THE CONTINUED MARGINALISATION OF BLACK WOMEN WHO ARE HIV POSITIVE IN SOUTH AFRICA

A report to the Special Rapporteur on rascim and the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

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KEYWORDS

1. The Office of the High Commissioner for Human Rights (OHCHR); Human Rights Council Resolution 42/16; Special Rapporteur: Dr Tlaleng Mofokeng (Thematic Report to the General Assembly in October 2022); Racism and the Right to Health; Physical and Mental Health; Reproductive Health Care Injustices on Women; Forced and Coerced Sterilisation as a Clear Manifestation of Racism in Health Care; HIV/AIDS; The Commission for Gender Equality (CGE); Her Rights Initiative (HRI).

INTRODUCTION

2. The individuals listed above are honoured to submit this report on "Racism and the Right to Health" to the OHCHR Special Rapporteur (Dr Tlaleng Mofokeng) on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, which will be presented to the General Assembly in October 2022.

INTRODUCTION TO THE ORGANISATIONS MAKING THE SUBMISSION

3. 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 of their Constitutional rights which are realised and affirmed.

THE INFORMING CONTEXT

4. As this call for submissions focuses on questions of race and underlines racism as a key social determinant of health and driver of health inequalities, we seek to focus our submission on the forcesd and coerced sterlisation of HIV positive women and broadly the rights of these women to sexual and reproductive health through the prism of race and the related grounds of discrimination. This report will accordingly focus specifically on the forced and coerced sterilisation of HIV positive women, highlight the discrimination experienced by these women in the public health sector and

seek to answer the following questions in accordance with the questionnaire set out by the Special Rapporteur;

a) *What are the historical and ongoing legacies and impacts of colonialism and slavery on the right to health in your country? And how has the lack of reparations for slavery, colonialism, apartheid and racial discrimination impacted the right to health in your country?*
b) *Who are the most affected people and why? Please describe existing disparities in the provision of and access to health services that affect people of different racial and ethnic origin, descent as well as other groups, such as migrants. The lack of data, analysis or health indicators in this regard may also be reflected.*
c) *What examples are there of good legal and policy frameworks that address past or ongoing racism and racial and related forms of discrimination, specifically in relation to access to underlying determinants as well as quality health care, goods, services and facilities, including sexual and reproductive health.*
d) *Under the right to health, States have a special obligation to refrain from denying or limiting equal access for all persons, comprising minorities, asylum seekers and migrants including undocumented migrants, to preventive, curative and palliative health services; abstain from enforcing discriminatory practices as a State policy as well as to ensure equal access to health care and health-related services provided by third parties. Please explain how the above point is implemented in your country, what works well and not so well and illustrate with disaggregated data if possible.*
e) *What are the main ongoing manifestations of racism, and related forms of discrimination enabled by racism that may be prevalent in your country in the area of the right to health broadly including in underlying determinants of health, health outcomes and access to health care?*

Intersectional identities of black women who are HIV positive in South Africa

6. The persistence of the HIV epidemic in South Africa and the related intersectional burdens faced by black women on the basis of race, gender, age, class social origin and pregnancy has devastating impacts on the health outcomes and realisation of the rights of black women who are HIV positive in South Africa. The HIV epidemic disproportionally affects young black women.[1] Young black women[2] are eight times more likely to be HIV positive.[3] There are various factors that increase the risk of young black 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*."[4]

7. Customary practices and habits that entrench black women as subordinates in their homes and society and exploit them for the benefit of men especially in intimate partner settings, increase black women's vulnerability to contracting HIV.[5] 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*."[6]

[1] 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
[2] Aged between 15 and 24 years.
[3] 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
[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] 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
[6] 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

Such norms and value systems hinder black women's ability to negotiate safer-sex.[7]

8. The majority of black women[8] 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.[9] "*The likelihood of engaging in risky sexual behaviour was higher among black women from poorer households relative to those from more affluent ones*."[10] The lack of access to confidential sexual and reproductive health services prevents girls and young black women from obtaining essential HIV prevention information which exacerbates their risk of infection.[11]

HIV positive black women in rural areas

9. In general, rural black 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 black women face extreme poverty and limited access to quality services, education, and information. Moreover, rural black women in areas governed by traditional leaders and customary law often face disadvantage and discrimination in various forms including property disinheritance, for instance.
10. For rural black women who are HIV positive, these structural barriers can have an exponentially adverse impact on their health and well-being.

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

[8] 92%.

[9] 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

[10] 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

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

Based on their geography, rural black women with HIV have poor access to quality education, particularly comprehensive sexuality education, which result in them having a more limited understanding of how HIV is transmitted. Based on their geography, they 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 black women face food insecurity. In turn, all these factors can adversely affect the ability of HIV positive rural black 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.

11. Further, rural black women often face property disinheritance and economic as well as tenure insecurity. These inequities are compounded by an HIV positive status. This is especially true for widows whose husbands have died from AIDS-related causes.
12. In rural locations, as well as urban ones, black women are often the primary caretakers of the sick and afflicted and, in rural settings, this responsibility can be especially onerous. The unpaid care burden carried by black women in our society is unmeasured and their contribution undervalued. Indeed, as noted by researchers: "*the disproportionate share of AIDS-related caregiving by black women and girls imposes a heavy toll on their own well-being, often leading to their increased vulnerability to HIV infection".*

KEY AREAS OF CONCERN:

STATE-SANCTIONED FORCED AND COERCED STERILISATION OF BLACK WOMEN WHO ARE HIV POSITIVE[12]

13. In a report dated February 2020,[13] the CGE found that the rights of HIV positive black women who lodged a complaint with them had been violated

[12] 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 black women living with HIV, on the work being done by the Black 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 black women living with HIV in South Africa.[#]

[13] Commission for Gender Equality, *Investigative Report: Forced Sterilisation of Black women Living with HIV and Aids in South Africa* February 2020, accessible at: http://www.cge.org.za/wp-content/uploads/2016/12/Forced-Sterilisation-Report.pdf. The investigative report was released in

including rights to equality; dignity; bodily integrity 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 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.

14. Black, pregnant, women who are HIV positive from lower-income families and communities, who rely solely on state-funded healthcare were specifically targeted. The intersection of their gender, race and class rendered them more vulnerable to forced and coerced sterilisation than any other group of women in South Africa.[14]

15. Based on the work done by HRI with women who are HIV positive we have come to learn that victims commonly reported being forced to sign consent forms/agreements to be sterilised because their health care professionals had "threatened not to assist them in giving birth" if they did not. The forms/agreements were commonly presented when the victims were suffering from "extreme labour pains", and the women were frequently told that they would die without the operation. Some of the women did not know that the procedure even took place and were never given a consent form nor were there any records to show that the sterilisation procedure had been performed.

February 2020 and investigated the practice of forced sterilisation of black 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 black women who had experienced forced or coerced sterilisation.

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

16. A study, undertaken between 2010 and 2011, screened 32 HIV positive women using a questionnaire. This identified 25 (68%) of those screened, as having undergone an involuntary sterilisation procedure. Additionally, the South Africa National Aids Council's 2015 stigma index revealed that, out of 6,719 HIV positive women interviewed, an estimated 500 said they had been forcibly sterilised and these women were predominantly poor black women who used public hospitals.

17. Victims of involuntary sterilisation have reported experiencing negative psychological symptoms most notably those related to anxiety, stress and depressive symptoms.[15] Many victims have also reported multiple physical or negative health effects (complications) as a side effect of the sterilization surgery.[16]

18. Generally, and especially in Africa, a woman's ability to bear children is closely linked to her worth and essential identity as a woman within a customary context. The inability to bear children due to being sterilised, willingly or not, is accordingly seen as a failure on her part. It renders black women as valueless and undesirable for men as reproduction is considered an essential component of any relationship.[17] The social, cultural and gendered pressure on black women to bear children inevitably implicates their self-worth and dignity.[18]

Enabling Environment as created by the Sterilisation Act 44 of 1998

19. The Sterilisation Act does not provide enough protection to ensure that proper and informed consent is obtained and it has been recommended that the National Department of Health ('NDOH') review its provisions and interrogate consent forms for sterilisations to ensure that they offer

[15] Mnguni *Report on forced sterilization*; K Bakare & S Gentz "Experiences of forced sterilisation and coercion to sterilise among black women living with HIV (WLHIV) in Namibia: an analysis of the psychological and socio-cultural effect" (2020) *Sexual and Reproductive Health Matters* 339.
[16] Mnguni *Report on forced sterilization*; Bakare & Gentz (2020) *Sexual and Reproductive Health Matters* 340.
[17] M du Toit "Involuntary sterilisation of HIV-positive black women in South Africa: A current legal perspective" (2018) 11 SAJBL.
[18] du Toit (2018) SAJBL 1.

adequate and effective protection. [19] The CGE also intends on submitting a petition to amend all legislation regulating consent to the South African Law Reform Commission ('SALRC').

20. 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 ('NDOH'); and The South African Law Reform Commission ('SALRC').

21. 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 black 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.

22. 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 who are HIV positive and 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 black women were in fact forced

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

/ 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. There are however concerns that a year after it has been established it has only held one engagement with women and has not commenced any meaningful work towards redress.

Prescription Hurdle

23. Though there is no shortage of mechanisms available to black women through Courts in South Africa, unfortunately, section 11 of the Prescription Act 68 of 1969 ('Prescription Act') limits women who have been sterilised's 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.

24. The majority of black 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. The black women were however unaware that the practice was contrary to their constitutional rights and that legal recourse was available to them. They also lacked access to legal advice and representation, but still run the risk that the state will argue that any claims that they may have in law had prescribed at the point where they signed the consent forms or found out that they were sterilised.

25. 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 black women. Hospitals are only required to keep medical records for a minimum of 6 years[20] 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 in the legal system.

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

26. The mechanisms available in law are not always utilised for a number of reasons. The contributing factors include socio-economic inequalities that impact the provision of, and 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 black women have and the mechanisms available to protect and exercise these rights.[21]

WOMEN'S HEALTH POLICY

27. 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 provides women with a mechanism through which to hold the public service to account. Black women can only enforce their rights in this area if there is a clear policy in place that speaks to their righs and how these rights will be met. A policy leads to the development of implementation plans and allocation of budget, which is sorely absent from the current framework.

28. The National Health Act of 2003 also does not provide for the particular needs of women's health; it only provides for maternal health and family planning, the women as mothers' approaches to health. Here again we see the heavy emphasis on women being seen as child bearers within a patriarchal society, but where other health needs are not considered as critical or important. The proposed National Health Insurance (NHI) policy discourse is hardly gendered nor informed by black women's lived realities of health. Indeed the lack of feminists' participation and analysis in the NHI policy development is indicative of the state of the black 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

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

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 black women's rights must have a focus on health as human rights, but also as one of the worst patriarchal institutions of power where black women's bodies and lives are captured and violated.

29. 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 and we are concerned that women and black women in particular who sit at the intersection of various forms of discrimination will not have realisation of their rights.

ENDING AND CONTROLLING BLACK WOMEN'S FERTILITY: DEPO PROVERA

30. Contraception is a paradox. Contraceptives give black women the power to control their fertility and make it possible for black women to exercise their reproductive autonomy. On the other hand, contraception is historically 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 been associated with the latter for more than four decades. For decades, DP programmes have been criticised for targeting poor black women and black women of colour in developed countries and later in developing countries .[22]

31. 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

[22] Brown, 1987; Kaufman, 2008; Klausen, 2004; Kaler, 1997; Cooper, *et al.* 20000.

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 black women in developing countries. DP is registered for use in many developing countries, including South African countries.

32. In recent times, the primary justifications for the radical distribution of DP in poor black 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 .[23]

Side Effects of Depo Provera

33. 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 black women. Side effects of DP include delays in returning to fertility; infertility, significant loss of bone mineral density; heightened risk of cervical cancer in black 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.[24]

34. Studies have also revealed that DP heightens the risk of tuberculosis in women.[25] 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.[26]

[23] Family Planning 2020, 2012; Bill and Melinda Gates Foundation, 2018.
[24] Pfizer, 2010.
[25] Tomasicchio, et al. (2019).
[26] Heffron, 2012.

35. The commonly communicated side effects in South Africa are bleeding and weight gain. These are verbally communicated to black women in clinics or when women report these to healthcare workers. The Contraceptives programme also does not provide information black women can take home to read iin their own indigenous languages. In fact the insert of the injection information and side effects is never even given to women. There are no dedicated programmes to prevent and treat side effects of DP and no mechanism to measure its cost to black women's lives and the health system. This lack of information means that women are unable to make informed decisions about their health and care.

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

37. It is a concern that DP continues to be dispensed to black 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

38. 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 black women at home and in other accessible areas.[27]. The South African Health Regulation Authority has approved these formulations.

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

39. 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.

40. 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.

41. 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 black 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.

42. Contraceptives 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 black 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.

43. 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.

Forced Use Of DP

44. DP is linked to the forced sterilisation as it is part of the systematic state led interventions to end fertility of HIV positive black women[28].The Human Sciences Research Council (HSRC) and the South African National AIDS Council (SANAC) 2015 Stigma Index Study found that 37% of black women who participated in the study were forced into taking DP in the past twelve months .[29] 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.

45. 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.[30] 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.[31]

[28] Mthembu, SP., (2022)'The Political Economy of Injectable Contraceptives in Post-Apartheid South Africa| A feminists Perspective' University of KwaZulu-Natal Research Space, 2022
[29] Cloete et al. 2014.
[30] SABC News, 2018.
[31] Maqhina, 2014.

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.

We submit that these measures are a gross violation of the rights of women to exercise control over their own bodies and reproductive health.

CERVICAL CANCER

46. Black women who are HIV positive are five to six-times more likely to develop Cervical Cancer compared with women who are not HIV positive.[32] According to Denny (2006) Cervical Cancer progresses faster, it is more aggressive, and appears at a younger age in black 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.[33] With expanded access to antiretroviral (ARV) treatments, HIV-positive black women are living longer and Cervical Cancer will increase the disease burden to HIV positive black women.

47. Cervical Cancer is a disease of poor Black black women.[34] In South Africa black 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.[35] Arnolu (2008) reported that between 60–70 percent of black 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 as a result 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.

[32] CDC 1993, Moodley 2006, Stelzle et.al. 2020.
[33] Moodley, 2006.
[34] Denny, 2006 Arnolu, 2008.
[35] Stevens & Adar, 2000, Doyal & Hoffman, 2009.

Intersection Of Cervical Cancer and the Forced Sterilisation of HIV Positive Black women

48. There are intimate intersections between forced sterilisation of black 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 black 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 as a result of the provision of treatment .[36]

Cervical Cancer Policy

49. South Africa currently does not have national policies which address Cervical Cancer prevention and treatment in HIV-positive black 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 black women is critical and a matter of priority.[37] 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.[38]

50. Pap smear as a cervical smear used as a method of screening for Cervical Cancer[39] is recognised by the South African Medicines Control Council and is therefore the only authorised screening method in South Africa .[40] 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

[36] Mthembu et al., 2011.
[37] Franceschi & Jaffe, 2007.
[38] WHO, 2000.
[39] Leopold and Koss, 1993.
[40] Hoffman et al., 2003.

delivered as women's rights to health and dignity, but as a form of charity and short-term welfare. Chartism and welfarism has its own politics and, among others, they may not be held accountable and may be detrimental to black women's rights advocacy. These tend to reinforce the dominant discourse of gender oppression, on the rights of black women and violation of rights of black women and the ideas of black 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 black 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 instrumentalization of bodies of HIV positive black women. [41]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 black 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 black 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 black women are not prioritised and advocacy on these issues is also limited. Other contributing factors include social, health systems, human rights and political barriers.

[41] Mthembu, SP., (2013)'Triple jeopardy or manifestations of gendered social exclusions?' : a study looking at cervical cancer policy and women living with HIV in South Africa, UKZ Research Space, http://hdl.handle.net/10413/11067http://hdl.handle.net/10413/11067

HPV vaccines

53. 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 .[42]

54. Despite recommendations by the WHO black women living with HIV do not have access to these vaccines in South Africa. These are not provided for in HIV/AIDS treatment policies 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 black women were excluded from the research. Exclusion of black women living with HIV in life saving treatments is a norm in biomedical research.

SOUTH AFRICA'S CONTRACEPTIVES POLICY

55. 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 black women and women of colour and was in concert with the global eugenics and population control at the time.

56. 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

[42] Hale, 2009.

South Africa. More than 90% of injectables and implants were dispensed from government clinics and community health centres.

57. The Department of Health's Contraceptives and Fertility Planning Service Delivery Policy Guidelines of 2012 and 2018 policy list HIV positive and young black women as target populations for contraceptives programmes. This provides a conducive environment for coerced and forced contraceptives in these groups of black women [43]

58. The justifications for targeting this population are to reduce the rates of HIV infection, teenage pregnancy and high rates of maternal mortality. The justifications being in line with global priority on contraceptives, FP 2020, codified by a private philanthropists' organisation and endorsed by WHO and UNFPA.

59. These justifications are hardly advancing black 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 black women in the economy and access to wealth and opportunities, colonialism, racism amongst others. [44]Deploying DP to poor female bodies is secondary victimisation, and unduly placing the blame and responsibility for teenage pregnancy, HIV AIDS and maternal mortality on poor black women and girls. This blame and targeting have severe consequences on these black women on a personal level and as groups [45]

GLOBAL HIV/SRH INTEGRATION PROJECT

60. 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 black women living with HIV and poor young black women who are at high risk of teenage pregnancy and

[43] Mthembu, 2022
[44] *Ibid.*

HIV infection. These policies have also failed to integrate Cervical Cancer in HIV programmes. Cervical Cancer is the main sexual and reproductive health issue in AIDS and HIV.

61. The global integration project has created a fertile environment for forced sterilisations of HIV positive black women. These integration projects have created a policy vehicle for forced contraception of poor HIV positive black women and young black women. In our case the integration project is integration of sexual and reproductive violations 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 HIV/AIDS POLICY

62. The stigma and discrimination language of the AIDS policy is not gendered and is silencing human rights violations in HIV. Human rights violations of black 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 black women living with HIV the 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.

63. The South Africa Stigma Index report is branded with the UNAIDS logo and logos of many other organisations advancing human rights in AIDS, however six years later, they did not take any actions to address violations

of other rights of black women living with HIV. They have not made efforts to listen to the voices of the victims, who are HIV positive black women, the population group they are mandated to protect and advance their interest.

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