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Cover photo: Mbali Ndlovu and her sister Zanele (holding her baby) at their homestead in Uthungulu District, KwaZulu-Natal, South Africa, January 2014 © Amnesty International

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GLOSSARY AND ABBREVIATIONS

AIDS Acquired Immunodeficiency Syndrome.

ACHPR African Commission on Human and Peoples' Rights

ARV Antiretroviral

CARMMA Campaign for the Accelerated Reduction of Maternal

Mortality in Africa

CEDAW (UN) Convention on the Elimination of All Forms of

Discrimination Against Women

CGE Commission for Gender Equality

Community health workers A cadre of non-medically trained (lay) care givers, including

home-based carers and community care-givers, who provide palliative care in people's homes and psycho-social support.

CRC Convention on the Rights of the Child

CSE Comprehensive sexuality education

currency South African rand (R). In this report, US\$1= R10.5

HIV Human immunodeficiency virus. HIV weakens the immune

system, ultimately leading to AIDS.

HIV-negative A person who is HIV-negative shows no evidence of infection

with HIV in a blood test

HIV-positive A person who is HIV-positive has had antibodies against HIV

detected in a test

HIV prevalence quantifies the proportion of individuals in a

population who are living with HIV at a particular point in

time.

ICESCR International Covenant on Economic, Social and Cultural

Rights

MDG Millennium Development Goal

maternal mortality "The death of a woman while pregnant or within 42 days of

termination of pregnancy, irrespective of the duration and site of the pregnancy, from any cause related to or aggravated by the pregnancy or its management, but not from accidental or

incidental causes" (the World Health Organization)

Maputo Protocol Name widely used for the Protocol to the African Charter on

Human and Peoples' Rights on the Rights of Women in Africa

NCCEMD National Committee on Confidential Enquiries into Maternal

Deaths, an independent, expert body contracted by the National Department of Health to investigate the causes of

maternal deaths in South Africa

NGO Non-governmental organization

NSP National Strategic Plan for HIV/AIDS, TB and STIs, 2012-16

OHCHR Office of the United Nations High Commissioner for Human

Rights

PICT Provider-initiated HIV testing and counselling, defined by

UNAIDS as "HIV testing and counselling recommended by a

health-care provider in a clinical setting"

PMTCT Prevention of mother to child transmission, defined by

UNAIDS as "a 4-prong strategy for stopping new HIV

infections in children and keeping mothers alive and families

healthy"

SAHRC South African Human Rights Commission

SANAC South African National AIDS Council

STI Sexually transmitted infection

TB Tuberculosis

Traditional leader Someone who is recognized, in terms of the customary law,

institutions and structures of a traditional community, to hold a leadership position. In South Africa, traditional leaders so recognized perform important roles in the public life and

governance of communities.

UNAIDS Joint United Nations Programme on HIV/AIDS

UNESCO United Nations Educational, Scientific and Cultural

Organization

WHO World Health Organization

In this report, in line with the definition in the Convention on the Rights of the Child, the terms "child" and "girl" refer to people aged under 18.

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The term "adolescent" refers to young people aged 15-24.

1. INTRODUCTION

'[P]regnant women... occupy centre-stage in the income poverty and economic inequalities that mark South Africa.'

Wits Centre for Health Policy¹

South Africa has unacceptably high rates of maternal mortality. Although the country is seeing improvements since 2011, the number of women and girls who are dying during pregnancy or shortly after giving birth has increased dramatically since 2000. Today, the maternal mortality rate stands at 269 deaths per 100,000 live births, far higher than the rate of 38 which the government committed to achieve by 2015.² Experts suggest 60% of maternal deaths in South Africa are avoidable.³

Appropriate and timely antenatal care plays an important role in improving maternal and child health,⁴ and preventing maternal deaths.⁵ It aims to detect and treat existing health problems and to screen for complications that may develop in the pregnancy. The World Health Organization (WHO) recommends a minimum of four antenatal care visits, starting in the first 12 weeks of pregnancy.⁶ Antenatal care is also an opportunity to provide vital health information to women and girls relating to lifestyle risks and to offer social support and counselling. It connects them with the health system, leading to an increased likelihood of delivery with a skilled birth attendant and continuing care after the baby is born.

Early attendance at antenatal clinics is particularly important for pregnant women and girls living with HIV.⁷ Nearly 30% of pregnant women and girls in South Africa are living with HIV,⁸ and illnesses related to HIV infection are the biggest cause of death among pregnant women and girls in the country, followed by bleeding during or after childbirth and complications caused by high blood pressure.⁹ Women and girls living with HIV are over five times more likely to die during pregnancy or shortly after birth than those without the virus.¹⁰

The South Africa government has taken commendable efforts to prioritise the need to reduce maternal deaths in recent years through key health policies. ¹¹ These policies recognise the importance of early and continued antenatal care. The government's stated target is for more than 60% of pregnant women and girls to access antenatal care before 20 weeks of pregnancy by 2016. ¹². Antenatal care is free in South Africa's public health system and nearly all pregnant women and girls attend an antenatal clinic at least once during their pregnancy. However, most pregnant women do not access antenatal care until the latter stage of pregnancy. ¹³ Such delays have been linked to nearly a quarter of avoidable maternal deaths in South Africa. ¹⁴

As part of its commitment to reduce maternal deaths, in 2010 the government began providing antiretroviral treatment to pregnant women and girls living with HIV specifically to improve their health during pregnancy. As a result, the rate of maternal deaths has finally begun to decrease. 15 South Africa has also achieved success in preventing the transmission of HIV from pregnant women and girls to the foetus, reducing the number of babies born annually with HIV from 70.000 to under 8.000 within a decade.

This report aims to help identify some of the problems that are contributing to the high number of women and girls who are still dying needlessly each year during pregnancy or shortly after giving birth, and to offer some recommendations for action. Qualitative studies, such as this one, which capture individual testimony from women and girls, provide insight into why early antenatal care is often inaccessible, so policy makers and health care workers can design and implement appropriate policies. In highlighting these barriers, Amnesty International advocates for a human rights based approach to health service planning and implementation.

The research was conducted within a human rights framework, including the State's obligation to respect, protect and fulfil the right to the highest attainable standard of care. This includes the right to accessible health care, and the right to equality and nondiscrimination. This report identifies and focuses on three barriers that Amnesty International found contribute to women and girls delaying or avoiding antenatal care, which in turn can contribute to South Africa's high rates of maternal mortality. ¹⁶ These are:

- Lack of privacy, patient confidentiality and informed consent at health facilities, especially around the implementation of HIV testing during antenatal care.
- Lack of information and knowledge about sexual and reproductive health and rights, including lack of training on the part of health care workers.
- Persistent problems relating to the availability and costs of transport.

This report also reflects that these barriers were exacerbated for women and girls who experience other challenges, particularly those linked to poverty and gender discrimination that often increase during pregnancy. Women and girls, according to official statistics, are often most disadvantaged by poor standards of housing and sanitation, access barriers to education and lack of secure employment opportunities. High rates of gender-based violence are well documented in South Africa.

Among its recommendations, Amnesty International is calling on the government to:

- Ensure that all branches of government are involved in the response to maternal mortality, HIV and gender-based discrimination, and develop programmes to promote safe pregnancies and deliveries, including by addressing the social and economic challenges women and girls face accessing early antenatal care.
- Ensure that all health system procedures uphold patient confidentiality and enhance non-discrimination, avoiding for instance the use of specific files for HIV treatment, separate queues and designated waiting areas for people living with HIV.
- Take steps to increase awareness about patients' rights, particularly the right to informed consent.

- Improve knowledge about sexual and reproductive health and rights, including through comprehensive sexuality education that involves men and boys.
- Urgently address the persistent lack of safe, convenient and adequate transport, and the poor condition of roads, particularly in rural settings, including through subsidized or free transport, grants to pregnant women and girls to cover transport costs, improving road infrastructure, and improved transport options

METHODOLOGY

This report is based on desktop and field research carried out in South Africa between March 2013 and September 2014. It builds on some of the work done for Amnesty International's 2008 report, 'I am at the lowest end of all': Rural women living with HIV face human rights abuses in South Africa,¹⁷ in which Amnesty International documented gender, economic and social inequalities as barriers to health care for women living with HIV. The current research was prompted by the high rate of maternal mortality among women living with HIV, a risk known to be exacerbated by late access to antenatal care during pregnancy.

The field research focused on two of South Africa's nine provinces, KwaZulu-Natal and Mpumalanga, as these had poor performance indicators in the area of maternal health and access to sexual, reproductive and maternal health services, according to government data. Mpumalanga was the only province where maternal mortality had increased in 2011.¹⁸ Prevalence of HIV among pregnant women had also increased ¹⁹ and the province included the health district with the highest prevalence of antenatal HIV in the country (46.1%).²⁰ Mpumalanga also had severe medical staff shortages, particularly of specialist doctors.²¹

KwaZulu-Natal, a densely populated province with high birth rates, is home to nearly a quarter of children in South Africa under the age of one.²² The province had the highest number of maternal deaths in 2011,²³ and the highest provincial-level antenatal HIV prevalence (37.4%).²⁴ A government-commissioned review of maternal deaths in 2008-10 identified delays in accessing health facilities as a concern in the province.²⁵ Furthermore, the high number of births taking place outside of health facilities (25.9% in 2010/11)²⁶ indicated that access to health care services was still a problem for women and girls in KwaZulu-Natal.

Amnesty International researchers visited KwaZulu-Natal six times and Mpumalanga four times during the research period. The research was mainly conducted in four health districts – two in KwaZulu-Natal and two in Mpumalanga. These were selected on the basis of the same criteria used to select the provinces, with the additional requirement that they needed to be districts where Amnesty International could have strong engagement and partnership with community-based organizations. Specific research sites were selected in both rural and urban areas. As nearly three-quarters of pregnant women are living in South Africa's poorest households,²⁷ Amnesty International focused on communities where incomes are low.

Amnesty International researchers spoke to over 200 women and girls in 15 communities. They conducted 29 individual interviews with pregnant women and adolescent girls, mothers and care-givers of young children, and 18 focus groups each involving 5-12 participants. Focus groups included pregnant women and mothers with young children, women's groups, traditional leaders, home-based carers, peer educators, sex workers and refugees and migrants. Amnesty International was introduced to these individuals and groups by

community-based organizations and local NGOs. Men were included in two focus group discussions held with traditional leaders, and in engagement with representatives from community-based organizations. Amnesty International also conducted five informal community-based discussions on maternal health, each involving 20-50 participants. Interviews and focus group discussions were held in English or Zulu, with the assistance of translators.

All interviews and discussions were voluntary and conducted in accordance with an ethically approved protocol of informed consent. Unless individuals gave Amnesty International fully informed consent to use their names, the identities of participants and interviewees have been protected to ensure their right to privacy and to avoid any possible harmful consequences. Identifying place names have also been excluded when referring to their testimonies. Community-based partner organizations have chosen not to be named to further protect the communities from identification and to protect their organization and their staff from any possible negative consequences. Amnesty International also spoke with a number of civil society organizations, academic institutions and national and provincial-level NGOs involved in research and service-provision relating to maternal health during an extensive period of consultation on the project. The organizations have preferred to remain un-named.

Amnesty International received ethical clearance from the South African Human Sciences Research Council to interview health care personnel. Amnesty International researchers interviewed 32 health care workers in 16 health care facilities, 11 in KwaZulu-Natal and 5 in Mpumalanga. The provincial Departments of Health in KwaZulu-Natal and Mpumalanga authorized Amnesty International to visit health care facilities and to interview health care workers. Further permission procedures were followed at the health district level. Appointments to visit facilities were arranged through hospital and primary health care managers. Permission was sought from clinic managers to visit the facility at convenient times.

Interviews were conducted using an open-ended, structured questionnaire. The names and locations of the facilities are not listed to ensure the anonymity of the health care workers interviewed. Health care personnel included nursing staff and HIV counsellors. Amnesty International researchers had hoped to interview doctors, but found a distinct lack of doctors at the health facilities and were told by health care workers that there was very limited support from doctors at their primary health care facilities in general. In KwaZulu-Natal, HIV counsellors are employed by the Department of Health; in Mpumalanga they are employed by NGOs.

The research methodology used is qualitative and seeks to highlight an apparent failure in the protection and fulfilment of human rights. While the study is not intended to be statistically significant, the decision to focus on barriers to early antenatal care emerged from a comprehensive literature review and from the indications from official statistics and government data. The initial research also highlighted a need for a human rights analysis of why women and girls delay accessing sexual and reproductive health services. A qualitative methodology was used to add the richness of individual testimony and to highlight the urgency of the need to address the barriers to early antenatal access during pregnancy.

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Interview data was analysed on a thematic basis for commonalities; the three barriers

highlighted emerged as key concerns. Evidence also emerged of barriers to other sexual and reproductive services, such as termination of pregnancy services. These warrant further study but were beyond the scope of this report. Amnesty International did not research all of the interconnected socio-economic inequalities faced by women and girls, such as access barriers to education, employment or social grants.

Amnesty International's research provides a human rights analysis of health-system trends confirmed by larger, government-led studies. Government data show that the barriers identified in this report are not isolated to KwaZulu-Natal and Mpumalanga, and indeed support the broader application of the report's findings.

Amnesty International wrote to the South African National Department of Health in September 2013 to notify them of the planned research. Email and written correspondence continued during the research period. In May 2014, Amnesty International held a phone meeting with a senior official in the Department of Health to discuss both Amnesty International's work and key developments in relation to maternal health that the Department had initiated or were planning.

In August 2014, Amnesty International wrote again to the National Department of Health and provincial departments in KwaZulu-Natal and Mpumalanga. A meeting was subsequently held with officials responsible for maternal health programmes at each office. Their comments have been reflected in the report. Amnesty International also wrote to the Ministry in the Presidency responsible for Women (formerly the Department of Women, Children and People with Disabilities) in September 2014, to request a meeting to discuss the findings of this report for comment. At the time of the writing of this report in September 2014, the Ministry of Women indicated that they were unavailable to meet with Amnesty International.

SOUTH AFRICA'S HUMAN RIGHTS OBLIGATIONS

The South African Constitution protects the rights to health, equality and non-discrimination, and many sexual and reproductive rights.²⁸ In addition, South Africa has ratified several human rights instruments that require the government to respect, protect and fulfil the rights of women and girls to health, equality and non-discrimination, and their sexual and reproductive rights. These include the International Covenant on Civil and Political Rights, the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), the Convention on the Rights of the Child, the African Charter on Human and Peoples' Rights, the Maputo Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, and the African Charter on the Rights and Welfare of the Child. South Africa has also signed the International Covenant on Economic, Social and Cultural Rights (ICESCR), but is yet to ratify it.²⁹ These commitments voluntarily made by South Africa mean that the government of South Africa must guarantee:

The right to privacy. Under Article 14 of the South African Constitution, "Everyone has the right to privacy," which read in the context of international law and standards, includes the following:³⁰

<u>The right to informed consent</u>: States should take all measures to ensure that women and girls are able to give informed consent to procedures affecting them.³¹ Informed consent is the ability to make a voluntary and sufficiently informed

decision, protecting the right of patients to be involved in medical decision-making, and assigning duties and obligations to health-care providers.³²

The right to confidentiality: States must ensure that patient confidentiality is protected, information on health status is not disclosed to third parties without the consent of the individual, and that health care providers are trained to keep medical information confidential.³³

The right to the highest attainable standard of health. Under Article 27 of the Constitution, everyone has the right to have access to health care services, including reproductive health care, which read in the context of international law and standards, includes the following:

The right to accessible health care: All health facilities, goods and services must be known to all and be physically, economically and socially acceptable to all, free from discrimination. They must be affordable for all individuals, 34 and must be within safe physical reach for everyone, especially marginalized groups.

The right to health-related information: All individuals have the right to seek, receive and impart information and ideas concerning health issues. 35 States must ensure "the right to have family planning education" 36 and "provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas". 37

The right to equality and non-discrimination. Under Article 9 of the Constitution, the State cannot "unfairly discriminate directly or indirectly against anyone on one or more grounds", which include race, gender, sex, pregnancy, age and marital status. International instruments have included health status (including HIV or AIDS) as a prohibited ground.³⁸ International law and standards mandate that where necessary, States must also put in place measures that allow vulnerable or marginalized groups to access their rights and entitlements equally.³⁹ Similarly, States must be aware of the impact of multiple and intersecting discrimination and take particular steps to eliminate it.

A TEENAGE MOTHER: A TYPICAL STORY



Eighteen-year-old Busisiwe (not her real name) lives with her baby girl, mother and siblings in an isolated homestead in rural KwaZulu-Natal. The family somehow survives on a tiny income from social grants, but Busisiwe has been unable access the child support grant for her baby as the transport costs to the social services payment office (R38/\$3 return) were prohibitive. In addition, Busisiwe told Amnesty International researchers she felt ashamed as a young mother to face the civil servants at the payment office.

When she was four months pregnant, Busisiwe went to the antenatal clinic because she wanted to know if she was HIV-positive so that she could protect her foetus if necessary. She had to walk to the clinic, a journey that takes between 60 and 90 minutes each way. She said that on arrival, the health care workers insulted her publicly, "passing the word" of why she was pregnant and they didn't attend to her;

"I was worried at the clinic — they started to shout 'why are you pregnant? You are so young'... every time [I went] they were shouting, saying 'your mother sent you to school and you are going to look [at] boys not school'."

Busisiwe eventually left the clinic without receiving antenatal care or being seen or tested. She explained:

"I was worried testing at the clinic. They started to shout at me 'why are you frightened?' and I don't feel better about that, so I think it was a good idea to test [elsewhere]."

Busisiwe said that she subsequently agreed to be tested at her school because the NGO involved in the testing there treated her better, but by that stage she was eight months pregnant. She didn't take her result to the clinic because "I dislike them, the way they treat me".

When she went into labour Busisiwe had to ask a neighbour to drive her to the hospital as she didn't have the R250 it would cost to hire private transport. The neighbour took her only as far as the nearest clinic, where staff called an ambulance. The ambulance took three hours to arrive. Busisiwe described how she felt as she waited there.

"I was feeling very worried and in pain but no one attended me... [health care workers] showed me one of the beds and they said I must wait there for the ambulance and they left me there. They didn't come back again until the ambulance arrived."

Busisiwe explained that she was scared of the way health care workers shouted and didn't feel able to ask for help while she was in labour because of how she had been treated at the clinic during the antenatal care visits

Despite her ordeal and lack of adequate treatment, she gave birth to a healthy baby.

2. BACKGROUND

'Delays in the decision to seek care or opting out of the health system entirely are treated not as idiosyncratic, personal choices or immutable cultural preferences but as human rights failures.'

Office of the United Nations High Commissioner for Human Rights, 2010^{40}

IMPORTANCE OF EARLY ANTENATAL CARE

South Africa is unlikely to meet its Millennium Development Goal (MDG) in relation to reducing maternal deaths by 2015. The target – to reduce maternal mortality by 75% from a maternal mortality ratio of 250 deaths per 100,000 live births to 38^{41} – looks impossible to achieve. The current ratio is estimated by the government as 269 deaths per 100,000 live births. All Nevertheless, while the ratio had risen considerably since 2000, peaking at over 600 by 2007, recent data indicates it is finally declining. The South African government has committed to ensuring that this trend continues, and has significantly improved the monitoring of maternal deaths.

The government recognises "provision of early and quality antenatal care" as an important factor in "aggressively reducing the unacceptably high maternal and child mortality rates in the country". 45 Indeed, high maternal mortality ratios are associated with a lower proportion of antenatal clients booking for early antenatal care (before 20 weeks). 46 Reflecting this risk, Department of Health policies aim to promote early access to antenatal care. Alongside the National Strategy for Maternal, Newborn, Child and Women's Health 2012-16, 47 South Africa has also issued a national strategic plan to implement its commitment under the African Union Campaign on Accelerated Reduction of Maternal and Child Mortality in Africa. 48 In addition, the National Strategic Plan (NSP) for HIV, TB and STIs 2012-16 contains important recommendations linked to maternal health. 49

Amnesty International recognizes the recent successes South Africa has made in improving access to health care for all South Africans and tackling the HIV epidemic. Commendably, the government has succeeded in increasing access to antenatal care and now 98% of pregnant women and girl receive at least one consultation.⁵⁰ However, while national guidelines recommend that antenatal care starts before 14 weeks of pregnancy,⁵¹ government data from 2012 highlights that less than half of pregnant women and girls sought antenatal care before 20 weeks of pregnancy.⁵² Critically, a 2013 household data study found that

women living with HIV received less maternal health care than non-infected women due to late access to antenatal care and less clinical supervision during birth.⁵³

Nearly a third of the 1.2 million⁵⁴ women and girls who experience pregnancy each year in South Africa are living with HIV.⁵⁵ Complications linked to HIV infection are the main cause of maternal death in South Africa,⁵⁶ followed by bleeding linked to childbirth, and complications related to high blood pressure.⁵⁷ There were 1,560 recorded maternal deaths in 2011 and 1,426 in 2012. More than a third of these deaths were linked to HIV.⁵⁸ The impact of HIV on South Africa's high maternal mortality ratio is due both to the increased health risks for the woman or girl living with the virus and the additional pressure on the health system as a result of testing and treating so many people living with HIV.⁵⁹

The high prevalence of HIV among pregnant women and girls and the high rate of maternal death among women living with HIV prompted the South African government to introduce a comprehensive programme of antenatal HIV testing in public health facilities (see Chapter 3). The implementation of this programme since 2011 has been linked to immediate antiretroviral treatment for those testing positive to improve their own health during pregnancy. As a result, the rate of maternal deaths has finally begun to decrease, with maternal deaths linked to HIV falling by 13% in 2011.⁶⁰ This policy was strengthened with the announcement that from April 2013 the treatment would take the form of a single pill with reduced side effects, instead of multiple tablets.⁶¹ South Africa has also achieved notable success in preventing vertical (mother-to-child) transmission of HIV to the foetus, for reducing the rate of transmission from over 20% to 2.7% within a decade.⁶³ The earlier antenatal care is accessed, the lower the chances of the virus being transmitted from the mother to the foetus and the risk of avoidable maternal death may also be more effectively addressed.⁶⁴

THE PUBLIC HEALTH SYSTEM, HIV AND MATERNAL HEALTH POLICIES

The government's policies for improving maternal health and reducing HIV rely on services delivered at the primary health care level – in clinics and community health centres rather than in hospitals – partly to increase access to services. These include sexual and reproductive health and rights services, such as contraception, testing and treatment of sexually transmitted infections, HIV testing and treatment, and, crucially, early access to antenatal care. 65

Delivery of public health services remains hampered by the legacy of South Africa's colonial and apartheid past.⁶⁶ Weakness in the management of public health facilities and systems;⁶⁷ insufficient investment,⁶⁸ especially in poorer regions of the country;⁶⁹ deteriorating infrastructure;⁷⁰ stock shortages of medicine⁷¹ and a staffing crisis in the public sector⁷² have entrenched past inequities in access to and quality of health care services.⁷³ Those living in rural areas (43.6% of the population) often experience the greatest adversities accessing quality health care. For example, they are served by only 12% of the country's doctors and 19% of nurses.⁷⁴ Furthermore, profound inequalities persist between the private and public health systems in terms of infrastructure and resources.⁷⁵ Nearly 83% of the population relies on the public health system,⁷⁶ yet the private health care sector employs the majority of health care professionals⁷⁷ and spends nearly 60 times more per patient.⁷⁸

Further disparities exist between South Africa's nine provinces and the 52 health districts.

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Divergent rates of spending on health care provision have been noted, with a documented correlation between lower rates of maternal mortality and districts with higher per capita spending on district health services. At the provincial level, varying maternal mortality ratios relating to deaths in health care facilities in 2012/13 highlight a low of "8.7 per 100,000 live births in the Western Cape to 177.9 per 100,000 live births in Limpopo. Mpumalanga was the only province to show an increase in the maternal mortality ratio in health facilities – from 135 in 2011/12 to 175.8 in 2012/13". Significant differences in sexual and reproductive health services and outcomes are also found between provinces, reflected in the varying rates of unplanned pregnancies, teenage pregnancies, and prevalence of HIV.

High rates of maternal mortality are recognised as one of four major pandemics facing South Africa, including high rates of HIV infection and TB, maternal and child mortality, non-communicable diseases and injuries caused by violence. ⁸⁴ Each has compounded ongoing challenges within the health system. In response, the government has committed to reengineering the primary health care system and improving equity in access to health services, through better community-based services. ⁸⁵ Since 1994, such measures have included removing fees for patients using public health services ⁸⁶ and introducing over 1,300 primary health care clinics. ⁸⁷ Government spending on primary health care also doubled between 2005 and 2011. ⁸⁸

HIV and AIDS are the biggest burden on the health system. Over 330,000 people are thought to have died as a result of the South African government's failure to implement effective antiretroviral treatment between 2000 and 2005. Since then, the government has significantly increased access to treatment through reliance on the primary health care system. The number of health facilities able to start patients on antiretroviral treatment has increased from fewer than 500 at the end of 2009, to over 2,500 in 2011. Additionally, according to the government, more than 23,000 nurses have been trained to initiate patients onto antiretroviral treatment; Prevention of Mother To Child Transmission (PMTCT) programmes are offered in more than 98% of public health facilities, and attempts have been made to integrate HIV services into primary health care centres. The government has reported that more than 2.5 million South Africans are now receiving antiretroviral treatment, the facilities and the sum of the sum

However, a shortage of health care professionals presents a challenge to the South African health system. The government acknowledges that adequate staffing and quality of care is necessary to improve "maternal survival" and other key objectives of the primary health care system. Current staff shortages have raised concerns about quality of services provided. Professionally, nearly half of the clinics (47%) and nearly 20% of community health centres reported no visit from doctors, while 48% of community health centres have no advanced midwives. Phile South Africa is struggling with a shortage of health professionals in the public sector, Professionals in the public sector, Professionals in the public sector, Carden for the staff shortages. In late 2013, the South African Human Rights Commission (SAHRC) found the Mpumalanga Department of Health in violation of the right to access health care services and the right to dignity for reasons of a lack of effective management structures, infrastructure, adequate access to primary health facilities and sufficient human resources required to deliver quality health care services. It also found that unfilled vacancies were the result of maladministration.

Poor management has been found to increase pressure on health care workers. 103 Demoralization among some health care workers has been linked to challenging working conditions, including occupational exposure to disease, increased workload burdens and lack of consultation in health planning. 104 Such factors, as well as the lack of training and poor functioning of accountability mechanisms, have been linked to poor patient care. 105 Nationally, only 30% of health care facilities were found to comply with the criteria for "positive and caring staff attitudes" in the 2012 audit of health facilities, and compliance was lower among primary health care facilities, at only 25%. 106

At the heart of the government's service delivery plans for primary health care is reliance on non-medically trained personnel working as community-based health workers. There are estimated to be 65,000 such workers, including over 9,000 HIV counsellors, ¹⁰⁷ and over 47,000 community care-givers. ¹⁰⁸ Amnesty International was told by a provincial Department of Health official that practices between the provinces vary, with KwaZulu-Natal employing community health workers directly while in other provinces they are contracted on a stipend basis through NGOs.

In general, HIV counsellors receive around 11 days' training and community care-givers around 60. 109 HIV counsellors are acknowledged as an essential aspect of the successful implementation of HIV testing and treatment initiatives, 110 but a recent review of HIV-related services commissioned by the government noted that there should be better regulation of training, supervision and employment conditions for HIV counsellors. 111 In addition, community care-givers are tasked with providing care and support in people's homes and disseminating preventative health information. Despite the importance of their role, community care givers often work in challenging conditions, are often reliant on small stipends instead of salaries, and have heavy workloads of up to 250 homes each. 112 Health advocacy groups have called for community care-givers to be formally absorbed into the health system so that uniform polices in relation to training, support, benefits and accountability may be implemented. 113 Likewise, a government review of human resources in the health sector recommended standardization of training, roles and responsibilities for community care givers. 114

Within any over-burdened system, marginalized groups struggle to access services. Individuals coping with multiple challenges and discrimination, such as adolescents living with HIV, and women living in poverty, often encounter additional difficulties accessing the specific services they need. 115 The problems can become more profound when the services require particular sensitivity to rights, such as sexual, reproductive and HIV services. 116

Although this report focuses on three particular barriers to early and ongoing antenatal care, it is important to recognize that access to antenatal and other health care for women and girls is deeply and directly affected by other intersecting factors, in particular gender-based discrimination, socio-economic status, and whether or not they are living with or at risk of HIV. Some of these are briefly discussed below.

THE IMPACT OF POVERTY AND GENDER-BASED DISCRIMINATION

As with the health system, the legacy of gender, racial, economic and geographic inequities from the apartheid era continue to impact on the health of women and girls in South Africa. The Office of the United Nations High Commissioner for Human Rights (OHCHR) has noted

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that, "[m]aternal mortality and morbidity is a consequence of gender inequality, discrimination, health inequity and a failure to guarantee women's human rights." ¹¹⁷ Social and economic factors, such as the lack of adequate housing, employment opportunities, clean water, sanitation, nutrition and education, play a huge role in people's health. ¹¹⁸

South Africa remains a highly patriarchal society with high levels of gender inequality and discrimination. Women and girls are often most disadvantaged by socio-economic inequalities that adversely affect access to sexual and reproductive health information, goods and services ¹¹⁹ A 2014 report by the South African Human Rights Commission (SAHRC) report on access to water found that those who are "black and poor" are most affected by inequalities in relation to access to water and that gender discrimination exacerbated the detrimental impact of such inequalities for women and girls. ¹²⁰ The 2011 census highlighted that households headed by black people earned on average less than a sixth of that earned by white-headed households. ¹²¹ Of the households living in poverty, the majority are femaleheaded, ¹²² which average half the annual income of male-headed households ¹²³ and are significantly more likely to experience poorer health. ¹²⁴ Many poor households suffer food shortages, ¹²⁵ as do a significant number of pregnant women and girls. ¹²⁶

The intersection of pregnancy, poverty and gender-based discrimination inhibits access to other fundamental rights. For example, UN and South African human rights bodies have expressed grave concern about the high rates of sexual abuse and violence in schools as a barrier to girls' right to education. ¹²⁷ In 2011, the CEDAW Committee found "the low level of education of women and girls [in South Africa] remains one of the most serious obstacles to their full enjoyment of their human rights." ¹²⁸ Education has been found to reduce the risk of exposure to HIV infection, particularly among girls. ¹²⁹ A recent study in South Africa indicated that small cash transfers to school-age girls may increase their ability to remain in school and lower the risk of HIV infection. Another study found the protective effect of cash transfers to be greater when supported by a care strategy, highlighting the widespread lack of emotional support that also impacts on adolescent health. ¹³⁰

Because a significant number of pregnant women and girls in South Africa have not completed secondary education, ¹³¹ and women and girls spend considerable time on unpaid care work, ¹³² they have worse and more insecure paid work opportunities, ¹³³ and more women than men are unemployed. ¹³⁴ The resultant financial dependence of women and girls on male partners, or family members, brings a range of risks, especially for women and girls living in poverty. Despite recognition of economic abuse as a form of domestic violence under South African law, ¹³⁵ the South African Commission for Gender Equality has highlighted that "[m]any women are forced to endure abusive and often violent relationships because they are financially dependent on the abuser." ¹³⁶

In a response aimed at poverty alleviation, the government introduced a range of social grants, including for pensioners, ¹³⁷ children ¹³⁸ and people unable to work due to disability. ¹³⁹ The child support grant is the one most commonly accessed. ¹⁴⁰ Valued at R310 (US\$30) per month per child, it is means tested and given to the primary care-giver if they earn less than R34,000 (US\$3,238) a year. ¹⁴¹ In 2011, over 10 million care-givers received this grant. ¹⁴² Social grants have been shown to reduce economic inequalities, increase human capital and empower care-givers in the context of household resource allocation. ¹⁴³ The child support grant is cited by some commentators as an incentive for pregnancy, especially among

teenagers. However, the government and research studies dispute this. 144 Notably, a significant number of teenage mothers who should be claiming the grant are not. 145

HIV AND GENDER-BASED DISCRIMINATION

"I told them [nurses] that my husband is sometimes OK with the condom and sometimes he does not like to use condoms and I could not stop falling pregnant."

A mother of four, speaking to Amnesty International in KwaZulu-Natal

South Africa has the largest population living with HIV in the world. 146 An estimated 6.4 million people in South Africa – 12.2% of the population – are living with HIV. 147 Women and girls are disproportionately affected, accounting for 3.4 million of those living with HIV (55.7% of those aged 15 and above who are living with HIV). 148 While incidence rates have declined considerably among girls and adolescents aged between 15 and 24, they still account for almost a quarter (24.1%) of all new HIV infections. 149 For young people aged 15-19, females are estimated to be eight times more likely to contract HIV than their male counterparts. 150

Heterosexual sexual intercourse is the main cause of HIV transmission in South Africa. ¹⁵¹ Despite the recent successes in the treatment of HIV during pregnancy, the national prevalence of HIV among pregnant women has stayed at around 29% since 2007. ¹⁵² Recent research based on national data that analyses the prevalence of HIV among pregnant women raises concern about links between high rates of unplanned pregnancies and the risk of HIV infection. ¹⁵³

"The power imbalance between men and women, coupled with the socio-economic dependence of women has caused many women to be without choice in terms of pregnancy and protection from HIV infection. In addition, stigma still follows those diagnosed with HIV infection and women often present late for testing for HIV."

South African government, 2010¹⁵⁴

Women's inequality of power within relationships and their lower status in society in general directly increase their risk of HIV infection by as much as 13%. There is a longstanding awareness that such power inequalities "create a context for men to have multiple concurrent partners and fuel their resistance to use condoms. The recent findings of a national HIV study that indicated a significantly reduced use of condoms in 2012 has raised similar concerns. The study notes that prevention efforts have been ineffective in protecting women and girls due to "prevailing transmission dynamics in the country. and warns that it will be "extremely difficult" for the government to meet its goal of reducing new infections by at least 50% by 2016.

Despite the government's recognition that women's and girls' risk of exposure to HIV is increased by gender inequality, including sexual violence, there has been little success in challenging patriarchal attitudes that promote gender inequality. South Africa's Ministry in the Presidency responsible for Women has been tasked to address the intersection between gender-based violence and HIV, the time of writing there was limited information available regarding steps taken to implement this responsibility.

Violence against women and girls is a persistent and devastating manifestation of gender-based discrimination. ¹⁶² South Africa has extremely high rates of gender-based violence, ¹⁶³

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with women and girls of reproductive age (14-44 years) most at risk. ¹⁶⁴ The South African Medical Research Council has criticized the government for the continued failure to accurately document and prioritize gender-based violence, including domestic violence. ¹⁶⁵ A review of studies from southern Africa show that both the risk and severity of inter-partner violence increases during pregnancy, and specifically that male "economic power" and "controlling behaviour" are closely associated with inter-partner violence during pregnancy. ¹⁶⁶ Documented risk factors for such violence include relationship status, age, economic status, level of education and marginalization. In one study based at an antenatal clinic in Soweto, Johannesburg, 87.9% of participants "reported at least one type of [inter-partner] abuse, while 55% reported a lifetime history of physical assault by a male partner". ¹⁶⁷ Further studies link increased risk of inter-partner violence with HIV-positive status. ¹⁶⁸ At the same time, the context of inter-partner violence and increased financial reliance by women and girls on their partners during pregnancy may increase the risk of HIV infection. ¹⁶⁹

HIV-RELATED STIGMA

People living with HIV and AIDS in South Africa continue to suffer multiple forms of stigma, discrimination and abuse as a result of their HIV status.¹⁷⁰ HIV-related stigma in South Africa is rooted in the context of the effect of the virus on individuals, families and communities over the past two decades. Before antiretroviral treatment was available through the public health system, a diagnosis of HIV or AIDS was considered to be an imminent death sentence, often preceded by disfigurement and suffering.¹⁷¹ Despite commendable advances on HIV treatment since 2006 (see above), HIV- and AIDS-related stigma and discrimination remain major barriers to effective HIV prevention and provision of maternal health services.¹⁷²

HIV testing is an integral part of HIV prevention and treatment policies.¹⁷³ However, the gendered nature of HIV testing – especially in relation to contraception and antenatal care where women and girls, not men and boys, are the ones who need to access health care services – means that stigma impacts more severely on women and girls and often exacerbates existing inequalities and disadvantages.¹⁷⁴

Despite the robust legal protection for human rights and non-discrimination under the Constitution and legislation in South Africa, 175 many people are unaware of their rights or are unable to access the legal mechanisms meant to protect them. 176 South Africa's National Strategic Plan for HIV calls for the creation of a government policy to tackle stigma, including through a Stigma Mitigation Framework and monitoring of the prevalence and nature of stigma through the compilation of a Stigma Index and involvement of the SAHRC. 177 However, practical development or implementation of this policy has been significantly delayed. 178

Many instances of human rights abuses are committed by the very people expected to provide support and care – family members, community members and health care workers. ¹⁷⁹ Reports of abuse, ostracism and neglect by families and partners include physical abuse, ¹⁸⁰ being asked to leave the family home, and people being afraid to share utensils with a person living with HIV. ¹⁸¹ HIV-related stigma is a key barrier to accessing sexual and reproductive health services, including early and ongoing antenatal care. ¹⁸²

3. PRIVACY AT CLINICS: FEARS AND UNINTENDED CONSEQUENCES

'It is not a problem to get tested. But [the decision] should come from you.'

A woman speaking during a focus group discussion in Mpumalanga

The government of South Africa has expressed determination to reduce the rate of maternal deaths and already has taken important steps towards that outcome, including through increased access to antiretroviral treatment for pregnant women. However, Amnesty International's research suggests that there remain other important factors impacting maternal health outcomes that must be addressed. These include violations of the right to privacy, which continue to deter women and girls from seeking early access to antenatal care.

South African government authorities are obliged to respect, protect and fulfil everyone's right to privacy, which is fundamentally linked to individuals' autonomy and dignity. In the context of health services, this includes the obligation to ensure that patient confidentiality is protected, information on health status is not disclosed to third parties without the consent of the individual, health personnel are trained to respect privacy rights, and no one is subject to procedures or treatment without their full and informed consent.¹⁸³

Many of the women and girls interviewed by Amnesty International said that their fears about lack of privacy and patient confidentiality in health facilities put them off visiting their local clinic, made them reluctant to access sexual and reproductive services, and led them to delay seeking antenatal care. This is particularly the case in relation to HIV counselling and testing policies and the manner in which they are implemented.

As discussed above, the gendered nature of HIV testing means women and girls often fear the social consequences of HIV testing. This fear is exacerbated when HIV testing is perceived to be mandatory. In addition, pregnant women and girls fear that if they refuse an HIV test, they will be denied other antenatal care services.

Their fears are not unfounded. Amnesty International found that practices at clinics and the behaviour of health care workers, combined with problems such as staff shortages and inadequate infrastructure, regularly compromise women's and girls' right to privacy and confidentiality at clinics, as well as their right to informed consent when asked to test for HIV. The consequent impact of these practices is to contribute to delayed access to antenatal care, with possible grim health consequences.

HIV COUNSELLING AND TESTING

"Some people test only when they get sick, whereas pregnant women have to test."

A woman in KwaZulu-Natal province, speaking to Amnesty International

HIV testing and counselling are essential for people to find out their HIV status, improve their knowledge and understanding of HIV, take necessary preventive and precautionary measures and, where applicable, start treatment.

South Africa has adopted the provider-initiated HIV testing and counselling (PICT) model, ¹⁸⁴ under which health care workers must offer information about the test and the option of testing to anyone attending antenatal check-ups. Guidance issued by the WHO stipulates that informed consent, confidentiality and appropriate and high quality counselling must be key components of this process. ¹⁸⁵ Informed consent must mean that the patient understands that they have the right to decline the HIV test and that declining the test "will not affect the patient's access to services that do not depend upon knowledge of HIV status". ¹⁸⁶

PICT GUIDELINES AND INFORMED CONSENT

In 2007, the WHO released its Guidance on Provider Initiated Testing and Counselling in Health Facilities, recommending this approach and providing guidance for how it can be implemented. ¹⁸⁷ Reasons for supporting the scaling up of this model included the inherent limitations of the voluntary counselling and testing model, including "many of the same factors that limit uptake of other HIV-related services, including stigma and discrimination, limited access to treatment, care and health services in general, as well as gender issues". ¹⁸⁸ The WHO Guidance says, "The adaptation process will require an assessment of the risks and benefits of introducing provider-initiated HIV testing and counselling in a particular setting [emphasis added], including an appraisal of available resources, prevailing standards of HIV prevention, treatment, care and support and the social, legal and policy framework that is in place". ¹⁸⁹ The WHO Guidance also sets out the minimum elements of each stage of the counselling and testing process, i.e. pre-test information and informed consent, post-test counselling, and referral to other HIV services. The stated minimum information for informed consent includes, "The fact that the patient has the right to decline the test and that testing will be performed unless the patient exercises that right," and "The fact that declining an HIV test will not affect the patient's access to services that do not depend upon knowledge of HIV status". ¹⁹⁰

In 2010, the government announced a change from voluntary counselling and testing to the PICT model as part of the standard antenatal screening process, ¹⁹¹ with Preventing Mother to Child Transmission (PMTCT) programmes made available from 14 weeks of pregnancy. ¹⁹² The government has stated that provider-initiated HIV testing has resulted in more than 98% of pregnant women and girls testing for HIV. ¹⁹³

Because testing has become a routine part of antenatal care, women and girls bear the burden of the national drive to increase South Africans' knowledge of their HIV status through testing. A 2012 survey confirmed that significantly more women than men in South Africa had been tested – 52.6% compared to 37.5%. Someone often find out that they are living with HIV at the same time as their pregnancy is confirmed. They worry about how to share this information with partners and families as they fear discrimination, stigma, violence, abandonment and the other social and medical consequences of living with HIV. They also have to cope with the double stress of pregnancy and learning to live with HIV. This

gendered dimension to HIV testing also means that women and girls potentially suffer more from breaches of privacy and confidentiality in health care facilities than men and boys.

LACK OF INFORMED CONSENT

"Testing was not optional, it was compulsory... If you didn't test you didn't have antenatal classes, everyone had to go through the tests".

A woman speaking to Amnesty International in KwaZulu-Natal

The government of South Africa is obliged to take all necessary measures to ensure that women and girls are able to give informed consent to procedures affecting them. In the context of HIV counselling and testing, the WHO and UNAIDS have said that services must be voluntary, confidential, accompanied by counselling, and only be conducted with informed consent. ¹⁹⁶ The WHO and UNAIDS do not support mandatory testing of individuals on public health grounds. ¹⁹⁷

Guidelines in South Africa make clear that health care workers must ensure that women and girls attending antenatal clinics give informed consent before they are tested for HIV. The health care workers must also provide counselling before and after the test that enables informed decisions. Under the PICT model, women and girls must be given the option to refuse the test.

South Africa's 2013 Preventing Mother to Child Transmission Guidelines are the most recent policy guidance on HIV counselling and testing for pregnant women. ¹⁹⁸ These state that informed consent requires:

- Initial information about HIV and its transmission is given to women in a group information session.
- Women should then meet a counsellor, nurse or midwife for an individual counselling session, where they should be given more information about the HIV test and asked to provide verbal consent to the test.
- Women who refuse to test are given post-refusal counselling to "explore the reasons for this choice, address any misunderstandings, and encourage her to reconsider her decision not to test, but without applying undue pressure". 199
- All women who test should receive post-test counselling, the content of which will depend on their HIV status.²⁰⁰

It appears that these Guidelines are not being followed. Nearly all the women Amnesty International interviewed understood HIV testing as a compulsory part of antenatal care at their clinic. For example, in focus group discussions in KwaZulu-Natal, women said:

"It is not an option [to say no to testing]... that's why people don't want to go [to the clinic]".²⁰¹

"[Women] are afraid of doing HIV testing, that's why they go late to the clinic".²⁰²

Nearly all the women interviewed also believed the test was required to access other routine antenatal services not dependant on their HIV status. Comments included but were not limited to:

"If you say no to testing, they tell you that you will never get help. You must go to testing first. If you don't go there, they will not help you." ²⁰³

"They will not attend to you if you are not tested. They just send you home".204

"They tell you if you don't [do the HIV test], then we won't give you help. People are forced to go whether they like it or not." 205

"Some are running away from being tested. They know they will be tested [at the clinic and] they know the nurses will not help you if you have not been tested". 206

A traditional leader confirmed this perception, telling Amnesty International that women often agreed to the test because *"they are afraid that if they have to deliver the baby, no one is going to help them"*.²⁰⁷

The perception of "compulsory" HIV testing breaches international and South Africa's guidelines and compromises the right to privacy and informed consent. Breaches of the guidelines and the lack of informed consent around HIV testing have the serious consequence of deterring pregnant women and girls from seeking antenatal care.

HEALTH CARE WORKERS' PERSPECTIVES

"We tell them that [HIV testing] is compulsory. It's under the regulations of the government. Each and every one who is pregnant must test to prevent transmission of HIV to the child."

A health care worker in KwaZulu-Natal, speaking to Amnesty International

Antenatal care nurses and HIV counsellors who spoke with Amnesty International explained how perceptions about the mandatory nature of HIV testing during antenatal care could develop. The health care workers knew that women and girls had the right to refuse HIV testing, and that a refusal should not prevent other aspects of antenatal care. However, the way they communicated information about HIV testing clearly fostered the perception among women and girls that testing was mandatory. Indeed, most health care workers acknowledged that women and girls had this understanding. As one HIV counsellor in KwaZulu-Natal explained:

"People now know that when you are pregnant, you are supposed to test". 208

When asked about the testing process for pregnant women, a nurse in KwaZulu-Natal said:

"They all do it during the first antenatal visit, it is a compulsory thing to do". 209

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Another nurse in the same province said:

"We don't start antenatal care before we know the status... it's as if [testing] is compulsory".²¹⁰

An experienced staff nurse in KwaZulu-Natal said her health facility did not "take in patients who have not tested for HIV". She explained:²¹¹

"[It's the] duty of the counsellor to tell patients who are pregnant that 'you must test HIV status' and they can't do antenatal without testing."

Similarly, an HIV counsellor in Mpumalanga told Amnesty International:²¹²

"All pregnant women are tested. They are not allowed to say they are not ready for the test".

A nurse in KwaZulu-Natal reported:213

"Our doctor does not see anyone who has not tested for HIV so all patients are encouraged to test for HIV."

All health care workers interviewed said that women could access other antenatal care services if they refused to test for HIV. Many confirmed that the only implication of not testing would be that the patient would be referred to pre-test counselling on her next antenatal care visit.

Nurses further acknowledged that girls did not come for antenatal care when they should because of the fear of testing. An experienced antenatal care nurse working in KwaZulu-Natal said:

"They feel that if they come to the clinic they will have to test for HIV". 214

Similarly, an HIV counsellor, working in another area of the same health district, said:

"They don't go to the clinic because they know they will be tested for $\mathit{HIV}".^{215}$

Many health care workers said that fear of the HIV testing process was due to reasons such as HIV-related stigma, a lack of knowledge of treatment options, and fear of disclosure. All said that it was very rare for women to actually refuse an HIV test and very few could recall situations where this had happened. For example, in KwaZulu-Natal two counsellors with nine years' counselling experience each said that no one they had counselled had ever refused testing. 216

This is consistent with available national data, which shows that in 2007/08 over 70% of eligible antenatal patients were tested for HIV at their first antenatal visit, a figure that had increased to nearly 100% by 2011/12.²¹⁷ A counsellor in KwaZulu-Natal with 11 years' experience said she thought the change was because the availability of treatment for HIV had made people more comfortable with being tested.²¹⁸ Health care workers said that many women ended up testing, despite their initial fears, because of the health benefits to the baby, which are explained in the pre-test counselling phase. In many cases, once information

on the benefits of HIV testing is received, women and girls agree to the test. However, based on Amnesty International's interviews, it is also likely that some women feel they have no real option to refuse the test. As discussed above, while HIV testing is an important public health intervention it must be done in a manner that respects the rights of women and girls and does not expose them to additional harm as a result of the testing process.

When asked what she would like to see changed in clinic processes, one interviewee requested that testing for HIV should be a choice.²¹⁹ This is in fact the current way HIV testing should be implemented. One young woman in KwaZulu-Natal explained how learning about her rights empowered her to access HIV services at her local clinic:²²⁰

"[A]fter I learned about my human rights, I thought] 'OK... I know now I have a right to say 'No'... let me go and try the counsellors in the clinic'."

Studies from a cross-section of African countries have found similar concerns regarding the implementation of the PICT model. For example, a 2006 study in Botswana found that 43% of respondents believed that routine PICT would cause people to avoid seeing their health provider for fear of being tested and 68% believed that they could not refuse the HIV test. A 2011 study found similar fears and perceptions around the PICT model in a district in Kenya. Women reported that HIV testing was mandatory during antenatal care, counselling was inadequate, and opting out would mean that further care would be denied. A 2011 study in Malawi found that women perceived routine testing for HIV at antenatal clinics as a requirement to receive antenatal care, as did a study of women's perceptions of PICT at antenatal clinics in rural Uganda. Similar findings about PICT in South Africa are illustrated in this report, showing that action is needed to ensure that the benefits of the PICT model are not at the expense of the rights of individual women and girls to informed consent.

BREACHES OF CONFIDENTIALITY IN HEALTH CENTRES

"People in my community don't want to go to the clinic... because there is no confidentiality at the clinic".

A woman from KwaZulu-Natal, speaking to Amnesty International

As part of the right to privacy and confidentiality, the South African government is obliged to ensure that patient confidentiality is protected, information on health status is not disclosed to third parties without the consent of the individual, and that health personnel are trained to respect privacy rights.

Most of the women who spoke with Amnesty International said that lack of confidentiality was a major reason for their reluctance to go to clinics – and was often their explanation for delaying antenatal care. They said they were worried that information about their health – including their HIV or pregnancy status – would become known to other people. This fear was particularly acute when women visited clinics close to their homes, as the chances of meeting someone they knew were high. Amnesty International visited 16 health facilities in KwaZulu-Natal and Mpumalanga, where health care workers confirmed the existence of such practices and told Amnesty International these fears about breaches of confidentiality were justified.

GUIDELINES ON MATERNITY CARE

In general, all health care workers described to Amnesty International a process for antenatal care that was consistent with the Department of Health's *Guidelines for Maternity Care in South Africa 2007*.²²⁵When a woman arrives for her first antenatal check-up, the health care worker takes a full medical history and does an initial physical examination.²²⁶ The woman is then tested and screened for a range of conditions.²²⁷ This includes an HIV test, which must follow national guidelines on routine testing and counselling, including that testing is voluntary. The woman is then given nutritional supplements. The visit ends with a final assessment, which must include a plan for further antenatal care and delivery of the baby.²²⁸ The Guidelines recommend a minimum of four antenatal visits and provide further guidance on subsequent antenatal care visits.²²⁹

FEARS AND CONSEQUENCES OF DISCLOSURE

"No one at home knows my status, they would be too judgmental. My youngest sister disclosed her HIV status to our family and she was treated as if she was different. She had to have her own spoon and cup".

A woman living with HIV, speaking to Amnesty International

People living with HIV in South Africa continue to face stigma, discrimination and violence, particularly in rural areas (see Chapter 2).²³⁰ In its 2014/2015 Annual Performance Plan, the South African National AIDS Council (SANAC) quoted a study acknowledging that "HIV-related stigma and discrimination is on-going and acts as a barrier for people living with HIV to access prevention, treatment and care services".²³¹ This was borne out by many women interviewed by Amnesty International. One home-based carer told Amnesty International about a woman who had disclosed her HIV status to her family and her brother responded by saying:

"You know we won't live with a rotten thing like you. You must go away".²³²

Privacy and confidentiality are key to ensuring that women and girls feel safe to go to health facilities for treatment. Understandably, many do not want other people to know they are living with HIV and take steps to keep it secret. Several health care workers told Amnesty International that pregnant women hide the container for their HIV medication, which is easily identifiable. According to one health care worker in KwaZulu-Natal:²³³

"Once we give them [HIV] medicine, they go to the toilet, they empty the contents into a pocket, and leave the container there".

However, breaches of confidentiality and privacy at clinics mean that women and girls cannot always keep their status secret or choose with whom to share it and when, nor do they always have the time to prepare for the consequences of disclosure.

Fear of breaches can also have financial implications, as some people feel they must attend a clinic further from their home to minimize the chance of running into someone they know. ²³⁴ This was confirmed by almost all health care workers interviewed. An HIV counsellor in KwaZulu-Natal said: ²³⁵

"People will have money saved to go to a faraway clinic, even if there is a clinic at the back of their house."

In general, Amnesty International found that women and girls who attended antenatal appointments at clinics went once a month after their initial visit; thus the travel costs mount up.²³⁶

Women living in poverty and girls dependent on their families often cannot afford to travel to clinics far from their homes to avoid confidentiality breaches. In a focus group discussion in KwaZulu-Natal, a woman said:237

> "I have to go to my local clinic to get my [HIV] medication, but that means you are disclosing unwillingly. You have to be quiet and smile... if you can't afford to travel".

Disclosure of HIV status puts women and girls at increased risk of physical, emotional and financial abuse. The WHO found that 16-51% women from Tanzania, South Africa and Kenya reported that fear of violence was one of the major barriers to disclosure. ²³⁸ UNICEF, the UN Children's Fund, reported that in Tanzania, young women living with HIV were 10 times more likely to report partner violence, compared with peers who were not living with HIV.239

Because of HIV testing during pregnancy, women and girls are often tested before their partner. If they test positive, their partner might blame them for infecting them, even if this is not the case. As one woman said in a focus group discussion in KwaZulu-Natal,²⁴⁰

"The man will say 'you are the one who brought HIV here'."

Women also told Amnesty International that they were accused of having contracted the virus from someone else, implying they were "not faithful". They also described how their partner put them under great pressure to disclose their HIV test result when they returned from the antenatal clinic. Some said that their partner did not want to be tested himself but made them disclose their test results, thinking he could find out his HIV status this way. 241

Sometimes, disclosure of a positive HIV status results in abandonment. In a focus group discussion in Mpumalanga, one woman summed up a commonly expressed experience:²⁴²

> "It's a problem, the boyfriends are running away. If [women and girls] say I have tested and I am HIV positive, that boyfriend will go to other girls".

This leaves women and girls pregnant and alone, often without any financial support for themselves and the child. This exacerbates poverty and inequality which can adversely affect their health.

HEALTH SYSTEM PROCEDURES AND PRACTICES

It emerged from clinic visits and focus group discussions in all nearly all research sites that certain clinic procedures and practices compromised patient privacy and confidentiality. For example, several clinics visited had a separate queue for HIV medication, thereby revealing the HIV status of people in that queue. In a focus group discussion in Mpumalanga, one woman said:243

"If I go for my diabetes, my line is this side, if I go for ARVs, my line is that side. All the people in this line they know these people are HIV. That's why people are afraid to come to the clinic."

Similar concerns were raised about clinics that had separate waiting areas for people living with HIV. A woman taking part in a focus group discussion in KwaZulu-Natal said:²⁴⁴

"All the pregnant women are sitting together but they divide them by HIV status into different rooms [before seeing the nurse]. It is not right that people may talk about [their] status."

In all but two of the clinics Amnesty International visited, a particular room was being used for HIV counselling and testing. Information from community dialogues and focus group discussions confirmed this was the norm and that everyone knows what this room is used for and assume that pregnant women going there are HIV-positive.

Several health care workers confirmed that their clinics had separate queues and waiting areas for people living with HIV. One showed Amnesty International researchers around a clinic in KwaZulu-Natal and noted:²⁴⁵

"There is a separate component [to collect ARVs] and they tried to put it near the door. But the thing is, if you go there, people already know you have HIV".

At another clinic in the same province, while antenatal care was available daily, Friday was the day allotted for antenatal care for pregnant women living with HIV, so people may assume that women attending the clinic on Friday are living with HIV.²⁴⁶ The health care workers explained that they were short-staffed, and having specific days for particular services saved time because they could provide relevant health education to people in groups rather than individually.

The Department of Health acknowledges that separation of services impacts on confidentiality and that ensuring confidentiality in health care facilities remains a challenge. A 2014 report by the Department found that in certain health facilities:

"HIV care and [antiretroviral treatment] services tend to be delivered in physically separate settings such as park homes and focal points from other health services. Patients interviewed [did] not prefer such separate service delivery points".²⁴⁷

Some clinics Amnesty International visited issue special files for people living with HIV to track their medication and associated tests. These were distinctive – some were yellow; others had particular patterns on them. This means that anyone holding one of these files at the clinic is known to be living with HIV. "The files and cards should all look the same", one woman said.²⁴⁸

Not all the clinics Amnesty International visited used different files for HIV treatment, but where they were used, health care workers confirmed that they undermined confidentiality. As one health care worker in KwaZulu-Natal said:

"During antenatal care, if women come out of the counsellor's room with two files, then everyone knows they are HIV positive."249

Most people in the community know what the HIV file looks like. One nurse said:

"The yellow file is the ARV booklet, everyone knows what that is for." 250

A health care worker in KwaZulu-Natal told Amnesty International that "when [women] come out [of the counsellor's office] they will put [the file] in their bag and hide it".²⁵¹ Health care workers in both provinces also told Amnesty International that when women sit in queues to see the nurse after the counselling session with their HIV file, people ask them why they are holding that particular file. A counsellor in Mpumalanga said: 252

> "People notice that only some people have extra papers... people say 'why are you giving them that file? I want that file too'."

Some health care workers were aware of patients' concerns and were taking steps to protect confidentiality. One clinic Amnesty International visited had started to give all patients larger, brown files in which to hold all their notes. A health care worker at another clinic said:

> "Most of the time they have bags, so they put [the file] inside the bags. If they don't, I take it and give it to the [nurse]".253

A doctor who worked for an NGO providing technical support at an antenatal clinic was also aware of this reluctance of patients to be seen leaving with antiretroviral medicine containers as they were easily identifiable. She kept a supply of plastic bags in her office for women to put the medicine inside.²⁵⁴

Cases such as these demonstrate that sometimes very little reform is needed to maintain the right to privacy and confidentiality, some of which have limited resource implications beyond training and raising awareness among health care workers.

When Amnesty International researchers visited a very busy clinic in a large town in KwaZulu-Natal, they saw patients being weighed and having blood tests and their medical histories taken in the communal waiting area. When the researchers asked the facility manager if she had considered using a screen, she said she had not thought of that and agreed it would be a good idea.

In September 2014, Amnesty International raised its concerns regarding these practices with officials of the KwaZulu-Natal Department of Health. In response, the Department of Health officials expressed concern that separate files were being used in some clinics and said they had been unaware of this practice. They acknowledged that this could compromise patient confidentiality and committed to taking steps to improve the protection of privacy and confidentiality in clinics.²⁵⁵

INFRASTRUCTURAL LIMITATIONS IN HEALTH CLINICS VISITED

The design of health facilities Amnesty International visited often undermined privacy and confidentiality. For example, in one clinic in KwaZulu-Natal a nurse's office was far from the HIV counsellors' office, and patients had to walk through public areas with their medical files in hand – potentially revealing their HIV status.²⁵⁶ In other clinics visited, counsellors' offices

were outside the main building, often because they were built later, posing similar risks.

Some clinics visited were in unsuitable buildings. One clinic in Mpumalanga is in a building that used to be a house. The rooms are small and become overcrowded, making it almost impossible to protect patient confidentiality. The poor conditions posed serious risks for health care workers – one HIV counsellor had recently died of TB contracted at the clinic. Amnesty International researchers noted how large stickers advising that doors be kept open for ventilation to reduce the risk of TB were stuck on the doors of consulting rooms, while patients queued in crammed conditions in the corridors outside, within easy earshot of private discussions.

Other, more systemic operational problems with the health system can cause privacy and confidentiality problems. These include staff shortages, which increase waiting times, and overcrowding and lack of space in health facilities.²⁵⁷ These emerged as concerns in focus group discussions, and were confirmed by health care workers interviewed. Where similar problems exist in clinics that Amnesty International did not visit, it is probable that they will have similar consequences on the protection of patient privacy and confidentiality.

Staff shortages were also noted to be a major barrier to training, as the remaining staff struggle to find time away from clinics. As one antenatal care nurse explained:²⁵⁸

"[N]ow it is a skeleton staff... there are not enough professional nurses, no assistants nothing, you have to [do everything with the patient] [by the end of the week] you are so tired."

Another noted that unfilled vacancies were a big problem:

"They don't tell us how many vacancies there are but there are about four sisters that have left and their posts have not been replaced. When I came here in [the late 1990s] there were about 12 professional nurses [now there are 8] and the patient load has increased dramatically because of this HIV and people have come [here to the community]... We are supposed to be a [maternity and obstretrics unit]. That means we are supposed to deliver every day, but there is no staff to do that." 259

A nurse in KwaZulu-Natal told Amnesty International that the lack of rooms meant that she was often unable to take women into a room alone to do their blood tests. ²⁶⁰ Women who are HIV-negative have one vial of blood taken while women who are HIV-positive have two taken (because of the additional tests needed). Doing the blood tests in public means people can tell a person's status depending on the number of vials taken. In many clinics, Amnesty International researchers observed that health workers conducted the initial assessment for women and girls during the antenatal check-up in the communal waiting room, meaning several people could see their vital signs (blood pressure, weight, etc).

Amnesty International visited a clinic in KwaZulu-Natal where a shortage of consulting rooms meant that HIV counselling was happening in the maternity wards. According to one nurse, when the wards were needed for women in labour, the counselling was shifted to the kitchen. 261

Another clinic visited in KwaZulu-Natal has an open-plan structure, with only curtains separating consulting cubicles. Here, according to participants in a focus group discussion held nearby, women feared that people in other cubicles could hear what health care workers were telling them. One pregnant woman complained that she had been humiliated by the nurse shouting at her during an antenatal check-up. Understandably, she did not want to repeat what had been said, but she explained that when she came out of the cubical she knew everyone in the waiting area had heard, noting "when the person is walking out of the room everybody can see this is the person [who was shouted at]."²⁶²

People perceived as migrants or refugees can face additional threats to maintaining confidentiality of medical information because of the lack of translators. In areas where this was a problem, health care workers explained they sometimes had to rely on husbands or partners to translate information about HIV counselling and testing during antenatal care. ²⁶³ This means husbands or partners find out the HIV status of the woman or girl first, and health care workers have no control over how this information is communicated.

Staff shortages undermined privacy and confidentiality in the clinics visited. In some clinics, only one nurse was dealing with antiretroviral treatment and this was known to all patients. As a result, anyone seen going to that nurse is assumed to be living with HIV.

The same problem applies when only one room is used for distributing HIV medication. In one focus group discussion in Mpumalanga, all the women knew that in their local clinic "Room [X] was for testing HIV and Room [Y] was for HIV medication". ²⁶⁴ Overcrowding in clinics also means that women have to wait in queues with their HIV files for longer.

PERCEPTIONS OF HEALTH CARE WORKERS' BEHAVIOUR

"And I was the one who was afraid to go to the clinic. I said, 'What if I find out I am HIV positive?' Ah.

Too much yarra yarra [gossip] there. No, I won't go there."

A woman from KwaZulu-Natal province, speaking to Amnesty International about visiting the clinic

Another privacy-related concern expressed by many women is the perception that health care workers will not keep their HIV and pregnancy status confidential. Women living with HIV and adolescents were especially nervous that health care workers would comment in public on the reasons for their visiting the clinics. While Amnesty International was not in a position to verify all complaints, this perception of confidentiality breaches has made women and girls reluctant to attend clinics.

In relation to HIV status, women and girls said that health care workers discuss results among themselves and with others. "The nurses are talking about people and their status", one woman told Amnesty International. 265 In another focus group discussion in KwaZulu-Natal, one woman said: 266

"I'm not going to go for testing at [name withheld] clinic because they know me and if I go there and they find out I have HIV they are going to spread news. I want to go to another clinic where they don't know me".

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Another woman said:267

"They have the counselling but it is the people that make people afraid, those people doing the counselling, they spread news about you, maybe they say 'this person is HIV positive'."

A woman living with HIV in KwaZulu-Natal told Amnesty International that once when she went to collect HIV medication from the clinic for her baby, the nurses shouted out "where is the baby?" so that everyone waiting at the clinic knew that her child was living with HIV.²⁶⁸

Women and girls expressed similar fears about health care workers' failure to keep other health information private, including their pregnancy status. Young women and girls in particular fear that people in their family, schools and community will find out that they are pregnant. Women, girls and health care workers interviewed by Amnesty International all said that this fear was one of the reasons for women and girls delaying antenatal care.

A young woman interviewed in Mpumalanga, who had her first baby when she was 18, recounted her experience at the clinic:²⁶⁹

"When you are sick [while pregnant], [the nurses] say 'you are sick now, but you like boys too much and that's why you get pregnant'... [and] shouting in front of other people ... if we have pain or cramps [during antenatal exercises], they shout 'look you're exercising so badly but when you sleep with your man you open wide'."

Similar experiences were shared in focus group discussions in both provinces. These experiences were often enough to deter others from accessing services at all. Amnesty International researchers interviewed an adolescent high school student who was four months pregnant. She was planning to delay going to the clinic for as long as possible. She explained:²⁷⁰

"I'm afraid of... all people in the clinics, the other patients, the nurses, everyone in the clinic, I don't like the people... they will just stare at me... they will talk behind my back and say all bad things."

Some women said that even when health care workers are generally respectful during examinations, they lacked sensitivity for concerns about confidentiality when communicating with patients. A home-based carer who is living with HIV shared her own story:²⁷¹

"There is no confidentiality! If you are looking good, the nurse will say in front of everybody 'see, the [HIV] medication is working', and then people know you are HIV-positive".

Another home-based carer in the group, who worked in the same area but used a different clinic, said that the counsellor at her clinic shouted for people by name to come and get the results of their CD4 count blood test, as a result of which "everyone will know their status".²⁷²

Often, concerns about confidentiality arise because nurses are from the same community as the women attending their local clinic. During a focus group discussion in Mpumalanga, a woman said:²⁷³

"The nurses who work at this clinic are also from this area, and that is a problem. So there should be a rotation of nurses from outside".

Health care workers recognised that many women and girls were worried about maintaining the confidentiality of their health information. One confirmed that people were scared of confidentiality breaches, even if health care workers had not actually done this. As one health care worker in KwaZulu-Natal told Amnesty International:²⁷⁴

"Let's say a person knows me, and she sees me in the clinic, she will assume I will expose her to the community".

When health care workers do share patient information with people not authorized to know it, they are breaching their obligation to protect the privacy and respect the confidentiality of the patient.

CONCLUSIONS

The manner in which many health workers communicate information about the HIV testing process at antenatal clinics causes women and girls to believe that the process is mandatory and, in many cases, necessary if they are to access other antenatal services. As a result, some delay or avoid antenatal care, with potentially grave consequences for their health. Such failings also contravene women's and girls' right not to be subject to procedures or treatment without their full and informed consent, as recognised in international human rights law.

The design of health facilities and waiting systems, certain distinctive procedures and practices for patients living with HIV, and perceptions regarding health worker behaviour, mean that women's and girls' right to confidentiality regarding their HIV and pregnancy status is often compromised. This too has serious consequences for their lives, often putting them at risk of stigma, violence and further discrimination – and again may deter them from seeking early and ongoing antenatal care.

4. INFORMATION DEFICIT: A HEALTH HAZARD

'Give girls health education and information to get them to come to the clinics early.'

An antenatal nurse in KwaZulu-Natal, speaking to Amnesty International

Everyone has the right to seek, receive and impart information and ideas concerning health issues. ²⁷⁵ The provision of education and access to information about the main health problems in the community is a core obligation under the right to health. ²⁷⁶ The African Charter on Human and Peoples' Rights on the Rights of Women in Africa (the Maputo Protocol), which South Africa has ratified, asks States to ensure "the right to have family planning education" ²⁷⁷ and "provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas". ²⁷⁸

States are obliged to provide comprehensive sexuality education (CSE) to all children and adolescents, both in and out of school, as part of upholding the right to health-related information.²⁷⁹ Such education is a human rights issue. It should be taught in schools and be part of government strategies to reduce unplanned pregnancies and STIs.²⁸⁰

Amnesty International's research highlighted two areas where these obligations were not being met by South Africa: a failure to ensure sufficient dissemination of and access to information relating to sexual and reproductive health and rights; and a lack of adequate training for health care workers. Among other consequences, these failings contribute to some pregnant women and girls delaying antenatal care.

LACK OF INFORMATION AND THE CONSEQUENCES

For many of the women and girls Amnesty International spoke with in KwaZulu-Natal and Mpumalanga, lack of information about the importance of going to the clinic early in pregnancy was a factor in late access to antenatal care. They highlighted the paradox that they had not received this information because it was only available at the clinics. The women and girls interviewed who had gone early for antenatal care had learned about the need to do so at health facilities, either because they knew they were living with HIV before they became pregnant and had been given information on the importance of early antenatal care to reduce the risk of transmission of HIV to the foetus, or because they had gone to a clinic for a pregnancy test.

Health care workers confirmed that in general, most people can only obtain this kind of information by visiting a clinic. They explained that they attempted to provide such information about the benefits of early antenatal care to patients through public health talks provided every day to patients in the waiting areas at clinics.

A mother of four in KwaZulu-Natal told Amnesty International that she had learned about the benefits of early antenatal care while working as a home-based carer and because her third child was exposed to HIV from her as a baby. As a result, she registered for antenatal care in the second month of her fourth pregnancy. Her youngest child, aged one at the time of the interview, was born HIV negative. She said:

> "I saw why it was important to go early and I also saw what happened when people were not checking and what happened after they had given birth to babies who were [HIV] positive." 281

This and similar experiences correspond with community-based focus group discussions which confirmed that primary health care facilities are the main source of health information. However, public health facilities are not always acceptable sources of information owing to fears about the lack of privacy and confidentiality (see Chapter 3), and in some areas are inaccessible owing to financial and logistical barriers related to transport (see Chapter 5).

Several women in rural areas of KwaZulu-Natal and Mpumalanga told Amnesty International that they had to travel a considerable distance to the clinic for HIV testing and health-related information. Mobile clinics were only available in a few communities and most were said to be unreliable. Only one clinic visited by Amnesty International in KwaZulu-Natal had a family health nurse working in the communities and raised the importance of this service.

Particular groups of women and girls that Amnesty International spoke to explained that they face additional barriers to accessing information. Those living on commercial farms are largely excluded from information because of lower levels of education and transport barriers. People perceived to be refugees or migrants face challenges due to language difficulties. Women who have paid jobs struggle to get time off work during clinic hours. Schoolgirls find it difficult to attend clinics during the day in term time.

A nurse interviewed in KwaZulu-Natal noted the high number of young girls out of school in her rural community, and said that their lower levels of education made it hard for her to help them to understand her when she gave advice about contraception and antenatal care. She emphasized the importance of having community care-givers or home-based carers who could go into communities to find women and girls who are pregnant. In these contexts community health workers and home-based carers are also an important source of information in places where access to health facilities is difficult, but they were not always able to reach communities in need. In a rural area of KwaZulu-Natal, a worker employed by a communitybased organization said:

"It is too difficult here. There is no community care-giver going door to door, they can't get information. They need more people to help them."282

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Young women noted, however, that when services did reach their communities, they were often excluded from these services as they were focused on people who were in poor health. Clinic Committees also provide a potential means of communication between the clinic and the community. The strengths of this system appeared to vary between clinics, depending on the capacity of the individual committees, but it was beyond the scope of this research to evaluate the functioning of the committees. Amnesty International was told that recent training for Clinic Committee members in one of the municipalities in Mpumalanga had clarified their communication role. One member, who was also an HIV counsellor at a clinic in the area, explained:

"[T]he Clinic Committee must work hand in hand [with the clinic] and to inform the community outside that it is Important that they must come to the clinic as soon as possible [in pregnancy] to prevent the death[s]."

Community-based organizations stress the importance of providing information on sexual and reproductive health and rights, including gender equality, to traditional leaders. Many health care workers called for more efforts to reach the communities, giving examples of community information events in KwaZulu-Natal. One young nurse at a remote rural clinic in KwaZulu-Natal said:

"If you have a function, that is when the community will listen, just do something fun that is how the youth will listen to you." 283

An antenatal nurse in KwaZulu-Natal told Amnesty International of a recent experience that summed up some of the dangers of lacking information about the need for early antenatal care:

"Even if not antenatal clinic day, we preach this thing that when you are pregnant you must come to the clinic, because some they come here and they are fitting, only to find that their blood pressure is elevated or the person is fully dilated, you have to deliver the baby at the same time. One came here at 28 weeks pregnant and she was in labour, she was fully dilated, she was hiding at home, not attending a clinic." ²⁸⁴

In August 2014, the government launched a mobile phone information service, MomConnect, ²⁸⁵ aimed at linking pregnant women with health services and providing them with information on pregnancy. While Amnesty International welcomes this important new initiative, it was not possible to make any assessment of it during the research period. Registering for the service relies on health care workers and accessing health services at clinics. In the context of reluctance or inability to access information at health facilities, as expressed by a considerable number of the women and girls interviewed by Amnesty International, and similar findings from other qualitative studies in South Africa, ²⁸⁶ this aspect of the MomConnect initiative needs to be monitored closely to ensure that the right to information is being upheld.

In all of the health facilities Amnesty International visited, there was a shortage or lack of printed information material about contraceptives, termination of pregnancy and antenatal care that women and girls could take home with them. Health care workers expressed an eagerness for such resources, so that they could supplement the information they tell patients, similar to an intervention that has recently started in the Western Cape province.²⁸⁷ Several nurses suggested that the antenatal clinic folder that holds medical files, which

pregnant women and girls take home between appointments, could include information sheets for pregnant women and girls. A request for additional posters or clinic-based materials was also made. Amnesty International researchers noticed a disparity between clinics as to the amount of visual information on display. There were no posters or murals noted that related to the importance of early antenatal care.

The majority of women and girls with young children interviewed by Amnesty International had unplanned pregnancies and most only began to use contraception after the birth of a child. Unplanned pregnancies and low rates of modern contraceptive use have been linked with higher rates of maternal mortality in South Africa.²⁸⁸ Access to contraceptives has also been found to vary according to socio-economic status, with access worst among poorest households.²⁸⁹ All of the health care workers interviewed by Amnesty International researchers raised concerns over the high rates of unplanned pregnancies among their patients, which many said was often owing to lack of useful or correct information about contraception and reproduction. This was especially the case in relation to teenage girls. An experienced antenatal nurse, who worked in a busy town clinic in KwaZulu-Natal, said that young girls often told her they had no idea how they fell pregnant:

"[For many teenage girls] it is their first intercourse, mostly, because when you ask them about contraceptive, some will say 'what are you talking about?' Then you have to say [what is available and] we'll say 'what are you going to use as a contraceptive method after delivery?' They will say 'I don't know, I have no idea' so then you know they accidently fell pregnant." ²⁹⁰

Four adolescent mothers in Mpumalanga told Amnesty International that they had been put off using contraceptives because of a lack of understanding or bad advice from friends. They had not gone to a clinic for advice and criticized the lack of information on sexuality and reproductive health that was given to them at schools. Their experiences reflect views shared in several focus group discussions, where misinformation about contraceptives was often given as an example of why contraceptives were not used. As one antenatal nurse in KwaZulu-Natal explained:

"Because now they prefer to go to their friends and they confide in all the wrong people, they get the wrong information and all hell breaks loose." ²⁹¹

The nurse felt that the lack of knowledge among girls of sexual and reproductive information contributes to the high rate of teenage pregnancies.

Another nurse in a rural area of the same province gave examples of reasons her adolescent patients had given for not using contraception. These included the boyfriend saying that condoms cause cancer. In two focus group discussions with home-based carers in a rural area of KwaZulu-Natal, other examples of misconceptions were cited as commonly held, such as women believing they may not be able to have children after using contraception.²⁹² This lack of information and misinformation in relation to contraception is consistent with recent studies on the issue in South Africa.²⁹³

At the national level concerns have been raised about the lack of information about ways to protect against HIV transmission.²⁹⁴ The National Committee for Confidential Enquiry into

Maternal Death has highlighted the failure to provide sexuality education relating to HIV. It noted:

"Young women in society are still not given adequate education about HIV and an opportunity to test for HIV and maintain their health accordingly. It is too late for women to find out their HIV status when they are already pregnant or critically ill." ²⁹⁵

A recent national HIV prevalence survey supports this finding in relation to lack of knowledge of HIV transmission. It noted:

"Overall, only 26.8% of South Africans had accurate knowledge about the sexual transmission and prevention of HIV." 296

The National Department of Health has expressed concerns over the high number of unplanned pregnancies, especially high among teenagers.²⁹⁷ One government study found over half of pregnancies in South Africa were recorded as unplanned²⁹⁸ and rates may be even higher among women and girls living with HIV.²⁹⁹

There is a growing awareness of the unmet contraceptive needs of women and girls, especially those who are living with HIV.³⁰⁰ The lack of integration of sexual and reproductive health services and HIV treatment and other services,³⁰¹ and the lack of or incomplete and inconsistent medical advice about contraceptive options³⁰² as well as issues of stigma related to HIV,³⁰³ have been shown to prevent high uptake of contraception for women living with HIV.³⁰⁴

It is essential that girls receive CSE as it offers an opportunity for boys and girls to receive information around sexuality, contraception and STIs, and relationships. Among other things, it should increase the understanding amongst boys of their responsibility in preventing unplanned pregnancy and the spread of infections. ³⁰⁵ While it is beyond the scope of this report to evaluate the provisions of this programme in South African schools, adolescent girls told Amnesty International that lessons related to CSE were not available in school or were too narrowly focused, for example "only talking about menstruation" or not providing relevant information about sexuality and relationship dynamics. Most said that the lessons did not target students at a young enough age. Recent studies have similarly highlighted that "education on sex, sexuality, gender and gendered violence is uneven, under developed and poorly implemented." ³⁰⁶

In KwaZulu-Natal, the school health programme was operating in several of the clinics visited by Amnesty International. There was positive feedback from the health care workers involved in this programme, though they complained that they were unable to give demonstrations of condom use (male or female) and could not prescribe contraceptives. There were further frustrations relating to lack of vehicles for the team to access schools far from the clinic. In a meeting with the National Department of Health,³⁰⁷ Amnesty International was told that the government was planning to improve service delivery for young people through the school health programme. The official emphasised that successful implementation of these policies relied on a range of stakeholders, including the Department of Basic Education and school governing bodies.

In both KwaZulu-Natal and Mpumalanga, NGOs and community-based organizations highlighted the refusal of schools to allow in-depth CSE. One experienced HIV counsellor in Mpumalanga said she felt "very sad" when she sees pregnant teenagers as she feels she is prevented from doing more to inform young people at schools:

"I can't say there is enough [information] but we are trying. We have been trying so very hard to go to the schools, but the Department [of Education] won't allow us to go to the schools. We thought it would be good to go there and educate them as young as they are... [T]hey say we are not allowed to teach it because we are going to teach about condoms so they don't allow us to go to schools." 308

In general, all of the health care workers interviewed expressed frustration that clinics are the main source of sexual and reproductive health information. One said:

"There is nothing we can do because we cannot go to the schools and give them family planning, they are supposed to come [here]... I don't know about the teachers [if they are giving information] but we are supposed to do it."

The Department of Health's National Strategy for Maternal Health recognizes the need for comprehensive family planning services to be available to all women and the importance of youth-friendly services. In a meeting with a senior official in the National Department of Health responsible for Maternal Health programmes, ³⁰⁹ Amnesty International was assured that improving sexual and reproductive health services for adolescents was a priority for the Department.

INFORMATION FOR HEALTH CARE WORKERS

Adolescent girls and women living with HIV told Amnesty International that the negative attitude of health care workers was a barrier to seeking health-related information and services. Such complaints were also frequently raised in focus group discussions. Consultations with community-based organizations with experience of working in the context of HIV and/or sexual and reproductive rights gave examples of poor health care worker attitudes, as did representatives of two medical NGOs who were providing training and medical assistance in health care settings. However, women and girls also provided examples of how positive and caring attitudes from health care workers had encouraged their attendance at clinics.

Health care workers interviewed by Amnesty International said they needed more information and training in relation to sexual and reproductive rights and working with adolescents. Such requests link to findings from other studies that call for better training of health care workers in the context of ensuring adolescent-friendly services. A number of health care workers felt the responsibility to provide sexual and reproductive health information was an additional burden for which they did not have the time, and often the skills, to cope with.

One nurse in KwaZulu-Natal articulated how they needed skills to ensure they offered services free of judgment, and wanted workshops for youth friendly services. She said:

"[N]urses... [w]e need to not look at them as our daughters, when they

come here, just see them as clients and not say 'you are 14 what are you doing with boys' you know, such things, it is difficult to let go of that maternal things and just be a nurse for once... Even as a nurse you look at the child, instead of saying 'we've got this [contraceptive option] we've got that, we have a morning after pill, we end up, it is just human nature, you get caught up in this maternal thing and forget about talking about contraceptives'... Because most are frightened to come and talk to us about contraceptive... They come in and tell us they have a headache without saying what they came for, they look at you and think 'oh she's got an attitude she is going to shout at me'."311

This nurse's understanding was confirmed by young women Amnesty International spoke with. One woman in KwaZulu-Natal said:

"[S]ometimes you find the nurses who don't have an approach to treat you, they don't even give you good knowledge, they shout at you. Sometimes you found a friendly one they help you with a smile and good relationship."312

The lack of "youth-friendly" services was also emphasized by community-based organizations.

In contrast to the views of women and girls in their communities, health care workers told Amnesty International that they felt their services and facilities were youth-friendly. However, the facilities that Amnesty International visited did not provide any distinct services for young people. In a useful initiative, the clinic opening times of the five health care facilities visited in Mpumalanga had recently been extended, which health care workers noted made it easier for girls to access services after school. The UN Educational, Scientific and Cultural Organization (UNESCO) describes youth-friendly services as:

"... those that specifically seek to be open at times that are suitable for young people, and are located in places where young people feel safe and comfortable accessing it. Most importantly, young clients should not face judgement or stigma from staff, and they should be able to trust that their confidentiality will be respected." 313

Women and community-based organisations expressed concern that women living with HIV encountered judgmental attitudes from health care workers if they had unplanned pregnancies. A mother in KwaZulu-Natal told Amnesty International of her experience:

"I went to the clinic [and] I found out that I was HIV-positive and they give me [ARVs]. Then I went to the clinic [after] four months [of taking ARVs] and I asked for the pregnancy test at the clinic and I was positive. The nurse was giving me hell. She said that it was four months since I had the pills, why didn't you prevent [pregnancy]?"314

When interviewed, most health care workers explained they wanted to support women living with HIV through their pregnancies and were enthusiastic about the new antiretroviral treatment protocols that better enabled them to do this. However, their feelings about seeing

women living with HIV who were pregnant when their health was compromised could be unprofessionally expressed. One health care worker told Amnesty International:

"We are not happy as you see them maybe in January she has started on ARVs and in June she is pregnant, even if you give her health education about the importance of checking the viral loads. Some they listen some they don't listen. Then the important thing is to tell them to take the treatment and to use the condom. Maybe others they are married and want kids... We are not happy [if] we note that the viral load is high."

While the health care worker was concerned by the health implications of the pregnancy, the views and possible manner of communication highlight why some women living with HIV may feel uncomfortable about accessing antenatal services.

Nearly all of the health care workers noted that they had not received any training in working with adolescents or groups of women and girls who may need additional support accessing services, for example, those with peri-natal depression or victims of gender-based violence. In addition, in several interviews, staff shortages and the heavy workloads were mentioned as barriers to providing women and girls with the additional information and support they may need in such contexts. Most health care workers said they did not ask pregnant women and girls about their social and emotional needs. As one counsellor explained, "we don't know what goes on at home". 315

In contrast, one newly qualified antenatal nurse in KwaZulu-Natal told Amnesty International that she felt the sexual and reproductive health problems of the women and girls needed a more holistic approach than just the provision of medical services at health facilities, especially for pregnant patients. She explained:

"We need to go to homes and visit them and see how they live there, because you will see she will come here very down, depressed, and she will go home and you will see that the problem is not here, not her, it's the family and the environment at home."

High levels of depression among pregnant women and girls living in poverty have been noted in South Africa. The Children's Institute, noting the importance of psycho-social support during pregnancy on children's health and development, has called for routine mental health assessments, to be part of antenatal care services at primary health facilities. 318

Officials from the KwaZulu-Natal Department of Health acknowledged the importance of additional training for health care workers and noted plans to train HIV counsellors as auxiliary social workers. They also noted the need for human rights training for all health care workers, but accepted this was sometimes not prioritised. However, one official suggested that the Department's training tool for sexual and reproductive health and rights could be included in the training guidelines for health care workers delivering antenatal care as one measure to address this gap.

Amnesty International also found that staff shortages impacted on the amount of time health care workers could spend with individual patients, which often meant that time spent giving

patients information was limited. In a meeting in September 2014 with senior officials in the Mpumalanga Department of Health, ³¹⁹ Amnesty International was informed that staff shortages were accepted as a major barrier to ongoing training for health care workers in the province. In addition, the lack of national norms and standards on training guidelines for health care workers was noted as a problem. One official highlighted that a regional training centre was tasked with auditing health care facilities to identify health care workers who were in need of additional training support, but that often training could not take place if it would leave a clinic without key staff.

A lack of understanding between health care workers and patients appeared to perpetuate a culture of misinformation and grievance. Many health care workers expressed a commitment to their jobs and desire to help their patients. However, they felt they were put under stress that was not understood. One nurse in Mpumalanga complained:

"Sometimes I feel that we [nurses] are doormats, because everyone wants to say nasty things about the nurse... as nurses they must recognise our rights, we must not keep quiet... [Y]ou feel that you are very small, you are useless, they way they talk to you... to be a nurse you are not recognised, the public is recognised but us, we are not recognised... we are working so hard."

The language of feeling "small" mirrors that used by women and girls, many of whom complained they were treated "as if we are nothing" by health care workers. 320

Despite a range of complaints in the standard of care they had received at health facilities, none of the women or girls Amnesty International interviewed had made an official complaint to the health care facility or to the authorities responsible for the health care facility. Nearly all knew that there was a suggestion box, but there was little understanding of how the complaint would – or should – be handled. Many women and girls feared that they would face challenges accessing further health care during pregnancy if they complained.

CONCLUSIONS

Virtually all the women and girls interviewed by Amnesty International, as well as the discussions in community focus groups, reflected a widespread failure in KwaZulu-Natal and Mpumalanga to ensure that information about sexual and reproductive health and rights is adequately disseminated and that all sections of the population are able to access it. One of the key problems is that clinics are usually the main source of information, but these are seen by many as places where patients' right to privacy is breached and where staff attitudes are poor, particularly towards girls. In some rural areas, clinics are difficult or too expensive to reach.

Amnesty International also found that health care workers in South Africa need additional training, including human rights training, particularly in working with adolescents or groups of women and girls who may need additional support, such as survivors of gender-based violence. The lack of such training increases professional stress for health care workers and contributes to attitudes by those workers that are perceived as disrespectful, creating additional barriers for women and girls to accessing health services. Staff shortages were found to be a barrier to training opportunities and also increase pressure on existing staff who

all noted that their heavy workloads and difficult working conditions impacted on their relationships with patients.

The Department of Health has demonstrated how effective it can be when disseminating information relating to aspects of HIV and contraceptive services. Two recent examples are the provision of the Fixed Dose Combination Antiretroviral Therapy for pregnant women who test positive for HIV during pregnancy, and the implementation of a new, long-lasting contraceptive device, the sub-dermal implant.³²¹ Both innovations are well-regarded by patients and health care workers alike, and information has been spread through a combination of media campaigns and word of mouth.

It is essential that the same level of commitment and innovation is given to ensure access to information relating to all sexual and reproductive rights and health services.

5. A BROKEN LIFELINE: TRANSPORT AND COST BARRIERS TO HEALTH

'What would help is for us to get a tarred road... because even the mobile clinic can't come when it is raining."

A women speaking to Amnesty International in KwaZulu-Natal

Under the South African Constitution and relevant international law and standards, the State's obligation to protect, respect and fulfil the right to health includes ensuring that all health facilities, goods and services are physically and economically accessible to all, without discrimination. They must be affordable for all individuals, 322 and must be within safe physical reach for all sections of the population, especially marginalized groups.³²³ The Maputo Protocol also requires that States "provide adequate, affordable and accessible health services... to women especially those in rural areas".324

Almost all women and health care workers Amnesty International spoke with cited the distance to health clinics, difficulties finding transport, poor roads, and the costs of travel to clinics as major barriers to attending antenatal check-ups, which prompted many to delay their initial visit to the clinic. Women and girls also described the health dangers they face because of impassable roads, the lack of ambulances, and their inability to afford to pay for transport to the nearest hospital during labour or for medical emergencies relating to pregnancy or childbirth. Their experience is consistent with the dangers highlighted by the CEDAW Committee, in the context of women's rights to health.

"Many women are at risk of death or disability from pregnancy-related causes because they lack the funds to obtain or access the necessary services, which include ante-natal, maternity and post-natal services. The Committee notes that it is the duty of States parties to ensure women's right to safe motherhood and emergency obstetric services and they should allocate to these services the maximum extent of available resources."

CEDAW Committee, General Recommendation on women and health³²⁵

TRANSPORT PROBLEMS

According to the official 2012 General Household Survey, most people reported walking to the clinic they attended. This is consistent with what women and girls told Amnesty International in rural areas.³²⁶ Some said it took them up to 90 minutes each way.

Many women said they took lifts from people on the road, or paid for a bakkie (vans converted to take passengers), often travelling in unsafe and cramped conditions, particularly uncomfortable for pregnant women. One woman in KwaZulu-Natal, who had recently had a baby, said:³²⁷

"It is painful because one doesn't sit comfortably in the van. You have to be bent all the time. That is painful and tiring".

In many places visited, the roads are in poor condition. One woman in a remote area of KwaZulu-Natal described how she had no option but to travel in a bakkie: 328

"It's hard because we travel on gravel road. It becomes a bumpy ride that is very uncomfortable for pregnant women. But there is nothing I can do, just have to accept the situation".

Some roads often become impassable when it rains, cutting off communities from vital health care. In some areas, the roads are unusable for long periods during the rainy season. Nationally, while most (87%) health care facilities are accessible by taxi, access via public transport is limited, with only 58% of facilities accessible by bus and 9% by train.³²⁹

Lack of adequate and safe transport further marginalizes groups that are already under-served and discriminated against, including remote rural communities and women and girls who live and work on commercial farms. They have to find their way from the farm to the main road, and then pay for transport or walk to the nearest clinic. A health care worker in Mpumalanga confirmed that many women from farms start antenatal care late for this reason.³³⁰

On visiting a farm in Mpumalanga, Amnesty International met two women with young babies who said they had not accessed antenatal care. One had given birth at home and the baby, aged around two months, had not been to the clinic. The women explained that poverty and transport problems meant they had received no antenatal care while pregnant.

PROHIBITIVE COSTS

The cost of transport poses a further barrier to accessing antenatal care. The government has acknowledged that transport costs are a burden, especially for rural and indigent communities.³³¹ Women reported fares ranging from R9 to R200 (about US\$1 to US\$19) for each antenatal check-up, and many said that this was the main reason they delayed attending antenatal clinics. Health care workers recommend a minimum of four antenatal check-ups during each pregnancy, so transport costs add up. Given that households in rural areas commonly survive on a monthly income of under R1000 (US\$95), and on social grants, it is not surprising that women start attending clinics later in pregnancy. For example, it cost one woman interviewed in KwaZulu-Natal R60 (US\$5.7) using public transport to reach her nearest clinic. She was only able to afford this because the father of the baby was financially supportive during her pregnancy.³³²

Transport costs can also force women and girls to reveal they are pregnant before they want to if they rely on their families or partners for money. This is particularly true for school girls who are financially dependent on their families or partners. One woman told Amnesty International:³³³

"My problem was that at home they didn't see that I was pregnant and I was worried about what they are going to say when they see I am going [to the clinic]".

When asked why her family would find out about her pregnancy, she said it was because she would have to ask them for transport money.

For women who have limited financial resources, choosing to pay for transport for antenatal check-ups means not having money for other essential expenses. In an area around 10km from a town in KwaZulu-Natal, a woman living with HIV told Amnesty International that it cost her about R200 (US\$19) to get to the clinic for antenatal check-ups and antiretroviral treatment. For this amount, she said, she could buy enough grain for her family to last a month, as well as vegetables.³³⁴

The combination of long journeys and staff shortages at health facilities means it can take a woman an entire day just to go for a check-up, possibly at the cost of a day's wage and payments for childcare. Again, this can prompt women and girls to delay starting their antenatal care. A mother of a baby girl in KwaZulu-Natal said:

"I went to [name withheld] clinic, I would wait from 7am to 3pm each time. I would get up at 5am and leave my house about 6am to get there for 7am."

Unexpected transport costs are sometimes needed because the mobile clinic does not turn up. In one district in Mpumalanga that Amnesty International visited, participants in a focus group discussion said the mobile clinic service had been suspended for more than four months because no driver had been hired.³³⁵

A traditional leader in KwaZulu-Natal told Amnesty International how they try to help pregnant women:³³⁶

"[W]e plead with the drivers to have compassion so that the person doesn't die just because they don't have money. I have asked for the donation from the community to help out in paying for the transport."

Another traditional leader in the same area said:337

"When it rains, the roads become dangerous and government ambulances cannot reach the more remote communities."

In these situations women in labour have no choice but to pay expensive fares or risk giving birth without medical assistance.

LACK OF AMBULANCES

The lack of ambulances was reported as a serious problem in all research sites. In some places, existing ambulances cannot reach some rural communities, especially during the rainy season, or they are only authorized to go to the local clinics. An unemployed mother of four children living in KwaZulu-Natal said:

"The ambulances are the worst, I called them at 7 in the night, it came at 11 or 12. Ay! [If] you phone they say no there are none in [name of area withheld] they are in [name of area withheld] but what are they doing there?"

In a meeting with Amnesty International, the KwaZulu-Natal Department of Health acknowledged that there was a shortage of ambulances in the province, noting that it had less than a third of the number of ambulances needed. 338

Women told Amnesty International that because of the problems with ambulances, they try to save money throughout their pregnancy to ensure that they can hire private transport when they go into labour. Hospitals are often much further away from their homes than the nearest clinic. Amnesty International heard varying costs of private transport to hospitals, ranging up to R900 (US\$85).

One pregnant woman in KwaZulu-Natal said that she had borrowed the R500 (US\$47) she needed to get her to the hospital if the ambulance did not come in time. She planned to pay the money back using the monthly R310 child support grant. She told Amnesty International that paying R500 would have upset her, but she would have had no choice. Fortunately, the ambulance reached her in time.

Another woman said that when her daughter went into labour, the ambulance failed to arrive. As a result, she had to pay R500 for a private car – more than her monthly wage as a parttime road cleaner. She heads a household of 10 people and is the only one with a job. The family's monthly income, including government social grants, is less than R1,000 (under US\$100).

Health care workers confirmed that they also advised women to save up for private transport during pregnancy "because an ambulance is not always available". 339 A health care worker in KwaZulu-Natal told Amnesty International:

> "We can't rely on an ambulance 100% [so we ask women to] plan for pregnancies by taking the private transport number and budgeting for

The KwaZulu-Natal Department of Health acknowledged that this was advisable, as the ambulance could not be relied on. They noted that they were trying to encourage women to make use of "waiting homes" (an annex or bed available in some rural health facilities for women awaiting labour).

In a focus group discussion in KwaZulu-Natal, a pregnant woman told Amnesty International that she thought it would cost her R600 (US\$57) to get to the hospital if she went into labour at night. She was hoping it would happen in the day time so she could take the public transport. She said:340

> "You must pray for me... that I don't need the R600 [car to take me to hospital]."

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Home-based carers also told Amnesty International that they advised women to "save for

transport" to the hospital during labour. 341 Because women have to, and are encouraged to, save for private transport during delivery, they have less money to pay for regular trips to the clinic for antenatal care. In a focus group discussion in KwaZulu-Natal, one of the home-based carers participating said: 342

"They don't attend the clinics [early] because they saw that if they attend when they are one month they will have to attend until they are nine months... that's why they start at six months".

Problems with the ambulances and costs of transport to hospitals mean that women and girls often go to the local clinic rather than the more distant hospital when they begin labour. The health care workers at the clinic then have to assist with the delivery, often without necessary equipment and training, which increases their professional stress and possible risks for the woman in labour. In one clinic there were a number of reports that nurses had refused entry to women in labour on several occasions. Amnesty International spoke with one woman who was turned away in this manner. A partner organization working in the community confirmed they had been made aware of this problem on other occasions.

CONCLUSIONS

Without access to reliable, affordable and safe transport to health services, women and girls who need to access antenatal care and maternity units, particularly those living in poor, rural communities, are placed at unnecessary risk. Because of the transport problems, women and girls, particularly in rural areas, delay or avoid antenatal care, with adverse impacts on their health. They also find themselves forced to pay for private transport to reach health facilities during and after labour because of the lack of ambulances serving their communities. This was found to be a cause of anxiety for women, as many knew they faced dangerous health consequences if they relied only on ambulances. Amnesty International has previously raised this issue of the impact of physical and economic barriers to the realisation of the right to health with government authorities, including the Department of Transport. 343 It is of great concern that the problem persists and threatens the health and lives of women and girls during pregnancy and labour.

HUMAN COST OF INADEQUATE TRANSPORT



Nokwethemba Skhakhane*, a single parent and volunteer teacher in the community crèche, had recently given birth to her fifth child when she spoke to Amnesty International in her home in KwaZulu-Natal in January 2014. She described her traumatic wait for an ambulance when her labour had begun two weeks earlier:

"I called the ambulance around 7pm... I was told to go wait for them on the road... they only arrived at 11.30pm... I waited for them by the road all that time. I was freezing in the road and... in pain, I didn't know if it was still labour pains or [if] I was dying."

There is no road to her homestead, so she had to walk up a steep 300-metre path while in labour to reach the point where the ambulance would stop. She knew that it might not come and described her fears as she said goodbye to her children:

"I was hurt when I left them, I didn't even know if I was going to come back."

After waiting nearly five hours for the ambulance, her mother began to negotiate with the owner of a bakkie over the fare to take her daughter to the hospital. It would have cost R500, nearly half their monthly income. Eventually, the ambulance came and Nokwethemba gave birth within minutes of arriving at the hospital.

Nokwethemba said that transport problems added to the stresses of her pregnancy. There is no clinic in her community and the mobile clinic that visits once a month, when it is not raining, does not provide antenatal services. Nokwethemba's only option was to pay a bakkie driver for the uncomfortable two-hour journeys to and from the antenatal clinic, which cost her R80 that she could ill-afford. Nokwethemba attended the clinic for the first time when she was five months pregnant.

One day, when she was seven months pregnant, Nokwethemba had waited so long at the clinic that the last transport back to her village had gone, leaving her stranded:

"[B]y the time I left there was no transport so I had to hitchhike... it was already after 4.30pm. I was not feeling well because it is not good for a pregnant person to sit in one place for a long time, and having to walk again to go hitchhike that was painful... I got a van without a canopy and I was at the back with no shelter and I was hungry... I was not feeling well."

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*Nokwethemba gave us informed consent to use her real name.

6. SOUTH AFRICA'S HUMAN RIGHTS OBLIGATIONS

'Everyone has the right to have access to health care services, including reproductive health care.'

The Constitution of South Africa344

South Africa has ratified several international and regional human rights instruments that require the government to respect, protect and fulfil the rights of women and girls to health, equality and non-discrimination, as well as the full range of their sexual and reproductive rights. These include the International Covenant on Civil and Political Rights, ³⁴⁵ the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), ³⁴⁶ the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment, ³⁴⁷ and the Convention on the Rights of the Child. ³⁴⁸ South Africa has also signed the International Covenant on Economic, Social and Cultural Rights (ICESCR), but is yet to ratify it. ³⁴⁹ Nevertheless, having signed it, the government of South Africa is obliged to refrain from acts that would defeat the object and purpose of the ICESCR. ³⁵⁰

At the regional level, South Africa has ratified the African Charter on Human and Peoples' Rights, 351 the Maputo Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, 352 and the African Charter on the Rights and Welfare of the Child. 353

Under the Constitution of South Africa, an international agreement is binding once it has been ratified and approved.³⁵⁴ Furthermore, while interpreting any law, the Constitution asks courts to "prefer any reasonable interpretation of the legislation that is consistent with international law over any alternative interpretation that is inconsistent with international law".³⁵⁵ South Africa's Constitutional Court has used the ICESCR and the ICESCR Committee's general comments in this way in the past to interpret socio-economic rights under the Constitution.³⁵⁶ The Constitution also guarantees many aspects of women's and girls' right to health, and their right to equality and non-discrimination.

This report has discussed the right to privacy, the right to information and education, the right to access health care, and the right to equality and non-discrimination. These are all examples of sexual and reproductive rights – rights recognised across several international instruments that protect individuals' autonomy over their sexual and reproductive choices. They include an individual's right to make decisions about her or his own health, body,

sexual life and identity, ask for and receive information about sex, contraception and related health services, and have access to comprehensive and integrated sexual and reproductive health services. Respect for sexual and reproductive rights is essential for human dignity and for the enjoyment of physical, emotional, mental and social well-being. The government of South Africa must respect, protect and fulfil all sexual and reproductive rights without fear, coercion or discrimination.

THE RIGHT TO PRIVACY

Article 14 of the Constitution states that "Everyone has the right to privacy". In the context of health services, this includes the obligation to ensure that patient confidentiality is protected, information on health status is not disclosed to third parties without the consent of the individual, health personnel are trained to respect privacy rights, and women and girls are not subject to procedures or treatment without their full and informed consent. 357

THE RIGHT TO CONFIDENTIALITY

The ICESCR Committee has said: "All health facilities, goods and services must be... designed to respect confidentiality". This means that public health facilities that make it difficult or impossible to keep information about health status and treatment confidential potentially violate the right to health.

Other specific obligations include laws or regulations that ensure that advice concerning treatment is kept confidential, ³⁵⁹ ensuring that health care providers are trained to keep medical information confidential, ³⁶⁰ and ensuring that specific groups in the population – such as children and adolescents – are aware of these rights and able to enforce them. ³⁶¹

Where confidentiality is not guaranteed, the right to health is adversely impacted. Marginalized and under-served groups face additional barriers to accessing and adhering to necessary services and treatment. For example, the CEDAW Committee has said: "While lack of respect for the confidentiality of patients will affect both men and women, it may deter women from seeking advice and treatment and thereby adversely affect their health and wellbeing. Women will be less willing, for that reason, to seek medical care for diseases of the genital tract, for contraception or for incomplete abortion and in cases where they have suffered sexual or physical violence". Similarly, the Committee on the Rights of the Child has encouraged States to "respect strictly their right to privacy and confidentiality, including with respect to advice and counselling on health matters" in order to promote the health and development of adolescents.

In 2011, the CEDAW Committee asked South Africa to "Undertake awareness-raising campaigns throughout the State party and among Government personnel in respect of prevention, protection and maintenance of confidentiality".³⁶⁴ South Africa was due to report to the CEDAW Committee in 2013, but had not done so as of the completion of the writing of this report (September 2014).

THE RIGHT TO INFORMED CONSENT

Informed consent is the ability to make a voluntary and sufficiently informed decision, which protects the right of the patient to be involved in medical decision-making, and assigns duties and obligations to health-care providers. ³⁶⁵ Informed consent requires that information must be provided voluntarily, without coercion, undue influence or misrepresentation. It

mandates disclosure of the benefits, risks and alternatives associated with any offered medical procedure or treatment.³⁶⁶ States should take all measures to ensure that women and girls are able to give informed consent to procedures affecting them.³⁶⁷

In the context of HIV counselling and testing specifically, the World Health Organization (WHO) and UNAIDS have said that services must be voluntary, confidential, accompanied by counselling, and only be conducted with informed consent. Hike confidentiality, ensuring informed consent improves health outcomes, as it improves trust, understanding of one's condition and treatment, and supports the long-term adherence to treatment. In the context of the PICT model, the Special Rapporteur on the right to health has warned that "Compulsory, and, at times, routine testing is disempowering and frequently compromises human rights. Such testing is coercive and generally results in inadequate provision of information and counselling, compromising informed consent and deterring individuals from accessing test results and appropriate services." According to the Special Rapporteur, "those tested under provider-initiated testing and counselling, particularly when from marginalized groups, often feel compelled to accept. The scale-up of testing services without pre-test counselling has the potential to further marginalize these groups and thwart long-term prevention measures and need re-examination". 370

THE RIGHT TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH

The right to the highest attainable standard of physical and mental health is reflected in several international instruments that South Africa has signed and ratified, as well as South Africa's Constitution.³⁷¹

The ICESCR Committee has said that States must ensure that all health care facilities, goods and services are available, accessible, acceptable and of good quality.³⁷² The right to health also extends to the underlying determinants of health – socio-economic factors that have bearing on individuals' health status. These include safe food and potable drinking water, basic sanitation and adequate housing and living conditions.³⁷³

The ICESCR Committee has stated that the right to health imposes certain obligations, known as core obligations, which are immediate, non-derogable and with which a State cannot "under any circumstances whatsoever, justify its non-compliance". These include the obligation of States to ensure the right of access to health facilities, goods and services on a non-discriminatory basis; to ensure reproductive, maternal and child health care; and to provide appropriate training for health personnel, including education on health and human rights. The Committee has also stated that States have a duty to adopt a national strategy to ensure to all the enjoyment of the right to health.

The right to health is closely linked to the right to life, particularly in the context of preventable maternal mortality. Where States fail to put in place measures to prevent maternal deaths where possible, this violates women's right to life.³⁷⁷ With the acknowledgment that preventable maternal mortality and morbidity are serious human rights issues,³⁷⁸ the Office of the United Nations High Commissioner for Human Rights (OHCHR) has issued Technical Guidelines on the application of a human rights based approach to the implementation of policies and programmes to reduce preventable maternal mortality and morbidity. They provide guidelines on designing and implementing policies and programmes to reduce maternal mortality and morbidity in accordance with human rights standards.³⁷⁹

In 2001, South Africa signed the Abuja Declaration on HIV/AIDS, Tuberculosis, and other related infectious diseases, where governments committed to allocating at least 15% of their annual budget to the improvement of the health sector.³⁸⁰

Accessibility is a key aspect of the right to health. All health facilities, goods and services must be known to all and be physically, economically and socially acceptable to all, free from discrimination. They must be affordable for all individuals, ³⁸¹ and must be within safe physical reach for all sections of the population, especially marginalized groups. ³⁸² The OHCHR has said that out-of-pocket costs cannot impede accessibility of care, irrespective of whether services are provided by public or private facilities. ³⁸³ Accessibility also includes the right to seek, receive and impart information and ideas concerning health issues. ³⁸⁴

Under these international human rights standards, barriers faced by women and girls include any requirements or conditions that prejudice their access, such as distance from health facilities and the absence of convenient and affordable public transport.³⁸⁵ Many of these barriers have been documented in this report. The CEDAW Committee has asked States to report on what measures they have taken to ensure that women have timely and affordable access to health services, and recommended that States ensure the removal of all barriers to women's access to health services, education and information, including in the area of sexual and reproductive health.³⁸⁶ Similarly, the Committee on the Rights of the Child has encouraged States to take measures to "remove all barriers hindering the access of adolescents to information, preventive measures such as condoms, and care",³⁸⁷ including by prioritizing "the establishment of facilities and services in under-served areas" and "invest[ing] in mobile outreach approaches".³⁸⁸

THE RIGHT TO HEALTH-RELATED INFORMATION AND COMPREHENSIVE SEXUALITY EDUCATION

All individuals have the right to seek, receive and impart information and ideas concerning health issues. 389 The obligation to provide education and access to information concerning the main health problems in the community is a core, non-derogable obligation under the right to health. 390 The Maputo Protocol asks States to ensure "the right to have family planning education" 391 and "provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas". 392

Access to accurate and appropriate information is essential for women and girls to be able to make informed choices about their sexuality and reproduction, and to be able to prevent diseases and access health care services when necessary. The Special Rapporteur on the right to health has said: "Health information needs to be of the highest quality, freely available on a non-discriminatory basis, accessible to the individual's particular communication needs (including special physical or cultural circumstances), and presented in a manner culturally and otherwise acceptable to the person". 393

The right to health-related information includes State obligations to provide comprehensive sexuality education (CSE) to all children and adolescents, both in school and out of school.³⁹⁴ The lack of accurate, evidence-based and age-appropriate information about sexuality puts adolescents at greater risk of unplanned pregnancies, STIs and HIV, and coercive sexual activity and exploitation. The Committee on the Rights of the Child has said that States

"should provide adolescents with access to sexual and reproductive information, including on family planning and contraceptives, the dangers of early pregnancy, the prevention of HIV and the prevention and treatment of sexually transmitted diseases". 395 CSE curricula must be consistent with the International Technical Guidance on Sexuality Education. The government of South Africa has made several political commitments to provide CSE to all young people. 397

THE RIGHT TO CONTRACEPTIVE INFORMATION AND SERVICES

The right to contraceptive information and services is grounded in women's and girls' rights to equality and non-discrimination, life, privacy, health, to decide freely and responsibly on the number and spacing of their children, and information and education. According to the Maputo Protocol, States have an obligation to ensure that women and girls have the "right to control their fertility" and the "right to choose any method of contraception. The landmark Programme of Action of the International Conference on Population and Development recognized the right of all individuals to have access to safe, effective, affordable and acceptable methods of family planning of their choice. According to the Constitution of South Africa, the right to freedom and security of the person includes the right to make decisions concerning reproduction, which is linked to the ability to access contraceptive information and services.

The obligation to protect women's and girls' rights requires States to ensure that third parties do not limit access to any guaranteed rights. 402 A State can be responsible for violations of rights by third parties if it failed to act with due diligence to prevent these violations, or investigate and punish them. 403 The Special Rapporteur on the right to health has noted that States must "ensure that neither third parties nor harmful social or traditional practices interfere with access to prenatal and post-natal care and family-planning or curtail access to some or all contraceptive methods". 404

THE OBLIGATION TO TRAIN HEALTH WORKERS

One of the core obligations of the right to health is promotion of "appropriate training for health personnel, including education on health and human rights". States must also ensure that health workers meet appropriate standards of education, skill and ethical codes of conduct and that they are trained to recognize and respond to the specific needs of vulnerable or marginalized groups". Along similar lines, the Committee on the Rights of the Child has specifically recommended capacity development activities that "ensure that service providers work in a child-sensitive manner". This Committee has also encouraged States to adopt "adolescent-friendly health services which require health practitioners and facilities to be welcoming and sensitive to adolescents, to respect confidentiality and to deliver services that are acceptable to adolescents".

Health workers should also receive human rights education, including comprehensive, mandatory, gender-sensitive courses on women's health and human rights, in particular gender-based violence. The Special Rapporteur on the right to health has said: "At a minimum, all health professionals should receive education on the human rights of patients, including their right to health; the health-related human rights of vulnerable groups, such as women, children... More specialized human rights education should be provided to health professionals working in those situations most likely to generate human rights violations, or bring them into contact with evidence of abuses, including in... family planning services". 410

THE RIGHT TO EQUALITY AND NON-DISCRIMINATION

The right to equality and non-discrimination is included in several human rights instruments ratified by South Africa. In addition, the South African Constitution makes clear that the State and/or any person cannot "unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth".⁴¹¹

In the context of the right to health, the ICESCR Committee has said that the ICESCR "proscribes any discrimination in access to health care and underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status".⁴¹²

The right to equality and non-discrimination requires States to do more than refrain from discriminatory acts: where necessary, States must also devote "greater resources to traditionally neglected groups" and put in place measures that allow vulnerable or marginalized groups to access their rights and entitlements equally. This right also requires States to invest in addressing discriminatory attitudes, stereotypes and behaviours amongst populations as a way to address systemic discrimination.

Individuals are often subject to multiple and intersecting forms of discrimination, that is, discrimination based on multiple, prohibited grounds which combine to produce distinct disadvantages, such as discrimination based on gender and health status. States must be aware of the impact of multiple and intersecting discrimination on individuals and take particular steps to eliminate it.

THE RIGHT TO BE FREE OF GENDER-BASED DISCRIMINATION AND VIOLENCE

States have an obligation to end all forms of gender-based discrimination. Under CEDAW, States must take "all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning". States must ensure "appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation".

The CEDAW Committee has found that gender-based violence is a form of gender-based discrimination. Ale The Maputo Protocol requires States to enact and enforce laws to prohibit all forms of violence against women, take measures to prevent violence, punish the perpetrators of violence against women and implement programmes for the rehabilitation of women victims. In addition to prohibiting gender-based discrimination by the State and individuals, according to the Constitution of South Africa, the right to freedom and security of the person includes the right of all people to be free from all forms of violence from either public or private sources. Ale

The CEDAW Committee has acknowledged that socio-economic factors are important determinants of women's and girls' health, and "their subordinate position in some societies

make[s] them especially vulnerable to HIV infection". 420 The experience of different forms of gender-based discrimination, from unequal power relations at home, to the exposure to violence, gender stereotyping, and rights violations by third parties, all negatively impact women and girls' health. 421

It is necessary for States to ensure their health legislation and programming acknowledges and addresses these factors. 422

In 2011, the CEDAW Committee noted with serious concern the "high prevalence of sexual violence against women and girls and widespread domestic violence" in South Africa. ⁴²³ It asked South Africa to "Develop policies aimed at addressing multiple discrimination and violence against women, based on the intersection between violence and HIV/AIDS". ⁴²⁴ Similarly, in 2006, the Committee against Torture was concerned about the widespread violence against women and children in South Africa, and asked the government to "adopt all necessary measures to prevent, combat and punish violence against women and children... undertake research into the root causes of the high incidence of rape and sexual violence so that effective preventive measures can be developed; establish awareness-raising campaigns; investigate thoroughly those grave human rights violations; and work towards a 'no tolerance' policy". ⁴²⁵

THE RIGHTS OF ADOLESCENTS AND YOUNG PEOPLE

Adolescents and young people have specific needs and experiences associated with accessing health care, and "states should ensure that health systems and services are able to meet the specific sexual and reproductive health needs of adolescents, including family planning and safe abortion services". A26 States must ensure that health facilities, goods and services of appropriate quality and sensitive to adolescents' concerns are available to all adolescents, Including training people to care for adolescents, and requiring health practitioners and facilities to be welcoming and sensitive to adolescents. A29 The Committee on the Rights of the Child has urged States to develop prevention programmes, "including measures aimed at changing cultural views about adolescents' need for contraception and [Sexually Transmitted Disease] prevention and addressing cultural and other taboos surrounding adolescent sexuality". The Committee has also said that "Discrimination based on adolescent pregnancy... should be prohibited, and opportunities for continuous education should be ensured".

THE RIGHT NOT TO FACE DISCRIMINATION BASED ON HEALTH STATUS

The right to non-discrimination extends to discrimination based on health status. 432 States are obliged to ensure that people living with HIV are able to exercise all rights and entitlements on an equal footing. South Africa is signatory to the 2001 Declaration of Commitment on HIV/AIDS, 433 and has adopted the 2006 Declaration of Commitment on HIV/AIDS and the 2011 Political Declaration on HIV and AIDS. 435 Among other things, these contain commitments to "advancing human rights to reduce stigma, discrimination and violence related to HIV". 436

Addressing the HIV- and AIDS-related stigma is an important aspect of ensuring that all individuals have equal access to health care, irrespective of health status. Discriminatory attitudes, and fear of stigma, within communities, families and amongst health workers deter people living with HIV from accessing health services. The Special Rapporteur on the right to

health has said "stigma and discrimination serve as disincentives for such patients to seek out services and providers to treat patients equally". Stereotypes and social judgments around female sexuality, particularly for groups like young girls and unmarried women, also limit access to necessary HIV preventative services like condoms.

In the design of strategies to respond to HIV, States must address the impact of stigma, stereotyping, and judgmental attitudes on the right to equality and non-discrimination through education and training programmes explicitly designed to change attitudes of discrimination and stigmatization associated with HIV.

THE RIGHT TO REDRESS FOR VIOLATIONS OF RIGHTS

"Critically, rights and obligations demand accountability: unless supported by a system of accountability they can become no more than window dressing."

Special Rapporteur on the Right to Health⁴³⁷

To be effective, the right to health must be accompanied by transparent, effective, independent and accessible accountability mechanisms. Accountability mechanisms are necessary to understand whether the health system is able to respond to the needs of all groups and what changes and specific initiatives might be necessary. States should ensure that data is collected on the use and efficacy of health systems, and that this data is disaggregated on grounds of gender, age, region and other relevant factors. States should also put in place mechanisms for the monitoring, review and oversight of access to public health care, and ensure that information from reviews reaches relevant stakeholders and informs future planning and service delivery.

Furthermore, anyone whose right to health has been violated must have access to effective judicial or non-judicial remedies at national and international levels. Victims must also be entitled to adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition.⁴⁴⁰ Access to effective complaints and grievance redress mechanisms is crucial: in addition to holding rights' violators to account, it is the first step towards identifying and rectifying systemic problems.

7. CONCLUSIONS AND RECOMMENDATIONS

South Africa's rate of maternal mortality remains unacceptably high. In 2012, 60% of maternal deaths in South Africa were avoidable, and more than a third were linked to HIV. The government has been taking commendable steps towards improving this situation, including by putting in place policies which emphasise primary health care, improving access to antiretroviral therapy for pregnant women and girls living with HIV, and providing free antenatal care. However, barriers to early and ongoing antenatal care continue to hamper these efforts. The high rates of maternal deaths, and poor health outcomes for women and girls more generally, are linked to the widespread poverty, systemic gender-based discrimination, and structural problems with the health system in South Africa.

Access to early and ongoing antenatal care is crucial for the health of pregnant women and girls. It helps reduce the risk of preventable maternal death by detecting and treating existing health problems, and by screening for complications that may develop during pregnancy. It also reduces the risk of HIV transmission to the foetus. However, even though antenatal care is free in South Africa, in 2012 less than half of pregnant women and girls sought antenatal care before 20 weeks of pregnancy. This late access poses a significant threat to their health and lives.

In this context, this report has analysed three barriers that women and girls in South Africa face in accessing early and ongoing antenatal care: violations of the right to privacy and confidentiality; the need for more health information and education; and violations of the right to health as a consequence of persistent transport and cost barriers to accessing health facilities, particularly for marginalized communities.

The manner in which health care workers communicate information about the HIV testing process at antenatal clinics leads women and girls to believe that the process is mandatory. This consequence, in conjunction with the impact of HIV-related stigma, and the lack of psycho-social support services, can lead them to delay accessing antenatal care. The design of health facilities and certain clinic procedures and practices, including the handling of patients' files, mean that women's and girls' right to confidentiality regarding their HIV and pregnancy status is often compromised, further deterring visits to clinics for antenatal care.

Women and girls also told Amnesty International that they often have difficulty accessing information about contraception, HIV prevention, the importance of antenatal care, and pregnancy. Primary health care clinics were known to be sources of information, but they were seen as unacceptable and avoided. This was due in part to a lack of information and training among health care workers, which sometimes led to poor standards of care for pregnant women and girls.

Finally, persistent problems with the availability, reliability and affordability of transport to health care facilities, combined with poor road infrastructure, further contribute to women and girls (particularly those in rural areas) delaying or avoiding antenatal care. These delays

are exacerbated when they are forced to pay for private transport to reach health facilities during pregnancy and labour because of the lack of ambulances serving their communities.

The government of South Africa has an obligation to respect, protect and fulfil the human rights of women and girls to privacy and confidentiality, and to access to health information and education as well as health facilities and services without discrimination.

RECOMMENDATIONS

TO THE SOUTH AFRICAN GOVERNMENT

To strengthen South Africa's international human rights framework and compliance with its obligations, Amnesty International recommends, as a matter of priority, that the government:

■ Ratifies the International Covenant on Economic, Social and Cultural Rights, and the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights and opts in to the inquiry and inter-State mechanisms; and submits any overdue periodic reports to the CEDAW Committee, the Committee on the Rights of the Child, the UN Human Rights Committee as well as other treaty bodies, and implements any outstanding recommendations made by those bodies in the review of past reports.

Amnesty International also recommends that the government:

- In developing programmes to prevent maternal mortality and promote maternal health, pays particular attention to the need to develop, resource and implement programmes to address the underlying determinants of health that promote safe pregnancies and deliveries.
- Continues to encourage cooperation amongst different ministries within the government to ensure that women and girls access antenatal care early, and for such inter-ministerial forums to report specifically on inter-departmental plans to increase women's and girls' timely access to antenatal care. Ministries, including the Department of Health, Department of Basic Education, Department of Social Development and Department of Transport, should collaborate and cooperate to ensure that all health-related policies are designed and implemented in an efficient manner.
- Increases awareness about patients' rights, particularly the right to informed consent, amongst potential patients and health care workers. Measures should include ensuring this information is visible in all health facilities in all relevant languages, and is expressly included as a part of the pre-test counselling process in the *Guidelines for Maternity Care in South Africa 2007*.
- Ensures that everyone knows about their sexual and reproductive rights, and that men and boys support women and girls in realizing these rights. More specifically, the government should provide education related to sexual and reproductive rights, including the right to bodily autonomy, and support the ability of women and girls to negotiate safe sexual practices by strengthening awareness-raising and education targeted at women, girls, men and boys on access to condoms and safe, effective, affordable and acceptable family planning services, including the full range of contraceptive services.

- Ensures women's and girls' access to safe, effective, affordable and acceptable methods of family planning, including the full range of contraceptive services.
- Ensures that women and girls are able to access their right to education, including by ensuring that mechanisms and services are in place to make it possible for pregnant girls and young mothers to continue their education.
- Takes urgent steps to reduce the prevalence of gender-based violence, including by addressing the recommendation by the Committee against Torture to "adopt all necessary measures to prevent, combat and punish violence against women and children... undertake research into the root causes of the high incidence of rape and sexual violence... establish awareness-raising campaigns; [and] investigate thoroughly those grave human rights violations."

TO THE DEPARTMENT OF HEALTH

- Take urgent measures to reform all health system procedures that compromise patient confidentiality, such as the use of specific files for HIV treatment, separate queues and designated waiting areas for people living with HIV.
- Conduct an audit of all health facilities to assess how existing health system infrastructure and practices impact privacy and confidentiality. The audit should adequately consult, and ensure that all service-users, especially women and girls living in poverty and people living with HIV, are able to participate in its design and implementation.
- Collect disaggregated data on women's and girls' access to antenatal care and develop indicators and benchmarks to measure progress towards ensuring all women and girls have access to early and consistent antenatal care.
- Recognising the intensification of the Department of Health's commitment to increasing access to HIV testing and services, intensify efforts to encourage and facilitate partners to test alongside pregnant women and girls and encourage couples' counselling and, in addition to the provider-initiated counselling and testing offered to all women and girls during antenatal check-ups, continue to encourage men and boys to get tested for HIV as part of the scaling-up of HIV testing.
- Provide all health care workers with regular and ongoing training on privacy and confidentiality so they are able to respect patients' rights with particular attention to the ways in which the design of health facilities and specific practices followed by clinics can compromise these rights. This should include training on the human rights of patients, and training to be able to respond sensitively to the specific needs of marginalized groups.
- Develop, fund and implement programmes, including through radio, pamphlets and posters, to educate the population about the importance of early and continuous antenatal care and the associated health benefits. These programmes should be developed and implemented in a way that ensures the inclusion of marginalized communities.
- Raise awareness of and capacity for screening by health care workers for the risks of

violence, peri-natal depression and other manifestations of inequality and discrimination faced by pregnant women and girls, including providing ongoing professional training.

Amnesty International recognises that successful implementation of such a policy will rely on support from and collaboration with other government departments, and calls on the Department of Health to demonstrate leadership in ensuring this initiative succeeds.

- Ensure that all young people can access youth-friendly sexual and reproductive health information and services, with the full respect of their right to privacy and confidentiality.
- Urgently address the fact that infrastructural shortages in the health care system are resulting in barriers in accessing health facilities for women and girls, including by increasing the number of obstetric ambulances and mobile clinics conducting antenatal check-ups.
- Establish national standards on staffing norms, standards and training requirements for all cadres of health care workers.
- In collaboration with other government departments and partners, investigate and establish measures to ensure access to safe and affordable transport to antenatal care for pregnant women and girls.
- Establish and capacitate the Office of Health Standards Compliance and Ombudsperson and promote knowledge among patients regarding the complaints process and duty of the Ombudsperson.

TO THE NATIONAL DEPARTMENT OF TRANSPORT

■ Urgently address the lack of safe, reliable, affordable, convenient and adequate transport, particularly for marginalized communities at national, provincial and municipal levels, including through subsidized or free transport, patient grants to cover transport costs, improving road infrastructure, and improved transport options, working with other government departments and agencies as necessary.

TO THE DEPARTMENT OF BASIC EDUCATION

■ Ensure that all young people, both in school and out of school, can access age-appropriate, evidence-based comprehensive sexuality education. Curricula should be reviewed to ensure that they include information on family planning and contraceptives, the implications of early pregnancy for individuals' health and lives, the prevention of HIV and the prevention and treatment of sexually transmitted infections.

TO THE DEPARTMENT OF SOCIAL DEVELOPMENT

■ Consider extending the system of child support grants to include the period of pregnancy, to enable pregnant women and girls to cope with the increased financial pressure of pregnancy, such as possible financial abandonment and payment for transport to antenatal clinics and hospitals.

TO THE SOUTH AFRICAN HUMAN RIGHTS COMMISSION

- Ensure completion and publication of the Stigma Index in partnership with the South Africa National AIDS Council and increase efforts to strengthen the Commission's mandate to monitor human rights under the government's National Strategic Plan for HIV, STIs and TB.
- To investigate the impact of transport barriers to maternal health services for women and girls living in rural or disadvantaged communities in South Africa.

TO THE INTERNATIONAL COMMUNITY

Take steps, individually and through international assistance and cooperation, especially economic and technical assistance, towards the full realization of women's and girls' sexual and reproductive rights in South Africa. All assistance must be distributed in a nondiscriminatory manner, promote human rights and gender equality, and address the specific experiences of disadvantaged and marginalized groups.

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- ⁸² Indicated by the birth rate for girls aged under 18 who gave birth at a health facility, the national average is 8%, "the highest proportion of 2012/13 under-18 deliveries was in the Eastern Cape (EC) (10.3%) and the lowest in Gauteng Province (4.8%)." See also HST, District Health Barometer 2012/13, page 60.
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- ¹²⁵ Stats SA, Poverty Trends in South Africa (2014) found the number of people living below the food line increased to 15.8 million in 2009 from 12.6 million in 2006, before dropping to 10,2 million people in 2011.
- 126 NDoH Evaluation of the Effectiveness of the National PMTCT Programme (2012) found, nationally, 16.4% of households with a baby aged around six weeks old reported a depletion of food supply in the past 12 months.
- ¹²⁷ SAHRC, Report of the Public Hearing on the Right to Basic Education (2006). Also, Stats SA, Census 2011. The findings also indicate that women have always been more likely than men to have no education with a slight narrowing of the gap between these two groups towards 2011, page 38. Also, CEDAW 2011, para 31.
- ¹²⁸ Concluding comments to South Africa in 2011 of the CEDAW Committee, CEDAW/C/ZAF/CO/4 (CEDAW 2011), para 31.
- ¹²⁹ Health Budget Vote Speech by the Minister of Health, Dr Aaron Motsoaledi, MP, 23 July 2014. "We also know that keeping girl children at school at least until matric, protects them from pregnancy and HIV/AIDS acquisition," page 6; NSP HIV "Completing secondary schooling is protective against HIV, especially for young girls," page 26.
- ¹³⁰ Cluver et al (2014) noting: "Whereas more than half of adolescents received a child-focused cash transfer or school feeding, only 3.7% had received support from a school counsellor and around 8% from a teacher", page S394.
- ¹³¹ Data from the NDoH Evaluation of the Effectiveness of the National PMTCT Programme (2012) showed only 5.4% of mothers had completed secondary school, at page 14; Wabiri et al. (2013) found that within the context of pregnancy, educational attainment has been strongly linked to socio-economic status, with a recent study finding as many as 59.9% of all women [in the study] had not completed

secondary school but around half of [those in the wealthiest quintile] QIV had tertiary education, 20-fold more than in QI [the poorest]. Also, Stats-SA, GHS, 2006, quoted by CGE 2010, who note, "In 2006, 13.9% of young girls in the 13-19 years of age category were not in school because of pregnancy, and 38.6% of persons aged 7-24 years were not attending educational institutions because they had no money for fees," page 16.

132 CGE (2010).

- ¹³³ Gouws, (2013) Commissioner, South African Commission for Gender Equality; "Women predominate in positions that are insecure, low-paid and of inferior status and are more likely to be part-time or temporary workers. They are also more likely to be employed in the informal than the formal economy". See also CEDAW 2011, para 33, noting: "The Committee is however concerned about the persistence of discrimination against women in the labour market, in particular the high rate of unemployment (30%) affecting women, a wide gender wage gap, and occupational segregation." And further that there is no provision under South African law for remunerated maternity leave.
- ¹³⁴ Based on the results of Census 2011, the official unemployment rate among men was 25.6% while among women it was 34.6% (Figure 3.37). Based on the expanded definition, the unemployment rate among men was 34.2% while among women it was 46%, page 52. Furthermore, between races there is further disparity, as the Census 2011 results also show that the unemployment rate among black African women is 41.2% based on the official definition and 52.9% based on the expanded definition. In contrast, the unemployment rate among white women is 6.9% based on the official definition and 12.5% based on the expanded definition, page 55.
- ¹³⁵ Under the Domestic Violence Act 116 of 1998, "economic abuse" includes "unreasonable deprivation of economic or financial resources to which the victim is entitled under law or requires out of necessity at Section 1".
- 136 CGE, South Africa's Compliance with the Beijing Declaration and Platform for Action March, (2010), page 25.
- 137 A maximum amount of R,1350 per month,

http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/oldagegrant/en_ZA Accessed 14 August 2014.

¹³⁸ Child support grant and the foster care grant. The foster care grant is payable to children in care due to reasons of being "orphaned, abandoned, at risk, abused [and/or] neglected". Care-givers receive R830 per month;

http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/fosterchildgrant/en_Z A Accessed August 14th 2014.

- ¹³⁹ For a full list of the available social grants and conditions see: http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/en_ZA
- ¹⁴⁰ South Africa's social assistance system has expanded tremendously since 2000, growing from around 3 million grants to 15 million by 2011. Growth in grants has been primarily driven by the expansion of child support grants which increased from roughly 150,000 recipients in 2000 to over 10 million in 2011. See further Stats SA, Poverty Trends in South Africa, (2014), page 20.
- ¹⁴¹ If married, the combined income must be less than R69,600. http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/childsupportgrant/en_

- ZA Accessed 14 August 2014.
- 142 The grant is paid to the primary care giver who is living with a child wh0 is be under the age of 18 years,

http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/childsupportgrant/en_ZA Accessed 14 August 2014.

- 143 PLAAS (2009).
- ¹⁴⁴ Health Budget Vote Speech by the Minister of Health, Dr Aaron Motsoaledi, MP, 23 July 2014; Myers 2014. PLAAS (2009).
- 145 PLAAS (2009).
- ¹⁴⁶ NDoH NSP for HIV, TB and STI 2012-2016, page 23; NDoH Antenatal Sentinel HIV survey (2012).
- 147 HSRC (2014).
- ¹⁴⁸ NDoH Antenatal Sentinel HIV survey 2012, page 65.
- 149 HSRC 2014.
- 150 HSRC 2014.
- 151 NSP HIV 2012, page 22.
- ¹⁵² The antenatal prevalence in 2012 was 29.5%, NDoH Antenatal Sentinel HIV survey 2012.
- ¹⁵³ NDoH Antenatal Sentinel HIV survey 2012, page 79; Wabiri et al. (2013)
- 154 NSDA (2010), page 9.
- ¹⁵⁵ Jewkes et al. (2010). This study was conducted in rural Eastern Cape and found "that 13.9% of incident HIV infections could be avoided if gender equity in heterosexual relationships was enhanced so that no women were in relationships with low power." Also, Dunkel et al (2004) found, that "11.9% of new HIV infections could be prevented if women did not experience more than one episode of physical or sexual partner violence"; Jewkes et al. (2010), page 46.
- ¹⁵⁶ HIV AIDS and STI Strategic Plan for South Africa 2007-2010, Pretoria, 2007 (NSP HIV 2007), page 32, quoted in Amnesty International (2008), page 52.
- 157 HSRC 2014, page xxxiv.
- 158 HSRC 2014.
- ¹⁵⁹ NSP HIV 2012-16. Also, see NDoH Antenatal Sentinel HIV survey 2012 in relation to MDG 6A: "The findings of monitoring trends in this age group in South Africa show that efforts to achieve the UN MDG target must be significantly strengthened", page 25.
- 160 NSP HIV 2012-16, pages 22 and 35-36, acknowledges the impact of existing gender roles, norms and inequality and of sexual violence against women on driving the transmission of HIV.
- ¹⁶¹ NSP 2012-16, page 32.
- ¹⁶² Amnesty International (2008).
- ¹⁶³ Seedat et al. (2009); Jewkes et al (2010).

- ¹⁶⁴ MRC (2009).
- ¹⁶⁵ MRC (2009). These failures have also been documented by Amnesty International (2008), page 19, citing Jewkes et al 2002 who estimate the actual number of rapes to be nine times higher than the number of reported offences; Seedat et al. 2009.
- ¹⁶⁶ Shamu et al. (2011), page 2.
- ¹⁶⁷ Dunkle et al. 2004, page 1586.
- ¹⁶⁸ Gibbs et al. (2012) at page 11; Shamu et. al. 2011, page 6-7.
- ¹⁶⁹ SAPMTCTE 2012.
- ¹⁷⁰ NSP HIV 2012-16.
- ¹⁷¹ Zuch and Lurie 2012, noting the link between disfigurement and death; see also P Henderson, A Kinship of Bones, 2013, who describes the isolation and suffering of people ill with HIV and AIDS in rural KwaZulu-Natal before the availability of antiretroviral treatment.
- ¹⁷² Prudden et al (2012). The NCCEMD 5th Comprehensive Report for 2008-10 at page 184; Turan et al. (2012), page 9; NDoH 2014 Joint review of HIV TB PMTCT, page 49.
- ¹⁷³ NDoH Antenatal Sentinel HIV survey 2012, page ii.
- 174 National Association of People Living with HIV and AIDS 'Human Rights Count, South Africa, Eastern Cape Assessment 2011 (NAPWA 2011), page 28; Justice Yvonne Mokgoro (2003).
- ¹⁷⁵ The human rights legal framework is reviewed in Chapter 6.
- ¹⁷⁶ NAPWA 2011.
- ¹⁷⁷ NSP HIV 2012-16, page 36, noting; "The departments in the security cluster must play a role in monitoring the impact of stigma, together with the South African Human Rights Commission".
- ¹⁷⁸ SANAC have only recently announced the commencement of the Stigma Index Research; June 2014, See further http://sanac.org.za/news/item/144-programme-review-committee. Last accessed 27 August 2014.
- 179 NAPWA 2011 found abuses were most often committed by "immediate family members", page 6. Also, Kehler et al (2013).
- ¹⁸⁰ NAPWA (2011).
- ¹⁸¹ Zuch and Lurie (2012).
- ¹⁸² Prudden et al (2012); The NCCEMD 5th Comprehensive Report for 2008-10, page 184.
- ¹⁸³ CRC, General Comment No. 3, HIV/AIDS and the rights of the child, CRC/GC/2003/1 paras 22–24; SR Report on informed consent; CEDAW, General Recommendation No. 24, para 22.
- ¹⁸⁴ As of 2012, 42 countries in Africa (including South Africa) have implemented the PICT Model for HIV testing.

- ¹⁸⁵ WHO, UNAIDS Statement on HIV testing and counselling (2012).
- ¹⁸⁶ WHO, Guidance on provider-initiated HIV testing and counselling in health facilities, (2007),

(Hereafter WHO PICT Guidance, (2007), page 36.

- ¹⁸⁷ WHO PICT Guidance, (2007).
- ¹⁸⁸ WHO PICT Guidance, (2007), page 12.
- ¹⁸⁹ WHO PICT Guidance, (2007), page 17.
- 190 WHO PICT Guidance, (2007), page 36.
- ¹⁹¹ NDSA, page 21.
- ¹⁹² NDSA, page 21; Department of Health, *HIV counselling and testing policy guidelines 2010*; HIV Counselling and Testing of Pregnant Women for the PMTCT Programme, page 41; HIV Testing Algorithm page 23; Action Framework on eliminating mother to child transmission entitled, *No child born with HIV by 2015 and improving the health and wellbeing of mothers, and babies in South Africa*.
- ¹⁹³ NDoH Annual Performance Plan2012/13-2014/15, page 33.
- ¹⁹⁴ This is also the case in several other countries. For example, only about half the African countries with the PICT model in place have recommended universal coverage of routine HIV testing. This means that in about half the countries which have PICT model in place, the testing is offered within select services (including antenatal care) and women are more likely to test than men because they visit clinics more often for reasons of pregnancy. This is confirmed by UNAIDS, who have said, "In all regions, women are more likely to have been tested than men, most likely due to the implementation of the routine offer of HIV testing in antenatal settings." Page 52. UNICEF also found this to be the case in many countries in eastern and South Africa, see UNICEF Getting to Zero (2013), page 46.
- ¹⁹⁵ HSRC (2014), page 116.
- ¹⁹⁶ WHO, UNAIDS Statement on HIV testing and counselling (2012).
- ¹⁹⁷ WHO, UNAIDS Statement on HIV testing and counselling (2012).
- ¹⁹⁸ NDoH PMTCT Guidelines 2013, pages 17 to 23.
- ¹⁹⁹ NDoH PMTCT Guidelines 2013, page 15.
- ²⁰⁰ NDoH PMTCT Guidelines 2013, page 15.
- ²⁰¹ Focus group discussion, May 2014, KwaZulu-Natal.
- ²⁰² Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁰³ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁰⁴ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁰⁵ Focus group discussion, October 2013, KwaZulu-Natal.
- $^{\rm 206}$ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁰⁷ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁰⁸ Interview with HIV counsellor, July 2014, KwaZulu-Natal.
- ²⁰⁹ Interview with a nurse, July 2014, KwaZulu-Natal.

- ²¹⁰ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²¹¹ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²¹² Interview with HIV counsellor, July 2014, Mpumalanga.
- ²¹³ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²¹⁴ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²¹⁵ Interview with HIV counsellor, July 2014, KwaZulu-Natal.
- ²¹⁶ Interview with HIV counsellors, July 2014, KwaZulu-Natal.
- ²¹⁷ Republic of South Africa Department of Health, Annual Health Statistics 2012, available at http://www.hst.org.za/sites/default/files/AnnualHealthStatistics2012_Aug2013.pdf, page 49.
- ²¹⁸ Interview with HIV counsellor, July 2014, KwaZulu-Natal.
- ²¹⁹ Focus group discussion, May 2014, Mpumalanga.
- ²²⁰ Amnesty International interview, January 2014, KwaZulu-Natal.
- ²²¹ Weiser et al. (2006).
- ²²² Njeru et al. (2011), found that women in rural districts in Kenya did not perceive PICT, offered as a part of antenatal care, to be a voluntary process.
- ²²³ Angotti et al. (2011).
- ²²⁴ Larsson et al. (2012), pages 69-75.
- ²²⁵ Republic of South Africa Department of Health, Guidelines for Maternity Care in South Africa 2007 (Hereinafter "Guidelines for Maternity Care 2007").
- ²²⁶ This should include information on the current pregnancy; previous pregnancies, any complications and outcomes; medical conditions, including psychiatric problems, and previous operations; familial and genetic disorders; allergies; use of medications; use of alcohol, tobacco and other substances; and family and social circumstances. See Guidelines for Maternity Care 2007, page 20.
- ²²⁷ This should include weight, height, heart rate, colour of mucous membranes, blood pressure, a check for oedema, and palpation for lymph nodes. See Guidelines for Maternity Care 2007, page 20.
- 228 See Guidelines for Maternity Care 2007, page 26.
- ²²⁹ See Guidelines for Maternity Care 2007, page 28.
- ²³⁰ Interview with a doctor working for an NGO, October 2013, KwaZulu-Natal.
- ²³¹ SANAC Trust Annual Performance Plan, 2014/2015.
- $^{\rm 232}$ Focus group discussion, October 2013, KwaZulu-Natal.
- ²³³ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²³⁴ NDoH Joint Review of HIV, TB and PMTCT Programmes in South Africa" April 2014, page 69. This review also noted that stigma remained a reason why patients would travel to clinics that were not the closest to them, finding that "Due to stigma, clinics treat many patients who do not come from the

facility catchment area".

- ²³⁵ Interview with HIV Counsellor, July 2014, KwaZulu-Natal.
- 236 The 2012 general household survey found that 0.9% of the population did not use the health facility closest to them, page 15.
- ²³⁷ Focus group discussion, November 2013, KwaZulu-Natal.
- ²³⁸ UNAIDS & WHO, *Violence Against Women and HIV/AIDS: Critical Intersections*, Information Bulletin Series, Number 1, page 4.
- ²³⁹ UNICEF (2013), page 71.
- ²⁴⁰ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁴¹ Focus group discussion, May 2014, KwaZulu-Natal.
- ²⁴² Focus group discussion, May 2014, Mpumalanga.
- ²⁴³ Focus group discussion, May 2014, Mpumalanga.
- ²⁴⁴ Focus group discussion, 2013, KwaZulu-Natal.
- ²⁴⁵ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁴⁶ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁴⁷ NDoH Joint Review of HIV, TB and PMTCT (2014), page 69.
- ²⁴⁸ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁴⁹ Interview with HIV counsellor, July 2014, KwaZulu-Natal.
- ²⁵⁰ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁵¹ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁵² Interview with HIV counsellor, July 2014, Mpumalanga.
- ²⁵³ Interview with HIV counsellor, July 2014, KwaZulu-Natal.
- ²⁵⁴ Interview with Amnesty International, August 2014, Gauteng.
- ²⁵⁵ Interview with KwaZulu-Natal Department of Health officials, September 2014.
- ²⁵⁶ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁵⁷ SAHRC (2013).
- ²⁵⁸ Interview with a nurse, July 2014, Mpumalanga.
- ²⁵⁹ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁶⁰ Interview with a nurse, July 2014, KwaZulu-Natal.
- $^{\rm 261}$ Interview with a nurse, July 2014, KwaZulu-Natal.
- ²⁶² Focus group discussion, October 2013, KwaZulu-Natal
- ²⁶³ Interview with a nurse, July 2014, Mpumalanga.

- ²⁶⁴ Focus group discussion, 14 July 2014, Mpumalanga.
- ²⁶⁵ Focus group discussion, 14 July 2014, Mpumalanga.
- ²⁶⁶ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁶⁷ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁶⁸ Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁶⁹ Amnesty International interview, July 2014, Mpumalanga.
- ²⁷⁰ Focus group discussion, November 2013, KwaZulu-Natal.
- ²⁷¹ Focus group discussion, November 2013 KwaZulu-Natal.
- ²⁷² Focus group discussion, November 2013 KwaZulu-Natal.
- ²⁷³ Focus group discussion, July 2014, Mpumalanga.
- ²⁷⁴ Interview with HIV counsellor, July 2014, KwaZulu-Natal.
- ²⁷⁵ CESCR General Comment 14, para 12.
- ²⁷⁶ CESCR General Comment 14, para 43.
- ²⁷⁷ Article 14 (1) (g), Maputo Protocol.
- ²⁷⁸ Article 14 (2) (a) Maputo Protocol.
- ²⁷⁹ CRC/GC/2003/4, para 26; International Conference on Population and Development (ICPD) in 1994 underlines the importance of sexuality education "both in and out of school" as part of the basic life skills that all young people require, cited in the UNESCO 2013 Summary, page 8.
- ²⁸⁰ UNESCO summary, noting that "The African Commission-led Maputo Plan of Action (2006) and Maseru Declaration on the Fight Against HIV/AIDS in the SADC Region (2003)" frame access to information in the context of a rights based argument. The Global Consultation on Education in the post-2015 debate has identified reproductive health as an important right and demonstrated linkages with education achievement and sexual and reproductive health status. The report highlighted the importance of CSE's contribution to the prevention of unintended pregnancy, violence and abuse, and gender-based violence." Page 8. In reporting on access to CSE in Southern and Eastern Africa, UNESCO (2012) highlighted the need to stop the "artificial divide" between "the health and education needs of adolescents and young people" noting these are often treated as "mutually exclusive issues". UNESCO defines "quality education" as including "teaching and learning, and learning outcomes in sexuality education." UNESCO also recognises the importance of school education to support the development of cognitive and other skills needed for the transition to adulthood. A review of the implementation of CSE in Southern and Eastern Africa by UNESCO, UNICEF and UNFPA (2011) found the implementation of CSE in South Africa had 'moderate to serious' gaps in a number of key areas.

- ²⁸¹ Amnesty International interview, April 2014, KwaZulu-Natal.
- ²⁸² Interview with NGO coordinator, April 2014, KwaZulu-Natal.
- ²⁸³ Interview with newly qualified antenatal nurse, July 2014, KwaZulu-Natal.
- ²⁸⁴ Interview with antenatal care nurse, July 2014, KwaZulu-Natal.

- http://www.sanews.gov.za/south-africa/momconnect-link-mothers-vital-healthcare; Health Minister Dr Aaron Motsoaledi launches MomConnect for pregnant mothers: http://www.health.gov.za/mini.php (Accessed September 2014).
- ²⁸⁶ Myers 2014; Wood, K. & Jewkes R. (2006); Ehlers, (2003).
- ²⁸⁷ http://pmhp.za.org/images/websiteMedia/documents/Materials/WCG_MaternityBooklet.pdf
- ²⁸⁸ HST District Health Barometer; Focus on Maternal Mortality, page 34, citing Burton (2013).
- ²⁸⁹ HST District Health Barometer 2012, page 97.
- ²⁹⁰ Interview with professional nurse, July 2014, KwaZulu-Natal.
- ²⁹¹ Interview with professional nurse, July 2014, KwaZulu-Natal.
- ²⁹² Focus group discussion, October 2013, KwaZulu-Natal.
- ²⁹³ Myers (2014); Crede et al (2012).
- ²⁹⁴ NCCEMD 5th Comprehensive Report 2008-10, page 96.
- ²⁹⁵ NCCEMD 5th Comprehensive Report 2008-10, page 96.
- ²⁹⁶ HSRC (2014), page xxxviii.
- ²⁹⁷ NDoH, NEWSLETTER OF THE HIV, TB AND MNCWH CLUSTER, No. 1 August 2013.
- ²⁹⁸ NDoH Evaluation of PMTCT (2012), page 15.
- ²⁹⁹ Wabiri et al. (2013).
- 300 NDoH 2014 Joint review of HIV TB PMTCT.
- 301 Orner at al (2010).
- ³⁰² Crede et al (2012), page 5; MacCarthy et al (2012), pages 121-123.
- ³⁰³ Orner et al (2011), page 8.
- 304 Cooper et al (2009); Orner et al (2011), Ramkissoon et al (2006); Orner et al (2010).
- ³⁰⁵ Myers 2014; Moult 2013. See also the UNAIDS Guidance that advises Strategic Plans on HIV to include "programmes that address women's and girls' inequality in sexual and reproductive decision-making; gender barriers to health services; discrimination in inheritance, property-holding, marriage, divorce and custody; sexual and other violence; lack of equal access to educational and economic opportunity; and lack of support to care-givers in HIV-affected households. Such programmes should be complemented by programmes targeting men and boys which address harmful gender norms that make women and girls, as well as men and boys, vulnerable to HIV infection."
- 306 Moult 2013.
- ³⁰⁷ Meeting with Senior Official from National Department of Health, 22 September 2014.
- 308 Interview with HIV Counselling Coordinator, July 2014, Mpumalanga.

- ³⁰⁹ Meeting with Senior Official from National Department of Health, 22 September 2014.
- 310 Wood & Jewkes, (2006).

- 312 Amnesty International interview, April 2014, KwaZulu-Natal.
- ³¹³ UNESCO note that, "Training service providers (e.g. nurses, doctors and community health workers) in issues related to adolescents and maintaining overall quality standards on confidentiality in mainstream services will be key to scaling up and maintaining adolescent and youth-friendly services." Page 37.
- ³¹⁴ Amnesty International interview, October 2013, KwaZulu-Natal.
- 315 Interview with antenatal care nurse, July 2014, KwaZulu-Natal.
- ³¹⁶ Interview with antenatal nurse, July 2014, KwaZulu-Natal.
- ³¹⁷ Recent studies in urban and rural contexts of poverty in South Africa found prevalence rates of perinatal depression as high as 47%. See further, Rochat, et al. (2011); The Perinatal Mental Health Project (PMHP) estimate one third of their patients suffer from perinatal depression and that prevalence rates are at almost 40% in South Africa, http://www.pmhp.za.org/about (Accessed June 2013).
- ³¹⁸ Children's Institute, South African Child Gauge 2013, Summary accessed http://www.ci.org.za/depts/ci/pubs/pdf/ciinthenews/press releases/2013/Press%20release%20-%20SA%20Child%20Gauge%202013.pdf
- ³¹⁹ Meeting with senior officials from Mpumalanga Department of Health, 15 September 2014.
- 320 Interview with nurse, July 2014, Mpumalanga.
- ³²¹ Launched in February 2014 under a new National Family Planning Campaign.
- 322 CESCR General Comment 14, para 12.
- 323 CESCR General Comment 14, para 12.
- 324 Article 2 (a), Maputo Protocol.
- 325 CEDAW Committee, General Recommendation 24, para 27.
- ³²⁶ The 2012 General Household Survey in South Africa found that 46.9% of people interviewed reported walking to the health facility they visited the most popular mode of transport for reaching clinics. For 39.9% of these people, the walk was between 15 and 29 minutes each way; for 16.5% it was between 30 and 89 minutes. See Statistics South Africa, General Household Survey 2012, page 143, available at http://www.statssa.gov.za/publications/P0318/P0318August2012.pdf

- ³²⁷ Interview with Amnesty International, January 2014, KwaZulu-Natal.
- 328 Interview with Amnesty International, January 2014, KwaZulu-Natal.
- ³²⁹ NDoH National Health Care Facilities Baseline Audit 2012, page 12.
- 330 Interview with nurse, July 2014, Mpumalanga.
- 331 NDoH National Health Care Facilities Baseline Audit 2012, page 12.
- ³³² Interview with Amnesty International, January 2014, KwaZulu-Natal.
- ³³³ Focus group discussion, October 2013, KwaZulu-Natal.

- 334 Interview with Amnesty International, April 2014, KwaZulu-Natal.
- 335 Focus group discussion, May 2014, Mpumalanga.
- ³³⁶ Focus group discussion, October 2013, KwaZulu-Natal.
- ³³⁷ Focus group discussion, October 2013, KwaZulu-Natal.
- 338 Meeting with Amnesty International, September 2014.
- 339 Interview with a nurse, July 2014, KwaZulu-Natal.
- 340 Focus group discussion, October 2013, KwaZulu-Natal.
- 341 Focus group discussion, May 2014, Mpumalanga.
- ³⁴² Focus group discussion, October 2013, KwaZulu-Natal.
- ³⁴³ See Amnesty International (2008), available at http://www.amnesty.org/en/library/info/AFR53/001/2008/en; Submission to the SANAC Secretariat on Draft Zero of the National Strategic Plan for HIV and AIDS, STIs and TB, 2012-2016 (NSP) From Amnesty International (including Amnesty International-South Africa), 7 September 2011.
- ³⁴⁴ Article 27 (a), Constitution of South Africa.
- ³⁴⁵ Signed on 3 October 1994, and ratified on 10 December 1998. See https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-4&chapter=4&lang=en
- ³⁴⁶ Signed on 29 January 1993, and ratified on 15 December 1995. See https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-8&chapter=4&lang=en
- ³⁴⁷ Signed on 29 January 1993, and ratified on 10 December 1998. See https://treaties.un.org/Pages/ViewDetails.aspx?mtdsg_no=IV-9&chapter=4&lang=en
- ³⁴⁸ Signed on 29 January 1993, and ratified on 16 June 1995. See https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-11&chapter=4&lang=en
- ³⁴⁹ Signed on 3 October 1994. See https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-3&chapter=4&lang=en
- ³⁵⁰ Article 18, Vienna Convention on the Law of Treaties. There has been no definition of what actions would violate the 'object and purpose' of the ICESCR. In its General Comment 24, the Human Rights Committee discussed this question in the context of reservations to the ICCPR. According to the Vienna Convention on the Law of Treaties, states cannot make reservations which are incompatible with the object and purpose of a treaty. The Committee said that reservations against peremptory norms (e.g. the prohibition against torture) would violate the object and purpose of the ICCPR. It also said that "While there is no automatic correlation between reservations to non-derogable provisions, and reservations which offend against the object and purpose of the Covenant, a State has a heavy onus to justify such a reservation", implying a close relationship between non-derogable provisions and the object and purpose of a treaty. As this chapter will discuss, the "core obligations" under each economic, social and cultural right, including the right to health, are considered non-derogable. See http://www1.umn.edu/humanrts/gencomm/hrcom24.htm
- 351 Signed and ratified on 9 July 1996, see http://www.achpr.org/instruments/achpr/ratification/
- ³⁵² Signed on 16 March 2004, and ratified on 17 December 2004. See http://www.achpr.org/instruments/women-protocol/ratification/

- ³⁵³ Signed on 10 October 1997, and ratified on 7 January 2000. See http://acerwc.org/the-african-charter-on-the-rights-and-welfare-of-the-child-acrwc/ratifications/
- 354 Article 231, Constitution of the Republic of South Africa Act.
- ³⁵⁵ Article 233, Constitution of the Republic of South Africa Act.
- ³⁵⁶ Minister of Health and Others v Treatment Action Campaign and Others (No 2) (CCT8/02) [2002] ZACC 15; Government of the Republic of South Africa and Others vs. Grootboom 2001 (1) SA 46 (CC). In the T.A.C. case in 2002, the Constitutional Court held that the concept of minimum core obligations, as developed by the CESCR Committee in its general comments, could be used to interpret the understanding of what was "reasonable" under certain provisions of the Constitution.
- 357 Article 4 (1), Maputo Protocol.
- 358 CESCR, General Comment 14, para 12 (c).
- ³⁵⁹ CRC, General Comment No. 4 para 33. Also see OHCHR and UNAIDS, International Guidelines on HIV/AIDS and Human Rights, 2006 available at http://www.ohchr.org/Documents/Publications/HIVAIDSGuidelinesen.pdf.
- ³⁶⁰ CRC, General Comment No. 4, para 33.
- ³⁶¹ See the section on accountability below.
- ³⁶² CEDAW Committee, General Recommendation 24, para 12 (d).
- ³⁶³ CRC, General Comment No. 4, para 11.
- ³⁶⁴ Concluding observations of the Committee on the Elimination of Discrimination against Women: South Africa, CEDAW/C/ZAF/CO/4, 2011, para 36 (e).
- ³⁶⁵ SR Report on informed consent, para 9.
- ³⁶⁶ SR Report on informed consent, para 15.
- ³⁶⁷ CRC, General Comment no. 3, paras 22-24.
- 368 http://www.who.int/hiv/pub/vct/en/hivtestingpolicy04.pdf?ua=1
- ³⁶⁹ SR Report on informed consent, para 27.
- ³⁷⁰ SR Report on informed consent, para 33.
- ³⁷¹ Articles 27 and 28 (c), Constitution of South Africa.
- ³⁷² CESCR General Comment 14, para 12.
- ³⁷³ CECR General Comment 14, para 11.
- ³⁷⁴ CESCR, General Comment 14, para 47.
- $^{\rm 375}$ CESCR, General Comment 14, paras 43 and 44.
- ³⁷⁶ CESCR, General Comment 14, para 53. According to the Committee, the strategy must be based "on human rights principles which define the objectives of that strategy, and the formulation of policies and corresponding right to health indicators and benchmarks. The national health strategy should also identify the resources available to attain defined objectives, as well as the most cost-effective way of

using those resources".

- ³⁷⁷ For example, the UN Human Rights Committee has asked states to provide information on "pregnancy and childbirth-related deaths of women" while reporting on article 6 (right to life) of the ICCPR. Human Rights Committee, General Comment 28, Equality of rights between men and women (article 3), U.N. Doc. CCPR/C/21/Rev.1/Add.10 (2000).
- ³⁷⁸ See, for example, Human Rights Council Resolution "Preventable maternal mortality and morbidity and human rights" A/HRC/11/L.16/Rev.1, 16 June 2009; Human Rights Council Resolution "Preventable maternal mortality and morbidity and human rights: follow-up to Council resolution 11/8" A/HRC/15/L.27, 27 September 2010.
- ³⁷⁹ Report of the Office of the United Nations High Commissioner for Human Rights, Technical Guidelines on the application of a human rights based approach to the implementation of policies and programs to reduce preventable maternal mortality and morbidity, A/HRC/21/22, dated 2 July 2012. [hereinafter "Technical Guidance"].
- ³⁸⁰ Abuja Declaration on http://www.un.org/ga/aids/pdf/abuja_declaration.pdf, available at http://www.un.org/ga/aids/pdf/abuja_declaration.pdf.
- 381 CESCR, General Comment 14, para 12.
- 382 CESCR, General Comment 14, para 12.
- 383 Para 46, Technical Guidance.
- 384 CESCR, General Comment 14, para 12.
- 385 CEDAW Committee, General Recommendation 24, para 21.
- ³⁸⁶ CEDAW Committee, General Recommendation 24, para 21. The CEDAW Committee also gave a landmark decision in communication number 17/2008, in the case of Alyne da Silva Pimentel Teixeira v. Brazil, who died of complications resulting from pregnancy. The Committee observed that Brazil had violated its obligations under CEDAW. It asked the government to, amongst other things, (i) ensure women's right to safe motherhood and affordable access for all women to adequate emergence obstetric care; (ii) access to effective remedies where reproductive rights are violated; and (iii) provide adequate professional training for health workers, including on women's reproductive rights.
- ³⁸⁷ CRC, General Comment 4, para 30.
- ³⁸⁸ CRC, General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health, CRC/C/GC/15, 17 April 2013, para 114.
- 389 CESCR General Comment 14, para 12.
- ³⁹⁰ CESCR General Comment 14, para 43.
- ³⁹¹ Article 14 (1) (g), Maputo Protocol.
- 392 Article 14 (2) (a) Maputo Protocol.
- 393 SR Report on Informed Consent, para 23.

- 394 CRC/, General Comment 4, para 26
- ³⁹⁵ CRC, General Comment 4, para 28.

- ³⁹⁶ UNESCO, International Technical Guidance on Sexuality Education, available at http://www.unfpa.org/webdav/site/global/groups/youth/public/International Guidance Sexuality Education_Vol_I.pdf. CSE programs must include information about reproduction, pregnancy and childbirth, contraception, HIV and STI prevention, gender-based violence and non-discrimination and equality; and the skills to enforce these rights and manage relationships, while addressing cultural attitudes and taboos regarding adolescent sexuality and keeping in mind informed consent and the evolving capacity of the child.
- ³⁹⁷ Ministerial Commitment on comprehensive sexuality education and sexual and reproductive health services for adolescents and young people in Eastern and Southern African (ESA), 7 December 2013, available at

 ${\color{blue} \underline{http://www.unesco.org/new/fileadmin/MULTIMEDIA/HQ/HIVAIDS/pdf/ESACommitmentFINALAffirmedon7} \\ {\color{blue} \underline{thDecember.pdf.}}$

- ³⁹⁸ Article 16 (1) (e), CEDAW.
- ³⁹⁹ Article 14, Constitution of South Africa.
- ⁴⁰⁰ See the Report of the International Conference on Population and Development, 1994, chapter VII on reproductive rights and reproductive health, available at http://www.unfpa.org/webdav/site/global/shared/documents/publications/2004/icpd_eng.pdf.
- ⁴⁰¹ Article 12 (2) (a), Constitution of South Africa.
- 402 In the context of the right to health, the ICESCR Committee has said that "States should also ensure that third parties do not limit people's access to health-related information and services". CESCR, General Comment 14, para 35.
- 403 CEDAW Committee, General Recommendation No. 19 (IIth session, 1992) on Violence against Women, para 9.
- ⁴⁰⁴ Interim report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/66/254, 3 August 2011, available at http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N11/443/58/PDF/N1144358.pdf?OpenElement, at para 55.
- ⁴⁰⁵ CESCR, General Comment 14, para 44 (e).
- ⁴⁰⁶ CESCR, General Comment 14, para 35.
- ⁴⁰⁷ CRC, General Comment 15, para 27.
- ⁴⁰⁸ CRC, General Comment 15, para 52.
- ⁴⁰⁹ CEDAW Committee, General Recommendation 24, para 31 (f).
- ⁴¹⁰ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health on Health professionals and human rights education, A/60/348, 12 September 2005, para 15.
- ⁴¹¹ Article 9 (3), Constitution of South Africa.
- ⁴¹² CESCR, General Comment 14, para 18.
- ⁴¹³ CESCR, General Comment 20, Non-discrimination in economic, social and cultural rights (art. 2,

para. 2, of the International Covenant on Economic, Social and Cultural Rights), para 39.

- 414 Article 12 (1), CEDAW.
- 415 Article 12 (2), CEDAW.
- ⁴¹⁶ CEDAW Committee, General Recommendation 19.
- ⁴¹⁷ Article 4 (2), Maputo Protocol.
- ⁴¹⁸ See article 9 (3) and 9 (4), Constitution of South Africa.
- ⁴¹⁹ Article 12 (c), Constitution of South Africa.
- ⁴²⁰ CEDAW Committee, General Recommendation No. 15 (ninth session, 1990), Avoidance of discrimination against women in national strategies for the prevention and control of acquired immunodeficiency syndrome (AIDS).
- ⁴²¹ CEDAW Committee, General Recommendation 24, para 12 (b).
- ⁴²² For examples, see WHO and UNAIDS, "16 Ideas for addressing violence against women in the context of the HIV epidemic" available at

http://apps.who.int/iris/bitstream/10665/95156/1/9789241506533_eng.pdf; UN Women, "Effective Approaches to Addressing the Intersection of Violence against Women and HIV/AIDS" available at http://www.unwomen.org/~/media/Headquarters/Attachments/Sections/Trust%20Funds/UNTrustFundEVA W/UNTF_2012_VAW-and-HIV.pdf

- ⁴²³ Concluding observations of the Committee on the Elimination of Discrimination against Women: South Africa, CEDAW/C/ZAF/CO/4, 2011, para 24.
- ⁴²⁴ Concluding observations of the Committee on the Elimination of Discrimination against Women: South Africa, CEDAW/C/ZAF/CO/4, 2011, para 36 (d).
- ⁴²⁵ Conclusions and recommendations of the Committee against Torture: South Africa, CAT/C/ZAF/CO/1, 7 December 2006, para 23.
- 426 CRC, General Comment 15, para 56.
- 427 CRC, General Comment No. 4, para 39 (c).
- ⁴²⁸ CRC, General Comment No. 4, para 41 (d).
- 429 CRC, General Comment 15, para 52.
- ⁴³⁰ CRC, General Comment No. 4, para 30.
- ⁴³¹ CRC, General Comment 15, para 56.
- ⁴³² The South African Constitution recognises the right to equality and non-discrimination, but does not expressly include health status as a ground of discrimination. Nevertheless, in case law, the constitutional court has found that discrimination based on HIV status violates the right to equality guaranteed by section 9 of the Constitution. See, for example, Hoffmann v South African Airways (CCT17/00) [2000] ZACC 17.
- 433 http://www.unaids.org/en/media/unaids/contentassets/dataimport/publications/ircpub03/aidsdeclaration_en.pdf

- ⁴³⁴ Political Declaration on HIV/AIDS, A/RES/60/262, 15 June 2006 http://data.unaids.org/pub/report/2006/20060615_hlm_politicaldeclaration_ares60262_en.pdf
- 435 Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS, A/RES/65/277, 8 July 2011,

 $http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_UN_A-RES-65-277_en.pdf$

⁴³⁶ See paras 77-85, Political Declaration on HIV and AIDS: Intensifying Our Efforts to Eliminate HIV and AIDS, A/RES/65/277, 8 July 2011,

 $http://www.unaids.org/en/media/unaids/contentassets/documents/document/2011/06/20110610_un_arres-65-277_en.pdf$

- ⁴³⁷ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/63/263, 11 August 2008, available at http://www.who.int/medicines/areas/human_rights/A63_263.pdf, para 8.
- ⁴³⁸ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, A/63/263, 11 August 2008, available at http://www.who.int/medicines/areas/human_rights/A63_263.pdf, Para 73.
- ⁴³⁹ See, for example, CEDAW Committee, General Recommendation 24, para 9; CRC, General Comment 4, para 13.

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⁴⁴⁰ CESCR, General Comment 14, para 59.



WHETHER IN A HIGH-PROFILE CONFLICT
OR A FORGOTTEN CORNER OF THE
GLOBE, **AMNESTY INTERNATIONAL**CAMPAIGNS FOR JUSTICE, FREEDOM
AND DIGNITY FOR ALL AND SEEKS TO
GALVANIZE PUBLIC SUPPORT TO BUILD
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STRUGGLE FOR MATERNAL HEALTH

BARRIERS TO ANTENATAL CARE IN SOUTH AFRICA

Access to antenatal care early in pregnancy is vital to protect the health and lives of women and girls. In South Africa, however, even though such care is free, many women and girls do not attend clinics until the later stages of their pregnancy. This has grave consequences for their health, and can be fatal in a country where around a third of pregnant women are living with HIV and three-quarters are living in poverty.

This report is based on 18 months' research focusing largely on KwaZulu-Natal and Mpumalanga, provinces with particularly high maternal mortality rates. It looks at three barriers that make women and girls delay or avoid antenatal care — lack of privacy, patient confidentiality and informed consent at clinics, particularly in relation to HIV testing; lack of information about sexual and reproductive health and rights; and persistent problems associated with the availability and costs of transport.

The report calls on the South African authorities to implement a series of recommended actions to remove these barriers, so that women and girls can access their right to health.

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