Addressing the “what next” question for Uganda’s Intersex youth and their parents:
Investing in actual lives!

(By Julius Kaggwa, Executive Director, SIPD Uganda. Article for OSIEA Publication)

Thousands of intersex children and youth are faced with double marginalization in Uganda having to deal with intersex stigma and extreme poverty. Over 1,000 children are now registered for counseling and healthcare referrals by SIPD as well as community engagement inclusion. Most of these have been brought to the program through the community and schools outreach programs mobilized by the SIPD projects team in partnership with field point persons and Village Health teams.

The SIPD outreach program both in communities and schools, is helping to empower intersex children by building the knowledge base of those who care for them, around intersex issues, as well as related health and rights issues. A recent report by one of our focal point persons shows that this engagement, which has been successfully run by SIPD, is having a direct and positive impact on both the carers and the intersex children they look after. It was exciting to learn from the same report that civic leaders of these communities are also becoming more empathetic to the issue and seeking ways in which they can support these families.

In Uganda, the traditional way of dealing with perceived sexuality “abnormalities” has largely been staying silent – and wishing them away through various kinds of traditional rituals, which often meant killing the intersex infants in question. This was, for decades, considered to be both the best and normal way to handle intersex births. One traditional birth attendant, however, tells how quickly and successfully a change in attitude brought about through SIPD community outreaches and trainings challenged her own views and improved her service with her patients.

In one of our school outreaches, the teacher tells the story of one of his pupils who was constantly aggressive, “dressed inappropriately”, and often used abusive language. In addition, the student constantly missed classes and one occasion, while being punished, the teacher discovered that the boy was intersex and his behavior had been a distraction mechanism to keep his peers in
fear of him and at bay. After our initial interactions with the student, the head teacher reported that the student, is now more confident and has changed his behavior. His need for medical intervention to rid him of the breasts he hides, however, is still critical.

The head teacher says, “SIPD has opened our eyes to what was a mystery to us. We now at least have some answers to give and an idea of how to respond to students with such needs. It is important to give them a chance to speak about it without fear.”

My own outreach to religious leaders promises that if we are relentless in our education drive to change hearts and minds, we will make incremental and lasting attitudinal changes concerning differences in sexual development. I have seen faith leaders, like affirming posts on face book and respond when a disturbing post about an intersex child or adult has been put up. It has also been interesting to see the willingness, through this engagement, of faith leaders to re-evaluate some of the moral and cultural impositions they promote. There is a slow transformation from harsh sidelining to more compassion, love, and care for those who are different, including intersex children, youth, and adults.

Most importantly, SIPD has brought the idea of collective responsibility and community parenting and child protection to the church fraternity and is helping in forming safe spaces within these spaces. Pastors and teachers are an intrinsic part of a Livelihood and skills development campaign, where youth in school and church clubs identify peers who have dropped out of education for being intersex or for developing non-conforming sex development characteristics. Pastor Peter of the Nakawa Baptist Church, engaged with us and his commitment was “I want to give you access to our youth to educate more on these issues because I know some who may be struggling, and from your example, I can even detect that a young person has something real deep to get off their shoulder without being judged.”

The parish priest of the Catholic Church in Nakulabye – a Kampala suburb – invited SIPD to submit an educational article in the church newsletter, which is widely distributed within the parish and in other parishes.

Through the support of our partners, like OSI, we have been able to celebrate great mind shifts but there is a lot more we need to do and more national coverage we need to reach but thanks to the power of collective action, hundreds of intersex children in Uganda are now safe from mutilations and infanticide.

The main challenge remains the sustainability of these changes, which are premised on a poverty and hunger stricken backdrop. If you can imagine the times you have felt famished and quickly had to interrupt your schedule to reach for a quick bite, or a glass of water, or tea – then you can imagine what it’s like to go hungry for days, weeks, even months on end without anything to eat coupled with the fear of exposure that keeps you confined and isolated from the rest of society because you are different or
you have a child that is different and would draw attention that is more painful than the hunger you suffer. It is being caught between a rock and a hard place.

SIPD clients living in Northern Uganda – in Gulu, Arua, Pader, Karamoja, Amuria, and Nwoya are used to extremely harsh and impoverished living conditions and having to go hungry for weeks and to extremely ration their food. Clients from other parts of the country have limited access to land and communities where they can provide services but don’t know how to. In linking practical relevance to successful advocacy, SIPD is undertaking a livelihood program for these mothers and intersex youth to equip them with skills that can enable them maximally use the land at their disposal – however dry it is – and the natural talents they have. This will stop these parents sending their children – who they see as a burden and social curse - to rebel camps or to abandon them in run-down mud huts.

Constantly seeing the extreme poverty, that cuts across all our clients’ life situations and greatly contributing to the violations they face, of abuse after abuse mainly because of the socio economic status of the mothers of the intersex children or intersex youth, SIPD has concluded that just creating awareness and training on human rights is not enough to grow a holistic advocacy following - and that there is need to attend to the clients’ quality of life. Most Injustices are born from lack of power or misuse of power and having no economic power to even feed oneself, is the most fertile ground to breed injustice.

We cannot constantly and intently determine that training and outreach – as critical as they are in availing information and safe spaces to share - is all our clients need to change their attitude, their lives, and their communities into better, accommodating, and supportive ones. The issue of poverty and livelihoods is one we can no longer evade as part of pursuing social justice for our clients.

In Rakai, a nurse told our outreach team: “I have been telling people all the time that these children, these people are sick from need,” a brief statement that reveals the heavy uncertainty among thousands who struggle to barely meet the basic day-to-day needs before they can attend to the burden of acute stigma and discrimination of their intersex – or different - children. These children, then rightly become a curse to an impoverished mother who is not sure if such a child even has any future in the normative cut-throat society as she knows it. It is a cry for help, to outwit the easier alternative of killing these allegedly inconvenient intersex children – supposedly for their (children) own good. This is echoed by all the medical and legal allies who provide some limited care to our clients. There has been
awakened hope and a sense of political consciousness around sexuality and rights – due to SIPD’s intervention with support from our amazing partners - for over the 1,000 clients we have worked with in the 50 districts of Uganda and beyond. Our engagement with the media has brought about a shift in the way they cover this issue and the amount of airspace they are willing to give it. We get free airtime offers, which was unthinkable three years ago.

However, there is an undeniable cry for help, help for a double marginalized intersex population that often also identifies as gender non-conforming, to be able to help themselves with a little push to build the capacities they already possess and release the productivity potential that is within them, using materials and capital close to them. Responding to this cry is our only way forward in building a critical mass of first-hand rights advocates and change agents. It has rightly been said in foregoing social movements that no change is real or sustainable without the holistic empowerment of those directly concerned. It is certainly no different with the intersex children and people in Uganda.