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Sexual and Reproductive Health Rights of Women Living with HIV in South Africa

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SEXUAL AND REPRODUCTIVE HEALTH RIGHTS OF WOMEN LIVING WITH HIV IN SOUTH AFRICA

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Contents

List of Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ALN	AIDS Legal Network
ART	Antiretroviral Treatment
CHW	Community Health Worker
DHS	District Health System
DoH	Department of Health
GBV	Gender-Based Violence
HCT	HIV Counselling and Testing
HHRP	Health and Human Rights Project
HIV	Human Immunodeficiency Virus
HPCSA	Health Professions Council of South Africa
HRI	Her Rights Initiative
MDG	Millennium Development Goals
NDoH	National Department of Health
NGO	Non-Governmental Organisation
NHI	National Health Insurance
NSP	National Strategic Plan on HIV, TB and STIs
PHC	Primary Health Care
RRA	Reproductive Rights Alliance
SA	South Africa/South African
SANAC	South African National AIDS Council
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health Rights
STI	Sexually Transmitted Disease
TAC	Treatment Action Campaign
UCT	University of Cape Town
UKZN	University of KwaZulu-Natal
WHO	World Health Organisation
WHP	Women's Health Project
WLC	Women's Legal Centre
WRHI	Wits Reproductive Health and HIV Research Institute
VCT	Voluntary HIV Counselling and Testing

Executive summary

South Africa's constitutional and legal framework reflects the country's commitment to women's Sexual and Reproductive Health and Rights (SRHR), in line with international commitments. Numerous policies detail the provision of services around sexual and gender-based violence, fertility, maternal, perinatal and newborn health, sexually transmitted infections (including HIV), and cancers of the reproductive system. However, these policies exist in a social climate of extreme inequality, with high rates of poverty and unemployment. Despite almost equal representation of women in government and other high-profile areas, women in South Africa experience unprecedented rates of sexual and gender-based violence, and women's autonomy is all too often compromised by poverty, limited access to education, limited access to health care, and ongoing gender inequality that is bolstered by patriarchal norms.

In this context, women living with HIV are particularly vulnerable to rights violations, due to persisting stigma and discrimination. This paper presents the current shortcomings in terms of realising the sexual and reproductive health rights of women living with HIV in South Africa, focusing on gaps in policies, barriers to implementation of existing policies, and specific areas where rights are readily bypassed. The paper consists of a review of the existing sexual and reproductive health and HIV policies in South Africa, a synthesis of the academic literature, and insights from interviews with key informants in the academic, civil society and policy arenas.

A strong and strategic civil society movement achieved crucial successes for women's sexual and reproductive rights in the early years after the country's democratic transition in 1994. By forging alliances with academic institutions and through strategic lobbying of key government stakeholders, these activists were instrumental in passing the new abortion act in 1996. However, in the following years, the movement started to decline, mostly due to a lack of leadership, a lack of funding, and the perception that key goals had been achieved. Concurrently, an activist movement for the rights of people living with HIV emerged in the late 1990s. While it gained vital support for the rights of people living with HIV, it did not have a specific focus on women's sexual and reproductive health rights.

This case study presents five examples of the violation of sexual and reproductive health rights of women living with HIV, and explores the underlying causes and dynamics. The misalignment between the national cervical cancer screening policy and recommendations on cervical cancer screening in HIV management highlights the need to harmonise existing policies and take into account the specific needs of women living with HIV. Documented cases of women living with HIV being coerced into accepting sterilisation have been collected by South African activists and illustrate how the directive power of health care workers undermine women's agency and autonomy. This problem is also reflected in the critical appraisal of the new provider-initiated HIV testing policy, which has led to reports of the violation of women's rights to autonomy and access to health care services. Access to fertility treatment (and information about childbearing options) as well as to contraception, (including abortions), is limited for women in general, but even more so for women living with HIV.

The review presents a number of key recommendations for South African activists, the South African government, and international donors. These recommendations suggest measures to harmonise existing policies to fit the needs of women living with HIV; to establish and institutionalise rights-based training for health care workers; to institute redress mechanisms for women whose rights have been violated; and to strengthen the capacity of civil society to support affected women and adopt appropriate advocacy strategies.

1   Introduction

1.1   Defining sexual and reproductive health rights

The World Health Organisation (WHO) has identified five core aspects of sexual and reproductive health: (1) improving antenatal, perinatal, postpartum, and newborn care; (2) providing high-quality services for family planning, including infertility services; (3) eliminating unsafe abortion; (4) combating sexually transmitted infections, including HIV, reproductive tract infections, cervical cancer, and other gynaecological morbidities; and (5) promoting sexual health. It is noted that, because of the close links between the different aspects of reproductive and sexual health, interventions in one area are likely to have a positive impact on the others (WHO, 2004, p. 21).

In a recent review of sexual and reproductive health rights, the South African Department of Health follows this comprehensive definition, and includes the following areas in SRHR policy planning: sexuality, desire, pleasure and function; sexual and gender-based violence; fertility; maternal, perinatal and newborn health; sexually transmitted infections, including HIV and AIDS; cancers of the reproductive system; and additional SRHR issues, to be determined on an as-needed basis (Department of Health 2011a: 6).

1.2   Situating SRHR in South Africa

South Africa has one of the highest rates of HIV worldwide. The latest antenatal HIV prevalence survey by the South African Department of Health shows that 29.6 per cent of pregnant women who attend antenatal services are HIV positive (NDoH 2011a). UNAIDS estimates that 17.3 per cent of the South African adult population (between 15 and 49 years of age) are living with HIV. Of these, almost 3 million are women (UNAIDS 2011). South Africa remains one of the most unequal societies in the world. Current estimates show that up to 59 per cent of South Africans are unemployed, and up to 53 per cent live in poverty (Statistics South Africa 2012). Despite the country's commitment to gender equality at government and constitutional level, patriarchy and gender discrimination are prevalent in all sectors of society. South Africa has among the highest rates of sexual and gender-based violence in the world (Jewkes et al. 1999). In the South African context, the language of 'reproductive rights' is used to describe the rights to accessible, affordable, appropriate, and quality health services; to information; to autonomy in sexual and reproductive decision-making; and to freedom from discrimination, coercion, and violence as they relate to reproduction. These rights are undermined by poverty as well as by discrimination on the basis of gender, race or ethnicity, sexual orientation, disability, and other bases of discrimination (NDoH 2001). The realisation of enshrined sexual and reproductive health and rights of all women, but especially of women living with HIV, poses complex and serious challenges – to the point that women living with HIV can be denied their sexual and reproductive rights. Certain violations are moreover difficult to identify and address.

1.3   Aim of this review

This paper reviews the existing SRHR policies in South Africa, with a special focus on the SRHR of HIV positive women. It aims to identify gaps in the current policies, examine the effect of these on the realisation of SRHR for HIV positive women and analyse current violations of HIV positive women's SRHR. The paper reviews past and present advocacy strategies around SRHR in order to to identify successful examples, challenges and gaps. To this end, the review will analyse the key actors, networks and institutions relevant for the policy process around SRHR. The case study example in this paper will highlight the challenges in the implementation of the existing SRHR policies, and identify areas of action as well as advocacy strategies to address these.

1.4 Methodology

This report is based on a review of current literature on SRHR issues for HIV positive women in South Africa, including academic literature, grey literature, a review of policy briefs and research reports. A review of the legal framework has been performed to examine the relevant legislation and policies. Following the analytic framework on policy process by Keeley and Scoones (IDS, 1999), the actors, networks and institutions involved in the process of SRHR policy were mapped. This desk-based research was complemented with interviews with key informants on SRHR for HIV positive women in South Africa from civil society organisations and academic institutions, including people involved in policy reform.

2   Legal Context

Sexual and reproductive health and rights discourse in South Africa is firmly enshrined in the country's legal framework. After the transition to democracy in 1994, the country followed a human rights approach to its new constitutional framework, which is reflected in national legislation. As demonstrated in the following sections, the constitution is backed up by a wealth of legal and institutional frameworks, which are intended to guide practice and ensure that individuals' human rights are respected in relation to health, sexuality and reproduction. Some of these policies, such as the National Strategic Plan on HIV, STIs and TB, 2012–2016 (discussed below) recognise that – despite this wealth of policies and frameworks – HIV positive women's sexual and reproductive health rights are frequently overlooked.

2.1   International commitments

South Africa has signed and ratified numerous international treaties and protocols that attest to a human rights approach to sexuality and reproduction. These include the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, 1979), the Convention on the Rights of the Child (1989) and the Convention on the Rights of Persons with Disabilities (2006). Furthermore, South Africa has signed international consensus agreements, such as the Programme of Action of the International Conference on Population and Development (United Nations, 1994) and the Platform for Action of the Fourth World Conference on Women (United Nations, 1995). Klugman (2000) reports that in Cairo in 1994, the South African delegation contributed to the clarification of the definitions of reproductive health and rights. Similarly in Beijing in 1995, it contributed to the acknowledgement that human rights must be applied to issues of sexuality.

In 2000, South Africa adopted the Millennium Development Goals (MDGs), which set the focus of global development until 2015. A number of these MDG goals relate directly to sexual and reproductive health and rights (MDG 2, MDG 3, MDG 4, MDG 5 and MDG 6), while others are relevant to achieving SRHR (for example MDG 1 on eradicating extreme poverty).

2.2   Constitutional commitments

The South African Constitution from 1996 ensured a progressive and comprehensive constitutional framework, and has a human rights approach to sexuality and reproduction. It guarantees:

- The right to equality (Section 9.1).
- The right to freedom from discrimination on the basis of race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth (Sections 9.3 and 9.4).
- The right to be treated with dignity and respect (Section 10).
- The right to life (Section 11).
- The right to freedom and security, including the right to be free from all forms of violence from either public or private sources and not to be treated or punished in a cruel, inhuman or degrading way (Section 12.1 (a-e)).
- The right to bodily and psychological integrity, which includes the right to make decisions concerning reproduction, to security in and control over their body, and to not be subjected to medical or scientific experiments without their informed consent (Section 12.2(a,b,c)).

Furthermore, the Constitution also guarantees the right to health care services, including sexual and reproductive health care (Section 27(a)).

2.3 National legislation on SRHR

As part of the initiative around creating a National Health Insurance, and strengthening the public health system, the South African Department of Health commissioned an extensive review of the existing sexual and reproductive health rights framework. The ensuing report, *Sexual and Reproductive Health Rights: Reviewing the Evidence* (NDoH 2011b) informed a new draft policy on SRHR, which was published in May 2011 (*Sexual and Reproductive Health Rights: Fulfilling Our Commitments*, NDoH 2011c). It has, however, not yet been formalised by the department.

Sexual and reproductive health services are subject to a number of national laws and policies. It is important to note that, according to the National Health Act (2003), each of the nine South African provinces has certain sovereignty with regards to health policies. The resources of the provincial health sectors differ vastly from province to province. As a result, richer provinces (for example the Western Cape) can provide better-resourced public health care, while poorer provinces (for example the largely rural province of KwaZulu Natal) struggle to provide adequate health care.

2.3.1 Fertility management

Women's access to contraception is outlined in the National Contraception Policy Guidelines – Within a Reproductive Health Framework (NDoH 2001) and the National Contraception Service Delivery Guidelines (NDoH 2003, currently being revised). The aims of these documents are to improve sexual and reproductive health, and facilitate 'informed choices' (DoH 2004:15). All reproductive policies are based on human rights principles and framed in accordance with section 12.2(a) of the Constitution which asserts that everyone "has the right to bodily and psychological integrity, which includes the right to make decisions concerning reproduction" (Republic of South Africa, 1996), thus acknowledging the problematic history of racist apartheid population control measures aimed at reducing the fertility rate of Africans, and encouraging white births (Department of Health, 2004). Accordingly, the current population policy focuses on 'the quality, accessibility, availability and affordability' of reproductive health services (Department of Social Welfare and Development, 1998:17).

The National Condom Policy and Management Guidelines (2011) provide a framework for the Condom Procurement and Distribution Programme, which deals with the distribution of male and female condoms by the public sector. The framework addresses gaps previously identified within the programme.

The Choice on Termination of Pregnancy Act (1996) sets out the conditions for a termination of a pregnancy before 12 weeks, between 13 and 20 weeks, and after 20 weeks of gestation. The Act allows for an abortion if a woman chooses to do so before 12 weeks or, in consultation with a medical practitioner, between 13 and 20 weeks. After the 20th week, termination is allowed if a medical practitioner, after consultation with another medical practitioner or a registered midwife, finds that the continued pregnancy would endanger the woman's life, result in a severe malformation of the foetus, or pose a risk of injury to the foetus. The Act is complemented by the Choice on Termination of Pregnancy Amendment Acts (2004 and 2008), both of which make it easier for facilities to become approved to provide termination of pregnancies.

The Sterilisation Act (1998) promotes autonomous decision-making and protects patients through requiring voluntary, informed and written consent before a sterilisation. The legal and policy framework does not promote sterilisations of a particular sector of society. Instead the Act aims to protect against coercion and includes special protection to prevent arbitrary sterilisations of disabled persons. It is complemented by the Sterilisation Amendment Act (2005).

In 2011, the Southern African HIV Clinicians Society published a Guideline on Safer Conception in Fertile HIV-Infected Individuals and Couples (Bekker et al. 2011) which will inform the forthcoming revision of Department of Health guidelines on fertility management. These propose a planned approach, including counselling of seroconcordant and serodiscordant[1] couples to identify the safest and most effective conception methods. The guidelines recognise the vastly different resources available in the public and private health sector, and suggest adequate fertility options for each sector. However, these guidelines fail to address the reproductive rights of and fertility options for lesbian and transgender women living with HIV.

2.3.2 Maternal, perinatal and newborn health

South Africa has a number of policies directed specifically at the health of mothers and their newborn children, among others the *Guidelines for Maternity Care in South Africa 2007: A manual for community health centres and district hospitals* and the *Saving Mothers: Essential steps in the management of common conditions associated with maternal mortality* guidelines (NDoH 2008). The *National HIV and STI Strategic Plan (NSP) 2012–2016* (NdoH 2011, see under STIs and HIV and AIDS below) outlines the strategies to further reduce mother to child transmission of HIV.

2.3.3 Sexually transmitted infections, including HIV and AIDS

The new *National Strategic Plan (NSP) on HIV, STIs and TB, 2012 – 2016* (NDoH, 2011) provides the strategic guide for the national HIV response, and informs national, provincial, district and community-level stakeholders on strategic directions to be taken into consideration when developing implementation plans. It reaffirms its commitment to a rights-based response to HIV, STIs and TB, and specifies that the national HIV response 'must be rooted firmly in the protection and promotion of human and legal rights, including prioritising gender equality and gender rights' (p. 22). Based on this vision, the new NSP identifies the following five broad goals:

1. Reduce new HIV infections by at least 50 per cent using combination prevention approaches.
2. Initiate at least 80 per cent of eligible patients on antiretroviral treatment (ART), with 70 per cent alive and on treatment five years after initiation.
3. Reduce the number of new TB infections, as well as the number of TB deaths by 50 per cent.
4. Ensure an enabling and accessible legal framework that protects and promotes human rights in order to support the implementation of the NSP.
5. Reduce self-reported stigma and discrimination related to HIV and TB by 50 per cent.

While the NSP lists key determinants for HIV risk (behavioural, social, biological and structural), only young women between 15 and 24 are listed as a key population. The new NSP recognises that women living with HIV are frquently denied their sexual and reproductive health rights and emphasises that particular attention should be given to the violation of women's sexual and reproductive health rights. Among the key populations listed in the NSP are sex workers and transgender people – two marginalised groups of women living with HIV. However, it is important to note that despite attempts in the NSP to reach the sex worker population, sex work remains criminalised under the **Sexual Offences Act** (2007).

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[1] In seroconcordant couples both partners are infected with HIV (or both are HIV negative), while in serodiscordant couples, only one partner is infected.

2.3.4 Cancers of the reproductive system

The *National Contraception Policy Guidelines* (2001) make reference to screening for breast cancer, but mammography is not recommended. There is no policy or routine screening and no guidelines for women living with HIV.

For cervical cancer, the *National Guidelines for Cervical Cancer Screening programme* (2000) recommends that women over the age of 30 receive three screening pap smears in their lifetime. There is no special provision for HIV positive women (who are at greater risk of developing cervical cancer), or women under the age of 30.

The 2011 review of SRHR policies by the Department of Health identified, among others, the following gaps in cervical screening policy, guidelines, and services.

- The current guidelines are inadequate in light of the interactions between cervical cancer and HIV.
- Implementation of existing guidelines is uneven.
- There is no policy for the provision of the human papilloma virus (HPV) vaccine in the public sector.
- Health providers lack the ability to treat women effectively following a positive pap smear, including to make referrals.

2.3.5 Sexual and gender-based violence (GBV)

The Sexual Offenses Act (2007) provides comprehensive and progressive legislation on rape and sexual assault. The DoH's National Management Guidelines for Sexual Assault Care (NDoH 2003a) and the National Sexual Assault Policy (NDoH 2005) outline the response to sexual assault in the health system, and aim to improve healthcare after sexual assault and rape for women, children, and men. While there are clear guidelines for the provision of post-exposure prophylaxis of HIV treatment after sexual assault, there is little integration between services addressing GBV and broader SRHR programmes.

2.3.6 Patient autonomy and consent

The right to only receive medical treatment with informed consent is outlined in the Constitution (Section 12, the right to freedom and security of the person) as well as in health laws, and this includes the right to make autonomous health-related decisions concerning reproduction. In order for any medical procedure to be legal, the patient must:

- have the capacity to consent;
- have knowledge of the nature and extent of the harm or risk involved;
- understand or appreciate the nature and extent of the harm or risk;
- be informed of the benefits, risks, costs and consequences of the proposed treatment in a language the patient understands and in a manner that takes into account the patient's level of literacy;
- voluntarily consent to the procedure without being induced to do so by fear, force, threats, duress, coercion, compulsion, deceit, fraud, undue influence, perverse incentive or financial gain.

In 2010, the *SA HIV Counselling and Testing Policy Guidelines* moved from client-initiated voluntary counselling and testing (VCT) to provider-initiated HIV counselling and testing (HCT). Health workers should thus offer testing. With this opt-out approach, the aim is to provide 'an enabling environment for HIV counselling and testing, where the majority of people in South Africa are knowledgeable about their HIV status, and able to act on this knowledge to ensure an HIV-free generation' (Section 3.1.). The guidelines also aim to provide 'universal

access to good quality, effective HIV counselling and testing and referral services to all the people in South Africa' (Section 3.3), and to 'ensure the delivery of standardised, high quality and ethical HIV counselling and testing services' (Section 3.4). The objectives of the Policy Guidelines are outlined in Section 3.4 of the document and include the commitment to 'ensure compliance with a legal and human rights approach to HIV counselling and testing [and] ensure appropriate referral to treatment'(Section 3.4).

2.3.7 Batho Pele Principles and Patients' Rights Charter

The South African government has also developed eight ***Batho Pele principles*** to serve as acceptable policy and legislative framework regarding service delivery in the public sector. These are also applicable to health care delivery, and consist of principles around consultation, service standards, access, courtesy, information, openness and transparency, redress and value for money. The principles were developed after the transition to democracy in 1994 and recognise that, for many decades prior, the vast majority of the South African population experienced either a denial or violation of fundamental human rights, including rights to health care services.

The Department of Health is committed to the realisation of the right to access to health care services as guaranteed in the Constitution. It has therefore adopted the Patients' Rights Charter as a common standard for achieving the realisation of this right. The Department of Health further provides complaint hotlines for each province (some of which are toll-free numbers)[2], but encourages patients to complain to the relevant clinic or hospital managers first. However, there is no institutionalised structure that collects and analyses these complaints.

The Health Professions Council of South Africa (HPCSA) elaborates on the consequences of the constitutional commitments and binds health care workers in South Africa to its ethical principles in the code of conduct. It requires every health care worker to recognise the human rights of all individuals, and honour the right of patients to self-determination or to make their own informed choices, and to live their lives by their own beliefs, values and preferences.

South Africa's national health system operates within the guidelines of the policy and institutional frameworks. The following section explores the challenges faced by the health system in a highly resource-constrained environment, currently under reform, which seeks to supplement primary health care with a community health worker system to ensure maximum reach.

2.4   The health system

South Africa's health system is historically highly unequal. The well-resourced private sector only caters for approximately 16 per cent of the population, whilst the public sector – financed through tax, government subsidies, and service user fees – provides care for the vast majority of the population. It also struggles with a 'quadruple burden of disease' higher than in most other countries of comparable economic profile (Lancet 2006), as well as a lack of human resources (especially nurses and physicians), and poor management structures. To ensure the delivery of a primary health care (PHC) approach, the National Health Act (2003) organised health care around a district health system (DHS). According to the DHS, services will be delivered at four levels.

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[2] These numbers are available on the website of the National Department of Health (www.doh.gov.za/show.php?id=1635)

1. Household and community levels.
2. District level: primary healthcare in district hospitals, community health centres and clinics, delivered by generalist health care workers.
3. Secondary level: specialist care in regional hospitals.
4. Tertiary level: highly specialist care in tertiary hospitals.

In 2011, the National Department of Health introduced a large-scale reform of the public sector under the proposal for a *National Health Insurance* (NHI, NdoH 2011). Whilst reforming the financing system of the public sector, it also envisions a re-modelling of the PHC model. The aim of the re-modelled PHC system (see Figure 1) is to extend health care into communities and households and thus strengthen the first level of service delivery under the DHS. Community health workers (CHWs) will go out into communities and homes. Through improved health promotion and prevention, PHC teams will try to keep people healthy in their own homes, as well as getting those who need healthcare into health facilities as early as possible. Community Health Workers are part of the primary care team and are envisaged to form part of community outreach teams headed by a professional nurse. They are also an important component of community-based PHC services, which encompass activities in communities and households. The roles of CHWs include the following.

- Conduct structured and comprehensive household screening and assessment relating to health priorities and refer appropriately.
- Provide education and information, and support preventive action (e.g. through condom distribution).
- Provide psychosocial support across the life cycle, including an integrated approach to adherence support for TB, Highly Active Antiretroviral Therapy (HAART), and other chronic diseases.
- Provide basic home management of common health problems (e.g. oral rehydration therapy in diarrhoea, foot care in diabetes, and first aid).
- Support community assessments, campaigns, and intersectoral action.

Figure 1: Re-modelled primary health care system (taken from NDoH 2011b)
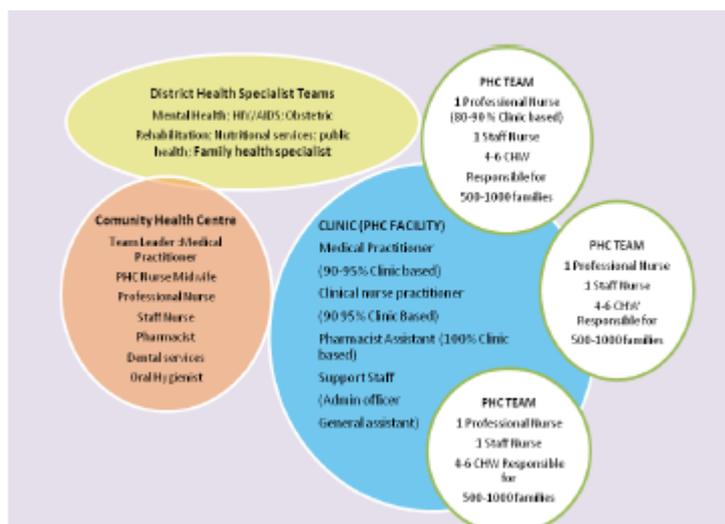
3   Actors and institutions

In the framework of an analysis of policy processes, as outlined by Keeley and Scoones (IDS Working Paper 89, 1999), the following sections explore the actors, networks and institutions involved in past and current advocacy work on SRHR in South Africa. This analysis aims to highlight the interplay of discourse, political interests and the agency of multiple actors and explore the strategies used to create networks to represent policy interest, create policy knowledge and inform policy change. It shows how women's rights activists campaigned to include sexual and reproductive health rights as part of the democratisation agenda, but also how they were unable to sustain this mobilisation due to the lack of leadership, management, or funds and also because of the changing political climate. A number of NGOs have taken on the role of working with HIV/AIDS, but have failed to build into their work a focus on sexual and reproductive health. While academic organisations have worked to improve and address public health provision and policy, they cannot fulfil the same role as that undertaken by civil society organisations. Similarly, state and international organisations currently have a very low profile in this area and the gap initially filled by sexual and reproductive health rights activists, who in the late 1980s and early 1990s put sexual and health rights on the political agenda, remains unfilled.

3.1   Civil society organisations

Civil society organisations have centred around sexual and reproductive health rights from the onset of democracy in 1994. Prior to that, anti-apartheid organising and activism almost never addressed women's health rights (Klugman and Budlender 2001). However, women's rights activists managed to get the topic of women's health onto the agenda of the political negotiations on the democratic transition. A civil society process of national networking was started and developed thirteen policy proposals on women's health. This culminated in a national Women's Health Conference, which tabled the proposals as part of the goals of the democratisation agenda. As one of the results of these activism efforts, the progressive 'Termination of Pregnancy Act' was passed in 1997. It replaced the 'Abortion and Sterilisation Act' from 1975, under which illegal abortions – often dangerous or fatal – skyrocketed because legal abortions were almost impossible to access. The passing of the Act is seen as one of the fundamental victories for SRHR advocacy: ;It has had a real impact, not a perfect impact, but an impact in giving women choices around reproduction' (Di Cooper, interview), and in the following years led to a 90 per cent reduction in abortion-related maternal mortality by 2001 (NDoH 2003b). After these crucial initial successes however, the SRHR civil society movement lost momentum, due to a number of factors. Mokoetle and Klugman (2012) highlight that the key organisations that enabled these early successes have collapsed in the past 10 years[3].

During a national consultation process in 2010 to explore why civil society mobilisation around SRHR had declined in the last decade (described by Mokoetle and Klugman, 2012), three factors emerged as most important in the closing of these organisations: lack of leadership or management; lack of funds; and the political climate, which initially seemed to carry the progressive agenda from civil society into the new government.

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[3] The Progressive Primary Health Care Network, which started in 1987 and brought together NGOs, community groups and health service providers, closed in 2002. The Women's Health Project (WHP), started in 1991 to build a wide base of support and alliances for SRHR across academia, NGOs and health service providers, closed in 2004. The Reproductive Rights Alliance (RRA), which had opened in 1996, closed in 2006, although it has since continued as an informal network. It used to facilitate collaborations to implement legal strategies, and undertake media advocacy and community organisation to advocate for the Termination of Pregnancy Act, and to protect it from challenges.

'In the early days of [HIV] advocacy, you had some very brave and strategic individuals and organisations but their point of view was very much shaped by a male perspective. It was hard for people who tried to inject some gender equity perspective into that […] people did loose sight of the broader questions […]. Even though, over time, more and more women have been mobilised around HIV, a lot of the power and resources for the work have not been attached to this kind of perspective [of SRHR] and then the fact that USAID was doing a lot of the funding meant that even the civil society work that they were funding was not going to look at fertility management as a big issue for women living with HIV. Over time people became more and more aware that this was a problem, but there were not and are not groups that bring a broader sexual and reproductive health perspective – including the question of violence – to the table. It's all been left to organisations of women living with HIV/AIDS, which [have] to deal with massive questions of coping with daily life, for both their leadership and members' (B. Klugman).

To address the gap in advocacy that resulted from the loss of SRHR-dedicated organisations, a new organisation was launched as a result of the consultation process. The new Sexual Health and Rights Initiative – South Africa (SHARISA) aims to promote SRHR in South Africa. It is currently in its early stage and is being established in Johannesburg.

While SRHR organisations struggled to remain functional, various HIV civil organisations emerged in the mid- to late-1990s and advocated for the rights of people living with HIV.

The Treatment Action Campaign (TAC), founded in 1998, drove the legal activism that challenged the South African Department of Health in the Constitutional Court, and won the right of women living with HIV to access antiretroviral treatment to prevent HIV transmission from mother to child (Robins and von Lieres 2004). TAC has subsequently developed into the largest HIV activist and advocacy group in the country and gained international support and recognition. Central to the TAC's activities is a mass-scale grassroots education campaign to enable active health citizenship, and the organisation combines various advocacy strategies ranging from legal challenges (especially in the early years), to collaborative approaches towards government (Heywood 2009). However, TAC does not have a specific focus on SRHR.

The AIDS Legal Network (ALN), founded in 1994, is a Cape Town-based NGO committed to the promotion, protection and realisation of fundamental rights and freedoms of people living with HIV. A main goal of the ALN is to address discriminatory practices and attitudes, to promote behavioural change, and to facilitate a holistic human rights-based response to HIV and AIDS.

The HIV Positive Women's Network (PWM) was founded in 1996 by a group of 60 women living with HIV, who felt that HIV services did not meet the requirements of HIV-positive women living in townships. PWM is committed to creating an environment in which people living with HIV are free from stigma and discrimination, and promotes gender equality and respect for human rights.

Her Rights Initiative (HRI) was formed in 2009 by a group of feminist South African women. The Initiative is building from the knowledge and experience of its founding members who all identified the gap between HIV/AIDS policies and HIV-positive women's experiences. They also sought to harness the potential that HIV positive women represent in improving existing policies or recommending new ones to ensure women living with HIV/AIDS are able to access their sexual and reproductive rights in South Africa. HRI is an advocacy organisation with the main objectives of advocating for the rights of women living with HIV, particularly positive women's sexual rights, reproductive rights, and the right to be free from all forms of violence. HRI proposes various areas of work and strategies to achieve its goals. To achieve these

objectives, HRI combines strategic research, access to legal services, and networks with academics and service providers.

The Wellness Foundation (previously AIDS Response) is a Cape Town-based NGO that provides education, support and advocacy for community care workers.

The Women's Legal Centre (WLC) is a non-profit, independent law centre that seeks to achieve equality for women in South Africa. As access to justice is largely inaccessible to poor women, particularly black women, the WLC plays an important role in litigating in their interest and providing them with access to free legal advice. Access to health care is one of the five strategic focus areas of the WLC.

For the majority of HIV-focused civil society organisations, it is important to note that, as Klugman points out, 'many of those who had been employed in non-governmental organisations (NGOs) and research institutions focusing on reproductive rights [are] now working on HIV and AIDS, without taking sexual and reproductive rights concerns into those spaces' (2003: 153). From the outset, women's SRHR were not significant demands in HIV advocacy.

3.2 Academic and 'expert' actors

Academic partners working to advance SRHR continued to exist throughout the 1990s when civil society organisations closed down. A number of research units and departmental divisions at South African universities research SRHR topics or topics on the right to health more generally. These are research-intensive, mostly soft-funded research units that aim to produce socially relevant research outcomes, often in collaboration with civil society organisations.

The Women's Health Research Unit at the University of Cape Town was established in 1996 and is located in the School of Public Health and Family Medicine. It acts as a multidisciplinary centre for women's health research in South Africa. The Unit's research is structured according to high priority areas identified by the South African government and in keeping with international trends: HIV/AIDS, health systems research, reproductive health, abortion, female cancers and contraception. It collaborates with the National, Provincial and Local Departments of Health to ensure that its research is relevant and contributes to health policy development and programme implementation. The Unit continuously produces research outputs that speak to the SRHR issues in current debates.

The Reproductive Health and HIV Research Institute (WRHI) at the University of the Witwatersrand (previously the Reproductive Health Research Unit) provides research, advocacy and health service delivery at the intersection of HIV and SRHR. WRHI's Community Programmes aim to facilitate the interface between community structures, both formal and informal, and SRH, through the lens of HIV services.

The Health and Human Rights Programme in the School of Public Health and Family Medicine at the University of Cape Town emerged out of collaboration with the Trauma Centre for Survivors of Violence and Torture, a human rights NGO in Cape Town, which took the form of a Health and Human Rights Project (HHRP) between 1997 and 1999. The HHRP provided input to the Truth and Reconciliation Commission's Health Sector hearings, and facilitated the promotion of human rights in the health sector more broadly. Currently, the HHRP is involved in teaching, research and advocacy. In addition, it runs an annual 'Train the Trainer' programme for staff who teach health professional students and produces materials on health rights. It does not have a specific focus on SRHR, but collaborates with various NGOs (including HIV and SRHR organisations) by providing training around the right to health.

The Faculty of Law at the University of KwaZulu-Natal has worked and published together with SRHR NGOs.

3.3 State actors

The Chief Directorate of Maternal, Child and Women's Health in the National Department of Health has in the past taken interest in advancing SRHR for women living with HIV. Currently, however, the directorate's course is unclear after personnel changes and shifting focus[4].

The implementation of NHI is a key focus area of the National Department of Health as defined by the Minister of Health, Dr Aaron Motsoaledi. Currently, the Department is piloting NHI in ten districts across the country[5].

The Directorate on HIV, TB and STIs is driving the national response to HIV, and releases the NSP. The South African National AIDS Council (SANAC), chaired by Deputy President Kgalema Motlanthe, liaises civil society with government and holds consultations with civil society organisations and actors in the development phase of the NSP[6].

3.4 Organisations with international affiliations

The South African Department of Health cooperates and consults with the WHO and UNAIDS, and South African health guidelines are based on their recommendations.

The International Planned Parenthood Foundation (IPPF) had a national office in South Africa, but this closed down in 2008.

The International Community of Women Living with HIV/AIDS (ICW) – the only global network of HIV positive women – supported the work of national and regional NGOs around coerced sterilisations. Research and fact finding conducted by ICW is principally carried out for and by HIV positive women.

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[4] Interview with M. Stevens, 8 February 2013.

[5] The districts are: OR Tambo in the Eastern Cape, Gert Sibande in Mpumalanga, Vhembe in Limpopo, Pixley ka Seme in the Northern Cape, uMzinyathi and uMgungundlovu in KwaZulu-Natal, Eden in the Western Cape, Dr K Kaunda in North West Province, Thabo Mofutsanyane in the Free State and Tshwane in Gauteng.

[6] Until 2012, the deputy chairperson of SANAC was Mark Heywood, a long-time civil society activist who currently is the executive director of Section27, a legal NGO working towards social justice.

4   Networks

Networks have a long history in South African advocacy. This section highlights strategic alliances between actors in the same advocacy sector, between actors from different advocacy sectors, and between actors from various organisational and institutional backgrounds.

In the past, SRHR advocacy around the Termination of Pregnancy Act facilitated a network of civil society organisations, academic partners and political parties. Many actors held multiple positions, which facilitated an organised and concerted approach to advocacy. As Klugman and Budlender (2001) describe, individuals involved in organising the first South African Women's Health Conference were also party members of the ANC and running academic and civil society SRHR organisations (namely, the WHRU and the WHP). Furthermore, many of the actors within and outside government had in the past worked together in the struggle against apartheid. These links of 'comradeship', also described as 'soft boundaries' (Stevens 2000), gave civil society organisations easy access to those in power. Furthermore, academic affiliations helped to provide academic knowledge for civil society organisations' advocacy demands. For example, an NGO conducted a study to obtain national baseline data on the morbidity and mortality related to abortion under the auspices of the Medical Research Council, an independent research body (Klugman and Budlender 2001).

Similarly, HIV organisations have partnered with academic institutions to form strategic alliances in HIV/AIDS advocacy. However, up until recently, little of this advocacy has included demands for comprehensive SRHR of women living with HIV.

A number of interviewees highlighted the fact that the initial advocacy strategy by TAC around accessing treatment for the prevention of HIV transmission from mother to child (PMTCT) excluded demands for comprehensive SRHR for women with HIV, and focused instead of the rights of the unborn child[7]. This strategy was successful in the court case against the SA Minister of Health in 1998, which set the precedent for the provision of PMTCT in the public sector. However, it also set the tone for the depiction of women in future advocacy. Women were usually depicted as child-bearers, and their comprehensive SRHR was not reflected in the demands made by activists.

> 'It was hard for people who tried to inject some gender equity perspectives into [early HIV advocacy]. A sort of tax on people who posed questions such as "If we chose to focus on PMTCT, how do we make sure we don't only focus on the mother?" People were saying it was a very good strategy, it's fine – but people did lose sight of the broader questions in there' (B. Klugman).

It is important to note that these strategic decisions were also influenced by the funding climate at the time. The United States President's Emergency Plan for Aids Relief (PEPfAR) and the U.S. Agency for International Development (USAID), two of the major international donors, restricted or withheld funding for organisations that advocated for comprehensive reproductive rights, for example abortion rights[8].

After many years since the closure of activist civil society organisations working on SRHR, there is now increasing recognition of the need for this advocacy. One of the newly formed

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[7] Interviews with D. Cooper, M. Stevens and B. Klugman. These interviews also referred to a 'patriarchy within the treatment movement'.

[8] This conservative approach has a long history in U.S. international funding and is known as the 'Global Gag Rule' since 1984, when a decision by Republican President Ronald Reagan stopped USAID (US Agency for International Development) funding to organisations that provided abortions or even merely discussed abortions as part of family planning (White and Pope 2007).

strategic alliances includes the AIDS Legal Network, Her Rights Initiative, and the Women's Legal Centre: HRI collected evidence of cases of coerced sterilisations of women living with HIV, and ALN and the WLC are providing the expertise for potential legal actions. In addition to this potential litigation strategy, HRI also partnered with researchers from the Faculty of Law of UKZN and published accounts of women living with HIV who were coerced into sterilisations in academic journals.

Regional networks on SRHR are well established, and play a significant role in providing information and strategies to national networks and organisations. These regional networks often act as catalysts for national advocacy foci and strategies. One such example is the AIDS and Rights Alliance Southern Africa (ARASA), which operates out of Namibia and organises regional conferences and meetings to facilitate collaborations around SRHR advocacy. In 2008, a regional meeting in Johannesburg brought together 35 partners from 15 countries in Southern Africa to discuss SRHR and the integration of HIV services. The South African representation was typical of the existing national networks between civil society organisations and academic partners (TAC, University of the Witwatersrand, OUT – LGBT Wellbeing, ALN).

Thus, to sum up, a wealth of good policy co-exists with a strong NGO sector working on HIV/AIDS and a number of academic researchers and institutions working to enhance the delivery of sexual and reproductive health. However, the initial groundswell of activism, which put SRHR on the political agenda at the time of democratisation, has not been maintained, and most HIV NGOs do not address SRHR. There is a gap in terms of women's rights activists and civil society organisations. This is starting to be addressed through the newly created strategic alliances (for example HRI, ALN and WLC) which, as is explored in the following case study, has picked up cases of coerced sterilisation in which HIV positive women's sexual and reproductive rights have been denied.

5 Case study: non-implementation of SRHR for women living with HIV

Current literature identifies a number of areas where existing SRHR policies fail women living with HIV. The issues range from gaps in the policy for cervical cancer screening to reports of women living with HIV being coerced into sterilisations. It is important to note that women who do not fit the heteronormative paradigm are often invisible in these reports. SRHR for women who have sex with women, lesbian women, transgender women, or women who are sex workers, are rarely addressed. These women often experience a double stigmatisation – because of their HIV status, but also because of their sexual or gender identity, or their occupation as a sex worker.

Access to sexual and reproductive health services is challenging for all women, despite the wealth of policies and good government guidance discussed above. Sexual and reproductive health is arguably marginalised because the conservative ideological stance on sexual and reproductive rights has not been challenged by a weak women's movement (Hassim, 2004). O'Reilly and Washington (2012) highlight how these conservative ideologies play out in service delivery, and describe the sexist, ageist and anti-poor prejudices and discrimination that young women experience when accessing a public SRH clinic. In the context of long waiting times, drug stock-outs, stigma and discrimination against HIV/AIDS, lack of health care workers, and delayed test results, these pose additional barriers to SRH services for women who use the public health sector.

> 'Women articulate very clearly that the infrastructural set up of our clinics is actually working as a deterrent, it is the fear of being screamed at, the fear of being disclosed [as being HIV positive], which [makes] many women not got to the clinic for any reason including treatment, or lead to […] women going at a far too late stage seeking assistance' (J. Kehler).

The following cases – which focus on cervical cancer screening, sterilisation, access to fertility treatment and access to contraception – highlight the current conundrum in providing SRH services to women living with HIV. Turning the view towards government and its service delivery, the lack of implementation of existing policies allows service providers to ignore or disrespect the rights of the women that they provide care for. On the other side, the ability of women living with HIV to decide freely and voluntarily, and exercise their patient autonomy is severely compromised by structural constraints as well as directive moral attitudes and actions from health care workers.

> 'It has a lot to do with infrastructure and the way it is set up, and with attitude and prejudices among health care providers but also […] with violence, stigma and discrimination happening at the community level – which act as barriers to accessing clinics because clinics are in the same communities' (J. Kehler).

5.1.1 Cervical cancer policy

The current policy for cervical cancer screening fails to mention that women living with HIV have an increased risk of developing cervical cancer. Currently, the policy provides for three preventive pap smears for women above the age of 30 in their lifetime. These provisions are inadequate for women living with HIV, the majority of whom is between the ages of 19 and 24. In contrast to the cervical cancer screening policies, the *South African National Antiretroviral Guidelines* (2010) specify that women who have not been initiated on antiretroviral treatment (ART) should receive a pap smear once a year.

'What was smart about that original policy [the cervical cancer screening policy] is that it was based on cost effectiveness, using the WHO standards. I don't think that kind of assessment has been done in light of what we are seeing, particularly with HIV positive people, especially young women – that's a gap' (B. Klugman).

This example points to the challenge of integrating policies, in order to accommodate for the special needs of women living with HIV.

'Since our policies are not making specific reference to HIV positive diagnosis or women's needs living with HIV, the lack of mentioning it then gives loopholes in the legislative framework, where the violation can just happen' (J. Kehler).

In 2011, HRI conducted a policy review and highlighted that the absence of a human rights advocacy initiative on cervical cancer has meant that there is no movement to push for an upscaling of services, or to serve as an oversight mechanism to the implementation of existing services (Mthembu 2012). HRI used a community-driven, needs-based assessment of the current policy, and involved women living with HIV, health care workers, HIV advocacy organisations (ALN, Positive Women's Network and South Africa Partners in the Eastern Cape) and officials from the Department of Health. This consultative process was strategically positioned to not only document rights abuses, but also provide networking opportunities for the organisations involved. HRI reports that the consultative process increased the awareness of cervical cancer screening as a human rights issue among the health care workers. As a result, one of the officials interviewed at Durban Hospital encouraged his staff to lodge a letter of complaint about the unavailability of screening services for women living with HIV to the South African Human Rights Commission (Mthembu 2012).

5.1.2 Coerced sterilisation

Cases of women living with HIV being coerced into sterilisations, or being sterilised involuntarily, have come to light through a number of channels in the past five years[9]. HRI partnered with UKZN to research and publish accounts of women living with HIV who had been sterilised against their will (Mthembu 2011, Strode 2012). Their research documented the experiences of 29 women living with HIV in the Gauteng and KwaZulu-Natal provinces. The reports highlighted how the power of health care workers and the constraints of an under-resourced health system allow for these grave violations of women's bodily integrity. Women gave evidence of how health care workers presented sterilisation as a birth control option because of the women's HIV-positive status and misinformed women about the need for sterilisations (in one case, a woman was told that if she had another child she would die). Furthermore, women were being compelled to sign consent forms without explanation under highly stressful circumstances, such as while they were already in labour or being wheeled into theatre (Strode 2012). The resulting societal vulnerabilities for women who were sterilised involuntarily are significant: women report high levels of stigmatisation, loss of access to other socio-economic spaces and opportunities (Nair 2010), loss of marriage potential on account of being unable to bear children, and resulting reduced social status. In the current South African context, these consequences contribute to the existing economic and social vulnerability of women. While the currently documented cases focus on Gauteng and KwaZulu-Natal, there is further evidence of cases in the Western Cape (Nicole Fick, personal communication[10]). Two interviewees, also based in the Western Cape, referred to similar cases that they had encountered, but which have not been publicised in the media. Interviewees highlighted that

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[9] Some of the first accounts were in the national media: for example 'Sterilised without consent' in the *Mail* and *Guardian* from 21 June 2009 (http://mg.co.za/article/2009-06-21-sterilised-without-consent).

[10] Nicole Fick, research coordinator of the Health and Human Rights Programme at the University of Cape Town, 07 February 2013.

the coercion often occurs through persuasion from health care workers, or directive counselling on contraceptive options.

> ''Sometimes the nurses ask: "Why are you doing family planning? Why are you not sterilising because you are HIV?" – as if people living with HIV don't have a choice to have babies. There are more cases, but there is the issue of reporting or talking about that because the people they don't even know if there is such a thing' (N. Kraai).

Beyond South Africa, there is regional and international collaboration in advocacy around coerced sterilisations. Namibian activists reported the first cases in the region at the ARASA regional conference in Johannesburg in 2008. The Namibian cases followed a strong rights-based approach, invoking various rights that women who had been forcibly sterilised had been denied, and sought legal compensation for these women (ARASA 2008)[11]. This strategy had been supported by the ICW (ICW 2009). Currently, a network of South African NGOs is considering legal steps following the publication of the accounts of coerced sterilisation. There are, however, important concerns around this strategy. These are described under strategies to address the implementation gap (see 5.3.3).

5.1.3 Access to fertility treatment

Recent literature points to the importance of discussions around fertility options to mitigate the concerns regarding the dangers of childbearing for women living with HIV (Cooper and Harries 2009). In the absence of policies on fertility treatment, the attitudes of health care workers are often dominated by medical concerns related to the risks of pregnancy for the HIV-positive women, and the risks of the unborn child to contract HIV (Harries et al. 2007), as well as by contemporary societal attitudes and norms.

> 'Choices around pregnancy – as I said, it's implicit that women should have the right to decide about reproductive health issues. That is a particular area – there's not even policy, let alone being implemented' (D. Cooper).

As a result, contraceptive options are promoted to a far greater degree than reproductive options (Myer and Morroni 2005). Myer and Akugizibwe argue that, 'within the expansion of access to HIV care and treatment, discourses around discouraging reproduction and encouraging contraceptive use among HIV-infected women, particularly those using ART, have often been justified in the name of public health' (2009: 53).

One of the interviewees stressed that while the absence of fertility treatment options results in a lack of access for women in general, women living with HIV face even more barriers.

> 'Accessing services to actively become pregnant in a safer way – that's virtually non-existent. The policy makers and providers are aware that it's an issue, but not much is happening' (D. Cooper).

This is most likely because many health care providers have negative attitudes towards women living with HIV who choose to become pregnant: 'Providers and policy makers tend to still feel better if women didn't become pregnant if they are HIV positive' (D. Cooper). Recent interviews with women living with HIV confirm this view (Orner et al. 2010). As a result, women living with HIV tend not to raise their fertility desire with their health care provider. This results in women not being able to access safer options of conception.

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[11] In 2012, a Namibian court found that three women had been sterilised without their consent. All three women were HIV-positive, but the court dismissed the claim that they had been sterilised simply because they were HIV-positive. Source: LM and others v Government of the Republic of Namibia, case number 1603/2008, quoted in Strode et al. (2012).

While all interviewees agreed that restricting women's choice of contraception is in contradiction to their reproductive rights, the issue has not been articulated in a rights framework. The literature around the topic mostly emanates from a biomedical perspective, and the concern about unsafe conception overrides views on the right of women to conceive safely. In an advocacy framework, safe conception has been exhausted in the campaign around access to PMTCT for women living with HIV as the primary approach to safe conception.

> 'HIV policy implementation, by and large, has focused on the women as transmitter, and that's because of the way the PMTCT programme has been implemented with a predominant focus on preventing transition to the child – and not enough use of the moment of pregnancy of labour/child-birth and post natal period as a moment of prevention' (B. Klugman).

It is important to note that a lack of knowledge and resources, in addition to moral concerns, often informs health care workers' attitudes and leads to poor counselling around fertility options.

> 'The HIV carers are very keen for HIV positive women to go onto contraception and not become pregnant. They are not equipped for counselling, not equipped for the most part to provide the contraceptive themselves if the woman wants that. They are not very well equipped to advise about what to do in the case of an unintended pregnancy, or what to do should you have sex and not use a condom – issues of emergency contraception for example, I don't think that's dealt with at all' (D. Cooper).

5.1.4 Access to contraception, including abortion

Contraception and abortion for women living with HIV are often situated in a contradictory discourse. Health care workers who provide reproductive health services often have conservative attitudes, which restrict access to contraception for all women (Holt et al. 2012). By and far the majority of women rely on injectable short-acting contraceptives, which usually last for three months (Crede et al. 2012). Yet, there have been concerns that these contraceptive methods are not the most suitable for women living with HIV.

> '[There are] massive issues with regards to contraception: what to do about the excessive reliance on Depo Provera [the most common injectable contraceptive], and on injectables, given the concern that it might be responsible for increasing vulnerability particularly in young women' (B. Klugman).

Crede et al. (2012) found that health care provider recommendations were instrumental in influencing the method of contraceptive that women living with HIV chose. Orner et al. (2010) found that women living with HIV reported negative perceptions by health care workers towards being pregnant. Hence, women living with HIV often experience pressure to either use contraception or have an abortion, rather than conceiving a child (One In Nine Campaign 2012).

The current contraceptive policy, although dated, provides fairly comprehensive guidance on the available contraceptive options. These guidelines are currently under review and a new policy is expected to be published soon[12]. However, the actual services provided, and the implementation of the contraceptive policy, often fails women living with HIV.

> 'I think there is quite a good policy and guidelines but I don't think they are particularly well implemented [...] I don't think we've made much progress in terms of women

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[12] B. Klugman, interview

getting more choice around which contraception they use […] policies haven't really changed mind sets of people […]. Although providers will say to you "Women should have a choice, this is what we need to do", I don't think it's been really incorporated into the training of providers to change the way they do things' (D. Cooper).

Nevertheless, like all women in South Africa, women living with HIV still face distinct challenges when wanting to access abortion themselves. A recent study from the Women's Health Research Unit at UCT highlighted that health care workers often stigmatise abortions even more than HIV status (Orner et al. 2011). Women often have to wait for weeks to have an abortion, and many women choose unsafe 'backstreet' abortions when the public health sector does not provide timely services to them. As Stevens (2012) highlights, the need for better quality and more widespread provision of termination of pregnancy services is mentioned in the recommendations of the Department of Health's Commission of Enquiry into Maternal Deaths, however there are no accountability mechanisms to ensure that these recommendations are met.

5.1.5 Coerced HIV testing – 'voluntary' consent?

The Health and Human Rights Programme at the University of Cape Town recently documented three instances where women were forced to undergo HIV tests at different Cape Town public clinics in order to access contraceptives or treatment for Sexually Transmitted Infections (Nicole Fick, personal communication). In 2010, four SA human rights organisations (ALN, HRI, Just Associates, and the Justice and Women Project) published a report on the experiences of women living with HIV who experienced HIV testing during pregnancy (Kehler et al. 2010). The report points to the complexities around HIV testing, and questions the legitimacy and voluntary choice in 'consent' in the current context.

> 'The need to increase the uptake in HIV testing seems too often linked with a disregard of fundamental rights, particularly in the context of HIV testing during pregnancy, as human rights of informed consent, autonomy, confidentiality and non-discrimination are increasingly threatened in the course of the HIV testing scale-up. Thus, at the centre of debate is the question of how to ensure both – the uptake of HIV testing and the protection of human rights' (p. 9).

Whereas the previous HIV testing policy focused on voluntary testing – meaning patients had to request to be tested – with provider-initiated testing (also called the opt-out model), the health care worker offers HIV testing to every patient, regardless of the complaint they are presented with. In reality,, provider-initiated testing often leads to women being coerced into testing, with providers abusing their positions of power.

> 'In the context of HIV testing, it's really from threats, as in, "if you do not test we're not going to help you," to brutal blackmail – "what kind of a woman are you if you do not care about your child?"' (J. Kehler).

While this may often emerge out of a genuine public health concern, it nevertheless gravely violates women's rights to autonomous decision-making about their own bodies. Furthermore, health care workers make access to reproductive health services conditional on HIV testing, so that women are regularly being denied services if they refuse a provider-initiated HIV test.

> 'In the context of family planning and access to contraception, [and] STI treatment […] there is this conditional HIV testing. If you want to have the services you actually came here for, you're only going to get that once you've been tested, even though the HIV test had nothing to do with the actual needs' (J. Kehler).

According to the ALN, women often do not know that they have the right to refuse testing.

'We have many situations in different settings all over the country, where women tell us "but you have to test", and not because they have a general argument attached to it, but because that's what they are made to believe. Many women are still in a situation [where] they do not understand that you have the right to make the decision whether you want to test or not. This is also one of the challenges which then unfortunately makes it much easier in a clinic setting to coerce women into – because women don't really know that they are actually not allowed to be coerced into testing' (J. Kehler).

These complexities around provider-initiated HIV testing attest to the constraints of decision-making that women experience due to their HIV status, their gender, their socio-economic position and other factors that impede their autonomy. In these contexts, women are often not able to make free and voluntary choices.

5.2 Reasons for non-implementation

'It's good to have those policies and the laws that have been passed in line with those policies, but we've got a long way to go in terms of changing the environment in which women live, in terms of attitude towards women's sexual and reproductive rights and in terms of service provisions, and actually implementing polices in a way that is reflected in the manner in which service delivery takes place' (D. Cooper).

There are numerous reasons why the existing SRHR policies are not implemented for women living with HIV. The following section explores the dynamics in the health system between health care workers and patients, and the stigma and discrimination that women living with HIV still face.

5.2.1 Health system challenges

One of the fundamental challenges in the health system is that health services are not offered in an integrated way. In the current organisation of the primary health care system, SRH services are not offered within HIV services, and vice versa. This often makes SRH services inaccessible for women living with HIV, who rely on HIV services as their main point of entry into the system.

'One of the fundamental challenges we have is that all our services are so-called specialised services – in real life it means we have segregated services, which is […] an issue of rights abuses' (J. Kehler).

The reality of non-integrated services means that women living with HIV have to access different services on different days, often at the cost of a whole day spent at the health facility.

'If a woman who is positive will go to HIV care for one need, and then to another service, even of the same building, but then have to join another line to get contraception if that's what they're wanting. They maybe don't go, because they have waited for a long time, in a line to access their HIV care and then have to go across to another clinic to other sections of reproductive health services. […] You go for HIV care in one place, you get referred elsewhere for sexual and reproductive health, you get referred elsewhere if you become pregnant while you are HIV positive, if you discover to be HIV positive during pregnancy you get services there – once your pregnancy is over then you get referred somewhere else. If you have an unintended pregnancy and you are in an HIV care service then you get referred somewhere else to deal with that, if you want to terminate the pregnancy' (D. Cooper).

Within the existing HIV services, there is a lack of knowledge about SRH options and services available to women living with HIV, and vice versa within SRH services about HIV care.

'Often the sexual reproductive health services don't know what to advise them, and even if they do disclose, those on the HIV side don't know what to recommend except [that] it's a good idea for you to use contraception and not become pregnant now that you are HIV positive' (D. Cooper).

The general lack of resources in the public sector affects the quality of SRH care that women living with HIV can access. Lack of staff results in long waiting times (including for abortions), and drug shortages result in a lack of available contraceptive options. Furthermore, the health system struggles to deal with a quadruple burden of disease[13], so that SRH services are often simply not prioritised.

'I think part of it is the fragmentation, part of it is judgmental attitudes that prevail amongst service providers and policy makers – it filters down. Part of it is trying to deal with a whole lot of needs and then order priority of needs – sexual reproductive health rights and needs, except for contraception and have a baby safely and make sure the baby remains un-infected, besides those two strong emphases I don't think sexual and reproductive health are dealt with in a particularly tailored sort of way' (D. Cooper).

5.2.2 Health care workers as barriers

'[Attitudes] play a huge role, not only about health service providers, and the health services themselves, they are barriers to women going for care along the line before they reach health services. Once they get to health services, the provider can play an enormous role in what they think their options could be – whether they have an option, what could those be. Whether they'd be received with a caring attitude, one that is in tune with their fears, concerns, needs or one that doesn't. They might not go if they don't think they're going to get a compassionate approach to their needs, or they might go and not raise issues that are really important to them if they think that they are going to be advised in a way that they don't think will be useful to meet their own particular need' (D. Cooper).

London et al. (2008) argue that the current non-prescriptive nature of guidelines regarding HIV and reproduction in South Africa increases the risk that views of health workers will influence how a person's right to choice is negotiated in clinic interactions. Health care workers act as barriers either because they don't possess the SRH knowledge, or because of their own moral attitudes and judgements.

The example of lack of access to fertility treatment highlights the importance of education in asserting women's SRHR. Women need to be aware of their fertility options in order to demand them from their health care workers. At the same time, health care workers need to be educated about the available choices, and need to challenge their own moral attitudes towards women living with HIV who wish to become pregnant.

'[Women living with HIV who wish to become pregnant] fear raising it with service providers because they fear being told, "well, you shouldn't be trying to become pregnant if you're HIV positive". And I don't think service providers are equipped to deal with that issue so it's easier to say to a woman living with HIV, "go and get contraception, it's not a good idea for you to have a baby". I'm sure there are some providers who deal with it quite well in an ad hoc way, but the majority of providers don't know how to deal with it, so they would rather not talk about it all with clients' (D. Cooper).

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[13] South Africa has among the highest burden of disease for infectious diseases (including HIV/ AIDS), an emerging and increasing burden of non-communicable diseases, high maternal and child mortality, as well as a significant burden resulting from violent crimes and accidents (The Lancet: Health in South Africa. Executive Summary, available at: http://download.thelancet.com/flatcontentassets/series/sa/sa_execsum.pdf).

Health care workers' attitudes towards women living with HIV have repeatedly been identified as major barriers to accessing services.

> '[Health care providers] can't make those decisions for [women living with HIV], or try and steer them in a direction that [they] think is the correct moral direction, in terms of [their] own views of the world. A lot of that still happens […] Providers discourage women from becoming pregnant while being HIV positive, and rather suggest that they go for contraception' (D. Cooper).

> 'Many health care providers […] actually see nothing wrong with it. They can justify the fact that upon HIV positive status diagnosis, your sexual and reproductive rights are limited. [They] are going to scream you out of the clinic and send you away with nothing – that happens everywhere' (J. Kehler).

Health care workers' attitudes stem from a variety of sources, and often these health workers live in the same communities that the clinics are located in, so their attitudes reflect a broader mindset. Furthermore, health care workers are also a product of the system that they have been trained in.

> 'Sometimes I have quite a lot of sympathy with […] providers, that they've been told these are the polices […] but then they don't know how to put it into practice because they've been trained in a different way […] a much more top down sort of approach in terms of dealing with clients' (D. Cooper).

One example of how the system itself creates health care workers' knowledge and attitudes are the fertility guidelines for people living with HIV (Bekker et al. 2011). These guidelines operate from a heteronormative perspective and don't include references to or fertility options for women living in same-sex relationships, women with non-conforming gender identities or HIV positive women who want to bear children without a partner.

It is, however, important to recognise the constraints within which health care workers themselves operate.

> 'I think it's not very helpful to say "oh, nurses have a horrible attitude – let's make interventions that only deal with attitude" – because without a doubt part of that attitude has to do with poor management of the health services. And the consequences of that, for nurses in rural areas, are having one nurse having to deal with everything. It's true that some of the attitudes in this field have to do with nurses themselves reflecting the social-cultural norms of the society, nurses themselves, being victims or survivors of violence, or being HIV positive or having family that are. There are generic health services problems, meaning management, information, drug procurement – but also inter-personal problems to do with tone, style of the work place, extent to which people feel recognised, and understand the distinction between their personal views and their responsibilities – those are management issues. Those are one set of issues, and the consequences for HIV positive women are in terms of access, services they receive, attitude[s] they experience there, in terms of lack of clarity of what services should be given where and how, and so on' (B. Klugman).

5.2.3 Stigma and discrimination

Women living with HIV still experience significant levels of stigma and discrimination, not only in the health system but also in the broader community. Health care workers are part of these broader communities.

> 'People who are implementing [the policies] are not free from prejudices and stigma […] but that's only the beginning of the challenge that we are going to be facing for

years to come, because that combined with [the] situation [of] our health care system in shambles: [...] we have poor infrastructure, we have limited budgets and over-worked health care providers' (J. Kehler).

There are high levels of stigma attached to certain reproductive choices, most notably abortions. Furthermore, people of non-conforming sexual or gender identities are highly stigmatised, as are women who work as sex workers. This discrimination affects women's health-seeking behaviour, and often women living with HIV do not access health services for fear of being publicly identified as desiring an abortion, as a sex worker, or as lesbian, and then being further stigmatised.

'There is stigma, there is barriers because of your disease, because you are sort of victimised – the issue of ignorance and attitude toward people living with HIV, it's still a problem – stigma and discrimination' (N. Kraai).

5.3 Strategies to address the implementation gap

A number of strategies have been used to advance SRHR since 1994. However, even after a successful reform of the Termination of Pregnancy Act in 1996, HIV advocacy often side-lined SRHR issues. The language and demands of SRHR for women living with HIV were reduced to fit the dominant discourse of HIV prevention. As a result of lack of leadership and redirected funding, the SRHR movement lost its momentum. It is only recently, with a revived network of organisations and new advocacy strategies, that advocacy for SRHR of women living with HIV has re-surfaced.

The case study highlights that different strategies were used at different times, depending on the political environment and the available networks and resources. The language around issues of coerced contraception is strongly rights-based, whereas issues of fertility management and contraception are not as politicised. The strategies used around the onset of democracy (around TOP) were constructive and aimed at working with government, whereas the TAC court case against the Minister of Health signalled a shift towards more adversarial strategies. Currently, adversarial strategies are seen as a 'last resort', when working with government yields no progress.

'By now we are beyond the stage of advocacy, we've done that since 2007 when the WHO came up with the new policy for HIV testing and it didn't take us far. It is time to do think carefully about litigation on individual cases' (J. Kehler).

5.3.1 Health system-oriented strategies

The health system faces a number of specific challenges in order to realise the SRHR of women living with HIV.

'On the one hand you don't want to single them [HIV positive women] out, as this is a special group that needs special focus, but in some areas you do need specific focus – because they are vulnerable to having their rights most often not appreciated and recognised, in a practical sense when they go for services and want to have their sexual reproductive rights and needs met' (D. Cooper).

First, where SRH policies exist, their specific guidelines need to be harmonised with conflicting policies. The case of the cervical cancer policy serves as example.

Furthermore, SRH policies need to be integrated into existing policies. This integration needs to acknowledge the whole range of SRHR, and not only selected issues.

Existing health services need to provide integrated services to women living with HIV. This means that HIV services must include SRH services and counselling options on gender-based and sexual violence. Health services must work with the law enforcement and criminal justice system on gender-based and sexual violence in order to ensure that women who have experienced GBV or sexual violence receive all necessary services in one place.

> 'The services need to be set up so that it's going to work – integration of services needs to happen, [so] that women don't need to go to different services […] I accept that there does need to be some referral, that HIV care is not going to be able to deal satisfactorily with baby deliveries of HIV positive women. But there is such a connection, and they are not talking to each other, some form of integration needs to happen. Whether at the service delivery level, or through them coming together and discussing how to tackle these problems' (D. Cooper).

The reform of the health system envisioned under the National Health Insurance provides crucial opportunities to facilitate changes that bolster SRHR for women living with HIV. Under NHI, community health workers are envisioned to be the foundation of a preventive, decentralised health system and are hence in a strategic position to facilitate women's access to SRH services by providing health education and promotion and referrals to services. Amollo (2012) underlines that the establishment of an NHI could represent a step towards realising women's rights to health, depending on the way that it structures and organises care in South Africa's health system. In order for CHWs to fulfil this crucial gatekeeper role, however, there needs to be comprehensive, rights-based training on SRHR. This is currently not provided, and CHWs often act as access barriers for women living with HIV.

> '[SRH services] is sort of a taboo thing that they don't even talk about, they don't even realise there are rights – hence that we felt that as an organisation we need to have to develop women in terms of their rights – to develop a programme around women and leadership so that we can capacitate them in some of the typical issues' (N. Kraai).

Currently, the Wellness Foundation (previously AIDS response) provides training for CHWs and partners with other NGOs and academic institutions to enlarge the scope of these trainings. It is crucial, however, that the training of CHWs becomes standardised and provided by the Department of Health.

NHI is based on a reengineered primary health care system; of which increased participation in health decision-making is one of the key principles.

> 'Building community demand, and monitoring of the quality of health services is very powerful and there are very nice models of that, particularly in Zimbabwe for example, for creating networks where you build the confidence and ability in the community, and at the same time you get the data right across the country of what's going on. This is a kind of upward demand creation, and at the same time there can be [strategies to] identifying existing training or developing training and advocating for managers to have to do that' (B. Klugman).

In order to increase participation, it is imperative that accountability mechanisms are in place and accessible to health service users.

> 'It also has a lot to do with calling to account to health care providers, or anybody for that matter, who is violating women rights based on the HIV status' (J. Kehler).

The current accountability mechanisms fail women living with HIV because they are either inaccessible without organisational support or legal representation (for example, the Human Rights Commission), or because women fear the repercussions of laying complaints about the only services available to them (when complaining to clinic managers directly). The National

Health Act calls for health committees who could help fulfil the role of patient complaint structures, but in most provinces there is no adequate provincial legislation to implement health committees[14]. The Health and Human Rights Programme at UCT provides research evidence and works with health committees and local government to establish functioning health committees in the Western Cape. This model could be replicated in other provinces.

5.3.2 Training of health care workers

All interviewees agreed that training health care workers is a key strategy to ensure that the SRHR of women living with HIV are respected at the level of service provision. These trainings need to challenge health care workers' own moral values, while simultaneously providing the knowledge to provide comprehensive SRH services.

> 'The first thing is around attitudes. The second, equipping them with knowing what to offer […] Within the health care system, a lot more can be done to train counsellors, providers – values clarification type of training where they examine their own attitudes around these issues. Some of that happened around abortion, and quite effectively, where people would acknowledge that this is how I feel for myself but that's not how everybody needs to feel for themselves, that I should respect their choices and counsel accordingly and then I think that providers also need to be equipped with knowing what you can advise' (D. Cooper).

Whereas in the past rights education was often geared at women living with HIV, the current rights violation in health care services highlight the need to provide education on human rights, and specifically on SRHR for providers and communities at large.

> 'We are […] over-focusing and believing in this assumption that women living with HIV do not know their rights – that they need training. I'm not saying that they don't need it, but we also need to realise that the communities are the ones who are the problem right now, the health care providers are the ones who need to be held accountable according to the policies' (J. Kehler).

> 'Education for community at large [is very important]. If you don't know then you don't ask for some of the services, because you don't know they are available – especially sexual reproductive health [services]' (N. Kraai).

> 'When you talk to providers they will tell you that they embrace a rights perspective […] but I think in their practice there hasn't been much training on [how to do] that concretely' (D. Cooper).

Provider training needs to be embedded in a broader discourse of SRHR, and a shift in the perception of sexuality.

> 'There is a real absence of a broader rights discourse and understanding of what that means, and having to do more than identify services that need to be provided but to actually build the capacity of managers and health care providers to understand and be able to talk in simple terms about sexuality. That is [the problem around] sexuality: you are not going to find a provider who is able to do more than either berate you or give you contraception; but not actually say to you, "what's going on, what are your hopes, what are the problems?"' (B. Klugman).

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[14] Currently only the Western Cape and Eastern Cape provide legislative guidance on the role, structure and functioning of health committees. Health committees are well established in other countries in the region, for example Zimbabwe, and research has shown their positive impact on the quality of services and participation of community members in health care (Loewenson et al. 2005).

One possible framework to facilitate participatory education of health care workers is the 'Health Care Workers for Change' framework, developed and successfully implemented by the Women's Health Project at the School of Public Health at the University of the Witwatersrand (Fonn and Xaba 2001). It is endorsed by the WHO[15], and has been evaluated in various countries in Sub-Saharan Africa and Argentina (Onyango-Ouma et al. 2001).

5.3.3 Legal strategies – redress and litigation

Redress and complaint mechanisms are currently lacking in the health system, and where they exist they are often not accessible. When they are accessible, women often are unwilling to lay a complaint because they fear negative repercussion in subsequently accessing care.

> '[Women said they] know about redress mechanisms but were not going to use them because [they] are afraid of further repercussions – because at the end of the day this is the only clinic [they] have and if [they] make noise in this clinic where do [they] get treatment from?' (J. Kehler, ALN).

> To date, there have been no litigation cases on SRHR for women living with HIV. However, there are considerations among a network of South African NGOs: ALN, HRI and the Cape Town-based Women's Legal Centre have each been documenting cases of coerced sterilisations in preparation for potential legal strategies, following the model of Namibia[16]. Litigation is perceived as a 'last, last resort' (J. Kehler) that speaks to the frustrations with the current lack of implementation of SRHR. 'I believe that [litigation] is the way to at least make sure that the current policies are amended in such a way that it minimises spaces for human rights violations' (J. Kehler).

However, there are concerns that might prevent the potential use of litigation strategies. There is limited capacity within NGOs to initiate and take on a case of litigation since there are very few law firm-based NGOs in South Africa, and commercial law firms may well be unaffordable to the affected women or their organisational representatives. Furthermore, there is concern that foreign donors would not provide funding to organisations that are actively engaged in taking their own government to court.

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[15] www.who.int/tdr/publications/documents/**health-workers**.pdf (accessed 19 March 2013)

[16] In 2012, a Namibian court found that three women had been sterilized without their consent. All three women were HIV-positive, but the court dismissed the claim that they had been sterilized simply because they were HIV-positive. Source: LM and others v Government of the Republic of Namibia, case number 1603/2008, quoted in Strode et al. (2012).

6 Conclusion

6.1 SRHR for women living with HIV: 'the policies are beautiful but the delivery is appalling'[17]

While the current South African legislation provides a progressive, rights-based framework for SRHR, the SRHR of women living with HIV are regularly violated. There are gaps in the existing policies that overlook the specific needs of women living with HIV, and existing SRHR policies are not implemented in a way that allows women living with HIV to access these services.

> 'We may have figured it all out on paper, […] there is very little one can criticise around the constitutional [and] legal framework. But as we all know [the framework is] only as good as can be implemented' (J. Kehler).

This implementation gap is due to the constraints of the resource-limited public health sector, and furthermore points to the gatekeeper role of health care workers. As MacGregor and Mills (2011) have argued, even where rights have been prominent in HIV programming, the framing of 'responsibilities' of women living with HIV can in fact encourage practices on the part of health care workers that diverge from an approach respecting individual rights, such as the right to choice. The evidence presented here suggests that this is, in fact, often the case when women living with HIV seek to access SRH services. Furthermore, as the case studies and discussion around actors, networks and institutions show, women are not necessarily aware of their sexual and reproductive health rights, and nor are the majority of health care providers. Even when women are aware, there are very few effective avenues for negotiating these rights, and addressing rights violations in positive ways.

6.2 Recommendations

6.2.1 Recommendations for activists/advocates

- Integrate SRHR into HIV advocacy and activism.
- Consider women's SRHR comprehensively, and be aware of the potential repercussions of only focusing on certain aspects.
- Build and maintain leaderships and networks in a social justice framework.
- Recognise that current HIV policy does not necessarily encompass SRHR.
- Carefully consider adversarial versus reconciliatory approaches, consider the consequences for individuals, and unintended effects of 'showcasing' individual experiences.

6.2.2 Recommendations for national government

- Review policies for inclusion of HIV positive women (i.e. cervical cancer screening policy).
- Review existing policies that contribute to the vulnerability of marginalised sexualities and other key populations (e.g. the criminalisation of sex work).
- Provide resources for the training of health care workers, in education curricula as well as in-service training.

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[17] Interview with B. Klugman.

- Ensure that comprehensive SRH services are included in the proposed 'package of care' under NHI and provide policy guidelines for the delivery of these services by community health workers.
- Facilitate complaint and redress mechanisms in the public health sector, ensure the anonymity of complainants and make complaint structures local and accessible.
- Ensure that the Office of Health Standard Compliance, planned under NHI, has the mandate and capacity to facilitate redress for rights violations.

6.2.3 Recommendations for international donors

- Provide financial support for the implementation of policy.
- Provide funding for NGOs who give legal advice, collect cases and initiate law suits[18].
- Provide technical assistance and knowledge for the implementation of quality monitoring, acknowledging the need for local reporting without fear of retribution.

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[18] Examples are the Women's Legal Centre, the AIDS Legal Network and Section 27.

7   Interviewees

Dr Di Cooper, Women's Health Research Unit, University of Cape Town, 19 February 2013

Dr Barbara Klugman, School of Public Health, University of the Witwatersrand, Johannesburg, 18 February 2013

Marion Stevens, WISH Associates, Cape Town, 8 February 2013

Ntombuzuko Kraai, Wellness Foundation, Cape Town, 26 February 2013

Dr Johanna Kehler, AIDS Legal Network, Cape Town, 21 February 2013

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