, 2022, the Peruvian Association of Intersex People held El Primer Taller Presencial sobre la Intersexualidad en Perú (the First Presential Workshop on Intersexuality in Peru), In the framework of Jornada Taller Sobre los Derechos Humanos de las Personas LGBTIQ+ (Workshop on Human Rights of LGBTIQ+ People), a formative space for the reflection and dialogue on the demands of LGBTIQ+ youth in Peru. This initiative was organized by the Peruvian Association of Intersex People in conjunction with the Diversxs of Amnesty International Peru and the Municipality of Lima.⁹

Thanks to the support of donors such as the IHRF, the Peruvian Association has built partnerhsips and sustained its strategies as well as participated and promoted different spaces for the intersex community.

https://peruintersex.org/2022/03/10/campamento-lesbico-bisexual-movimiento-lesbia/

⁷See Diversidad Intersexual – Vivencia Disca – Intersex con Katia Marlene IS, https://peruintersex.org/2022/04/25/diversidad-intersexual-vivencia-disca-intersex-con-katia-marlene-is/

⁸ Campamento Lésbico Bisexual,

⁹ See Primer taller presencial sobre intersexualidad del Perú,

https://peruintersex.org/2022/06/17/primer-taller-presencial-sobre-intersexualidad-del-peru/

Decolonial strategies

IHRF grants to organizations in the global South support the advancement of decolonial strategies such as questioning the traditional colonial understanding of history. The Peruvian Association of Intersex People has been working with other organizations to recover and document the memories and histories of intersex people before colonization in Latin America. These research works are very valuable because they question traditional conceptions about gender, health and body; making visible that binarism and pathologization are a colonial imposition.

Doing this work is not easy, as it involves consulting the few existing historical and archival resources, but its results are important because they provide testimony of the existence of intersex people in history as well as other LGBTQ+ people, even revealing that in some societies prior to colonization there was respect, acceptance, or inclusion of LGBTIQ+ people. These rediscovered indigenous narratives reveal that the true invention of modernity was the pathologization of non-normative corporealities.

The IHRF has been an important actor in supporting activists implementing these decolonial strategies to rewrite history and reclaim what has been stolen, thus contributing to a conception of diversity as part of life, to question pathologizing and binary conceptions, as well as to fight to amplify the representation of intersex and LGBTQ+ people and other groups oppressed by colonial conceptions.

LESSONS LEARNED

- Promoting local, regional and international meeting spaces helps generate partnerships and networks between different intersex organizations having similarities in context
- Social and digital networks are an opportunity to establish communities in different geographies
- The intersex movement intersects with the demands of other social movements
- The intersex experience is diverse and documenting the precolonial history of intersex people enriches and empowers the movement
- An intersectional decolonial perspective has allowed deep alliances with other decolonial movements in Latin America
- Supporting organizations from the Global South contributes to advancing decolonial, diverse, and intersectional activism





ENGAGING PARENTS AS ALLIES FOR INTERSEX RIGHTS: OII EUROPE, INTERSEX GREECE, AND ABRAI

BACKGROUND

The voices and leadership of intersex activists themselves are key to the global movement. However, given the medicalization of issues that emerge for intersex persons from birth, parents are an important partner and stakeholder in the movement. While the movement seeks to depathologize being intersex, aided by changing laws and healthcare norms to protect the right to bodily autonomy of babies born with sex variations, engaging parents remains vital when the health system does not provide sufficient protection from unnecessary medical interventions, or an adequate framework to allow true informed consent. Moreover, studies show that parents of intersex children have their own unmet needs, as they do not receive enough scientifically accurate information or psychological support.¹⁰

STRATEGIES FOR WORKING WITH PARENTS

Visibility

Increasing the visibility of intersex people among the general public, including through intersex adults sharing their own stories, has been a strategy of OII Europe (Organisation Intersex International Europe) among many others. OII Europe was founded in 2012 during the Second International Intersex Forum in Stockholm, and has been one of the IHRF's grantee partners since the Fund's inception, receiving one of its largest grants due to the umbrella nature of the organization, working throughout Europe and Central Asia. OII Europe seeks to combat discrimination against intersex people and guarantee the rights to bodily integrity and self-determination.

OII Europe's work on visibility includes providing a platform for intersex people to speak frankly about decisions their parents made with which they disagreed and would not want to be repeated with children now, as well as parents to speak about how medical systems neglected to inform them or support them sufficiently to make human rights-based decisions for their children. OII Europe launched the intervisibility.eu website, in part funded by the IHRF, that contains personal testimonials from intersex people from Europe, Central Asia, and the Middle East. The testimonials contain many examples of the crucial role of parents in intersex children and young people's lives:

"My parents did not understand what the doctors told them, but they were convinced that treatments were needed to correct the problem. So the problem was me! It is not easy to live when you feel that in your heart, when you are afraid of not being loved by your own parents and family, when you are mocked and rejected.¹¹"

¹⁰ Frontline Dispatches: Intersex Children And Medical Sex Assignment – Whose Right To Choose? (video) https://oiieurope.org/video-frontline-dispatches-intersex-children-and-medical-sex-assignment-whose-right-to-choose/

¹¹ My Intersex Story, P. 13. https://intervisibility.eu/testimonials-in-europe/

There are many examples of medical providers providing incorrect information, or even performing interventions without consulting parents, much less implementing an informed consent process, and parents' lack of support system:

"They told my parents that I was a boy that needed to be "perfected", this is something my parents accepted, because there was no internet back then, and they were never introduced to any other parents whose children were going through the same thing, they were never told that I didn't need fixing, that I would grow up to be just fine." 12

"So, the operation that I had allowed in the belief that it would be the only choice to secure a healthy life [sic] for my daughter, actually ruined her health. On top of that I had kept this a secret from my daughter, and her trust in me was completely broken when I finally told her. I learned that secrecy is the mother of shame." 13

Resources for Parents

In addition to raising awareness of intersex issues, in 2018, OII Europe with the International Lesbian, Gay, Bisexual, Transgender, Queer & Intersex Youth and Student Organisation (ILGYO) and the European Parents' Association (EPA) produced a resource called Supporting your intersex child, which addresses not only the rights to self-determination and bodily autonomy for intersex children and adolescents, but the concerns and needs of parents as well, including making medical decisions, talking to their children about being intersex, and talking to the larger community about having an intersex child.

Creating community

In addition to OII Europe, many other IHRF grantee partners engage with parents, including through conferences and gatherings. Intersex Greece, a member of OII Europe, has been active for more than a decade, but its engagement with IHRF allowed the organziation to formalize in order to receive much needed support, including funds to hold the first-ever intersex conference in Greece in 2021. Throughout the evaluation of the IHRF, grantees cite lack of resources as the primary obstacle to in-person meetings, which are vital to movement building. Intersex Greece credits IHRF with providing the resources necessary to build community through meetings, workshops, and importantly, having meals together through which trust was built among both intersex activists and parents. Similarly, IHRF grantee partners Associação Brasileira Intersexo (ABRAI) in Brazil, founded by a mother of three intersex children in partnership with intersex activists, has prioritized community building through meetings and learning.

¹² My Intersex Story, P. 43. https://intervisibility.eu/testimonials-in-europe/

¹³ My Intersex Story, P. 58. https://intervisibility.eu/testimonials-in-europe/

Thanks to IHRF, the organization was able to host a website with courses and videos for professionals and parents, and provides medical and pyschological care to intersex people and their families, in addition to shelter if needed. Though parents are a core part of ABRAI's structure, the members ensure that intersex people themselves lead the organization.

LESSONS LEARNED

- Because the guarantee of intersex rights starts at birth, parents are a key stakeholder and ally
- Parents have their own concerns and needs that can be addressed through greater intersex visibility and more available information
- Movement building includes trust building, the creation of safe spaces, and community for parents to support each other as they promote the human rights of their children
- Funders such as IHRF support initiatives to engage parents of intersex children and youth by providing flexible funding that facilitates visibility, resources, and in-person exchanges
- IHRF's funding and technical assistance is vital to organizations who need to formalize their structures in order to receive financial support