POSITIVE HEALTH, DIGNITY AND PREVENTION IN SOUTH AFRICA:

FINDINGS AND RECOMMENDATIONS FROM STUDIES LED BY PEOPLE LIVING WITH HIV

NAPWA SOUTH AFRICA

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

UKaid from the British people

Acronyms

ARASA	AIDS and Rights Alliance for Southern Africa
ART	Antiretroviral therapy
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CSO	Civil Society Organization
DfID	UK government Department for International Development
ECAC	Eastern Cape AIDS Council
ECPCC	Eastern Cape Provincial Council of Churches
EPOC	Ekurhuleni Pride Organizing Committee
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
HIV	Human Immunodeficiency Virus
HTL	House of Traditional Leaders
ICW	International Community of Women Living with HIV/AIDS
IPPF	International Planned Parenthood Federation
LGBT	Lesbian, gay, bisexual and transgender
MSM	Men who have sex with men
NAPWA	National Association of People Living with AIDS
NAPWA-SA	National Association of People Living with AIDS, South Africa
NGO	Non-Governmental Organization
OR	Oliver Reginald (as in OR Tambo region)
PLHIV	People living with HIV
PMTCT	Prevention of Mother-To-Child Transmission (also referred to as PVT)
RULIV	Rural Urban Livelihoods
SRH	Sexual Reproductive Health
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

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Overview

South Africa has the largest economy in Africa and is ranked as an upper-middle income economy by the World Bank. At the end of apartheid in 1994, nine new provinces were created. The provinces are in turn divided into 52 districts: 8 metropolitan and 44 district municipalities. The district municipalities are further subdivided into 226 local municipalities. The powers of provincial governments include such fields as health, education, public housing and transport.

By purchasing power parity, South Africa has the 5th highest per capita income in Africa and is considered a newly industrialised country. However, about a quarter of the population is unemployed. Poverty and inequality remains one of the major challenges facing South Africa. While there has been a decline in poverty over time, inequality remains very high. Adult life expectancy is 57 years and data indicates that the maternal mortality ratio in South Africa is high, and increasing.[1]

The epidemic

South African society continues to be seriously affected by HIV, together with its related diseases, especially tuberculosis. South Africa currently ranks the third highest in the world in terms of the TB burden, and the incidence has increased at alarming rates in the past decade. There have been signs of a steady decline in the HIV infection rate but South Africa continues to have the highest number of people who are living with HIV in the world, with an estimated 5.7 million people living with HIV.[2] The 2012 *Country Progress Report*[3] highlights the progress made and challenges remaining in the current response:

Progress: New policies to increase universal access to free antiretroviral therapy (ART) were introduced in 2009. These interventions focus on all pregnant women who are living with HIV, all infants born to mothers who are HIV-positive, all persons with CD4 of less or equal to 350 CD4 Cells/mm3 and all persons with TB who are co-infected with HIV. The number of persons who started ART in 2010 and 2011 has more than doubled. The national HIV counselling and testing campaign reached about 13 million people against the target of 15 million by June 2011. Data also shows a reduction in HIV-related mortality particularly among women. In addition, mother to child transmission of HIV has declined from 8.5% in 2008, to 3.5% in 2010, a direct impact of the accelerated programme to end vertical transmission.

Challenges: Progress with paediatric treatment rollout was slower in 2010/11 than in the previous year. There needs to be an increased priority given to prevention efforts. Spending on prevention in South Africa actually decreased in 2009/10 by 8%. There is also a need to expand the HIV response beyond the health sector.

A major challenge for the national programme is to provide effective services and a protective environment to key populations. According to the 2012 Country Progress report, changes in definition of 'most-at-risk populations' (MARPS) have led to inadequate reporting on indicators related to sex workers, injecting drug users (IDUs), and to a lesser extent men who have sex with men (MSM). Apart from specialised MSM health services in three metropolitan areas, no national MSM programming exists and none of the National Strategic Plan (NSP) targets relating to MSM have been reached. The decriminalisation of sex work, and sex worker targets were not achieved during the NSP 2007-2011 period, despite their specific recommendations. Programmes for supporting people who use drugs, including IDUs, are limited and most are provided through the private sector. South African health facilities do not provide access to clean needles and syringes, and discrimination by health care workers and fear of arrest prevent people who use drugs from accessing health services, leading to needle reuse and needle sharing.

[1] Fifth edition of the Development Indicators, March 2012, www.thepresidency-dpme.gov.za
[2] UNAIDS (2008) Epidemiological Fact Sheet on HIV and AIDS, Core Data on epidemiology and response, South Africa
[3] Global AIDS Response, Progress Report 2012, Republic Of South Africa

National Policy and Legal environment

Human rights

Post-apartheid South Africa has one of the most comprehensive bills of rights in the world, entrenched in the Constitution of the country.[4] It includes an unqualified right to life. South Africa has a number of laws and policies that ensure that people living with HIV are protected, including within the labour market. There are no laws that restrict entry, stay or residence in the country for HIV positive non-nationals. In addition, sexual orientation is expressly mentioned as a ground upon which discrimination is forbidden. However, these protective laws and policies are not adequately promoted and enforced with the result that many people experience discrimination and or abuse on account of, amongst other things, their sexual orientation and/or HIV status.

The *Criminalisation Scan*[5] study explored three of the areas of law that are the subject of public scrutiny and debate:

- Lack of criminal sanctions for intentional or negligent transmission of HIV;
- Legal prohibition against sex work and;
- Negative societal attitudes and low enforcement rates against hate crimes perpetrated against people of the same sex.

The study found that South Africa has not enacted specific laws that criminalise HIV non-disclosure, exposure or transmission; nor can other criminal laws be used to initiate a prosecution. Whether or not people living with HIV should be criminalized for transmitting HIV has been a subject of vigorous debate; involving amongst others high ranking politicians, judges and academics.[6]

Same sex sexual relations are legal in South Africa. The 1996, Constitution outlawed unfair discrimination; with sexual orientation[7] being one of the many explicitly named protected grounds. However, there have been many reported cases of discrimination, and torture of people on the basis of perceived or real engagement in same sex sexual relations.[8]

Selling or buying of sex is illegal in South Africa,[9] regardless of whether it is amongst consenting adults. As it is illegal to sell or buy sex, people who engage in this work are subject to exploitation and abuse, sometimes perpetrated by law enforcement officials.

Unless prescribed for medicinal use, it is illegal to use, carry and deal in narcotic substances.[10] However, injecting drug use is growing within South African communities.[11] Adult HIV prevalence amongst people who use drugs is estimated at 12.4%.[12]

[4] Chapter 2: Constitution of South Africa (1996). Found at www.info.gov.za/documents/constitution/
[5] Global Criminalisation Scan, South Africa: Country Assessment 2011, NAPWA, March 2012
[6] See, for example: http://www.politicsweb.co.za/politicsweb/view/politicsweb/en/page71619?oid=141446&sn=Detail. Accessed on 20 /11/2011
[7] Chapter 2: Section 9 (3) The state may not 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
[8] See for example: Vasu Reddy, Cheryl-Ann Potgieter, and Nonhlanhla Mkhize, "Cloud over the rainbow nation: 'corrective rape' and other hate crimes against black lesbians", *HSRC Review*, 5(1) (March 2007): 10–11
[9] Section 20(1A)(a) of the Sexual Offences Act, 23 of 1957 and Section 11 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act of 2007
[10] Drugs and Drug trafficking Act, no. 140 of 1992. South Africa
[11] Plüddemann A, Parry CDH. *The Nature and Extend of Heroin Use In Cape Town: Part 2 - A community survey*. Medical Research Council; Cape Town: 2004.
[12] http://www.ihra.net/sub-saharan-africa

The constitution, as the highest law in the country, was adopted to heal the divisions of the past and establish a society based on fundamental human rights listed in the Bill of Rights. The South African Human Rights Commission (SAHRC) was inaugurated on 2 October 1995 as provided for by the South African Constitution Act 200 of 1993. The SAHRC has a mandate to develop human rights awareness amongst South African citizens, to make recommendations to improve the respect of human rights, to report to parliament on all matters related to human rights, to investigate all human rights violations, and to seek appropriate relief. The SAHRC works with government, civil society and individuals, both internationally and within the country, to act as a watchdog and a route through which people can access their rights.

However, despite this strong legal framework protecting the rights of all people in South Africa, effective strategies to address the human rights violations experienced by people living with HIV on account of their HIV-positive status are yet to be developed. The research conducted for *Human Rights Count*[13] study found that people living with HIV are still subject to serious forms of stigma and discrimination. They are at risk of losing their jobs or not being offered jobs, being ostracised by their families, friends, workmates and communities, and suffering various forms of ill treatment including discrimination, harassment and physical abuse.

Rights, laws and policies – knowing and effecting change

- The AIDS Charter on Rights and Responsibilities[14] was known to nearly one quarter of respondents.
- During the previous 12 months, over 10% of respondents reported that they were subjected to one or more discriminatory practices by governmental, legal, and/or medical institutions.
- Of 99 respondents who experienced a rights violation 18% had tried to get legal redress. The most common reason cited for not seeking legal redress was feeling intimidated or scared to take action.
- Nearly 20% of respondents reported having confronted, challenged or educated someone who was stigmatising and/or discriminating against her or him.
- Nearly half of respondents reported having provided some form of support to other people living with HIV in the previous 12 months.
- While 98% of respondents felt able to influence policies, laws and programmes at either national or local levels, around 15% had actually been involved in efforts to develop HIV-related legislation, policies or guidelines.

Source: PLHIV Stigma Index [15]

Economic and Social rights

As well as the Constitution which prohibits discrimination, and guarantees fair labour practices,[16] the Employment Equity Act,[17] prevents employees and job seekers from being discriminated against because of a disability or HIV status.

> ***Chapter 2 - Prohibition of Unfair Discrimination***
> ***2.1*** *No person may unfairly discriminate, directly or indirectly, against an employee in any employment policy or practice, on one or more grounds including race, gender, pregnancy,*

[13] Human Rights Count South Africa, Eastern Cape Assessment 2011, NAPWA, November 2011
[14] The charter is accessible at http://www.aidsconsortium.org.za/About.htm#charter. The charter of itself has no legal force though it has been adopted as a guiding principle by many organisations responding to HIV in South Africa.see note 28 for further information.
[15] PLHIV Stigma Index, South Africa: OR Tambo Region Assessment 2012, NAPWA, August 2012
[16] The Constitution of the Republic of South Africa Act, No 108, 1996. Chapter 2, sec 23(1)
[17] Employment Equity Act, 55 of 1998

marital status, family responsibility, ethnic or social origin, colour, sexual orientation, age, disability, religion, HIV status, conscience, belief, political opinion, culture, language, and birth.

Additionally, HIV testing is prohibited unless a labour court deems it justifiable.[18] The Labour Relations Act (LRA) prevents employees from being discriminated against on the grounds of having a disability (the definition of disability include HIV infection). This protection has been invoked to prevent dismissal on the basis of HIV status.[19] The South African Labour Court also held that HIV-positive employees did not have to disclose their status to prospective employers

Employers are responsible for ensuring that their employees are not at risk of HIV-infection at work. The act places a duty on employers to take all reasonable steps to ensure that the work place is safe and that employees are sufficiently trained to avoid risks.[20] Employees have a right to compensation if they contract HIV in a workplace accident.[21]

Women and other key populations

Since the end of Apartheid and the adoption of the Constitution, more than 30 items of legislation have changed to guarantee freedom from discrimination by the State or legal and natural persons, on the grounds of sexual orientation. Changes include:[22]

- Protection for gay people and lesbians in the workplace;
- Prohibiting the registration of political parties which advocate hatred and violence on the basis of sexual orientation;
- Recognition of families led by a same-sex couple;
- Protection of children of families led by a same-sex couple;
- Allowing same-sex spouses to register for medical benefits
- Prohibition of discrimination for same sex couple when securing accommodation; and
- Elimination of death duties for same-sex spouses.

However, despite this protection in the law, there have been many reported cases of discrimination, and torture of people on the basis of perceived or real engagement in same sex sexual relations.[23]

Initial studies have confirmed high HIV prevalence among key populations in South Africa and several socio-economic factors, including poverty and marginalisation, are associated with increased vulnerability to HIV among these populations. To date, no national programmes exist within the South African HIV response to address HIV prevention, treatment, care and support the needs of key populations.[24]

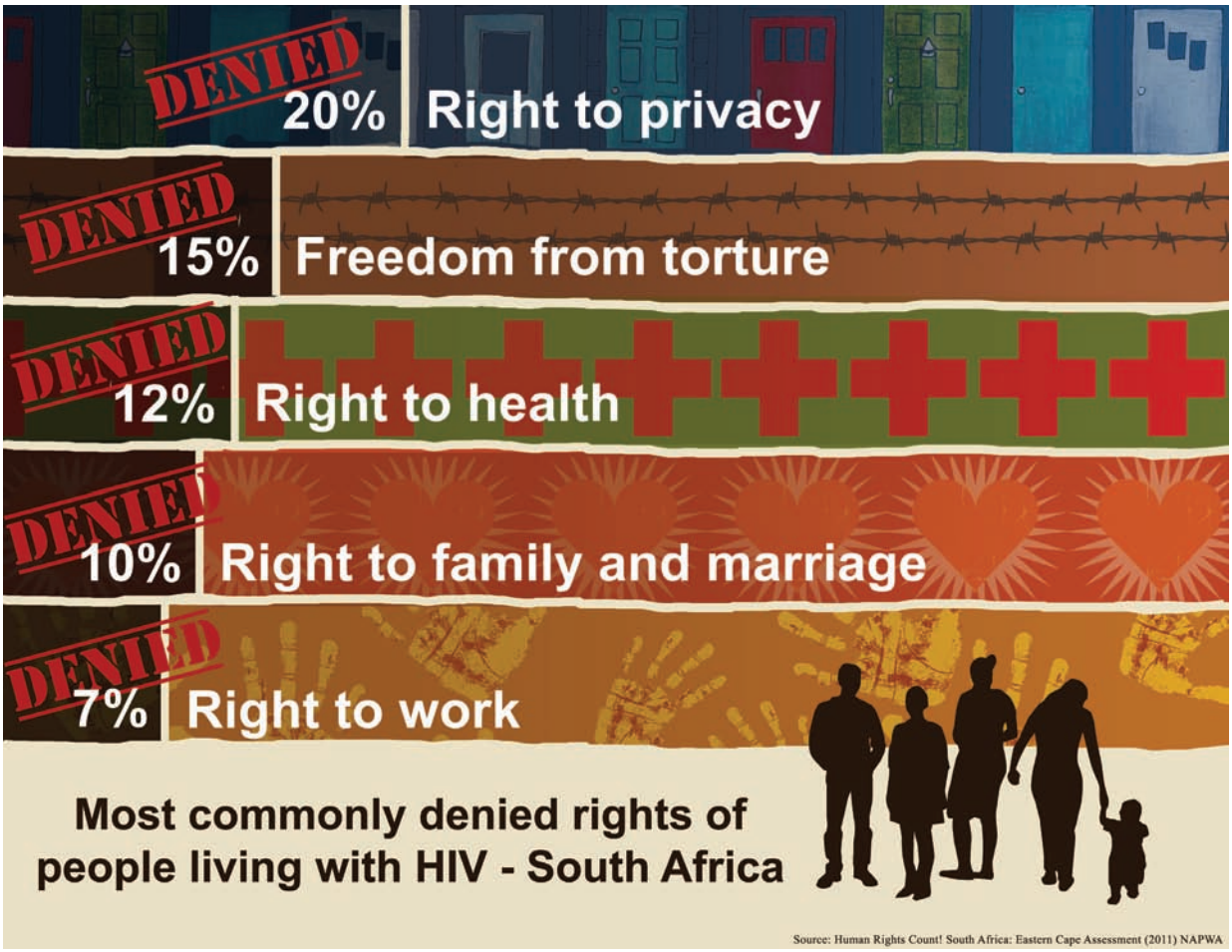
[18] Employment Equity Act, 55 of 1998. 2 (2.3)
[19] In 2008, in the case of S.A Security Forces Union vs Surgeon General AO, the High Court ruled against the South African National Defense Force's discriminatory policy of excluding HIV-positive persons from recruitment, external deployment and promotion in the military.
[20] The Occupational Health and Safety Act, No. 181 Of 1993 and Mine Health and Safety Act
[21] Compensation for Occupational Injuries and Diseases Act (COIDA)
[22] "Lesbian and Gay Equality in South Africa: What has been achieved?," The Lesbian and Gay Equality Project, 2004-AUG-22 at: http://www.equality.org.za/
[23] See for example: Vasu Reddy, Cheryl-Ann Potgieter, and Nonhlanhla Mkhize, "Cloud over the rainbow nation: 'corrective rape' and other hate crimes against black lesbians", *HSRC Review*, 5(1) (March 2007): 10–11
[24] Key populations, Key responses, Desmond Tutu HIV Foundation, October 2011

Human rights

Violations and discrimination

In the Human Rights Count study carried out in Eastern Cape in 2011, most respondents were female, and three quarters knew they were HIV-positive. Half the respondents had attained secondary school education, and only a small proportion had no formal education. At the time they experienced a human rights violation, the majority of respondents were unemployed.

Graphic 1



Physical abuse, ranging from being raped, beaten, stabbed or even murdered, was the most commonly experienced type of abuse. Family members like parents, spouses or their own children abused most of the victims of physical violence. In fact, immediate family members in general most commonly committed human rights violations. The next largest groups violating rights of people living with HIV were reported to be community members and health care providers. Respondents described several cases where health care workers refused to give treatment by not giving out the necessary medication or by turning clients away.

The violations had various negative impacts on the respondents; they frequently mentioned experiencing psychological, social, physical, and — to a lesser extent — economic impacts. The majority of the respondents (65%) felt that they were treated this way because of their HIV-positive status Less than a third of the respondents reported the violations to the relevant state authorities, either because they did not know that they could report, they did not know who to report to, they were afraid, or they did

not think it would make a difference. While some people said that the perpetrators were arrested, very little concrete actions were taken in most cases.

When asked whether they thought there were government policies or laws to prevent violations against people living with HIV, over half the respondents did not know.

Stigma and exclusion

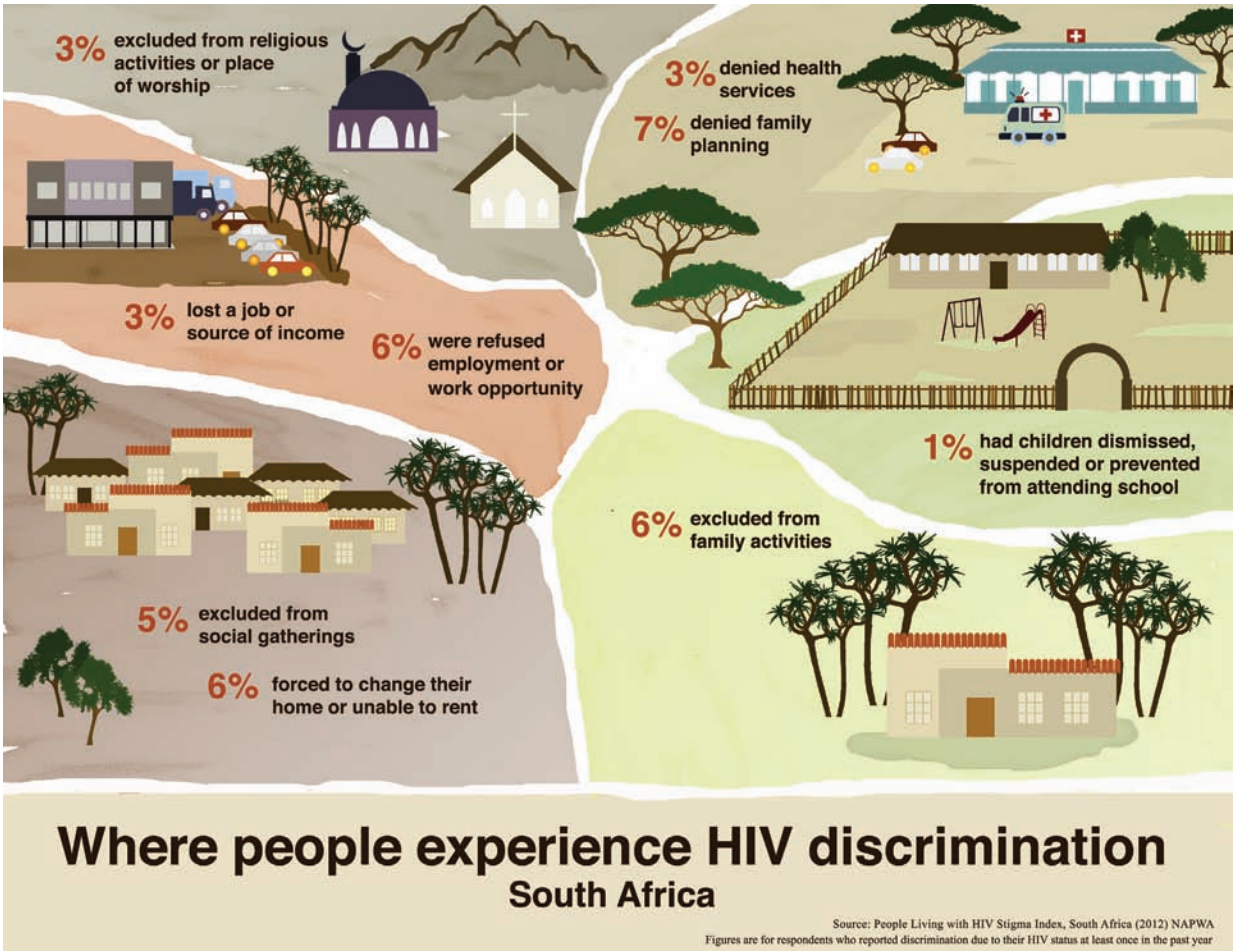
The *PLHIV Stigma Index* found strong evidence of internalised stigma: Over one third of respondents blamed themselves and over a quarter felt ashamed. **Nearly 10% of respondents (9.6%, n=76) reported feeling suicidal.** Levels of internalised stigma were higher among male than female respondents. For example, 42.9% of male respondents compared to 31.1% of female respondents reported blaming themselves, and 12.7% of male respondents compared to 8.9% of female respondents felt suicidal.

The most frequent decisions made by respondents during the last 12 months because of their HIV status were not to have more children (41.6%), not to attend social gathering(s) (18.9%), not to marry (16.1%); and to isolate themselves from friends and relatives (12.8%)

Overall, 45.4% of respondents feared being gossiped about and nearly 20% of respondents indicated that they were scared someone would not want to be sexually intimate with them because of their HIV-positive status with higher levels reported by male than female respondents (27.4%, compared to 15.3%).

Social exclusion is known to exacerbate and compound existing inequalities and inequities.[25] See graphic below mapping the experiences of exclusion reported by the respondents.

Graphic 2



[25] Social exclusion as been defined by Department of International Development (DFID) "a process by which certain groups are systematically disadvantaged because they are discriminated against on the basis of their ethnicity, race, religion, sexual orientation, caste, descent, gender, age, disability, HIV status, migrant status or where they live.

Women's rights

In the *Human Rights Count!* study, females represented 74% of the people who reported their rights being violated. Women have always been vulnerable in society and HIV has further exacerbated this.

One respondent noted that:

> **"I was badly beaten by my boyfriend. Saying that I slept with a person with AIDS, he beat me on the road, he hurt me in the head. I was admitted to hospital because he beat me with a stick".**

Another was blamed by her mother-in-law for the death of her son.

> **"My mother-in-law said that her son, my husband, was killed by AIDS as I am suffering from it and she told everyone in the community. She said that I was not going to get my husband's money and does not even eat the food that I cook because she is afraid of AIDS."**

Another respondent noted that:

> **"The people at my house do not like me and do not want me to play with their children because I am HIV-positive. They say that if their children do not listen, they will end up like me because I did not take care of myself hence I am dying of AIDS. I do not have any more friends and the whole village knows my status without me telling them."**

Key populations

Research for the *Criminalisation Scan* found that despite the protection in the law, bullying and harassing of gay people and lesbians is still very common in the community. In particular, there has been an increase in reported incidents of lesbians who have been gang-raped, beaten and in a few cases murdered[26] on account of their sexuality. Cases of 'corrective' rape against women who are identified as being lesbians are on the increase[27] especially in the townships. In April 2011, Noxolo Nogwaza was raped by eight men and murdered in KwaThema township near Johannesburg. According to Luleki Sizwe,[28] a charity which helps women who have been raped in the Western Cape, more than 10 lesbians per week are raped or gang-raped in Cape Town alone. Many of the cases are not reported because the victims are afraid that the police will laugh at them, or that their attackers will come after them. Human rights activists are lobbying the government to take action against the perpetrators of these attacks (termed corrective rape).

In March 2011, the Triangle Project together with Rape Crisis Cape Town presented a memorandum at a meeting hosted by the Ministry of Justice and Constitutional Development. The focus of the meeting was on the 'Corrective Rape' of lesbian women. The memorandum was endorsed by a number of organisations and activists across South Africa. The Memorandum called on the Justice Ministry to implement immediate and concrete measures to improve the way in which the criminal justice system handles violent crimes against lesbian, gay, bisexual, transgendered and intersex (LGBTI) people.

[26] Kelly, Annie (12 March 2009). "Raped and killed for being a lesbian: South Africa ignores 'corrective' attacks". The Guardian. http://www.guardian.co.uk/world/2009/mar/12/eudy-simelane-corrective-rape-south-africa. Retrieved 2012-02-23
[27] http://www.actionaid.org.uk/101756/hate_crimes_the_rise_of_corrective_rape_in_south_africa.html
[28] http://www.change.org/groups/luleki_sizwe

Commercial sex work is a significant driver of the epidemic in South Africa, with an estimated 19.8 percent of all new HIV infections relating to sex work in 2010.[29] Sex workers are often exposed to other factors that, such as injecting drug use, poverty and gender based violence, which increase their vulnerability to HIV infection.[30]

In the run up to the 2010 FIFA World Cup, sex work received a great amount of attention; it was feared that the international sporting event would increase demand for paid sex. However, a study funded by the United Nations Population Fund (UNFPA) and implemented by the Sex Work Education and Advocacy Taskforce (SWEAT) found that demand and supply of sex work remained constant across the World Cup period. The study data did not support fears of an increase of children or foreign migrant sex workers into the sex industry during the World Cup period. It did, however, conclude that police contact with sex workers remained high and included police brutality, corruption and harassment.[31] As it is illegal to sell or buy sex, people who engage in this work are subject to exploitation and abuse, sometimes perpetrated by law enforcement officials.

In South Africa, SWEAT has been in the fore front in calling for the decriminalisation of sex work; arguing that this would give sex workers an opportunity to better protect themselves against abuse, violence and other health threats. The organisation works with sex workers on health and human rights issues.[32]

It is illegal to use, carry and deal in narcotic substances.[33] However, injecting drug use is growing within South African communities.[34] Harm Reduction International (HRI) estimates that there are nearly a quarter of a million people who inject drugs in South Africa.[35] Adult HIV prevalence amongst people who use drugs is estimated at 12.4%.[36] Injecting drug use could lead to a further increase in HIV prevalence if necessary measures to curb the practice are not taken into consideration.

Double discrimination

Respondents in the *PLHIV Stigma Index* were requested to elaborate upon the reasons for the discrimination they experienced in instances in which it was not because of their HIV status. Of the 258 respondents who experienced stigma and/or discrimination for reasons other than their HIV status, 33 (12.8%) indicated that the main reasons was their sexual orientation, 26 stated it was because they were a migrant worker (10.1%) and 21 because they were a sex worker (8.1%). Other reasons included being a member of an indigenous group (5.8%, n= 15), an ex-prisoner (3.5%, n=9), refugee or asylum seeker (3.5%, n=9), internally displaced person (1.9% n =5), or person who uses drugs/injecting drug user (1.2%, n=3). More than half of these respondents (53.1%, n=137) cited reasons other than those presented in the questionnaire.

Empowerment of people living with HIV – the GIPA Report Card

National HIV and AIDS Strategic Plan

Respondents in the *GIPA Report Card*[37] study differed as to whether the principle of the Greater Involvement of People Living with HIV (GIPA) principle was included in the National AIDS Plan and whether studies had been carried out on the GIPA principle in South Africa. Most respondents, however, agreed that people living with HIV played a meaningful role in the development of the National AIDS Plan.

[29] http://www.sanac.org.za
[30] Rispel L C. Et al (2001) *Transactional Sex among women in Soweto, South Africa, prevalence, risk factors and association with HIV infection*. Social Science and Medicine 59 (8)
[31] Marlise Richter, Matthew Chersich, Dudu Ndlovu, Gerrit Maritz, Marleen Temmerman & Sisonke Johannesburg, Rustenburg & Cape Town "Maybe it will be better once this World Cup has passed" http://www.migration.org.za/sites/default/files/sweat_report.pdf
[32] http://www.kit.nl/net/KIT_Publicaties_output/ShowFile2.aspx?e=1280
[33] Drugs and Drug trafficking Act, no. 140 of 1992. South Africa.
[34] Plüddemann A, Parry CDH. *The Nature and Extend of Heroin Use In Cape Town: Part 2 - A community survey.* Medical Research Council; Cape Town: 2004.
[35] http://www.ihra.net/sub-saharan-africa. Accessed on 20/03/2012
[36] http://www.ihra.net/sub-saharan-africa
[37] GIPA Report Card, South Africa Country Assessment 2012, February 2012

GIPA at State and Provincial Levels

None of the respondents strongly agreed with the statement that the GIPA principle had been adequately implemented into state or provincial level HIV planning. Seventeen respondents agreed that people living with HIV had been meaningfully involved in developing state or provincial level HIV policy and none of the respondents disagreed with this statement. Most participants mentioned that there is involvement but noted a lack of coordination when it comes to planning and policy development. One participant also observed that the spheres of government were not complementing each other.

United Nations General Assembly Special Session on HIV/AIDS (UNGASS)

Although some respondents did notice that people living with HIV had been meaningfully involved in the development of the progress report on UNGASS, respondents were concerned about the lack of feedback. Some of them had never heard about UNGASS. Lack of resources made it difficult for them to access the relevant information. Several participants stated that the provinces had not been involved in developing the UNGASS report. According to some respondents, inadequate consultation had made it difficult for people living with HIV to be meaningfully involved.

Policy Development

Many of the respondents stated that in terms of policy development, people living with HIV were mainly being involved through organisations such as TAC and NAPWA. SANAC was also seen as playing an important role in setting a national agenda. Respondents made it clear that the continued involvement of people living with HIV was imperative in order to decrease stigma and discrimination, especially since they have a better understanding of the actions that need to be taken.

Representation and Networks of People Living with HIV

The general feeling was that people living with HIV are represented on the decision-making bodies. Several platforms were mentioned where participants believed that PLHIV participate and give input. People living with HIV were also well known for providing frameworks that lead to better policies. Obstacles to participation, involvement and representation included amongst others, stigma, lack of HIV disclosure, politics and power struggles, and competition over scarce resources. Suggestions included amongst others: promoting accountability, implementing monitoring and evaluation exercises once the infrastructure is in place, strengthening advocacy and lobbying organisations like NAPWA in order to promote coverage/outreach, and improving communication between the networks and their respective constituencies.

Barriers and Obstacles to applying the GIPA Principle

Funding constraints were mentioned by nine of the organisations, while seven organisations saw poverty as a barrier or obstacle. One respondent noted that poverty and funding constraints acted as a dual burden. Eight organisations stated that the fear of stigma and the lack of understanding and clarity surrounding the GIPA principle acted as obstacles or barriers.

Opportunities for Involvement

Community-based initiatives, research and advocacy, collaboration and partnerships were cited as the best opportunities for the greater involvement of people living with HIV.

Prevention, Treatment & Care

Health care services are supposed to provide services to patients regardless of their HIV status in South Africa and these services are guided by the Batho Pele principles. However, in the *Human Rights Count!* study, several respondents gave examples of either being refused services, ill treatment or being mocked for their HIV status. One reported this incident in a clinic setting:

> **"I was sick, and the nurse said to me in the clinic after she looked at my card: 'There is nothing I can do because you have AIDS and there is no cure for AIDS. Go home, you are going to die anyway'. This was said in front of the other people. I went home crying as a result. I developed meningitis and I was admitted to hospital."**

While the findings were generally positive, the *PLHIV Stigma Index* research highlighted instances of violations of health rights including coerced testing and for women pressure to terminate a pregnancy or be sterilised.

Testing and diagnosis

Over 30% of respondents reported taking an HIV test just to know their status. Nearly a quarter of respondents were referred for HIV testing when already symptomatic. In terms of coerced testing or testing without a person's consent, 48 respondents (6.1%) reported that they were forced to take an HIV test or were tested under pressure from others, and 16 respondents (2%) were tested without their knowledge. While nearly 90% of respondents received both pre- and post- test counselling, 2.8% received no counselling at all.

Disclosure and confidentiality

Over three quarters of respondents described disclosing their HIV status as an empowering experience. High levels of disclosure by respondents included to: spouse or partner (86.7%), other adult family members (82.2%), other people living with HIV (85.2%), health care workers (89.4%), children in the family (72.7%), clients (68.2%), social workers and counsellors (66.3%), and friends and neighbours (45.9%). Approximately 90% of respondents reported that they had not felt pressured to disclose their HIV status by others, though some reported pressure from other people living with HIV and other people to disclose their HIV.

In general respondents felt that health care professionals respected their confidentiality but a few reported that a health care professional had told other people about their HIV status without their consent. Nearly half of respondents indicated that they do not know if their records are kept confidential; while it was clear to 43 respondents (6.5%) that they were not being kept confidential.

Treatment

Over 70% of respondents were currently taking ART and nearly 90% said that they could access ART should they need it. Over 80% of respondents had discussed HIV treatment options and over 70% had

discussed other subjects such as sexual and reproductive health, sexual relations, emotional well-being, drug use, etc., with a health care professional during last 12 months.

When asked about the challenges or problems they face, over 30% cited ART side effects as the most problematic issue related to ART; and almost a quarter cited lack of access and taking ART for life as key challenges.

Reproductive choices

Less than 40% of respondents indicated that they had never received counselling on their reproductive options since their HIV diagnosis.

Over two thirds of women had received ART to prevent vertical transmission when they were pregnant, however 6.2 % indicated that they did not know that such treatment existed and 0.8 % did not have access.

While the majority of respondents indicated that they had never been coerced into sterilisation, around 52 respondents (6.6 %) had. **Over 10% of respondents reported that their ability to obtain ART was conditional on using certain forms of contraception.** And while most female respondents, who have been pregnant in last 12 months, have experienced no coercion; 36 (4.5%) indicated being coerced by health care professionals into terminating a pregnancy.

IN FOCUS – Experiences of the LGBTI community on sexual and reproductive health and rights

As part of a series of reports on Sexual and Reproductive Health and Rights , NAPWA undertook research on the needs and experiences of LGBTI community, especially among people who are living with HIV in the greater Johannesburg area in Gauteng, South Africa.

Methodology: Two focus group discussions (FGDs), of 8 gay men and 12 lesbian women, were conducted with LGBTI people and their age ranged from 19 to 47 years. Furthermore, 6 key informant interviews (KII) with stakeholders and 7 with LGBTI people were conducted respectively.

Challenges and rights violations

Protected by law…

South Africa has a very good and progressive policy for the equality of all its citizens irrespective of inter alia its sexual orientation, gender, race, HIV status. Almost all the participants in these sessions were aware of this assertion. For instance, same sex marriages are allowed in South Africa, LGBTI people can adopt children and that all South African citizens are equal in the eyes of the law irrespective of their sexual orientation hence discrimination within reasonable doubt in this regard is regarded as a criminal offence.

Many of the participants stated that even though they were often discriminated against they felt that the law protected them. Some noted that they were better off compared to neighbouring countries. However, participants unanimously agreed that the dictates of the Constitution are not being followed most of the time and hate crimes were common.

> **"As much as we have this progressive constitution, where people know that South Africa is a country that welcomes the LGBTI community but there is still lot of challenges, people are still being killed. We have seen lesbian women who have been raped and who have also been killed and also because of that … lesbian women have contracted HIV."** (KII, m)

Respondents were divided on whether the National Strategic Plan (NSP) addressed all LGBTI peoples' needs and rights adequately and if it went beyond focusing on HIV.

> **"It does talk about the rights, it does talk about the fact that Men who have Sex with Men need to be considered within the health in South Africa but it doesn't unpack the real needs you know, the real needs as in, if a … man [living with HIV] discloses [his sexual orientation], what if a [HIV] positive man needs the ARVs is he gonna be treated like any heterosexual member within the clinic…"** (KII, m)

Unequal access

According to the respondents, safer sex products such as condoms, fingerdoms, dental dams, and cling wraps are not provided and not easily accessible for them:

> **"As we are lesbians, we are not provided with condoms which are obtainable at the clinic but the others are able to get them for free while we have to buy ours so that is not okay."** (FGD, f)

The South African Health Care system is not viewed as being male friendly and LGBTI people are no exception to this:

> **"If you are looking at STI clinics, it's usually women-orientated, yes, with some proportion on issues around males but not specific package for MSM or LGBTI group, so there is no service package for males in my own experience that is integrated with what is identified as the LGBTI package for LBGT group."** (KII, m)

Institutional discrimination

Overall it seems that even though South Africa has such a progressive constitution, there is a trend of an institutionalised homophobia, including at schools, police and justice departments, clinics, churches, workplaces, and youth clubs.

In Schools: Some children were reported to have been chased away from schools for their sexuality. LGBTI parents also face problems at parents' meetings and teachers/educators do not seem to accept their sexuality.

Some children were reported to have been denied access to the schools after being classified as LGBTI people or felt the need to leave following discrimination.

> **"At schools like I have said they are not admitted or if they are already admitted…a certain teacher will discriminate up until the child leaves. Maybe a gay man or a lesbian would like to dress like a man, maybe she wants to wear pants, she feels comfortable in it, the school will have a problem with that, you know all those issues."** (KII, m)

Employers: Some reported that prospective employers often dismiss CVs that indicate that they are LGBTI people (for example because of their volunteering work) and others only get as far as the interview. "And sometimes in jobs we do not easily get employed because of the way we are. They could phone and invite you for an interview and when you get to an interview and they see your appearance. They will give you a promise to phone you within a week." (FGD, f)

The unemployment rate in South Africa is high, and given the enormous discrimination in the employment arena, some LGBTI people opt for commercial sex work:

> **"You find that the LGBTI community flocks to the urban cities because of that, they run away from the rural areas to come to town because of such issues, others become prostitutes. Even within Soweto, you find gays who will go and stay in Hillbrow… and in Hillbrow they are able to sell."** (KII, m)

Religious and Traditional Leaders: Respondents stated that they did not feel protected in the churches they attended and some mentioned how the church is not only dismissive of LGBTI people but also of people living with HIV.

> **"…the priest will not mind to open up a verse and direct it straight to you."** (LGBTI, m)

> **"Sometimes you find that the priest is already busy with his sermon when a lesbian comes in he will change the topic and start preaching about Sodom and Gomorrah… They say that God created Adam and Eve, and they tell us that He did not create Steve and Adam."** (FGD, f)

Furthermore, some FGD participants reported having been relieved from their duties at their respective churches and denominations as a result of being a LGBTI:

> **"My partner was a chairperson in the church board because we went to the same church, they ended up having a meeting at church and they called him in to tell him that he cannot be a chairperson in the church board because he is married in a same sex marriage." (FGD, m)**

Societal expectations are still strong.For instance, it is expected that a man will date a woman, in instances where this does not take place, in areas that are still under the traditional authoritative demarcations, LGBTI people are expelled through a traditional phenomenon called 'ukudingiswa' expulsion:

> **"The chief was told that my child is gay, we are going to be evicted here, those type of things, things that are sad, you see… in some cases the whole family gets evicted." (KII, m)**

In clinics and hospitals: LGBTI people face different types of discrimination in health care settings. For example, nurses do not understand how lesbian women, in particular, can acquire HIV or they are seen as a threat to other women in the ward and their status is disclosed.

> **"It's also similar when you go to test and you are found to be positive. Some questions arise as to how you could have contracted [HIV]…[as a lesbian." (FGD, f)**

> **"At the hospital if you are lesbian and HIV positive and maybe you have to be admitted, they don't want you to sleep in the same ward as other females. Or they might even refuse to give you pyjamas and give you a nightdress and tell you to go and sleep alone there because you are going to want to be busy with the other females and that is not the right perception because you go there for a simple reason that you are sick not because you are there to abuse other people, so that is not right." (FGD, f)**

> **"…they even know me there they (the HCWs) call me Ma-AIDS this means the mother of AIDS." (FGD, f)**

Police Services and the Justice System: LGBTI people are often treated unfairly at the police stations and some have opted to not report their cases to the police at all as a result of this treatment.

> **"I cannot go to the nearest police station if I am being sodomised or if I am being raped, I will be a laughing stock, being asked, how can a man be raped, you know all those kind of things." (KII, m).**

Hatred for LGBTI people in South Africa is manifested in terms of the killings and murders of LGBTI community members, especially lesbian women.

> **"They murder us brutally. We are no longer supposed to walk at night but they do walk at night." (FGD, f)**

Additionally,

> **"The killings of lesbian women, you know I think that's something of lately that has just been going out of hand and we have seen lots and lots of lesbians being killed and so I think our**

government just need to do something it because even when we as organisations go and report about these cases and say these are hate crimes, they will say how do you know that this is a hate crime, can you prove, you know so it has been very difficult but the hate crime in terms of lesbian women has really been going out of hand." (KII, m)

Stigma and Social Expectations

Respondents highlighted the widespread stigma and discrimination LGBTI and HIV positive people face, even from within their own community – based on class or how they contracted HIV. But for LGBTI people living with HIV it was even worse.

"The stigma that is attached to being gay or lesbian in a community almost far outweighs the stigma that you get, that's attached to being HIV positive." (KII, f)

Some LGBTI people reported societal pressure to change their sexuality.

Being [a person who is] LGBTI and being gay for instance is sometimes confused with being a soft man, hence they will suggest that a gay man goes for traditional male circumcision so that they can change, they believe that if you go to entabeni (male circumcision) you will come back being a man, all those issues. Some, they… [allow being forcefully circumcised] because they believe maybe the clan believes that if he goes to the mountain/circumcision school he will come back a man (KII, m).

Since some gay men reported being excluded from aforementioned traditional rituals, other participants mentioned that they are going for traditional circumcision, irrespective of them not being welcomed.

Respondents also mentioned that in society they are given derogatory names.

"When I walk with my girlfriend they haul insults at us: 'Hey these 'zitabane' (a derogatory word which is used by township people to express disapproval for the homosexual lifestyle)." (FGD, f)

There are family, community and societal expectations from children and family members. For instance, when a male is born into the family, in the South African culture, they will voice that a family will grow since that male will be expected to grow, get married and start a family. It is therefore presumably difficult for the family members to explain or accept that in the case of their children that will not be the case.

These issues in turn lead to abuse that remains unreported to relevant authorities, this sometimes leads to thoughts of suicide for those that are being victimised and ostracised:

"Or maybe in your family, your uncle is abusing you; you cannot [tell anyone] because you are going degrade the dignity of the family and your uncle's dignity. How can your uncle rape you as a man." (KII, m)

This also leads to problems of disclosure amongst families:

"He didn't disclose at home that he was gay, now the issue was now, having to disclose to his mother who did not accept his gay life and he on top of that had to give him the mere fact that he is HIV positive and that the mother couldn't take and then unfortunately he tried to commit suicide but he didn't succeed." (KII, m)

Fed by fear and ignorance

LGBTI people reported that discrimination can be a result of the fear of the unknown and the lack of knowledge about their community.

> **"So people are very scared I think these are the challenges and I think we need to go out and educate our communities and also educate our nurses and doctors, all the people that are in the leadership that are working in the communities so there is still a lot of work that still needs to be done."** (KII, m)

Some participants stated that people are socialised to believe that being a person who is LGBTI is wrong:

> **"If a child at home is going to grow up being told that 'those gays are just rubbish and deserve to be killed', a child will grow up with that mind. If they say that in my work area, when I sit down to eat and a doctor says that 'you are a homosexual, you need to be killed. In the bible they say this...' What does the person sitting next to me think when he hears this, he will go and tell them at home and when his children meet me on the street or when I'm drinking somewhere other people will be saying that I, as a homosexual must be killed...And I also think that the religion as well does contribute quite a lot because as we know that Lugotshwa luse manzi (a Zulu idiom which translates as "the earlier you attack a problem the more chances of conquering it"). I mean even where I grew up it was fun to make fun of people who are gay and lesbian because everybody else in the community said it was okay, nobody well nobody said it was wrong. But nobody ever you know stopped or reprimand or whatever, you know, so, in essence it's that socialisation and if it goes as back, as far back when I grew up it means that it's been, it's had a long time to be instilled."** (KII, f)

Sexual Assault and Violence

It is only now that South Africa recognised that men can be raped, otherwise this was always viewed as sodomy. Participants mentioned that they were concerned that South Africa took long to recognise this:

> **"You look at the issue of male rape, though now the laws have changed after we have toy-toy (mass action/march) so much for it to be recognised as rape, because before male rape was not originally recognized as rape, so now it is recognised as rape."** (KII, m)

As a result in South Africa there is still stigma and ridicule as far as reporting male rape is concerned.

> **"Anything less than that it's a crime, you understand that? So things like that present one with problems that even when you fight it..., if for example I can say that at my job I have a person who violated me sexually, as a male for me to say 'I'll go to such and such a place in order to find recourse', it's difficult because where I'm going I'll find straight people who will raise their ears and even laugh at me and then I'll feel embarrassed and crawl back into my small corner, you understand?"** (FGD, m)

The number of rape cases in South Africa remains alarming. The LGBTI community is highly affected by a phenomenon called 'corrective rape'. Reporting these cases still remains a difficult task, as there are many justifications used for 'corrective rape'.

> **"If a lesbian says I am a lesbian, she needs to be raped to be shown that she is a woman indeed."** (KII, m)

Additionally,

> **"Yes, and I think it's still remains an issue in communities, day after day you get the…, corrective rapes, to this day there are people that believe that if they rape a guy who is gay then he will, he will be [a] 'normal' [heterosexual] ." (KII, f)**

There were several assertions that even after reporting them to the police, the cases are not handled according to their severity:

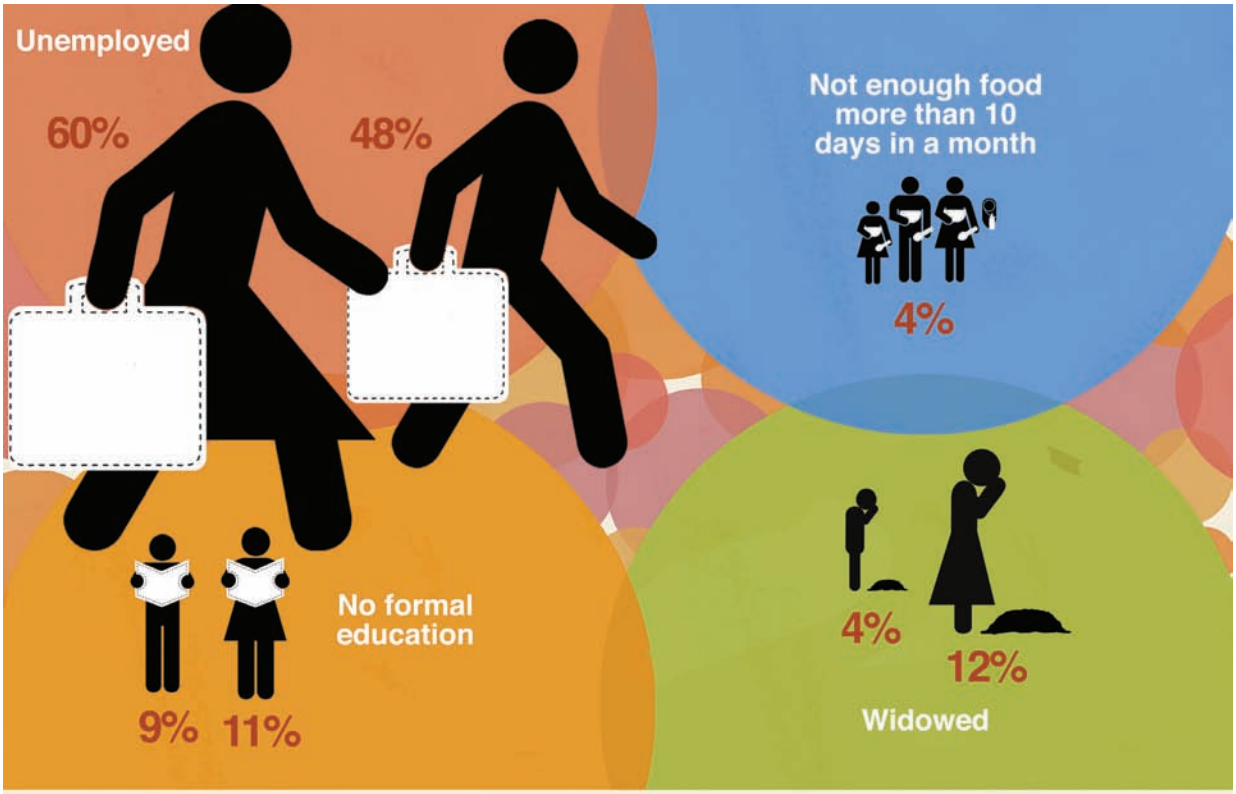
> **"Like in my case, there is a guy who called me "isitabane" (a derogatory word which is used to defame homosexual individuals), and I went to the police station to report it and then this police official just said to me "hey young man, you are suffering from depression, so go back home." (FGD, m)**

Safeguarding the Rights of LGBTI community

Some of the key messages and recommendations to safeguard and promote the rights of the LGBTI community included:

- Protection from Killings and Assault
- Equal Access to Employment
- Funding for LGBTI Projects
- Meaningful involvement of LGBTI people
- Training Health Care Workers

Graphic 3



Poverty and unemployment

It is well known that despite high unemployment rates, being HIV-positive confers a disadvantage and reinforces existing inequalities in South Africa.[39] This was found to be true amongst the respondents of the *PLHIV Stigma Index*. Over half of respondents were unemployed, and nearly half reported a monthly income of between R1000-R3000[40] and a further 12.8% had a monthly income of between R3000-R5000.

When respondents' employment status was disaggregated by level of education, a higher number of respondents with no formal education (80%), primary education (67.3%), and secondary education (49.5%) were unemployed. A greater percentage of males (53.3%,) were engaged in some form of employment, whereas most of the females (60.6%) were unemployed.

[39] HIV Status and Labor Market Participation in South Africa, James A. Levinsohn, Zoë McLaren, Olive Shisana, Khangelani Zuma NBER Working Paper No. 16901 accessible at http://papers.nber.org/papers/w16901

[40] If we consider $1 a day as the official poverty line, divvidin R5000 by 8 (estimate exchange rate) over 30 days gives R20.80 a day, is more than twice the official poverty line. However, most of interviweesreported either through work earnings (or unemployment) an income of e less than R2000, i.e R8 a day, equivalent to $1 a day.

Nutrition and Food security

In the *PLHIV Stigma Index*, when asked the number of days in the last month during which any member of the respondents' households had gone without food, over half of the respondents indicated food shortages within the household. Those who had gone without food more often had low monthly income (from nothing to R3000 a month) and were mostly unemployed

Education

In terms of level of education, while over half of the respondents in the PLHIV Stigma Index had attained secondary school education, over one third of respondents reported only primary level education), and around 10.3% reported no formal education.

Human Rights Count! and PLHIV Stigma Index in Eastern Cape:

The Eastern Cape is the poorest and the third most populous province in South Africa. The OR Tambo District was chosen for both studies because of the following:

- It has the second highest HIV prevalence in the Eastern Cape Province.
- High stigma and discrimination of people living with HIV led to a woman, Nokuzola Mfiki, killing herself together with her four young children.[41]
- The HIV counselling and testing campaign was launched in the Ngquza local municipality in the OR Tambo District.
- Generally, the OR Tambo district has a very high illiteracy rate coupled with high unemployment. These can impact on an individual's knowledge of their rights and further still, on services that are at their disposal when faced with such violations.

[41] Daily Dispatch 8th August 2009

Recommendations

Reform of laws/policies

- Support the active participation of people living with HIV in the development of support laws, policies and guidelines; and in providing community-based services and support that safeguard the rights of people living with HIV.
- Institute a body with the specific task of monitoring incidences of and data on homophobia-related hate crimes, ensuring effective law enforcement and victim support and providing more resources towards apprehending the perpetrators of these crimes.
- Review all laws that might have the unintended consequences of increasing HIV risk and social exclusion and impeding access to HIV treatment, care and support. These include laws that prohibit sex work.

Addressing human rights violations, discrimination and stigma

- The SANAC must implement the People Living with HIV Stigma Index nationally to measure experiences of stigma and discrimination over time.
- The government must prioritise HIV-related stigma and discrimination reduction, particularly against people living with HIV and key populations in national strategic planning, funding and programmes, and include HIV-related stigma and discrimination indicators as part of the national AIDS response M&E systems to monitor and evaluate progress over time.
- NAPWA together with other civil society organisations should work closely together to challenge existing societal attitudes and prevailing cultural norms. This work should include training their membership and communities to know and assert their human rights issues and to document human rights violations.
- There should be adequate resource allocation for the implementation of advocacy programmes to de-stigmatise HIV, raise awareness, and engage in community dialogues.

Respecting sexual and reproductive rights

- There needs to be greater monitoring of the rights violations faced by the LGBTI community including their sexual and reproductive rights.
- Health workers need specific training to reduce the double stigma faced by the HIV positive LGBTI people and to meet their needs.

Access to comprehensive healthcare

- NAPWA should intensify education efforts with people living with HIV on Positive Health, Dignity and Prevention and provide complete and accurate information on the benefits of ART, HIV transmission, having children and preventing vertical transmission.

Notes

Published by:
NAPWA SA, The National Association of People living with HIV and AIDS in South Africa
175 Meyer Street, United building
PO Box 66
Germiston
1400 South Africa

Website: www.napwasa.org
Email: sg@napwasa.org

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