THE CONTINUED MARGINALISATION OF WOMEN LIVING WITH HIV IN SOUTH AFRICA

A report to the Committee on the Elimination of Discrimination against Women

80th Session – October 2021

This report has been compiled by the following persons on behalf of organisations listed here:

1. Sethembiso-Promise Mthembu- Her Rights Initiative - sethembisomthembu24@gmail.com
2. Mandi Mudarikwa - Women's Legal Centre - mandi@wlce.co.za
3. Khuliso Managa - Women's Legal Centre - khuliso@wlce.co.za
4. Qiqa Nkomo - Women's Legal Centre - qiqa@wlce.co.za
5. Alice L. Brown - ProBono.Org - alice@probono.org.za
6. Juan S. Jaime - Sexual Rights Initiative, juan@srigeneva.com
7. Vicci Tallis - vicci.tallis@gmail.com

INTRODUCTION

1. The organisations and individuals listed above are honoured to submit this report to the Committee on the Elimination of Discrimination against Women (**Committee**) in preparing for the review of the implementation of the Committee on the Elimination of Discrimination against Women by South Africa during the 80th Session – October 2021.

INTRODUCTION TO THE ORGANISATIONS MAKING THE SUBMISSION

2. **Her Rights Initiative (HRI)** is a social impact organisation formed in 2009 to advocate for the sexual and reproductive rights of women, particularly women living with HIV in South Africa. HRI is made up of a group of feminists and women rights advocates claiming their human, sexual and reproductive rights in the context of HIV. Their vision is to create a world where all women including women living with HIV enjoy all their Constitutional rights which are realised and affirmed.

3. The **Women's Legal Centre** ("The WLC") is an African feminist legal centre that advances women's rights and equality through strategic litigation, advocacy, education and training. We aim to develop feminist jurisprudence that recognises and advances women's rights. The Centre drives a feminist agenda that appreciates the impact that discrimination has on women within their different classes, race, ethnicity, sexual orientation, gender identity and disability. The Centre does its work across five programmatic areas including the right to be free from violence, women's rights in relationships, and women's rights to land, housing property and tenure security, women's sexual and reproductive health rights and women's rights to work and at conditions of work.[1]

4. **PROBONO.ORG** was started in South Africa in 2006, as a clearing house to engage lawyers to take on the cases of people who could not afford to pay for their services. With offices in Johannesburg, Durban and Cape Town, it focuses on civil law and operates several legal clinics as well as help desks at courts and other sites. With a staff of 30 and its panel of over 800 pro bono attorneys, ProBono.Org provides legal assistance to over 10,000 indigent and marginalised clients annually. ProBono.Org helps in the areas of labour law, family law, child law, housing, deceased estates, police brutality and refugee law and it supports several community advice offices. In addition, ProBono.Org trains legal professionals and candidate attorneys in various areas of law. Since 2019, with funding from the AIDS Foundation of South Africa as part of a larger programme funded by The Global Fund to Fight AIDS, Tuberculosis and Malaria, ProBono.Org has rendered legal support to members of key and vulnerable populations who face barriers in accessing HIV and TB services.[2]

5. **The Sexual Rights Initiative** is a coalition of national and regional organizations based in Canada, Poland, India, Egypt, Argentina, and South Africa that work together to advance human rights related to sexuality at the United Nations.[3]

[1] Website: www.wlce.co.za
[2] https://probono.org.za/
[3] https://sexualrightsinitiative.com/

INFORMING CONTEXT

Intersectional Identities of Women Living With HIV in South Africa

6. The persistence of the HIV epidemic in South Africa and the related intersectional burdens faced by women based on race, gender, age, class social origin and pregnancy has devastating impacts on the health outcomes and realisation of the rights of black women living with HIV in South Africa. The HIV epidemic disproportionally affects young Black women.[4] More women than men specifically young women[5] are eight times more likely to be HIV positive.[6] There are various factors that increase the risk of young women contracting HIV which include women's traditional subordinate role in society; the expectation of women to fulfil caretaking responsibilities; violence; "*the general misinformation regarding and ignorance regarding HIV; disrupted family and communal life due in part to apartheid, migrant labour patterns and high levels of poverty; and finally, the existence of a settled transport infrastructure allowing for the high mobility of persons and therefore the rapid movement of the virus into new communities.*"[7]

7. Customary practices and habits that entrench women as subordinates in their homes and society and exploit them for the benefit of men especially in intimate partner settings, increase women's vulnerability to contracting HIV.[8] For instance, resistance to use condoms because of distinct sexual, cultural norms, values and "*social norms which allow or promote high numbers of sexual partners especially among men; the phenomenon of an extended family household structure; preference for male children; the practices of polygamy; the bride price; wife inheritance, the prevalence of superstition, and adherence to the culture of silence.*"[9] Such norms and value systems hinder women's ability to negotiate safer-sex.[10]

8. The majority of women[11] in a study on poverty, knowledge of HIV and risky behaviour, stated that lack of control over decisions pertaining to financial issues as one of the reasons for engaging in risky sexual behaviour.[12] "*The likelihood of engaging in risky sexual behaviour was higher among women from poorer households relative to those from more*

---

[4] Mswela M. 'CULTURAL PRACTICES AND HIV IN SOUTH AFRICA: A LEGAL PERSPECTIVE' (2009) 12:4. *PER.* Pg. 174-175. See: http://www.scielo.org.za/pdf/pelj/v12n4/a07v12n4.pdf

[5] Aged between 15 and 24 years.

[6] UNAIDS. 'Report on the Global AIDS epidemic' (2010). Pg. 10. See: https://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20101123_globalreport_en%5B1%5D.pdf

[7] Mswela M. 'CULTURAL PRACTICES AND HIV IN SOUTH AFRICA: A LEGAL PERSPECTIVE' (2009) 12:4. *PER.* Pg. 174-175. See: http://www.scielo.org.za/pdf/pelj/v12n4/a07v12n4.pdf

[8] Mswela M. 'CULTURAL PRACTICES AND HIV IN SOUTH AFRICA: A LEGAL PERSPECTIVE' (2009) 12:4. *PER.* Pg. 175-176. See: http://www.scielo.org.za/pdf/pelj/v12n4/a07v12n4.pdf

[9] Mswela M. 'CULTURAL PRACTICES AND HIV IN SOUTH AFRICA: A LEGAL PERSPECTIVE' (2009) 12:4. *PER.* Pg. 175. See: http://www.scielo.org.za/pdf/pelj/v12n4/a07v12n4.pdf

[10] Kasiram M, I. et al. 'HIV/AIDS AND WOMEN: SOUTH AFRICAN PERSPECTIVES' (2013) 12:1. *African Journal of Indigenous Knowledge Systems.* Pg. 68. See: https://www.researchgate.net/publication/265595300_HIVAIDS_AND_WOMEN_AFRICAN_AND_SOUTH_AFRICAN_PERSPECTIVES/link/54136a610cf2788c4b3597dd/download

[11] 92%.

[12] Tladi LS. 'Poverty and HIV/AIDS in South Africa: an empirical contribution' (2006) 3:1. *SAHARA-J: Journal of Social Aspects of HIV/AIDS.* Pg. 370. See: https://www.tandfonline.com/doi/pdf/10.1080/17290376.2006.9724863?needAccess=true

affluent ones."[13] The lack of access to confidential sexual and reproductive health services prevents girls and young women from obtaining essential HIV prevention information which exacerbates their risk of infection.[14]

Gender Exclusions in Global AIDS Policy Framework

9. The global HIV/AIDS policy is gender discriminatory and further marginalises women living with HIV. The policy framework has resisted to consider HIV positive women as a key population vulnerable and impacted by HIV. Key populations in HIV are prioritised for research and policy interventions. This exclusion and marginalisation express gendered geopolitical controversies in HIV/AIDS policy. In developing countries like South Africa, it is young, poor Black women who are vulnerable and living with HIV. Women account for 60% of people living with HIV in South Africa. Young women account for more than a third of this population. The AIDS policy should be defining women living with HIV as key populations in the case of South Africa. This situation confirms the status, the position, silencing and exclusion of HIV women in AIDS policy.

10. The global HIV policy views women living with HIV as mothers. Women as mothers' approaches by their very nature are about inclusion and exclusion of women in the institution of motherhood. Here the personal becomes political. These approaches validate, intensify and silence the racialised, class-based, disease-based exclusions and post-colonial governability of women's reproductive abilities through medical interventions, government policy and laws. As it can be seen in this submission, women as mothers' approaches lead to human rights violations, is gender discriminatory and is violence against women living with HIV. Eugenics, neo- Malthusianism and population control establishment thrive in this environment.

KEY AREAS OF CONCERN:

STATE-SANCTIONED FORCED AND COERCED STERILISATION OF WOMEN LIVING WITH HIV/AIDS[15]

11. In a report dated February 2020,[16] the CGE found that the rights of women who lodged a complaint with them had been violated including rights to equality; dignity; bodily integrity

[13] Tladi LS. 'Poverty and HIV/AIDS in South Africa: an empirical contribution' (2006) 3:1. *SAHARA-J: Journal of Social Aspects of HIV/AIDS.* Pg. 370. See: https://www.tandfonline.com/doi/pdf/10.1080/17290376.2006.9724863?needAccess=true

[14] UNAIDS. 'HIV prevention among adolescent girls and young women' (2016). Pg. 4. See: https://www.unaids.org/sites/default/files/media_asset/UNAIDS_HIV_prevention_among_adolescent_girls_and_young_women.pdf

[15] This section of the report relies on the work being done by Her Rights Initiative ('HRI') as an organisation working directly with victims of forced and coerced sterilisation who are also women living with HIV, on the work being done by the Women's Legal Centre ('WLC') in offering legal advice and litigating the violations of rights related to forced and coerced sterilisations as well as two studies that have documented the practice of forced or coerced sterilisation of women living with HIV in South Africa.#

[16] Commission for Gender Equality, *Investigative Report: Forced Sterilisation of Women Living with HIV and Aids in South Africa* February 2020, accessible at: http://www.cge.org.za/wp-content/uploads/2016/12/Forced-

and freedom and security over their bodies; and the highest attainable standards of health including sexual and reproductive rights were violated. The CGE found that:

- Complainants were not provided with adequate information on the sterilisation procedure before their consent was obtained;
- Complainants were not advised of alternative methods of contraception;
- They were subjected to cruel, torturous or inhuman and degrading treatment;
- The medical staff breached their duty of care towards the complainants; and
- The consent forms produced in some of the cases were not indicative of informed consent.

12. Black, pregnant, women living with HIV from lower-income families and communities, who rely solely on state-funded healthcare were targeted. The intersection of their identities rendered them more vulnerable to forced and coerced sterilisation than any other group of women in South Africa.[17]

13. Victims of involuntary sterilisation have reported experiencing negative psychological symptoms most notably those related to anxiety, stress and depressive symptoms.[18] Many victims have also reported multiple physical or negative health effects (complications) as a side effect of the sterilization surgery.[19] Generally, and especially in Africa, a woman's ability to bear children is closely linked to her worth and essential identity as a woman. The inability to bear children due to being sterilised, willingly or not, is seen as a failure. It renders women as valueless and undesirable for men as reproduction is considered an essential component of any relationship.[20] The social, cultural and gendered pressure on women to bear children inevitably implicates their self-worth and dignity.[21]

Enabling Environment as created by the Sterilisation Act 44 of 1998

14. The Sterilisation Act does not provide enough protection to ensure that proper and informed consent is obtained and has recommended that the National Department of Health ('NDOH') review its provisions and interrogate consent forms for sterilisations to ensure that they offer adequate and effective protection. [22] The CGE also intends on submitting a petition to amend all legislation regulating consent to the South African Law Reform Commission ('SALRC').

15. The CGE also recommended that the report be referred to: The Health Professionals Council ('HPCSA'); The South Africa Nursing Council ('SANC'); The National Department of Health

---

Sterilisation-Report.pdf. The investigative report was released in February 2020 and investigated the practice of forced sterilisation of women living with HIV/AIDS following a complaint lodged in March 2015 by HRI and others represented by the WLC. The complaint documented the accounts of 48 women who had experienced forced or coerced sterilisation.

[17] Strode, Mthembu & Essack (2012) Reproductive Health Matters 63;

[18] Mnguni *Report on forced sterilization*; K Bakare & S Gentz "Experiences of forced sterilisation and coercion to sterilise among women living with HIV (WLHIV) in Namibia: an analysis of the psychological and socio-cultural effect" (2020) *Sexual and Reproductive Health Matters* 339.

[19] Mnguni *Report on forced sterilization*; Bakare & Gentz (2020) *Sexual and Reproductive Health Matters* 340.

[20] M du Toit "Involuntary sterilisation of HIV-positive women in South Africa: A current legal perspective" (2018) 11 SAJBL.

[21] du Toit (2018) SAJBL 1.

[22] Commission for Gender Equality *Investigative Report: Forced Sterilisation of Women Living with HIV and Aids in South Africa*.

('NDOH'); and The South African Law Reform Commission ('SALRC'). The HPCSA and SANC determine the standards of ethical and professional practice for registered health practitioners and have the power to institute disciplinary proceedings against a person registered with the Council in accordance with the rules set by the Professional Board. Thus far, however, neither of these bodies have taken any proactive steps in response to the CGE's recommendation. They have extended an invitation to women wishing to lay a complaint against specific health care personnel but unfortunately, this remedy depends on the complainant knowing the name and position of the person who violated their rights, and this is most often not the case in these complaints. Both organisations have not taken any remedial measures to ensure that the practice does not continue to be practised by medical practitioners.

16. The CGE has also recommended that the NDOH facilitate a dialogue with the complainants to find ways of providing redress for the complainants, among other recommendations. In response to this, the Minister of Health put together a Ministerial Task Team made up of medical professionals employed in the Department of Health and under the directorate of dealing with family planning services. The Task Teams mandate is to engage with women living with HIV/AIDS who have been forced and coerced into sterilisations on an appropriate response to the forced and coerced sterilization that took place in public hospitals. The establishment of the Task Team and their terms of reference is indicative of the fact that the Department of Health acknowledges that women were forced / coercively sterilized in public hospitals in South Africa and that they are willing to take steps to address the issue. The work of the Task Team is currently pending.

Prescription Hurdle

17. Though there is no shortage of mechanisms available to women through Courts in South Africa, unfortunately, section 11 of the Prescription Act 68 of 1969 ('Prescription Act') limits women who have been sterilised access to courts and civil claims as it only allows for the institution of claims within the 3 years after a victim is aware of their cause of action.

18. Most women who were forced/coerced sterilization were aware at a medical level that the procedure had been done or became aware shortly after but due to circumstances and language and terminology used to justify the procedure as necessary, commonplace and/or due processes, a lot of the women were unaware that the practice was done contrary to their constitutional rights and that legal recourse was available to them. Many of the cases dated before 2018 have accordingly prescribed.

19. The problem of a passage in time not only affects access to courts. This is likely to be a problem with all possible avenues available to women. Hospitals are only required to keep medical records for a minimum of 6 years[23] and with time some files may go missing and related personnel might pass or move on to other undisclosed locations making it difficult to acquire the information necessary to pursue reparations.

20. The mechanisms available to women are not always utilised for several reasons. The contributing factors include socio-economic inequalities that impact the provision of, and

[23] HPCSA *Guidelines on the Keeping of Patient Records* (2016) 3.

access to, adequate legal representation for the poor; systemic inefficiencies in the administration and functioning of the courts and government bodies, which leads to an inordinate number of postponements of cases and a loss of faith in the system; a high demand for legal aid services which remain unmet by the current resource provision; a lack of access to information about the rights women have and the mechanisms available to protect and exercise these rights.[24]

WOMEN'S HEALTH POLICY

21. South Africa does not have a women's health policy, as such government programmes are not able to make provisions for women's health, as defined by the World Health Organisation. Policies facilitate the measurement of progress and hold the public service to account. Women can only enforce their rights in this area if there is a policy in place. A policy leads to the development of implementation plans and allocation of budget.

22. The National Health Act of 2003 does not provide for women's health, it only provides for maternal health and family planning, the women as mothers' approaches to health. The proposed National Health Insurance (NHI) policy discourse is hardly gendered nor informed by women's realities of health. Indeed, the lack of feminists' participation and analysis in the NHI policy development is indicative of the state of the women's rights movement in South Africa. Human rights in health and in HIV are understood from the perspective of access to health care. In this logic, the oppressive nature of health as a system of power is silenced. As such human rights commitments in health are not coupled by programmes, budgets and implementation plans. The right to choose and access safe contraceptives are articulated in policy background pages, but not provided for financially and programmatically in the delivery of contraception. It is for this reason that institutions advancing women's rights must have a focus on health as human rights, but also as one of the worst patriarchal institutions of power where women's bodies and lives are captured and violated.

23. The evaluation of these programmes from the human rights perspectives are neither included in the policies, nor funded within the contraceptives funding frameworks. The policies have not been subjected to human rights evaluation or analysis by any of the human rights bodies.

ENDING AND CONTROLLING WOMEN'S FERTILITY| DEPO PROVERA

24. Contraception is a paradox. Contraceptives give women the power to control their fertility and make it possible for women to exercise their reproductive autonomy. On the other hand, contraception is embedded in patriarchal systems of eugenics, racisms; politics, and geopolitical relationships of exploitation, population control and colonial and neo-colonial population control strategies. Depo Provera (DP), an injectable hormonal contraceptive has

[24] L Greenbaum "Access to justice for all: a reality or unfulfilled expectations?" (2020) *De Jure Law Journal*.

been associated with controversy for more than four decades. For decades, DP programmes have been criticised for targeting poor women and women of colour in developed countries and later in developing countries.[25]

25. During the 1970s and 80s, DP has been subject to deregistration and in some instances registrations with strict restrictions in the United States and many European countries. DP has been subject to banning, plethora of litigation, class actions on consent, side effects, among many other reasons. DP has been litigated in its form as an injection and an implant, the Implanon. DP has also been litigated for unethical research practises targeting poor women in developing countries. DP is registered for use in many developing countries, including South African countries.

26. In recent times, the primary justifications for the radical distribution of DP in poor women is to curb the spread of HIV and AIDs pandemic, and to minimise the high rates of maternal mortality, teenage pregnancy and reduce urban poverty.[26]

South African Contraceptives Policy

27. The National Family Planning Programme of 1974 was the first coherent contraceptives policy of Apartheid South Africa. This policy was intended to control and end the fertility of Black women and women of colour and was in concert with the global eugenics and population control at the time.

28. This long-standing policy was only replaced in 2003 – almost a full decade after democracy in South Africa. The Department of Health's Contraceptives and Fertility Planning Service Delivery Policy Guidelines 2012 (revised in 2018) are two most recent policies in South Africa. The Department of Social Development (2019) reported that in 2016, about 59% of sexually active women of ages 15-49, were using contraception in South Africa. More than 90% of injectables and implants were dispensed from government clinics and community health centres.

29. The Department of Health's Contraceptives and Fertility Planning Service Delivery Policy Guidelines 2012 and 2018 policy lists HIV positive and young women as target populations for contraceptives programmes. This provides a conducive environment for coerced and forced contraceptives in these groups of women. The justifications for targeting this population are to reduce the rates of HIV infection, teenage pregnancy and high rates of maternal mortality. The justifications are in line with global priority on contraceptives, FP 2020, codified by a private philanthropists' organisation and endorsed by WHO and UNFPA.

30. These justifications are hardly advancing women's rights and choices. Teenage pregnancy, vulnerability to HIV infection and high rates of maternal mortality are outcomes of patriarchal commodification and violation of female bodies, poverty fuelled by the exclusion of women in the economy and access to wealth and opportunities, colonialism, racism amongst others. Deploying DP to poor female bodies is secondary victimisation, and unduly placing the blame and responsibility for teenage pregnancy, HIV AIDS and maternal

[25] Brown, 1987; Kaufman, 2008; Klausen, 2004; Kaler, 1997; Cooper, *et al.* 20000.
[26] Family Planning 2020, 2012; Bill and Melinda Gates Foundation, 2018.

mortality on poor women and girls. This blame and targeting have severe consequences on these women on a personal level and as groups.

Side Effects of Depo Provera

31. Despite several warnings, including the 2004 FDA's Black Box warning for Depo Provera ('DP') due to serious side-effects, it is registered for use in South Africa and listed on The Standard Treatment Guidelines and Essential Medicines List for South Africa 2018 (National Department of Health, 2018). The 2004 FDA's Black Box warning is not included in any South African policies, nor has formed part of public regulation and policy discourse on contraceptives. The 2012 and 2018 policies make no mention of the Black Box warning. Side effects of DP have long been a concern for South African women. Side effects of DP include delays in returning to fertility; infertility, significant loss of bone mineral density; heightened risk of cervical cancer in women who start to use DP under the age of 35, excessive menstrual bleeding, weight gain, depression; ectopic pregnancies, blood clots in arms, legs, lungs, and strokes.[27]

32. Studies have also revealed that DP heightens the risk of tuberculosis in women.[28] DP also has an unintended consequence of significantly increasing a woman's susceptibility to HIV/AIDS and all other STDs as the high dose of progesterone in DP induces thinning of the vaginal epithelium.[29]

33. The commonly communicated side effects in South Africa are bleeding and weight gain. These are verbally communicated to women in clinics or when women report these to healthcare workers. The Contraceptives programme does not provide information women can take home to read. The insert of the injection information and side effects is never given to the women. There are no dedicated programmes to prevent and treat side effects of DP and no mechanism to measure its cost to women's lives and the health system.

34. Side effects of DP listed above intersect with HIV infection, cervical cancer and other issues of concern to women living with HIV. Most side effects impact on the bodies, lives, and rights of women in the long term. Women's bodies cannot be divided into parts. Women are subject to all these injustices, as such, issues of health rights and dignity of HIV positive women should be acknowledged and addressed systematically, rather than vertical issues.

35. It is a concern that DP continues to be dispensed to women, given all this knowledge about its dangers. The regulators issue warnings, but not ways to improve the drug, or completely remove it from the medical lists. The pharmaceutical industry, the drug regulators, international governance, and national governments all bear responsibility.

DP Innovation, HIV and Unethical Research

36. In recent times, the science-biomedical innovation field is innovating and developing new preparations of DP in order to expand the use of DP in large scales. The syringe will expand access to use of the injection. Health care workers can take this to women at home and in

[27] Pfizer, 2010.
[28] Tomasicchio, et al. (2019).
[29] Heffron, 2012.

other accessible areas.[30]. The South African Health Regulation Authority has approved these formulations.

37. This injection will eliminate the need for health care workers to administer the injection. Research on the efficacy and feasibility studies and regulatory framework of this injection have been completed in South Africa; and the injection will soon be rolled out to communities. These innovations and repackaging of DP follow the novel implant, Implanon, recently introduced into South Africa. Norplant is essentially DP prepared as an implant; and is released to the body over the period of three years. Implanon has similar side effects as straight DP and has been subjected to litigation in different countries – the US, Canada, and the United Kingdom.

38. According to the Rebecca Project for Justice (2014), the safety and side effects of DP have not been responded to by the scientific community. Improving DP through the lens of safety has not been prioritised in research, while research and development on other preparations of contraceptives has been limited. Most research has focused on justifying DP in its current form and on developing various preparations of DP as a way of expanding its usage. DP is integrated into post-abortion care programmes.

39. The Evidence for Contraceptive Options and HIV Outcomes -Echo- was a study investigating linkages between the use of DP and high risk of HIV infection published in 2019. This was a reaction to one of the studies that had confirmed the link between DP and heightened vulnerability to HIV infection, the 2011 Heffron study. There was huge ethical discourse about conducting an additional confirmatory study on linkages of DP to HIV infection whilst a plethora of retrospective studies had confirmed DP's associations with high rates of HIV infection in women. The study did not ask the question about safety of DP, but rather looked at all hormonal contraceptives in relation to exposure to HIV infections. Indeed, the results kept DP's position intact.

40. Contraceptive's funding frameworks are systematically flowing from bilateral agencies, UN agencies, high levels of governments, and pharmaceutical companies. The UNFPA does not resource them in the system neither do they evaluate or at the very least ensure that women have access. These agencies are intimately involved in the implementation of DP even at the community clinic level, and schools. UNFPA officials are placed at National, Provincial, Regional, District and Local government health authorities throughout South Africa.

41. In recent times UNFPA officials are also populating the offices of the Department of Education at all levels of government. Their primary role is policy and to ensure efficient implementation of contraceptives programmes. They set the policy agenda and have a central role in policymaking. UNFPA believes that human rights safeguarding, and protection are the responsibility of states, and that they will not be involved in matters of human rights in states.

[30] Cover et al., 2016; Bill and Melinda Gates Foundation, 2012.

Forced Use of DP

42. DP is linked to the forced sterilisation as it is part of the systematic state led interventions to end fertility of HIV positive women. The Human Sciences Research Council (HSRC) and the South African National AIDS Council (SANAC) 2015 Stigma Index Study found that 37% of women who participated in the study were forced into taking DP in the past twelve months.[31] This violation is facilitated through the global HIV/AIDS and SRH integration project alluded to earlier in this submission. In some instances, DP is positioned as a conditionality for HIV treatment.

43. In 2018, there were reports that girls in schools in one of South African rural provinces, Limpopo were forced to take DP without consent of their parents and guardians.[32] In the same year the MEC for Health in the province of KwaZulu-Natal, Dr Dlhomo was reported to have forced students who benefitted from a government bursary to study medicine and pharmacy in Cuba, the Mandela-Castro Programme to be inserted with the implant, Implanon as a conditionality for their bursary.[33] The MEC's justification for this violation was to ensure that pregnancy did not interrupt their studies and jeopardise the investment of the Department in the students.

CERVICAL CANCER

44. Women living with HIV are five to six-times more likely to develop Cervical Cancer compared with women who are not HIV positive.[34] According to Denny (2006) Cervical Cancer progresses faster, it is more aggressive, and appears at a younger age in women living with HIV than in other groups of women. Studies also found a bidirectional relationship between Cervical Cancer and HIV infection in that women with Cervical Cancer were much more likely to acquire HIV infection.[35] With expanded access to antiretroviral (ARV) treatments, HIV-positive women are living longer, and Cervical Cancer will increase the disease burden to HIV positive women.

45. Cervical Cancer is a disease of poor Black women.[36] In South Africa, black women, particularly in rural areas, are at heightened risk for Cervical Cancer to the extent that approximately 84 percent of all South African women diagnosed with Cervical Cancer are black.[37] Arnolu (2008) reported that between 60–70 percent of women dying of Cervical Cancer are from rural areas. The rate of morbidity and mortality due to Cervical Cancer has increased and in the year 2000, deaths because of Cervical Cancer in South Africa exceeded maternal deaths. This increase in morbidity and mortality has been associated with the emergence of HIV and AIDS.

HPV Vaccines

[31] Cloete et al. 2014.
[32] SABC News, 2018.
[33] Maqhina, 2014.
[34] CDC 1993, Moodley 2006, Stelzle et.al. 2020.
[35] Moodley, 2006.
[36] Denny, 2006 Arnolu, 2008.
[37] Stevens & Adar, 2000, Doyal & Hoffman, 2009.

46. HPV vaccines are licensed and registered in South Africa. Provision of these in the public health sector for primary prevention purposes is limited to girls in schools between ages 9-14. Furthermore, as primary prevention interventions, HPV may be of no value to HIV-positive women because many already have HPV; therefore, secondary prevention and treatment of Cervical Cancer efforts should be explored.[38]
47. Despite recommendations by the WHO, women living with HIV do not have access to these vaccines in South Africa. These are not provided for in HIV/AIDS treatment policy and global funding mechanisms. There is a need for WHO to expand knowledge on HPV vaccine and HIV infection in women. The impact of the HPV vaccine in delaying disease progression and safety in HIV-positive women is unknown because HIV positive women were excluded from the research. Exclusion of women living with HIV in life saving treatments is a norm in biomedical research.

Intersection of Cervical Cancer and Forced Sterilisation of HIV Positive Women

48. There are intimate intersections between forced sterilisation of women living with HIV and Cervical Cancer. Some of the victims of forced sterilisations were sterilised through hysterectomies (removal of the womb). The doctors justified this violation of women's bodily integrity and violently ending women's fertility as an intervention to prevent the development of Cervical Cancer later in life. These were conducted without conducting screenings for such Cancer. Calls for HIV-positive women to claim their rights to prevention and treatment of Cervical Cancer should be cognisant of the need to safeguard and monitor other rights, which may be jeopardised because of the provision of treatment.[39]

Cervical Cancer Policy

49. South Africa currently does not have national policies which address Cervical Cancer prevention and treatment in HIV-positive women. Cervical Cancer is not provided for in HIV policy, treatment and other national funding mechanisms, in HIV, SRH, and the proposed NHI policy framework. Screening and treatment of Cervical Cancer in HIV-positive women is critical and a matter of priority.[40] The WHO first recommended that HIV-positive women should be screened annually for abnormal cells through a Pap smear and that treatment should be treated as early 2000.[41]
50. Pap smear as a cervical smear used as a method of screening for Cervical Cancer[42] is recognised by the South African Medicines Control Council and is therefore the only authorised screening method in South Africa.[43] This guideline is not followed in South Africa. Where programmes are available, they are piecemeal, conducted on a small scale, poorly coordinated, dependent on non-governmental organisation (NGO) support, and not delivered as women's rights to health and dignity, but as a form of charity and short-term

[38] Hale, 2009.
[39] Mthembu et al., 2011.
[40] Franceschi & Jaffe, 2007.
[41] WHO, 2000.
[42] Leopold and Koss, 1993.
[43] Hoffman et al., 2003.

welfare. Charitism and welfarism has its own politics and, among others, they may not be held accountable and may be detrimental to women's rights advocacy. These tend to reinforce the dominant discourse of gender oppression, on the rights of women and violation of rights of women and the ideas of women as mothers in approaches. Piecemeal public sector programmes emphasise Pap smears, paying scant attention to whether smear results are accessed or whether abnormal smears, and that Cervical Cancers are treated.

51. The global HIV policy views women living with HIV as mothers. The ideology of early global responses to HIV focusing on prevention of mother to child transmission whilst not saving the lives of the mothers is the source of this continued instrumentalisation of bodies of HIV positive women. This ideological position of AIDS policy has directly impacted on Cervical Cancer not being prioritised in HIV/AIDS treatment advocacy and delivery work. Cervical Cancer is systematically excluded from global AIDS treatment policy and funding mechanisms.
52. Cervical Cancer is a marginalised disease because it affects women outside of their reproductive age. It affects empty wombs and female bodies which are deemed not worthy of public investment. We believe that social status, social exclusions, and the level of public participation of women living with HIV as citizens is one of the reasons for lack of prioritisation of Cervical Cancer policies. In addition, in South Africa health-rights issues pertaining to HIV-positive women are not prioritised and advocacy on these issues is also limited. Other contributing factors include social, health systems, human rights and political barriers.

Global HIV/SRH Integration Project

53. UNFPA, WHO and UNAIDS have, over two decades, promoted policies and programmes integrating SRH services into HIV treatment and prevention. Looking closer at these policies, they integrate contraceptives and fertility control interventions targeting women living with HIV and poor young women who are at high risk of teenage pregnancy and HIV infection. These policies have failed to integrate Cervical Cancer in HIV programmes. Cervical Cancer is the main sexual and reproductive health issue in AIDS and HIV.
54. The global integration project has created a fertile environment for forced sterilisations of HIV positive women. These integration projects have created a policy vehicle for forced contraception of poor Black HIV positive women and young women. In our case, the integration project is integration of sexual and reproductive violation in HIV programmes. UNFPA, WHO, UNAIDS have stood on the side when violations of our rights surfaced. There has never been a discourse about the direct role of these global policy instruments in the violation of our rights.

Human Rights Policy in Aids/Aids Policy

55. The stigma and discrimination language of the AIDS policy is not gendered and is silencing human rights violations in HIV. Human rights violations of women living with HIV tend to fall out of these parameters. This is in the backdrop of the level of participation and safe spaces for women living with HIV in policy spaces. Issues of forced sterilisations, cervical cancer and many others have been for years, regarded as belonging to human rights bodies, SRHR bodies, rather than HIV bodies. The outcome has been that the issues have remained

unacknowledged and unresolved. The HIV human field has adopted a culture of documentism. This is perpetual documentation of human rights violations without context, analysis, gender analysis, and desire to address those rights. The example can be found in how the field documented forced sterilisations and contraceptives but did not act on their own findings. The Stigma Index is the global programme of UNAIDS.

56. The South Africa Stigma Index report is branded with the UNAIDS logo and logos of many other organisations advancing human rights in AIDS, however five years later, they did not take any actions to address violations of other rights of women living with HIV. They have not made efforts to listen to the voices of the victims, who are HIV positive women, the population group they are mandated to protect and advance their interest.

THE INTERSECTION OF VIOLENCE AGAINST WOMEN AND HIV STATUS

57. The relationship between GBV, interpersonal violence (IPV), and HIV is bidirectional and closely connected.[44] *'Violence against positive women is any act, structure or process in which power is exerted in such a way as to cause physical, sexual, psychological, financial or legal harm to women living with HIV.'* .[45]
58. Some women are at risk of IPV following disclosure of their HIV positive status or following screening during pregnancy. Moreover, the fear or threat of IPV can also act as a deterrent to testing for HIV and discourage women from disclosing their HIV-positive status. This fear or threat may also act as a barrier to treatment uptake and adherence and may disrupt HIV prevention services and result in poorer HIV outcomes. "Compared with an HIV-negative woman, a woman who discloses her HIV-positive status to a partner of unknown HIV status is more likely to experience physical and emotional abuse."
59. Women (and men) who have been subjected to GBV are more likely to engage in behaviours, such as alcohol or drug abuse, which can increase their risk of acquiring HIV. [46] "In South Africa, women with violent and controlling male partners were 1.5 times more likely to acquire HIV compared with women who had not experienced partner violence." [47]
60. An HIV positive diagnosis for a woman does not suddenly end the violence; in fact, such a diagnosis means that the violence takes a different nuance. Structural, cultural and direct violence against women ('VAW') living with HIV is an integral part of the experience of being an HIV positive woman. This ecological model of responding to VAW identifies society, community, relationship and individual as four forms and sites of VAW.[48]
61. There is an overlap of social determinants of HIV infection and social determinants of violence. This suggests that often the violence experienced by HIV positive women mirrors violence experienced by women generally. HIV positivity, however, exposes

[44] Kasiram M, I. et al. 'HIV/AIDS AND WOMEN: SOUTH AFRICAN PERSPECTIVES' (2013)12:1. *African Journal of Indigenous Knowledge Systems.* Pg. 68. See: https://www.researchgate.net/publication/265595300_HIVAIDS_AND_WOMEN_AFRICAN_AND_SOUTH_AFRICAN_PERSPECTIVES/link/54136a610cf2788c4b3597dd/download

[45] Hale, Vazquez, 2011.

[46] [SAMJ December 2016, Vol. 106, No. 12, "The dual burden of GBV and HIV in adolescent girls and young women in South Africa']

[47] [SAMJ December 2016, Vol. 106, No. 12, "The dual burden of GBV and HIV in adolescent girls and young women in South Africa'] Lancet 2010; 376 (9734): 41 – 48. See footnote 11]

[48] Heise, 1998; Dahlberg & Krug, 2002; World Health Organization & London School of Hygiene and Tropical Medicine, 2010).

women to violence in new situations.[49] HIV positivity becomes one more determinant of violence against women.

62. The HIV positivity induced forms of violence intersect with pre-HIV positivity forms. One example can be found in the violence experiences of HIV positive women who are victims of forced sterilisations as explained above. HIV positivity pushes women further down the hierarchy of power in society. This makes it harder for women living with HIV to attract social solidarity or successfully seek justice for violence.

National Policy and Research

63. The information on violence against HIV positive women and types of violence HIV positive women experience remain hidden in South Africa. This is partly due to lack of systematic research and programmes on this issue and a resistance to categorise violence because of HIV positive diagnosis.
64. In some instances, violence against HIV positive women is framed under the headings *'stigma and discrimination'* and/or '*violation of sexual and reproductive rights'*. This language silences violence HIV positive women face as a direct consequence of HIV infection intersecting with other determinants of violence in their lives.
65. Statistics South Africa does not include HIV infection in collecting data on incidents of violence against women. All South Africa administrative data (data from police, criminal courts, healthcare centres, Thuthuzela Centres and others) on VAW does not include HIV positivity in women as an indicator and variable in documenting and understanding VAW.
66. South Africa has high rates of femicides. A young South African woman living with HIV, Gugu Dlamini was murdered for disclosing her positive HIV status in 1997. This was the first case of a woman living with HIV murdered for disclosing her HIV status and certainly not the last. However, HIV positivity in women is not listed as a variable in collecting data on femicides. Anecdotes from the community, media reports from femicide criminal Court cases do indicate that some perpetrators list HIV infection as a reason/justification for killing a woman.
67. The National Strategic Plan on Gender Based Violence and Femicides 2020-2021 considers violence from the perspective of vulnerability to HIV infection, and neglects VAW from the perspective of HIV positivity perspective. Forced sterilisations and other forms of violence against HIV positive women were not incorporated into the strategy apart from HIV positive women making written submissions of the issues such as forced sterilisations.
68. Participation of HIV positive women in policy spaces for VAW and HIV is limited owing to the lack of organisations, social status and position of HIV positive women in South African policy; political discourses and violence against women establishments.
69. The National Strategic Plan on HIV, Tuberculosis and STI's 2017-2022 does not acknowledge nor make provisions for research and programmes on HIV positive women.
70. South Africa's response to violence against women is limited as it focuses on the criminal justice approach.
71. Policies and programmes on HIV positive women's sexual and reproductive health and rights have not been framed as 'violence against women', although these falls squarely into

[49] Hale and Vazquez, 2011.

the definitions proposed by the United Nations Declaration on VAW, or the Beijing Platform for Action.

Ideology of International AIDS Policy, Research and Programmes

72. The violence women living with HIV face are framed as 'stigma and discrimination', or lack of respect for human rights, and only rarely are they referred to as violence against women, even when they are clearly within the definitions of VAW.[50]
73. Many experiences of violence are framed as being a 'lack'; of capacity, of access, or of informed consent. This type of language suggests that there are technical deficits.
74. This application of public health logic in understanding violence against HIV positive women amounts to neutralisation of experiences which are clear manifestations of structural, cultural and/or direct violence against living with HIV.
75. Some interventions are designed by behaviourists and epidemiologists to change 'risk behaviour', or to achieve public health goals of reducing HIV transmission, rather than to address violence against HIV positive women specifically.
76. Rights based approaches are clearly important in addressing VAW against women living with HIV. However, rights-based approaches are hardly not gendered; they fail to consider the lived experiences of women, in this case HIV positive women, underlying geographical, world system, racial and class.
77. Application of rights-based approaches may not capture violence against HIV positive women because rights-based approaches in health are centred on public health understanding of rights as limited to 'access to health services as a right'. Furthermore, rights-based approaches are mostly written in the background pages of policies, they do not make it to programmes, budgets, and implementation plans of the policies.

HIV Status and parenthood

78. Some women living with HIV have reported losing custody and access of their minor children as the HIV status is unjustifiably brought as a consideration in the case and used against her ability to parent. Bringing HIV status humiliates the women. Some of the women will drop to pursue custody because of the humiliation. Some HIV positive women face similar situations in Divorce Courts.

WOMEN LIVING WITH HIV LIVING IN RURAL AREAS

79. In general, rural women in South Africa often face numerous structural barriers that limit their ability to fully exercise their rights. These barriers arise from inequities and discrimination based on their gender, their economic status, and their geography. Amongst other things, rural women often face extreme poverty and limited access to quality services, education, and information. Moreover, rural women in areas governed by traditional leaders and customary law often face disadvantage and discrimination in various forms including property disinheritance, for instance.

[50] Hale and Vasquez, 2011.

80. For rural women living with HIV, these structural barriers can have an exponentially adverse impact on their health and well-being. Based on their geography, rural women with HIV can have poor access to quality education, particularly comprehensive sexuality education, which can result in them having a more limited understanding of how HIV is transmitted. Based on their geography, they can have poor access to infrastructure, which negatively impacts upon their ability to travel to, and access, health care facilities. In addition, based on their economic status, many of these women face food insecurity. In turn, all these factors can adversely affect the ability of HIV positive rural women to, in the first instance, access antiretroviral (ARVs) and other medications and, if they are already on ARVs, to remain adherent to their drug regime and avoid defaulting on their medications.
81. Further, rural women often face property disinheritance and insecurity. And these inequities can be worsened by HIV, especially for widows whose husbands have died from AIDS-related causes.
82. In rural locations, as well as urban ones, women are often the primary caretakers of the sick and afflicted and, in rural settings, this responsibility can be especially onerous. Indeed, as noted by some researchers: "the disproportionate share of AIDS-related caregiving by women and girls imposes a heavy toll on their own well-being, often leading to their increased vulnerability to HIV infection".

*******ENDS********