PRIORITIES BY WOMEN LIVING WITH HIV FOR CONSIDERATION IN THE GLOBAL FUND TO FIGHT AIDS, TUBERCULOSIS ND MALARIA COUNTRY PROPOSAL

ICWEA:

The International Community of Women Living with HIV and AIDS (ICWEA) carried out national consultation on the needs and priorities of women living with HIV, according to the four thematic areas while working with cultural, clan and religious leadersas listed below in 18 districts of Soroti (Teso), Mbale (Bamasaba), Tororo (Japadhola), Budaka (Bugwere), Kabalore (Tooro), Bundibugyo (ObudingaBwaBamba), Kasese (ObusingaBwaRwenzuru), Hoima (Bunyoro), Nakasongola (Buruli), Gulu (Acholi), Arua (Lugbara) and Nebbi (Alur).

Based on the outcome of the consultations, and with financial support from Common Wealth Foundation, ICWEA organized a national priority setting meeting which involved women living with HIV in all our diversity and other stakeholders to inform the GF Concept Note 2018-2020 drafting processes on January 18, 2017. Below are the concerns and priorities for each thematic area in the matrix

CARE AND TREATMENT

Retention in care for women living with HIV their affected and infected babies is a huge concern

The consultation revealed that the retention in care of mothers on ART was a challenge due to nutritional challenges, and gender and human rights related issues at household, community and national level.
Majority of loss-to-follow-up mothers and their babies occurs early in the course of the eMTCTprogramme. Unmarried healthy, pregnant mothers living with HIV need additional support and a safe environment free from social violence for HIV programme retention.

SOCIAL SUPPORT AND SOCIAL PROTECTION

Unfavourablelegal and discriminatory policy environment
Women living with HIV also raised concern of the HIV and AIDS Prevention and Control Act 2014. Their concern is not about the entire legislation but the three (3) discriminatory provisions in HIV and AIDS specific law that are potentially harmful and discriminatory. These include; forced disclosure of HIV test results, the offence of attempting to transmit HIV and the offence of Transmitting HIV. These three provisions undermine the fight against HIV in Uganda.

Stigma and discrimination
HIV-related stigma and discrimination continue to plague women's experiences at every turn. Service providers deny dignity, human rights, and good health to women living with HIV. In doing so, they fail to provide correct or full information and inadequate counseling that has resulted into women not being able to address their individual and pertinent questions as they start ART. Women also experience breaches of confidentiality and the right to informed consent.

Gender based violence
Women living with HIV revealed that they are particularly vulnerable to sexual, physical and psychological violence. They reported violations of their sexual and reproductive rights, including coerced abortion and forced sterilization. Addressing gender-based violence is therefore critical to preventing new HIV infections and AIDS-related deaths.

Lack of nutritional support while being initiated on ART**:**Nutrition and HIV are strongly related to each other. Women living with HIV revealed thataperson with HIV infection is more at risk of malnutrition and that provision of nutritional support is an effective intervention that is fundamental to other HIV/AIDS

care activities. They pointed out that good nutrition may result in increased resistance to infections and disease, improved energy and a stronger and more productive person.

HIV PREVENTION

Sexual and Reproductive Health and Rights violation
Women living with HIV including adolescent girls and young women living with HIV experience significant obstacles while exercising their sexual and reproductive health rights. The consultations revealed that women living with HIV frequently experience abuses and violations of their sexual and reproductive rights, within their families, healthcare settings and communities.

The SRHR violations that were revealed include physical violence against pregnant women, failureto provide accurate information on the sexual and reproductive health services available, stigma, discrimination and detrimental and judgmental treatment. They also pointed out lack of confidentiality and of informed consent based on their HIV status, and forced or coerced sterilization and abortion. As a result of these violations, women living with HIV receive substandard or harmful sexual and reproductive healthcare or feel forced to shy away from using HIV, SRHR and maternal and child health services. Some termed it as, "being bullied out of services".

Women living with HIV reported receiving confusing messages around breastfeeding and risk of vertical transmission of HIV. They frequently report misinformation, conflicting information, or even a complete lack of information and advice from healthcare providers on breastfeeding their children

Unavailability or disruption of contraceptive supplies: Women living with HIV experience unavailability or disruption ofcontraceptive supplies especially in government health facilities. As a result, they experience forced and or coerced family planning options.

COMMUNITY AND HEALTH SYSTEM STRENGTHENING

Low investment in community systems

Community systems including support groups of women living with HIV are essential for psychosocial support, treatment adherence, changing social norms and stigma-reduction, creating awareness of programs and schemes, and mobilization of communities for demand creation. Communities connect people to services, they are flexible and responsive to needs and address important factors in accessing services and supporting what happens beyond clinic walls.

BEST PRACTICE 1

Facility and community-based structures are instrumental in the HIV, TB and malaria response in Uganda. This is based on ICWEA' experience of implementing the **Improving and increasing access to SRHR and eMTCT services for Women living with HIV in four districts of South Western and Central Uganda between 2013 - 2015.** ICWEA trained peer counselors who continue to tremendously play a critical role in increasing retention and treatment adherence of mothers under the eMTCT program.Most of the trained peer educators were Village Health Team (VHTs) members who had never had access to information on SRHR, gender and violence against women. ICWEA and UGANET trained and supported these peer educators through coaching, mentorship and support supervision to have reasonable skills to engage the respective stakeholders on SRHR. Now health workers rely on them for mobilizing and increasing the number of pregnant women for eMTCT. This implies that the program activities are being implementedbeyond the project life.
Peer educators followed up and traced up to 196 out of 254 registered lost and lost to-follow up pregnant and lactating womento return for services.

Communities support the continuum of care – from putting people in touch with health care systems, diagnosis, through treatment and ongoing care and support. However, there is a low investment in community systems

THEMATIC AREAS	LIST OF PRIORITIES FOR GF FOR TB, AIDS & MALARIA
SOCIAL SUPPORT AND PROTECTION	**Lack of nutritional support** for people who are on ART and TB therapy, adolescents and young women living with HIV, pregnant and breastfeeding mothers, women living with HIV and disabilities. The following were prioritized: • Invest in sustainable livelihood support. For instance: o Creating self-employment opportunities for young women living with HIV by providing by providing practical skills, training and educational tools ***(See best practice below)*** o Implement a cash flow system. Give young people in groups of 10-20 people seed money based on their own innovations. o Establish village support loans. Lessons can be drawn from TASO o Establish savings schemes for people living with HIV • Establish a revolving fund targeting people living with HIV
	Gender Based Violence (GBV) Increase community awareness on their individual and collective rights and role on HIV/SRHR and GBV prevention and management Improve the capacity of cultural and religious leaders to carry out effective referrals for victims of VAWGs to essential services Train and Equip GBV and HIV service providers on timely and coordinated provision of GBV services including, Counselling on GBV, PEP, emergency contraceptives , Legal advice and identification of human rights and gender-specific violation and referrals • Allocate funding to implement the work plans that were developed by religious and traditional leaders to respond to GBV • Conduct studies to identify harmful practices and work with communities to identify ways through which such practices can be modified to become safe for both men and women. • Identify and build capacitates of cultural and religious leaders to spearhead community level processes for promoting constructive customs and norms
	The following were prioritized in responding to HIV legal environment • Repeal the HIV and AIDS Prevention and Control, 2014

	• Train key stakeholders to develop better understanding of the key legal barriers for women living with HIV • Train police officers and prosecutors on human rights and HIV treatment so that children living with HIV can be supported to adhere to treatment even when they are detained. • Conduct legal research and score card on the legal environment for HIV, Malaria, TB and GBV responses • Disseminate progressive laws and policies to formal and informal justice actors- • Develop bridged versions of laws and policies in the context of HIV, Gender, TB and malaria (HIV act, GBV policy. • Hold quarterly dialogue sessions with three (3) committees of Parliament (Human rights, HIV, Legal) on the new discriminative sections of the current and upcoming laws that disable the response to HIV and the sexual offences bill, • Hold dialogues with the local leaders (chair persons LCV, Speakers) on byelaws and other decentralized legislative processes in the context of Gender, HIV, Malaria and TB such as byelaws on early marriages etc. • Review the current HIV, TB, Malaria and gender legal framework against the regional and international laws and conventions for improved response. • Review the current legal framework for improved domestic financing and social accountability for effective governance in the response. • Develop position papers, briefs on the desired legal environment to support the response **Build capacity in human rights and access to justice for an effective HIV, Gender and TB response.** • Train gate keepers of justice i.e judicial officers, police, prosecutors on how to handle HIV and GBV related files • Train CSOs and other community level duty bearers on human rights based approaches • Equip Groups of people affected by the disease and KPs with human rights approaches in the context of HIV, malaria, TB (disseminate the Patients charter in different languages, finalize the sexual reproductive health guidelines in the context of Women living with HIV), • Strengthen the national HIV response human rights working group to focus on rights issues in HIV, Malaria, TB and gender responses • Hold quarterly dialogue sessions with judicial officers and prosecutors on discriminative sections of laws that affect the public health outcomes of the response. • Strengthen legal aid services and structures in selected hard to reach and high burden districts in the context of HIV, TB and GBV. (Train community paralegals to raise awareness; on HIV/TB/Malaria and

	Gender progressive laws at community level; do rights assessments, report abuses etc. • Conduct legal aid outreaches to selected health facilities with high cases of patients' rights abuses, in HIV/TB/GBV high burden districts. • Conduct operations research on patients' rights abuses that deter access to HIV, TB, Malaria and Gender sensitive services **Resilient community and health systems strengthening in the human rights context:** • Strengthen the community paralegals structures for improved reporting and tracking patients' rights abuses at community level, for improved demand and access. • Empower community level informal and formal justice sector actors (Cultural leaders, religious leaders, LC1 leaders, Local police, Lower level health workers, *Ssengas*) in the legal and human rights framework for GBV, HIV and TB. • Hold dialogue sessions with local leaders (LC111 Chairpersons and councilors) on byelaws, ordinances and legislative processes that can support community response to HIV, TB and GBV. • Disseminate policy and legal framework on leadership and social accountability of duty bearers at health unit management committees, police stations, among others. • Facilitate access to critical services such as police forms for GBV survivors, legal dialogue sessions with police on timely access to PEP services by victims of rape and defilement etc.
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CARE AND TREATMENT	**To facilitate adherence and retention of adolescents and young women on care and treatment** • Train youth counselors on HIV and TB treatment for youth friendly corners in health facilities. • Establish youth friendly corners outside the health facilities and include ART in them • Review the SRHR package developed by the MoH for youth corners to include HIV treatment • Encourage peer to peer support. Train young motivators as youth Ambassadors. • Take a human rights based approach in care and treatment programmes of people living with HIV • Build capacity and equip networks of PLHIV as partners in enrollment and retention in HIV prevention and care • Women who are aging with HIV be given special attention since they usually experience a lot of stigma at the health care setting

	Commoditization of the 95% of the GF grant 2015-2017 weakened other arms of the response to the 3 diseases. The following are prioritized for GF grant 2018-2020: • CSOs should influence the government to put emphasis on retention and adherence instead of commoditizing GF grant 2017 – 2019 to 100%. CSOs should propose to de-commoditize up to 85% so as to strengthen the advocacy arm to the response and the government can make financial contribution. • CSOs must push for allocation of resources before the drafting team starts writing the concept none • Emphasis be put on funding programmesfor HIV prevention, girls and boys, SRHR and GBV, adherence and retention, and key population living with HIV. **For increased access to health services by the female key populations, the following are prioritized** • Invest in biomedical method of tracking facilities where key populations especially sex workers access their treatment. • Engage the community of women living with HIV considering the female key populations in implementing differentiated service delivery.
COMMUNITY SYSTEMS STRENGTHENING	**Invest in community based responses** Increase investment in community-based responses (CBOs, Networks of women living with HIV) to improve referral and linkages to services, treatment literacy, preparedness, and agency that enable women to receive quality services and adhere to treatment. This includes support to deliver community-based services, which are key in health care systems, community support groups, peer support and expert clients living with HIV, and linkages to networks of women living with HIV. • Investments towards the engagement and participation of communities in shaping and driving the response led to many gains over the years. There is an urgent need to ensure resources are invested strategically to support interventions and populations that yield the highest impact and progress on HIV, TB and malaria. • Recognize and invest in community engagement of women living with HIV as central to the success of the HIV response. • Commit to mobilize resources, especially at community level, and fully fund and support robust community participation. • Fund the implementation of the community-facility referral, linkages and service delivery framework.

ICWEA:

BEST PRACTICE 2

ICWEA is implementing an economic empowerment Project in Mubende and Mityana Districts called" **Sparked women**" aimed at "Creating 7,750 job opportunities for adolescent girls and young women (AGYW) at risk of HIV infection in Uganda. ICWEA received support from the AIDS FOND – A Dutch based organization to implement a Dreams Initiative Project that further aims at reducing the new HIV infections in the young women aged 15-24 years.

ICW EA provides strong opportunities to the young women by selecting them to become a healthy entrepreneur and has partnered with SAWA World, an NGO that uses an innovative approach to ending extreme poverty by providing practical skills, training and educational tools and large-scale access to local solutions that are created by people living in extreme poverty. This is done by starting small enterprises (raising incomes by $2 to $4 per day) or improving their livelihoods at the household level.

ICWEA is working in 6 sub counties within the two districts and has mobilized 180 adolescent Girls and young women who are being trained in the small local business enterprises of their choice, that include making Liquid soap, cakes and *Daddies (*cookies*)*, paper bags, reusable sanitary pads, Fruit juice , candles and Book making. The project has been strengthened further by the Sub county volunteers the district coordinator team that supports in the monitoring and follow up of all the young women who have benefited from the initiative The young women will benefit from the project with an increase in their income, savings and also gain self-confidence to enable them to make safer sexual reproductive choices

THE INTERNATIONAL COMMUNITY OF WOMEN LIVING WITH HIV EASTERN AFRICA

ACTIVITY: National Dialogue for priority setting for Global request for TB, AIDS and Malaria
VENUE: Metropole Hotel
DATE: January 18th, 2017
DONOR/LEDGER CODE: CommonWealth Foundation

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