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/AIDS. EGPAF has been supporting the Kingdom of Swaziland since 2004 to prevent HIV infections and reduce HIV-related morbidity and mortality among women, children, and families. EGPAF works with the government of Swaziland and other partners to implement programs that prevent the transmission of HIV from mother to child and provide testing, care, treatment, and psychosocial support services to children and adults living with HIV.[1]
2. The Kingdom of Swaziland has the highest HIV prevalence rate in the world, with almost 28% of persons 15 and older living with HIV.[2] Swaziland has shown remarkable political commitment to ending the HIV/AIDS epidemic, and is close to achieving elimination of mother-to-child transmission of HIV. On the other hand, there remains more work to be done to prevent new cases of HIV among women and adolescent girls and to address the large gap in treatment between children and adults.
3. Making further progress on HIV in the Kingdom of Swaziland will require changes at the structural and societal levels, including a strengthened national health system.[3] Stigma and discrimination are also recognized by the Kingdom of Swaziland as significant barriers to ensuring an adequate HIV/AIDS response for all people living with HIV, as are gender inequality and gender-based violence.[4]
4. This report will consider progress and remaining challenges EGPAF has observed in Swaziland'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/AIDS health services, domestic financing for HIV, and sexual and reproductive health. It will also examine the right to non-discrimination and women's rights as they relate to HIV prevention and treatment.

II. HIV and the Right to Health

5. The right to health is guaranteed under several international human rights instruments. In the context of HIV/AIDS, this right entails a legal responsibility for each country to progressively ensure fully available, accessible, acceptable, and quality HIV prevention, testing, treatment, and care services for women, men, girls and boys of all ages. Furthermore, states must review all laws and policies and revise or repeal any elements that act as barriers to effective HIV diagnosis, treatment, care, and counseling.
6. His Majesty, King Mswati III and the government of Swaziland have demonstrated significant political and financial commitment to ending the HIV/AIDS epidemic.[5] In addition to previous ambitious strategies, Swaziland is now developing an "investment case" to end AIDS by 2022.[6] Given the high prevalence of HIV in Swaziland, its estimated requirements for an effective response represent over 4% of its GDP.[7] The government reports spending an increasingly high proportion of this investment over the past several years, representing almost 40% of the total HIV/AIDS expenditure in 2013.[8] As a clear

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[1] More information about EGPAF's activities in Swaziland can be found at: http://www.pedaids.org/countries/swaziland.
[2] UNAIDS, AIDSInfo: http://aidsinfo.unaids.org/.
[3] See EGPAF, *Using Data to Understand and Address Gaps in the Treatment Cascade for HIV-Positive Infants and Young Children: Experiences from Lesotho, Malawi, and Swaziland,* July 2012.
[4] *Swaziland Global AIDS Response Progress Reporting, 2014,* 28 March 2014, p.3 and Swaziland National Network of People Living with HIV/AIDS, *Stigma Index Report,* June 2011, p.29.
[5] *Swaziland Global AIDS Response Progress Reporting,* p. i.
[6] Mandla Luphondvo, "Road map to an AIDS-free Swaziland," *Observer,* 27/08/2015.
[7] Peter Piot et al, UNAIDS–Lancet Commission on Defeating AIDS, *Advancing Global Health- Defeating AIDS,* 25 June 2015, p.18.
[8] *Swaziland Global AIDS Response Progress Reporting,* p. 18-19.

indication of its commitment to the HIV response, since 2009 Swaziland has been financing the procurement of all anti-retroviral medication (ARV). [9]

7. The Kingdom of Swaziland has prioritized decentralizing services to bring them closer to a population living with HIV.[10] As of 2013, almost three-quarters of the country's health facilities had HIV/AIDS treatment capacity.[11] Yet Swaziland still suffers from a shortage of healthcare workers, a significant barrier to an effective HIV response as quality provision of HIV testing, counseling, initiation on treatment, and care is human resource intensive.[12]

8. There are several societal drivers of the HIV epidemic in Swaziland, including multiple and concurrent sexual partners, stigma and discrimination against persons living with HIV, and gender inequality and gender-based violence.[13] Transactional sex, another high-risk activity for HIV, is common in Swaziland as women seek financial support for rent, food, transport, or other necessities.[14]

9. Women and children suffer heavily from HIV in Swaziland. Of the 210,000 people living with HIV in Swaziland, about 9% are children under the age of 15.[15] Women represent 60% of the adult population living with HIV. HIV prevalence is twice as high among young women aged 15-24 years as among young men. New incidence of HIV transmission is almost twice as high among women aged 18-49 as it is among men.[16] Access to ART is lower among children, with only 43% of children living with HIV on ART in 2014, compared to 60% of HIV-infected adults.[17] Such data signifies a need for Swaziland to make a more determined effort to improve HIV prevention and treatment among these vulnerable populations to better protect their right to health.

10. The prevention of mother-to-child transmission (PMTCT) is an essential part of protecting children from HIV as 90% of HIV among children comes from the mother. Swaziland has demonstrated a clear commitment to PMTCT**,** scaling up programs considerably since 2010. Efforts have been made to expand mentoring on PMTCT at health facilities, strengthen and expand PMTCT services at the community level, seek greater involvement of male partners, and improve tracing and follow up of antenatal care clients and HIV-exposed infants.

11. PMTCT involves several prongs of activity. The first step is to prevent HIV among women and adolescent girls through access to age-appropriate information about HIV and sexual and reproductive health (SRH). Proper education of men and adolescent boys is also critical in an environment like the Kingdom of Swaziland, where "cultural values and norms uphold men's privileges and tend to constrain women's decision-making on their sexuality and reproductive health."[18]

12. Swaziland has undertaken efforts to expand SRH in both schools and in communities, including through a Social Behaviour Change Communication (SBCC) Strategy (2009 – 2014) on HIV and Sexual Health, toolkits to support implementation of SBCC interventions, and age-appropriate information guides to facilitate peer and family life skills for youth both in and out of school. Swaziland has also developed a Comprehensive

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[9] *Swaziland Global AIDS Response Progress Reporting, 2014*, 28/03/14, p. 22.
[10] Ibid, p. 9-15.
[11] Ibid, p. 15.
[12] EGPAF, *Barriers to Antiretroviral Therapy Initiation for Eligible HIV-Positive Pregnant Women in Antenatal Car*e, October 2012, p.22.
[13] *Swaziland Global AIDS Response Progress Reporting, 2014*, 28/03/14, p. 2-3.
[14] EGPAF, *An Exploratory Study of the Behaviors and Practices that May Increase HIV Risk among Pregnant and Lactating Women in Communities in Swaziland*, 24 June 2015, p.10 & 17.
[15] UNAIDS, AIDSInfo: http://aidsinfo.unaids.org/.
[16] *Swaziland Global AIDS Response Progress Reporting*, p. 1.
[17] UNAIDS, AIDSInfo: http://aidsinfo.unaids.org/.
[18] *Swaziland Global AIDS Response Progress Reporting*, p.3.

Lifeskills Education (CLSE) Programme for all secondary schools in the country, which has also been adapted for use at the community level to reach youth outside the school setting.[19]

13. Effective HIV prevention for women and girls will, however, require wider societal behavioral changes and intensified education and awareness-raising among all parts of the population. Many men of all ages do not appear to be following the lessons being communicated, especially about the need to limit sexual partners and use condoms, including while one's partner is pregnant or lactating. Such behavior increases the risk of a woman becoming infected during pregnancy or lactation. Both men and women in a recent EGPAF study on behaviors and practices displayed continuing ignorance about the utility of condoms beyond family planning, questioning why one would use a condom if a woman is already pregnant.[20] HIV-negative women that are receiving counseling about HIV prevention report that they do not apply what they learn because they believe their partner would not be receptive to the messages.[21]

14. The second prong in the PMTCT cascade is sexual and reproductive health services to support HIV-positive women in their decision on whether to have children, and at what intervals. Swaziland has put in place a Reproductive Health Commodity Security Strategic Plan 2008-2015, and has made progress in contraception commodity availability.[22] Yet post-natal family planning services to control timing of future pregnancies appear to be weak, with one study showing that almost 70% of interviewed women living with HIV saying their most recent pregnancy was either unwanted or mistimed.[23]

15. Next, pregnant women living with HIV need to be tested and initiated on ART as early as possible during the pregnancy and through at least the end of the breastfeeding period in order to maximize protection for the baby and keep themselves healthy. PMTCT has been fully integrated into ante-natal care (ANC) services in Swaziland, which helps facilitate initiation on treatment and follow-up for mother-baby pairs.[24] Swaziland has made excellent progress in increasing the number of women on ARVs for PMTCT, with over 95% of HIV-infected pregnant women taking ARVs in 2014.[25] As a result, the mother to child transmission rate was at 3% at age 6-8 weeks, with a final rate of 10% after breastfeeding in 2013.[26] This is one of the lowest rates of transmission in sub-Saharan Africa, but falls short of the WHO definition of "elimination," which requires a transmission rate of under 2% at 6-8 weeks, and a final rate (after the breastfeeding period) of under 5%.

16. A number of factors may contribute to the higher rate after breastfeeding in Swaziland. First, the rate of adherence to ART during breastfeeding was only 49% in 2013.[27] A study by EGPAF showed that many women still lack sufficient information about HIV and ART, especially the importance of adherence through breastfeeding.[28] The lack of adequately trained health care workers and physical space for counselling were cited as persistent

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[19] *Swaziland Global AIDS Response Progress Reporting*, p.5.
[20] EGPAF, *An Exploratory Study of the Behaviors and Practices that may Increase HIV Risk among Pregnant and Lactating Women in Communities in Swaziland*, 24 June 2015, p.21 & 27.
[21] Ibid, p.23.
[22] UNAIDS, *2014 Progress Report on the Global Plan Towards the Elimination of New HIV infections among Children by 2015 and Keeping their Mothers Alive," p*. 27 and World Contraceptive Patterns 2013 (United Nations, 2013), available from www.unpopulation.org.
[23] Charlotte E Warren et al, "Family planning practices and pregnancy intentions among HIV-positive and HIV-negative postpartum women in Swaziland: a cross sectional survey," *BMC Pregnancy & Childbirth*, 2013, p.6.
[24] *Swaziland Global AIDS Response Progress Reporting*, p. 12.
[25] UNAIDS, AIDSInfo: http://aidsinfo.unaids.org/.
[26] *Swaziland Global AIDS Response Progress Reporting*, p.2 and UNAIDS, *2014 Progress Report on the Global Plan*, p.28.
[27] UNAIDS, *The Gap Report*, 2014, p. A81.
[28] EGPAF, *Barriers to Antiretroviral Therapy Initiation for Eligible HIV-Positive Pregnant Women in Antenatal Care*, October 2012, p.1.

issues contributing to the lack of proper understanding on adherence. Mistreatment by some health care workers and a lack of privacy when receiving ART also discourage some women from returning to clinics during the post-natal period.[29]

17. As noted above, HIV awareness-raising campaigns and individual counseling have not sufficiently stemmed the societal proclivity to unprotected sex with multiple partners. If an HIV-negative woman acquires HIV while pregnant or breastfeeding, there is an even higher risk of transmission as a person's viral load surges at the earliest stage of infection. EGPAF has therefore observed that "Pediatric HIV in Swaziland is unlikely to be sustainably eliminated without attention to new HIV infections during pregnancy and lactation."[30]

18. The final prong of PMTCT is to initiate infants exposed to HIV on prophylactic drugs at birth, test them for HIV by six weeks, and initiate HIV-positive infants on ART as quickly as possible. Due to their immature immune systems, infants with HIV are at much higher risk of developing AIDS. Without treatment, 50% of children with HIV will die by their second birthday, and 80% will die before they turn five. Yet progress on diagnosing and treating infants and children with HIV has been much slower than prevention in Swaziland, as in most countries with high HIV prevalence. Only 43% of children living with HIV were on ART in 2014, compared to 60% of HIV-infected adults.[31]

19. Specific barriers to initiating and maintaining children on ART in Swaziland include difficulty identifying, testing, and tracking HIV-exposed infants, especially over the long breastfeeding period. The result is missed opportunities to carry out early infant diagnosis (EID) and begin infants on treatment. Linkage to care and treatment in clinical care services has been a challenge, as has the lack of youth-friendly testing and counselling services. On the other hand, much progress has been made in recent years due to a new policy enabling nurse-led ART initiation and the creation of an "expert client" system in which HIV-positive persons guide patients to ART services. These two innovations have doubled the number of HIV-positive infants initiated on ART over two years.[32]

III. The Right to Non-Discrimination

20. Stigma and discrimination due to a person's actual or perceived HIV/AIDS status violates their rights under international law to freedom from discrimination and to equality before the law, and undermines the "inherent dignity" of all persons. They stand 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.[33] Children living with HIV in particular suffer from the impact of stigma, and poor treatment by teachers and schoolmates often discourages children from staying in school or taking their medicine.[34]

21. Swaziland recognizes stigma and discrimination as key barriers to an effective national HIV/AIDS response.[35] For example, they affect women's decisions to stay on ART, especially if they feel that there is insufficient privacy when they receive counseling or pick up medication refills.[36] Many women also fear their spouse will end their relationship or

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[29] EGPAF, *Barriers to Antiretroviral Therapy Initiation for Eligible HIV-Positive Pregnant Women in Antenatal Care*, p. 13-14.
[30] EGPAF, *An Exploratory Study of the Behaviors and Practices that may Increase HIV Risk among Pregnant and Lactating Women in Communities in Swaziland*, p.6 & 27.
[31] UNAIDS, AIDSInfo: http://aidsinfo.unaids.org/
[32] EGPAF, *Using Data to Understand and Address Gaps in the Treatment Cascade for HIV-Positive Infants and Young Children: Experiences from Lesotho, Malawi, and Swaziland*, July 2012, p.6.
[33] UNAIDS, *How AIDS Changed Everything*, 2015, p. 109.
[34] Angel Navuri, "Children`s right to information on HIV prevention, treatment and care vital," IPPMedia, 17 July 2015, http://www.ippmedia.com/?l=82336.
[35] *Swaziland Global AIDS Response Progress Reporting,* p. 2-3.
[36] EGPAF, *Barriers to Antiretroviral Therapy Initiation for Eligible HIV-Positive Pregnant Women in Antenatal Care*, p. 1.

otherwise treat them poorly if they disclose their HIV status. Yet a "lack of disclosure significantly decreases a woman's chance of initiating and adhering to ART."[37] Better counseling on disclosure and integration of HIV services in ANC both has been helping women overcome these barriers.

22. According to the government of Swaziland, "Issues of Stigma and discrimination reduction are discussed but not prioritized in national response."[38] Given the lack of prioritization of this issue, stigma and discrimination related to HIV/AIDS have been widespread within Swaziland. According to the 2011 Stigma Index Report, over 35% of the persons interviewed reported being gossiped about because of their HIV status; 22% said they had been verbally insulted, harassed and or threatened; 12.8% were physically harassed and/or threatened; and 7.7% reported being physically assaulted.[39] Of those reporting such treatment, 57% judged it was because of ignorance of how HIV is transmitted.[40]

IV. The Rights of Women and Girls

23. In addition to the biomedical prevention elements discussed above, protection of the rights of women and girls is an important part of reducing the risk of HIV transmission. Gender inequality greatly increases the risk of acquiring HIV by women and girls and interferes with the ability of those living with HIV to seek treatment.[41] Swaziland reports that "gender inequality is prevalent in the Swazi society due to social-cultural, economic and political factors" and that gender inequality and gender-based violence are part of the key drivers contributing to the spread of HIV in Swaziland.[42]

24. At the same time, Swaziland admits that "Issues of high unemployment, especially among the youth and women, poverty alleviation and stigma and discrimination do not have mitigation plans within the HIV response." The lack of a determined political effort to protect and uphold the rights of women in the context of HIV enables the power imbalance between men and women in Swazi society to continue, making it harder for women to protect themselves and their children from HIV. For example, the traditional power that men maintain in intimate relationships led most female participants in a recent study conducted by EGPAF to report that their partners refused to use condoms.[43]

25. In addition, traditional practices that place women at a higher risk of HIV continue, including "wife inheritance" by a male relative of the deceased husband. The dearth of economic opportunities for women incites many to engage in transactional sex.[44] But the EGPAF study found that "when men are paying for sex, they have full control as women are generally unable to negotiate condom usage and are more vulnerable to abuse in this situation. One man explained that you just needed to offer more money to the woman in order to not use a condom."[45]

26. Swaziland reports an increase in the number of young women aged 15-24 who engage in intergenerational sex, either due to economic necessity or continued societal acceptance of pairing young women and older men. Older men have typically already had several sexual

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[37] Ibid, p. 1 &13.
[38] *Swaziland Global AIDS Response Progress Reporting*, p.24.
[39] Swaziland National Network of People Living with HIV/AIDS, *Stigma Index Report*, June 2011, p.29.
[40] Ibid, p.32.
[41] Eliane Drakopoulos, "UN Committee on Women's Rights Takes Strong Stand on Gender and HIV," 29 July 2013, http://www.pedaids.org/blog/entry/un-committee-on-womens-rights-takes-strong-stand-on-gender-and-hiv. See also: http://www.treatybodywebcast.org/cedaw-55-session-hiv/.
[42] *Swaziland Global AIDS Response Progress Reporting*, p.2.
[43] EGPAF, *An Exploratory Study of the Behaviors and Practices that may Increase HIV Risk among Pregnant and Lactating Women in Communities in Swaziland*, p. 17.
[44] *Swaziland Global AIDS Response Progress Reporting*, p.24.
[45] EGPAF, *An Exploratory Study of the Behaviors and Practices that may Increase HIV Risk among Pregnant and Lactating Women in Communities in Swaziland*, p. 17.

partners and thus a higher exposure to HIV. They also exercise greater power within the relationships and therefore on decisions about using adequate protection. [46] While underage marriage was banned in 2012, it has long been a socially accepted norm and may take time to adequately enforce this ban.

27. Finally, protecting women and girls in Swaziland from gender-based violence and sexual abuse remain a "daunting challenge" for Swaziland that is closely linked with HIV prevention.[47] Swaziland only very recently passed the Sexual Offences and Domestic Violence Bill, and it has yet to conduct a nationalsurvey on gender-based violence.[48] Many women living with HIV report being mistreated or rejected by their husbands or male partners after disclosing their HIV status to their partner, who often refuse testing for themselves and blame women for bringing HIV into their home.[49] Anticipation of such a reaction leads many women to refrain from testing themselves or their children, and may discourage them from adhering to a treatment regime that will give their status away.

V. Proposed Recommendations

Based on the analysis above, the Elizabeth Glaser Pediatric AIDS Foundation would like to propose the following recommendations for consideration by Human Rights Council members:

1. Continue to provide significant financial support for the national HIV/AIDS response, and ensure sufficient numbers of properly trained health care workers to test, counsel, and treat women and infants through the pregnancy and breastfeeding period.
2. Take further steps to improve access to high-quality, age-appropriate sexual and reproductive health care education and services, with a special emphasis on HIV awareness-raising among men.
3. Make greater efforts to address stigma and discrimination, as well as gender inequality and gender-based violence as part of the national HIV/AIDS response, making sure these issues are featured in the investment case to end AIDS in Swaziland by 2022.
4. Take all appropriate measures to end against traditional practices that increase the risk of HIV for women and girls, including "wife inheritance" and intergenerational sex.
5. Ensure full implementation of the Sexual Offences and Domestic Violence Bill, through both public awareness-raising of its prohibitions, and the prosecution of all offenders.

[46] Peter Piot et al, "Advancing Global Health- Defeating AIDS," p.7.
[47] *Swaziland Global AIDS Response Progress Reporting,* p.2-3.
[48] Ibid, p. 20.
[49] EGPAF, *Barriers to Antiretroviral Therapy Initiation for Eligible HIV-Positive Pregnant Women in Antenatal Care*, p. 17.