

# FINAL NARRATIVE REPORT 2014



## **SIPD UGANDA**

### **SUPPORT INITIATIVE FOR PEOPLE WITH CONGENITAL DISORDERS**

*Advocating the support and advancing the rights of intersex children and people in Uganda.*

Location and address for SIPD - UGANDA

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## Acronyms

CORSU -	Comprehensive Rehabilitation Services of Uganda
HRAPF -	Human Rights and Promotion Forum
RLP -	Refugee Law Project
SIPD -	Support Initiative for People with Congenital Disorders
GBV -	Gender Based Violence
IPPF -	International Planned Parenthood Federation
SRH -	Sexual and Reproductive Health
UHSPA -	Uganda Science Press Association
TBAs -	Traditional Birth Attendants
MOH –	Ministry of Health
ACME –	African Centre for Media Excellence
ABUBEF –	Burundi Association for Reproductive Health
GMAT -	Gender Minority Advocacy Trust - Kenya
MARPS –	Most At Risk Populations
CFCS –	Changing Faces Changing Spaces
UPA –	Uganda Pediatric Association
PSG –	Parent Support Group
RHU –	Reproductive Health Uganda
ICASA –	International Conference on AIDS and STIs in Africa
SOV -	School Outreach Visit

## Executive summary

This final narrative report contains activities implemented in 2014. The funded projects included documentation for purposes of producing a documentary that would in turn be used for further policy advocacy, capacity building and outreach to create safe spaces in schools and communities for intersex young people.

As indicated in our interim narrative report, much of the first phase of funding for this project cycle went to outreach visits to schools and communities to provide support and to collect information and stories. This was also done in a bid to meet our target of establishing safe spaces in at least one school or higher institution of learning a month within the twelve months of the project cycle. The last month of the project cycle included evaluation of work done, compilation of reports from all project activities and planning for sustaining the achievements made as well as deliberating on solutions for the challenges the team has encountered.

As a result of this support, we have been able to implement the following planned activities – schools outreach, media engagement, and maintain a strong institutional presence in all 25 target districts. Other activities we have been able to conduct with other support include parents support groups, policy advocacy, alliances building, and documentation. Our main focus and goal through all these activities continues to be public education.

A key challenge – as mentioned in our interim report - remains the critical need for improvement in actual service delivery in terms of access to medical care, psychosocial support for young people in schools and those who have been forced to drop out of school because they are intersex. By the beginning of quarter 4 of 2014, we had developed a plan to meet this need and bridge the gap through an apprenticeship skills development program, which will initially focus on practical, marketable, and entrepreneurial skills of brick laying and building, tailoring, carpentry, basic mechanics, welding, and micro-business management.

### New Intersex cases 2014

In 2014, SIPD registered 168 new cases from different districts of Uganda. Some of the clients have been registered but SIPD does not currently have specific outreaches in the districts they come from and so cannot refer them to a support group or supportive point person. However, they still receive counseling, and medical referral services according to the needs they present to us. 80% of all the new cases remain children under 18 years.



### Strategic and Performance Assessment

SIPD has carried out an assessment meeting together with parents and focal point persons from the different communities to ascertain whether we all still have the same understanding of vision and goal as to why the

organization was formed and whether SIPD is still playing an important role in shifting the paradigm around sexual health and rights for intersex children and people in the country.

***A photo showing participants in the assessment meeting***



The assessment meeting was so helpful since it enabled SIPD staff, parents and focal point person representatives to re-visit the mission, vision and goal of why SIPD was formed and this helped a lot in keeping all concerned parties on track in the human rights struggle of uplifting the plight and rights of intersex children and people in Uganda. It also revealed that SIPD has a critically important role at this particular time in the country and region to influence the social and political conversations around sexuality, sexual and reproductive health, and gender.

**Schools Outreach Visits (SOVs)**

**New Clients registered with SIPD from schools**

There has been no platform for discussion on sex development disorders in schools and this has made many intersex youth to continually be discriminated against, stigmatized, bullied and to finally drop out of schools because of these birth differences. SIPD started a schools outreach programme where teachers, non-teaching staff, and students are equipped with knowledge on Disorders of Sex Development (DSDs)/ Intersex. This aims to augment our efforts of engaging the Ministry of Education and sports and look into policies and programmes in schools that can help intersex children and people stay in school like any other children.

SIPD has to date made initial visits to 11 schools and has mainly engaged with school administration personnel in order to gain trust and plan with them on the best way these student safe spaces can work. These include Kiyeya high school, Sanje Senior Secondary School, Bulanga Parents School, Nwoya High School, Namutumba Senior Secondary School, and Butalejja Secondary, Ntenjeru Parents School, Kyambogo University, and Makerere University among others. Out of these, we have received 60 cases known to school administration of students with sex development irregularities that they did not know how to deal with and only 19 of these have remained in school. Teachers and non-teaching staff indicated that they had lost track of the other students because due to the stigma from fellow students and particularly non-teaching staff, the students did not return to school.

**Photographs showing some of the schools outreach activities**

Our outreach campaign has been greatly supported by the field based point persons. Additional information and knowledge sharing has always been the target of the projects officer. A total of 110 educators in 11 different schools



have been engaged and given more and current information about intersexuality. We continue to receive informal evaluation monthly reports from field point persons and maintain constant telephone contact.

**Institutional Capacity support**

SIPD has been able to operate successfully with physical offices and been able to pay its committed team of staff as well as meet key operational costs such as transport to communities to trace cases, and network with local allies, maintain the client tracing functions of community based point persons, and engage media. Having moved into safer office premises, we have had the capacity to implement besides schools outreach the following activities:

a) Media campaign and public responses

Our media campaigns have been ongoing though out the year to ensure that we maintain public interest and dialogue. Several of our adult clients have received local support to access healthcare by listeners. For example an intersex person from Rakai district received support to go for surgery and another mother with a child from Mukono got 404,000= which she wanted to take the child for proper medical assessment. Another parent has had both her intersex child and another disabled child find a benefactor to cater for their medical expenses and school needs. Another listener to our media program funded the surgery for undescended testes for one of our clients in Kiwatule. Another partner provided transport facilitation for four impoverished clients in Rakai to be able to visit a proper healthcare facility and dialogue with a doctor on life threatening conditions they were facing as a result of improper mutilations of their genitals. We continue to receive concerns from callers into our media programs about a key

human rights violation of denying intersex children and adolescents to attend school. Media houses engaged include The New Vision, The Daily Monitor, The Observer and Bukedde. Television and radio appearances have included Radio Pearl, Metro, Ddembe FM, Mama FM, WBS, NBS, and NTV.

### **A cross section of photos during the follow up outreach activities 2014**

#### *b) Parents Outreach and follow up activities*



We conducted initial visits to 24 new districts and follow up activities to different intersex families in all old districts. The visits are intended for direct support to intersex families and also making sure that children are not subjected to harmful cultural practices in a bid to “normalize” what society thinks is not normal. Hope has been restored to the different families and they felt that someone is part and parcel of the journey that they are walking.

#### *c) Client tracing*

The fact remains that there are still many intersex people in Uganda and parents who lack information. Most of them still think its witchcraft and other related superstitions. SIPD has been receiving calls all over Uganda and outside Uganda with reports of intersex cases that require response with either information or referral. For cases in Uganda, SIPD has continued to reach out and provide information and support by either a physical visit or a phone call. For cases outside Uganda, SIPD continues to work with our regional alliances – particularly in the East African region, mainly in Kenya, Ethiopia, Tanzania, Burundi and Rwanda.

#### *d) Psychosocial support*

Counseling is proving to be among the most important aspects of our work. The need for this service has been expressed by the different parents over the past three years as trauma has become very hard for them and the intersex individuals to deal with. Medical care in itself does not fully take care of all the social and political implications of being different, and most of our clients require psychosocial support prior to and after medical attention, particularly where sex re-assignment is a possibility. In 2015, we plan to have two fulltime counsellors; one of them will cater for increasing demand among students and the other will serve parents and carers.

#### *e) Regional Alliances building*

SIPD has organized two regional meetings – one was a regional consultative meeting that had 22 different representatives from the 5 East African Countries. The meeting discussed how best to form strong advocacy and networking relationship amongst the 5 East African countries with the aim of making the Intersex movement grow and also to increase visibility in other East African countries. Different views were given by participants from the different countries and also member organizations in Uganda had representatives that specifically contributed and discussed issues around intersexuality.



In May 2014, SIPD held the first ever regional parents' meeting in partnership with Transitioning Africa, to brainstorm on how effectively to use the advantage of mothers in decision making positions, such as the speaker of parliament and the first lady. The meeting, which brought together 12 parents of intersex children from Uganda, Kenya, Rwanda, and Tanzania was a huge success.

Participants decided that their submission should initially be done diplomatically and thereafter engagement can start. A couple of ideas were brought up which included but not limited to; recognition of intersex people in different areas, a collective and practical engagement by all parents present – starting to speak politically about this issue in their work places, families, places of worship, village or council meetings, or other spaces in their countries.

It is anticipated that when this is done, there will be a paradigm shift in attitudes and subsequently in policies.

Parents agreed and put their signatures on a petition that has now been submitted to the different committees in parliament that are responsible for Maternal and child health care, to the speaker of parliament, and to the first lady. We hope that this will amplify our advocacy engagements with the Ministry of Health (MoH).

Parents also showed their enthusiasm and willingness to engage if they are called for different engagements and discussions by members of parliament or to meet with the speaker of parliament.



**Some of the key recommendations by parents in the meeting included;**

- ❖ Continued collective and practical engagement with all the different stakeholders in effecting change.
- ❖ An increase on the TV and radio appearances (More media interviews and sensitizations)
- ❖ More sensitization and training of Doctors (including more posters placed in hospital notice boards and reception/waiting areas). These posters to be shared with parents from the region so they can put them up in their own spaces. Request if there can be some posters in Swahili to ensure they speak to the region at large.
- ❖ The need to challenge some laws that affect our constituency – thus the urgency of utilizing the woman speaker of Parliament continuously – through writing to her and keeping the issue “in her face” constantly. Successes in Uganda will set a good precedent for engagement in other East African countries.
- ❖ Call for adequate facilities and machines that do appropriate tests of intersex clients.

- ❖ More sensitization needs to be done especially in villages.

A submission to the Ugandan parliament was drafted, deliberated on and endorsed. The submission has been made to the speaker of Uganda's parliament, Hon. Rebecca Kadaga, through two relevant parliamentary committees, namely Committee on Gender, Labour and Social Development and Committee on Social Services. The Committee on Legal and Parliamentary Affairs and the office of the first lady has also received a copy.

f) National alliances building

SIPD has maintained a strong partnership with service provider allies such as different hospitals and health centers and these included CORSU hospital, Rugarama Hospital in Kabale, Arua National referral hospital, Soroti Health centre II, Kalisizo referral hospital, Mulago, Ntungamo health centre IV among others. Other national alliances include the Ministry of Health (MoH), Uganda Pediatric Association (UPA), CSOs such as Straight talk Uganda, Raising voices, Centre for domestic violence prevention, HRAPF, RLP, and Uganda Health Science and Press Association (UHSPA), Reproductive Health Uganda (RHU), Uganda Counselling Association, and Uganda Pediatric Association. Several activities have been done in conjunction with different partners like the awareness project that was organized by the RLP and SIPD was part of these activities and SIPD in conjunction with HRAPF organized a meeting with Intersex people and parents for feedback to be submitted to the Equal Opportunities Commission (EOC), a dialogue at the CSO fair to discuss the role of the ordinary citizen in protecting minority populations.

HRAPF has helped SIPD in different legal aspects that it needed i.e. A case in Rakai where an intersex family was being chased out of the land, SIPD referred this case to HRAPF and the intersex family managed to access justice. Those who wanted to chase away the family urged that this family was bringing bad omen to the entire family because of the intersex birth that occurred.

Another case was in Mukono where a father was denying support to his child because he was born intersex and the case was referred to HRAPF, who came in, looked for a father together with SIPD and after the different engagements and discussions where even the police was notified, the father has now started to extend help towards the intersex child and the mother. SIPD also continues to actively engage ACME, the Civil Society Coalition on Human Rights and Constitutional Law, several churches – mainly branches of the catholic, Pentecostal, and Baptist churches.

**Other international partnerships: - Hosting the AJWS Global Justice program**

At the beginning of the year, SIPD hosted 18 visitors on an AJWS Global Justice Fellowship program. The group was hosted at the SIPD offices and staff shared extensively with them the strategic approach SIPD uses to do its community engagement and policy advocacy work. The staff team at SIPD also learnt a lot from the group on how similar issues are handled in the USA. Following this visit and engagement with SIPD, one of the participants posted the following write up about her experience and lessons from SIPD: <http://scopeblog.stanford.edu/2014/03/04/in-uganda-offering-support-for-those-born-with-indeterminate-sex/>

***Photograph showing the AJWS Global Justice Fellowship group outside SIPD's office***



### **Production of the “Identities in between” Documentary**

SIPD has continued to document conversations, interviews, and lived realities in the communities where we do outreach. The documentation strategy provides us with an evidence based premise for advocacy since statistics has been a key question in each and every forum of our engagement. Policy makers, formulators and implementers asked for statistics to enable their planning and we are providing them with huge numbers of real people asking them to plan and act.

In October, the process of fusing, editing, and producing the “Identities in between” documentary was started. We had collected footage from as many communities and schools as possible. Ultimate media was contracted to do the editing and production work. The documentary should be ready for distribution by the end of March 2015.

The projects officer attended the Benetech meeting in Nairobi that was targeting on finding ways on how documentation should be put on a priority list and ways of making it sustainable. The team also participated in another Benetech refresher workshop in October, 2014 in Kampala that focused on documentation of violations and human rights abuses.

#### ***g) National Presentations and engagements with health and legal service providers***

### **Healthcare referrals – CORSU, Mulago and Nsambya hospitals**

SIPD continues to strengthen the partnership with CORSU hospital and by the close of the year, we had 23 teenagers and young adults access much needed medical procedures at CORSU through our referral system and partner support and many others have started on their hormonal treatments. Many others from previous years have also had their reviews done. We are happy to report that all operations have been a success. We are still holding counseling sessions with the teenager from Kabale and his parents to enable them deal with the social implications of a possible sex re-assignment and to know what his rights are if he chooses to take this route. Over the past months, we have established relationships with more interested doctors based in Mulago and Nsambya hospitals. Two of our client had their surgeries from Nsambya hospital at reduced costs.

### World Prematurity, Save the children and Community Integrated Development Initiatives (CIDI)

SIPD participated in a one-day dialogue around improving the survival of babies with proven cost effective approaches to care. This was an opportunity for SIPD to dialogue about new interventions which are cost effective and also take on continued national advocacy to create awareness about intersex infanticide with a view to reducing it.

### National Policy Dialogue on Traditional Birth Attendants (TBAs)

SIPD participated in a 2-day National Policy Dialogue, whose focus was on understanding better the role of Traditional Birth Attendants (TBA) at Serena hotel Kampala. The purpose of this dialogue was to come up with a common national position on Traditional Birth Operations in Uganda. Some of the issues we discussed included a) determining the magnitude of unskilled providers on Reproductive, Newborn, Maternal, and Child Health services in Uganda, b) Examining factors within the healthcare environment which are responsible for persistent deliverance under unskilled care, c) Proposing policy and programme action recommendations including how the healthcare system can relate with the various community providers we and other civil society organizations work with, i.e. TBAs, Village Health Teams (VHTs) and other community resource persons. This dialogue was organized by the Ministry of Health (MOH), World Health Organization (WHO) and Uganda National Health Users'/consumers' organization.

### The Equal Opportunities Commission (EOC)

SIPD and HRAPF went into a partnership to meet members from EOC and strategize on how the issues concerning intersexuality can be well represented in Uganda right from a community to a national level. The meeting was a success and there is ongoing dialogue around this.

### Legal aid

Our partners, HRAPF, intervened in a case where an intersex family was being chased out their land in Rakai because their child was intersex and the village authorities deemed them to be witches and was evicting them from their land. The family was able to remain on the land and follow up on the case is on-going. We have embarked on a name and marker change for a 15 year old client who was raised as a girl and has chosen to live as male. Initial surgical operations, such as descending his testes from his abdomen into the sac have already been done at Nsambya Hospital.

### Summary of review – results, lessons learned and planned activities

<b>Activity result</b>	<b>Achievements &amp; Lesson learned</b>	<b>Recommendation</b>	<b>Planned activity/Action 2015</b>
Increased outreach in all scheduled 25 districts	There is an influx of children and adults with intersex cases reported with need for psychosocial support and other basic healthcare services.	Need to sustain and expand outreach approaches to include young people in schools and institutions of learning	Continued Schools outreach planned for 2015 in the existing districts as well as the remainder of the 25 new districts.
	The public is ignorant about intersex issues but very welcoming of information	SIPD continues to invest in educational programs and materials at both grassroots,	Continue to partner with other stakeholders on community outreach trainings

		regional and national level.	
	Parents are more confident to speak out and create a political voice	SIPD should continue supporting safe spaces for parents and young people in and out of school with information and technical support for sustainability	Continue fundraising strongly for this activity to maintain this public momentum from grass roots. Sustainability is key.
	There is a critical and sustained need to reduce poverty and a destitute state among clients. Expressed need to acquire a skill they can trade despite lack of formal education	An apprenticeship skills development program to be designed and planned for youth and mothers in our parents support groups in 2015.	Conduct a pilot apprenticeship skills development program for 10 youth and 4 parents support groups over twelve months
Screened "My Secret Life" during advocacy and awareness outreaches	There is a thirst for information on intersexuality and willingness to engage and participate among young people, educators, service providers, and parents	Clear follow up be maintained  There is a need to keep educating on the unique differences between sexual orientation and body development dynamics	SIPD will invest more in the follow up processes to earn tangible policy actions
Collection of footage and production of Identities in between documentary	Visual advocacy tools such as documentaries and storytelling sessions have proven to be a high impact activity	There is need to intensify the thirst for information through visual mediums to the public and youth	SIPD will use these images to ensure there is an irreversible change of attitudes and action toward sexuality differences
Provided counseling to intersex people and their parents and documented lived realities.	Counseling is a critical need among intersex children, youth, adults, and parents of intersex children. Documentation is a formidable advocacy tool	Continue to provide psychosocial/counseling services	Hire the services of two fulltime counselors specialized in youth and parental counseling in the first quarter of 2015
Built regional networks of intersex advocates in Kenya, Tanzania,	Intersex awareness programs integrated in at least 4 regional partners' mandates (ABUBEF, GMAT, BURUNDI, RHU already committed to do this)  Burundi, Kenya, and Rwanda voices included in the		Regional reference database on intersex friendly spaces published in second quarter of 2014 will be disseminated to partners and other spaces  Second documentary with

	awareness documentary to speak to the issues from regional perspectives. (ABUBEF, GMAT, AND BURUNDI)		national and regional voices to be screened.
Policy advocacy	Policy concept note submitted to the Ministry of Health and the Uganda Human Rights Commission	SIPD to continue maximizing its appointment to the Ministry's Maternal and Child Health Technical Committee to push for recognition of health and rights needs for intersex children and people. Widen engagement spaces on policy and interventions.	Parents letter from the advocacy dialogue to the president to be delivered to him in first month of 2015

Key Development partners that supported the success of SIPD advocacy and outreach work in 2014 included HIVOS, American Jewish World Services, Open Society Foundations, means of transport facilitated by MIVA, Anonymous, and Benetech.