Elizabeth Glaser Pediatric AIDS Foundation

Until no child has AIDS.

Submission by the Elizabeth Glaser Pediatric AIDS Foundation

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I. Introduction

1. The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) was created in 1988, and is now the leading global nonprofit organization dedicated to eliminating pediatric HIV and AIDS. EGPAF has been supporting efforts to prevent, care for, and treat pediatric HIV and AIDS in Uganda since 2000. EGPAF works closely with the Ministry of Health and other partners to increase access to comprehensive, high-quality HIV prevention, care and treatment services among women, children and families living with and affected by HIV and AIDS.
2. The HIV epidemic in Uganda has had a particularly heavy impact on young women and children. During the 2011 Universal Periodic Review (UPR), states made several recommendations with a bearing on HIV/AIDS and broader health issues, including the need to improve the health system, raise access to medicines and quality health services, and continue to reduce child and maternal mortality.
3. Since 2011, Uganda has made significant progress in preventing mother-to-child transmission of HIV, but less progress has been made on ensuring access to early HIV testing and treatment for children and on preventing HIV among young women. Achieving and sustaining elimination of pediatric HIV and AIDS in Uganda will require increasing political leadership, strengthening the national healthcare infrastructure and management, and tackling harmful societal attitudes towards people living with HIV and against women and girls.[i]
4. This report highlights progress and remaining challenges EGPAF has observed in Uganda's protection of the rights of women and children affected by, or living, with HIV. The primary rights that will be examined are the right to health, including HIV and AIDS health services and sexual and reproductive health. It will also examine the right to non-discrimination and the right to gender equality as they relate to HIV prevention and treatment.

II. HIV and the Right to Life, Survival, and Health

5. In the context of HIV/AIDS, the right to life, survival, and health entails a legal responsibility for each country to progressively ensure fully available, affordable, accessible, and acceptable HIV prevention, testing, treatment, and care services for women, men, girls and boys of all ages. Yet in Uganda, prevention efforts for young women and HIV treatment for children have lagged far behind the wider population.
6. Since 2011, Uganda has demonstrated strong commitment to preventing mother-to-child HIV transmission (PMTCT), the primary HIV prevention method for children. It launched a national plan to achieve virtual elimination of mother-to-child transmission and to reduce HIV morbidity and mortality among HIV-positive women and HIV-exposed and infected infants. Uganda has made remarkable progress in eliminating vertical transmission between 2009-2014, with a 69% reduction in new HIV infections among children, a reduction in transmission rate from 35% to 8%, and an increase in pregnant women with HIV accessing anti-retrovirals for PMTCT from 27% to 92%.[ii] Yet further work is required to reach the 5% final transmission goal and to sustain progress over the long term.[1]
7. First, more needs to be done to provide age-appropriate sexual and reproductive health education and services to prevent HIV infection among women and adolescent girls and to enable those living with HIV to decide if and when to become pregnant.[iii] Continuing lack of knowledge and understanding of HIV remains one of the biggest drivers of the HIV epidemic in Uganda.[iv] Awareness among young people about how to prevent the sexual transmission of HIV is low; ranging from 32% in 2012 to 38.7% in 2014.[v] Only 28% of Ugandan women are using a modern method of contraception, and the unmet need for

[1] According to the WHO, elimination of mother to child HIV transmission requires a transmission rate of under 2% in populations without breastfeeding, and under 5% in breastfeeding populations.

contraception rate (33%) is one of the highest in Africa.[vi] Such factors, as well as harmful gender norms described below, contribute to the slow decline in new HIV infections among women 15-49 years old since 2009.[vii]

8. Pregnant women living with HIV need to be tested and initiated on anti-retroviral treatment (ART) as early as possible during their pregnancy and stay on ART through the end of breastfeeding and beyond in order to maximize protection for the baby and keep themselves healthy.[2] In 2014, 93% of pregnant women in Uganda were tested for HIV during ANC visits, and 92% of HIV-infected women received ARVs to prevent transmission of HIV to their infant while pregnant and breastfeeding.[viii]

9. On the other hand, low rates of institutional deliveries and postnatal care services are recognized as key obstacles in making greater progress towards elimination.[ix] While 93% of pregnant women have at least one antenatal care visit, essential for HIV testing and initiation on ART, only 48% have the recommended four or more visits, which would enable retesting for sero-conversion and ART adherence monitoring. As well, only 57% of women in Uganda deliver at a health facility, vital for minimizing risks of transmission during delivery, administering newborn prophylaxis, instructing on safe infant feeding, and encouraging early infant HIV testing.[x]

10. Low male involvement in the PMTCT process and other family planning activities is also problematic as their dominance in family decision-making empowers them to help or hinder access to care. Uganda asserts that increased male participation in PMTCT could reduce the risk of vertical HIV transmission by more than 40%, but has been hampered by "cultural perception coupled by patriarchal based traditions which are dominant in Uganda."[xi] Uganda has recently launched a Male Involvement Strategy to support male engagement in reproductive health services.[xii]

11. HIV-exposed infants (HEI) are at high risk of rapid illness and mortality and must therefore be tested for HIV within two months of birth. Yet only 33% of HEI had an early HIV test in 2014, a decline from 42% in 2013.[xiii] Of those tested, lengthy turn-around times for test results mean many children die before ever being initiated on treatment. Uganda is working to expand identification and testing of HEI in all entry points in health facilities where children receive care and otherwise increase early infant diagnosis.

12. Without treatment, 50% of children with HIV will die by their second birthday, and 80% will die before they turn five. Yet only 37% of children living with HIV were on ART in 2014, as opposed to 52% of adults, despite new Ugandan treatment guidelines in 2013 calling for all HIV positive children up to 15 years of age to be initiated on treatment immediately.[xiv] Poor retention and adherence is also a great concern among infants, adolescents and mothers.[xv] Uganda attributes the low rate of treatment initiation and retention to "limited capacity in many facilities especially the peripheral units for Paediatric care and treatment, frequent stock outs, weak follow-up systems, and loss to follow up."[xvi] There are ongoing innovations to address some of these gaps and challenges.

13. The data above points to a need for Uganda to make a more concerted effort to improve pediatric HIV prevention, testing and treatment to ensure adequate protection of children's right to health, life and survival. Doing so will require significant improvements across Uganda's health care system, particularly at the lower levels where the majority of women receive PMTCT and other relevant services.[xvii] Uganda recognized in its 2011 UPR report the "need to address the challenges related to human and logistical resources under [the health] sector."[xviii]

[2] As of 2013, WHO guidelines call for all pregnant and breastfeeding women to remain on ART for life no matter what their HIV clinical stage or CD4 count.

14. In particular, human capacity gaps as well as "weak procurement and supply chain management systems" have been consistent challenges for Uganda. [xix] A recent Global Fund audit of Uganda highlighted numerous shortcomings in the management and delivery of life-saving ARVs, including missing supplies, regular stock-outs of medication and tests, and the unauthorized sale of medicines purchased by the Global Fund for free distribution.[xx] Uganda reports that 47.9% of health facilities dispensing ARVs experienced a stock-out of at least one required ARV in the last 12 months as of December 2014.[xxi]

15. Moreover, domestic funding for the health sector is low, and far below the 2001 Abuja Declaration target of 15% of total government spending on health. Although the absolute health sector budget has grown in recent years, its proportion of the total budget decreased from 8.9% in 2010/11 to 7.9% in 2012/13.[xxii] Domestic contribution to the HIV remained at only 11% between 2011 and 2014.[xxiii] Finally, strengthened political leadership at all levels is needed to make further progress towards eliminating mother-to-child transmission and sharply increasing HIV treatment for children.[xxiv]

III. The Right to Non-Discrimination and Equality of Rights

16. Stigma and discrimination remain key barriers to an effective HIV/AIDS response, standing in the way of people seeking a diagnosis, disclosing their status to others, and keeping up with treatment for fear of the impact this might have on personal, societal, or professional relations. For example, stigma from healthcare workers will discourage women from starting or continuing to use PMTCT services and men from accompanying them through the process. Children living with HIV in particular suffer severe psychological distress from HIV-related stigma in the school, home, and community that can interfere with their treatment adherence.[xxv]

17. Uganda's HIV and AIDS Prevention and Control Act of 2014 bans discrimination due to one's actual, perceived, or suspected HIV status in several specific contexts, including the workplace, schools, and healthcare institutions. In 2014 Uganda also issued a ministerial directive guaranteeing access to health services without discrimination on the basis of "disease, religion, political affiliation, disability, race, sex, age, social status, sexual orientation, ethnicity, etc."[xxvi] Yet the government recognizes "there still exist high levels of stigma and discrimination among PLHIV and in the wider community. Stigma and discrimination is still institutionalized as often PLHIV [people living with HIV] are excluded from government economic empowering programs, are denied from accessing credit, lose employment, and also fail to access health insurance on the basis on their health status."[xxvii]

18. According to a national survey conducted in 2013, the commonest forms of stigma and discrimination are gossip, experienced in the past year by 60% of those surveyed, as well as verbal harassment, insults and or threats, experienced by 37%.[xxviii] In addition, 33% of those surveyed reported that they had been advised by health care professionals not to have children after being diagnosed as HIV-positive. Eleven percent reported to have been forced by health workers to undergo sterilization because of their HIV positive status.[xxix] Government figures actually show an increase in discriminatory attitudes towards PLHIV from 2011 to 2012.[xxx]

19. The government of Uganda has a duty to continue to combat such discriminatory attitudes through education and awareness-raising campaigns, as well as by full enforcement of the HIV and AIDS Act provisions and Ministerial Directive against discrimination. Uganda recognizes that there remains low coverage of comprehensive psychosocial services that could help support victims of mistreatment, and "limited knowledge among teachers, caregivers, family members and the community in handling psychosocial needs especially for young people." [xxxi] Low funding for psychosocial support activities, inadequate

knowledge of what support is needed, and an absence of leadership were some of the reasons cited by Uganda.

20. In addition, Uganda should also review its laws and policies to ensure they do not contribute to discrimination and societal stigma. For example, the HIV and AIDS Act criminalizes the transmission of HIV. Such provisions contribute to the stigmatization of PLHIV and encourage such persons, including pregnant women, to hide their status, or to refrain from testing in the first place, for fear of the legal ramifications of unintentional transmission.

IV. The Rights of Women and Girls

21. Women in Uganda make up 59% of those people living with HIV, and account for 58% of new infections among adults. The prevalence rate remains consistently higher among women (8.3%) than men (6.4%), and higher among young females 15-24 years old (3.7%) than males (2.3%).[xxxii] Gender inequality – including unequal access to education, health care, and social services - as well as harmful gender norms and practices greatly increase the risk of acquiring HIV by women and girls and interfere with the ability of those living with HIV to seek treatment.[xxxiii] Several 2011 UPR recommendations touched on improving the rights of women and taking steps to ending all violence against women, such as through full implementation of the Domestic Violence Act.

22. Uganda considers "sexual and gender based violence resulting from gender inequalities" as one of the key drivers of HIV incidence.[xxxiv] In 2011, 80% of women aged 15-49 reported experiencing recent physical or sexual violence from a male intimate partner.[xxxv] Uganda notes that "programming for GBV has been marred with low reporting, documentation, and follow up and handling of SGBV and abuse cases. This could be explained by limited knowledge on what constitutes abuse; fear of animosity from the perpetrator and other members of the community; corruption; stringent procedures and high cost of litigating abuse cases; and weaknesses of the legal system in handling SGBV cases of children and fear of stigmatizing the victim. Rural women do not usually report sexual and mental abuse by their spouses or other men for fear community stigma."[xxxvi]

23. Many women living with HIV are abused psychologically or physically after disclosing their HIV status to their partner due to a societal tendency to blame women for bringing HIV into the family. Anticipation of such a reaction leads many women to refrain from testing themselves or their children or disclosing their HIV status, and may discourage them from adhering to a treatment regime that will give their status away. Even if they have disclosed their status, women often do not have the final say in decisions regarding their own health, their children's health or their own daily household expenditure, and may not feel empowered to seek or stay on treatment.

24. Ensuring girls' equal access to education through secondary school is also critical as studies show the longer girls stay in school, the lower their risk of acquiring HIV.[xxxvii] On the contrary, uneducated girls are twice more likely to acquire HIV than those who have some schooling.[xxxviii] Yet only 25% of girls finished primary school in Uganda in 2010, and only 19% of girls were attending secondary school as of 2011.[xxxix] Improving access to education for all was a common element of many recommendations in Uganda's 2011 Review. While Uganda noted its commitment to providing free primary education in its UPR report, it did not comment on plans to improve access to secondary education.[xl]

25. Finally, early and forced marriage creates a heightened risk for HIV acquisition among girls. Typically, such marriages occur between young girls and older men, who have already had several sexual partners and thus a higher exposure to HIV. These marriages are also associated with higher levels of intimate partner violence and an unequal power balance that can prevent girls from asking for use of protection or seeking HIV testing or treatment.[xli] Early marriage usually halts girls' education and is associated with a lower likelihood of

seeking help in cases of intimate partner violence.[xlii] In Uganda, despite a legal age of marriage of 18, 10% of girls are married by the age of 15 and 40% are married by age 18.[xliii] In June 2015, the Government of Uganda launched its first National Strategy to end Child Marriage and Teenage Pregnancy.[xliv] Greater social protection for vulnerable girls and families and other efforts to improve household incomes can reduce the economic motivation for such marriages.

V. Proposed Recommendations

Based on the analysis above, the Elizabeth Glaser Pediatric AIDS Foundation would like to propose consideration of the following recommendations for Uganda:

1. Take further steps to achieve the elimination of mother-to-child HIV transmission, including through expanded sexual and reproductive health education and services, the promotion of ante-natal care and institutional birth deliveries, and encouragement of male participation in reproductive health services.
2. Increase efforts to ensure full access to early testing, treatment, and care for children living with HIV.
3. Take further steps to strengthen the healthcare infrastructure, particularly the pharmaceuticals supply chain management and healthcare workforce.
4. Ensure full implementation of Part VII "Stigma and Discrimination" of the 2014 HIV and AIDS Prevention and Control Act, and revise or repeal any laws or policies that act as barriers to effective HIV diagnosis, treatment, care, and counseling, such as Section 37 of the 2014 HIV and AIDS Prevention and Control Act that criminalizes transmission of HIV/AIDS.
5. Take all appropriate measures to increase girls' attendance of secondary school.
6. Take all possible measures to eradicate gender-based violence and harmful gender norms and practices such as early and forced marriage, and ensure adequate social protection for vulnerable girls and young women.

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