POSITIVE HEALTH, DIGNITY AND PREVENTION IN ZAMBIA:

FINDINGS AND RECOMMENDATIONS FROM STUDIES LED BY PEOPLE LIVING WITH HIV

Network of Zambian People Living with HIV/AIDS (NZP+)

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

UKaid from the British people

Acronyms

CSO	Civil Society Organisation
DFID	United Kingdom's Department for International Development
GIPA	Greater Involvement of People Living with HIV and AIDS
GNP+	Global Network of People Living with HIV
GRZ	The Government of the Republic of Zambia
HIV	Human Immunodeficiency Virus
HRCZ	Human Rights Commission Zambia
HRC!	Human Rights Count!
LTA	Leadership Through Accountability
NGO	Non-Governmental Organisation
NZP+	Network of Zambian People Living with HIV
PLHIV	People Living with HIV
SAfAIDS	Southern Africa HIV and AIDS information Dissemination Service
TALC	Treatment Advocacy and Literacy Campaign
TB	Tuberculosis
UK	United Kingdom
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNHCHR	Office of the United Nations High Commissioner for Human Rights
WAC	World AIDS Campaign
WILSA	Women in Law of Southern Africa
ZARAN	Zambia AIDSLaw Research and Advocacy Network

Contents

Overview

Zambia is one of the more urbanised countries of sub-Saharan Africa with a high rate of population growth. The country has ten provinces that are subdivided into ninety-five districts. Within the districts, the administrative units are Chiefdoms and Constituencies and the latter is made up of Wards.

Our people

- Almost 40 percent live in urban areas
- Average household size is 5.2
- Life expectancy is 51.2 years
- 45.4 percent of the population below the age of 15 years
- 60% live below the national poverty line (2006)[1]

The epidemic

The HIV prevalence among adults 15-49 years was 14.3% in 2007. Prevalence varies across regions, ranging from 7% in North-Western province to 22% in Lusaka province. The prevalence was about twice as high in urban (20%) than in rural areas (10%). In Zambia, HIV disproportionately affects more women than men, with women constituting 57% of the 1.2 million adults estimated to be living with HIV (UNAIDS, 2008). Women aged 20-24 are 2.3 times more likely to be HIV-positive than men of the same age group (Central Statistical Office, CSO, 2008).

Progress

Since 2005, with support of development partners, the Government has provided free antiretroviral therapy (ART) in all public health institutions. The proportion of people who are both eligible for and able to access ART has increased from 38.9% in 2007 to 68% in 2009 (NAC, 2010). Over the years, the number of public and private facilities providing ART related services such as CD4 counts has increased, resulting in improved services in both rural and urban areas. According to the 2009 Zambia Sexual Behaviour Survey,[2] levels of HIV-related stigma and discrimination have in general been declining since 2005. Modest positive changes have been observed in proxy indicators to measure the level of stigma and discrimination (CSO, 2010).

The 2012 *Zambia Country Report*,[3] listed several indications of the HIV epidemic being reversed including: a slight reduction in the percentage of the adult population living with HIV from 15.6 in 2001-2002 to 14.3 percent in 2007; a significant reduction in the percentage of young women 20-24 years living with HIV from 16.3 in 2001-2002 to 11.8 percent in 2007; in the antenatal sentinel surveillance the percentage of pregnant HIV-positive women in this age group dropped from 34.3 percent in 1994 to 28.1 percent in 2008-2009.

[1] CSO website Monthly bulletin May 2012
[2] http://www.zamstats.gov.zm/media/zambia_sexual_behaviour_2009.pdf
[3] Zambia Country Report to UNGASS (2010 – 2011), March 2012

Among children born to mothers living with HIV, the percentage of infants contracting HIV reduced from about a peak of 7.72 per cent in 1997 to about 1.99 per cent in 2011 because of the reduction of HIV infection among pregnant women and the prophylaxes administered to women living with HIV in the prevention of vertical transmission. National coverage for this programme in 2011 at about 80 per cent was approaching near universal levels.

Challenges

The report also summarised challenges remaining: There are still sub-optimal numbers of children accessing ART, due to challenges in relation to the availability of infant diagnostic tests. Although the percentage living with HIV reduced among all the groups by sex and area of residence, it increased among men 15-49 years in rural areas from 8.9 per cent in 2001-2001 to 11.0 per cent in 2007. In fact, the gains in rural areas where the level of the epidemic can be said to be about half of that in urban areas were modest. Although the level of the epidemic in rural areas is much lower than in urban areas, the population affected is quite high since about 65 percent of the population lives there.

National Laws and Policies

In the 2011 review of assessing the commitment to the UNGASS Targets in Zambia, stakeholders rated the political commitment in Zambia to have been lower in 2011 than in 2009. They also downgraded the commitments to the Human Rights approach from the 2009 level.
Zambia Country Report, 2012

The first major national AIDS framework was developed for 2001-2003 with subsequent revisions incorporating newly evolved best practices and impact targets for the periods 2002-2005 (replaced the one for 2001-2003); and 2006-2010. In 2003, the Government launched its national policy of providing free and universal access to ART, which was expanded in 2005 to include all related services. Currently the national response against the epidemic is guided by the 2011-2015 National AIDS Strategic Framework (NASF) which was developed through a consultative process and included representation from civil society, people living with HIV, government institutions, development institutions, the private sector and development partners. Consultations with groups such as sex workers, traditional leaders and others were conducted through representative organisations.

Adoption of a human rights approach and gender sensitivity are two of the nine guiding principles of the 2011-2015 NASF. In the just ended 2006-2010 FNDP, and the recently launched 2011–2015 SNDP, HIV/AIDS and Gender were the major cross-cutting issues in all the programmes of the plan.

The money

The national health budget for 2012, announced at the end of 2011, is 45 percent higher than the 2011 budget in absolute terms. In addition the Government has increased its budget for ARVs from USD 5 million in 2011 to USD 10 million in 2012. However, in 2010, public expenditure on health was 3.6% of GDP, among the lowest in southern Africa.[4] Another major challenge is the sustainability of the national HIV response given the overwhelming donor dependence as well as the lack of sufficient mobilisation of local resources. The establishment of the National AIDS Trust fund and other mechanisms for local mobilisation are therefore critical in this regard. The NASF reflects the need to develop sustainability mechanisms. To this end, a feasibility study for the establishment of such a fund has been done and recommendations have been made. The Government is committed to enhancing domestic financing of the response, and especially establishing an AIDS fund in view of the declining support from traditional partners.

[4] http://apps.who.int/nha/database

Human rights

The 2009 *PLHIV Stigma Index*[5] study found that while there are no HIV-specific laws which concern discrimination against people living with HIV (NAC, 2010), Zambia does have laws and regulations to protect vulnerable populations such as women, youth and migrants. It is a signatory to a number of international treaties and declarations related to the protection of the rights of people living with HIV, and there are a number of national policies and guidelines that govern HIV service delivery.

This was confirmed during the *Human Rights Count*[6] research, also carried out in 2009, which listed a number of critical issues that had a bearing on the findings. The first one is that under the current Zambian constitution Article 23, which addresses protection from discrimination, does not include the phrase "other status" as one of the characteristics that should not be used to discriminate against an individual. The grounds that are protected in Article 23 are race, tribe, and sex, place of origin, marital status, political opinion, colour and creed. The phrase "other status" has been acknowledged by the UNAIDS to include HIV and other health status (UNAIDS, 2006). **The absence of the term "other status" limits the extent to which people living with HIV can find protection for HIV related human rights violations under the constitution.**

As seen in the evidence gathered, social and economic rights such as the right to health and the rights to work lie at the centre of HIV related discrimination. Even though social and economic rights are argued by some to be non-justiciable, their inclusion in the constitution (currently under review) would be a demonstration of government's will to better the lives of its people. This would directly affect people living with HIV because it would give them the basis for holding government accountable for taking steps to ensure that these rights are protected and fulfilled. The approach taken by the South African constitution could be followed here. The state has an obligation to protect social and economic rights "within available resources". This approach demonstrates the commitment of the state to protect these critical rights but also recognises that there may not be resources available to ensure full recognition.

The reports of the Human Rights Commission Zambia of 2008 and 2009 (HRCZ, 2008, 2009) highlighted that the human rights situation in Zambia was undesirable and that their data collection exercises had unearthed "unfettered'' violations of human rights. The police, local and international investors were pointed out as having been perpetrators of human rights violations. The local and foreign investors were said to have a widespread disregard for labour laws and violations were observed in areas such as unjustified terminations and failure or refusal to pay terminal benefits. These violations were also evidenced in NZP+ findings. **If there was such wide spread violation of human rights in Zambian society, then there is greater need for organisations such as the HRCZ to consider the rights of people who by virtue of their circumstances, may be susceptible to human rights violations. This includes people living with HIV. However, there is a glaring absence of the mention of HIV and how they relate to human rights in the HRCZ reports.**

In principle, there are a number of policy documents that can be used to protect the rights of people living with HIV. ZARAN (2009) offers a comprehensive list of HIV related laws in a review document that seeks to analyse whether the laws can adequately protect against HIV related human rights violations or can be used to perpetuate them. From the findings of the *Human Rights Count* report, there seems to be on the one hand, a general lack of awareness of these policies and how to use them to redress the violation of human rights and on the other hand, a disregard of these policies by employers and other people whose responsibility it is to protect those rights.

Government has the primary responsibility to ensure that the human rights of all people, including people living with HIV are respected and protected. However, the Human Rights Commission, in its

[5] The PLHIV Stigma Index, Zambia Country Assessment 2009, NZP+, January 2012
[6] Human Rights Count! Zambia: Country Assessment 2009, NZP+, April 2010

report titled 'State of human rights report in Zambia' (2008) notes that government structures, such as the police, lack the institutional and infrastructural capacity to protect human rights. This, taken together with the shortcomings in existing legislation, shows that the government is yet to develop the necessary capacity to protect the rights of people living with HIV.

Criminalisation of HIV transmission: Although there are no known prosecutions specific to HIV transmission in Zambia to date, the government may be considering developing criminalisation legislation. All respondents in the *Criminalisation Scan*[7] study felt that it may be possible to use current laws to prosecute exposure to or transmission of HIV or other STIs. Whilst this had not been tested in a court of law, respondents suggested that the following provision in the Penal Code could be used in HIV transmission cases:

> **Negligent Act likely to cause infection:**
> 183. Any person who unlawfully or negligently does any act which is, and which he knows or has reason to believe to be, likely to spread the infection of any disease dangerous to life, is guilty of a misdemeanour.

Anecdotal evidence supported the claim by half the respondents that the government is considering developing legislation specific to criminalisation of HIV transmission, citing the Attorney General as having made the remark "in passing" at a ZARAN workshop.

According to the *Zambia Country Report*, the recently enacted Anti Gender Based Violence Act of 2011, read with the Penal Code, criminalises wilful HIV transmission. This is due to the fact that the Act defines sexual abuse to include "the engagement of another person in sexual contact, whether married or not, which includes sexual conduct that abuses, humiliates or degrades the other person or otherwise violates another person's sexual integrity, or sexual contact by a person aware of being infected with HIV or any other sexually transmitted infection with another person without that other person being given prior information of the infection".

Health and other economic and social rights

There has not been a national healthy policy in place since 1992. The National Decentralisation Policy and National Health Strategic Plan 2011-2015 informs current health service delivery. There are plans to convene a multi-disciplinary working group to develop a health policy in 2013.

HIV testing as part of pre-employment screening is prohibited under a government policy. However this policy[8] is more honoured in the breach than the observance, and though it is government policy, pre-employment testing is not explicitly prohibited in law.[9] However it has been held[10] that mandatory testing without consent is unconstitutional.[11]

The *Human Rights Count* report stated *"It could be because of lapses in the constitution as mentioned above that human rights violations take place in government institutions such as the armed forces."* Despite national policy that discourages mandatory testing for HIV for scholarships or employment, Chuulu et.al (2001) highlights that in the Defence Forces, an HIV positive result is used to reject prospective recruits.

[7] Global Criminalisation Scan Zambia Country Assessment 2009. NZP+, December 2009
[8] http://www.usaid.gov/our_work/global_health/aids/Countries/africa/zambia.pdf.(at page 2) refers to this policy but also states 'Zambia does not have many laws and regulations specifically protecting PLWHA against discrimination' and that 'knowledge of human rights and discrimination laws remains very low, especially in rural areas'.
[9] Information provided by Zambia AIDSLaw Research & Advocacy Network (www.zaran.org)
[10] Information from ZARAN: 'in a recent (2010) court case two ZAF (Zambian Air Force) employees were tested without their consent. As part of the outcome of this case the High Court ruled that mandatory testing for HIV was unconstitutional.
[11] Details of the ruling are available at http://www.zaran.org/index.php/news-a-press-releases/114-mandatory-testing-unconstitutional

Chuulu et.al (2001) indicate that the law allows for an employer to ask for a medical examination to ascertain an employee's ability to carry out work including at a time when the employee may be ill but that HIV testing is not one of the tests required. Chuulu and colleagues add that the policy of the Zambia Federation of Employers is that employers should not require an HIV test. The findings of the *Human Rights Count* report indicate that some employers were taking their employees for HIV testing as part of the medical test and sometimes without the employees' consent. Once found HIV-positive, some respondents in the study reported that they were dismissed on the basis of that result.

For those respondents that sought redress for the violation of their human rights, only one respondent reported a satisfactory resolution of his employment-related violation after his employer reinstated him. In some cases, as with a group of people living with HIV employed in a hospice, redress for the violation of their rights was not sought for fear of losing employment.

Women and other key populations

According to the *Zambia Country Report*, many efforts have been made to ensure the rights of women and other key populations in national policy. To ensure that the NASF had a strong gender perspective throughout the development process, consultations were held with the Gender Steering Committee including the Gender in Development Division. The NASF also addresses issues of key populations and marginalised groups. These include but are not limited to men who have sex with men, people who inject drugs, sex workers, women and girls and people with disabilities. Key settings such as prisons, schools and workplaces are also taken into account. Cross cutting issues related to human rights protection, stigma and discrimination, gender inequality, poverty and involvement of people living with HIV feature prominently in the NASF. In addition to highlighting the vulnerabilities of these groups, the NASF outlines specific strategies such as creating public awareness of stigma and discrimination and the legal barriers that prevent key populations from accessing and utilising services appropriately.

With regard to the laws to reduce violence against women, the long awaited Anti Gender Based Violence Act was enacted in 2011. It outlaws gender-based violence which is defined broadly to include physical, sexual, economic and psychological violence. Among other things, it obligates the government to create shelters for victims of violence.

However, the report also states that there are other laws that present obstacles to effective HIV prevention, treatment, care and support for key populations and marginalised groups. These are laws that criminalise same sex relations, sex work and injection drug use. The illegality of these activities has been used to prevent research on and provision of services to key populations and vulnerable groups. The Penal Code, CAP 87 of the Laws of Zambia classifies same sex relationships as unnatural offences and punishable by law. Section 19 of the Prisons Act, CAP 97 of the Laws of Zambia classifies committing sodomy as a major prison offence. The Narcotic and Psychotropic Substances Act lists methadone, burenophine and naloxone as controlled substances thereby preventing IDUs access to OST, which is a critical component of the comprehensive package for preventing HIV among IDUs. The Act further limits any harm reduction interventions for IDUs as specified in the comprehensive package for HIV prevention and refers to harm reduction as "aiding and abetting".

Human rights

Rights, laws and policies

- About 60% of respondents were unaware of national laws, policies or guidelines that protect the rights of people living with HIV.
- Over a third of respondents were unsure whether they had experienced violation of their rights as people living with HIV in the previous year.
- However, 10.4% of respondents reported experiencing forced medical procedures, while 4.8% reported detention, isolation, being quarantined or segregated.
- Of those who reported that their rights had been abused and had sought legal redress, over half reported that nothing had happened; while less than 20% reported that the matter had been dealt with.
- A majority (82%) of respondents did not know or were unsure of the reason for HIV-related discrimination; however, the most commonly cited reason was people's fear of being infected (10.4%).

Source: 2009 PLHIV Stigma Index report

Violations and discrimination

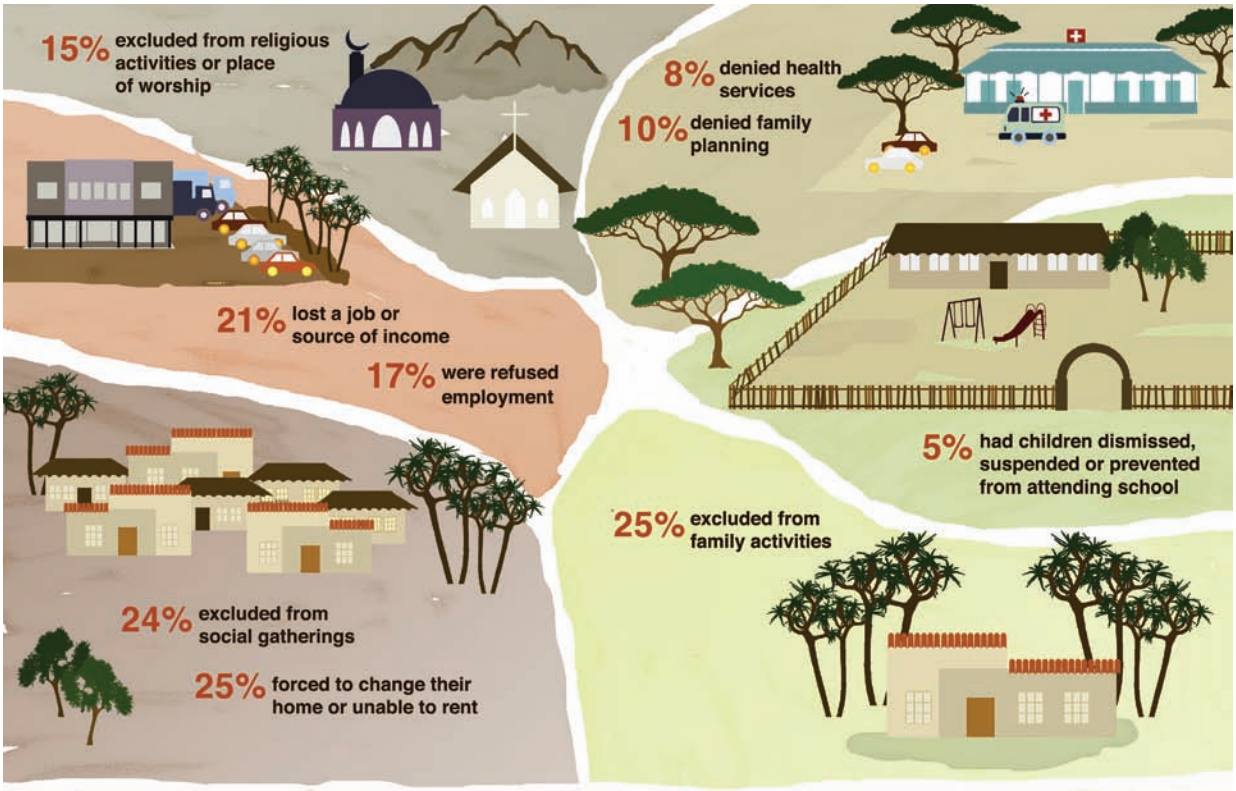
The Human Rights Count study recorded 42 violations from 28 respondents. **The highest numbers of recorded violations were issues related to the right to work, the right to non-discrimination, and equality under the law, which had nine reports each** (see graphic below).

Graphic 1

Other reported violations related to the right to the highest attainable standard of care, the right to privacy, the right to favourable conditions of work and the right to own property. In some cases, the link between the violation and the HIV-positive status of the respondent was not very clear but these violations were also recorded because they constituted the respondent's perceptions of the experience, which is important to acknowledge and respect.

More women (25%) reported violations compared to men (17%). Close to 50% of the respondents reported that their rights were violated in an employment context and the person who violated their rights did so in the course of carrying out his or her job. The range of employment settings in which violations were reported included faith based organisations, HIV service organisations, government ministries, private for profit organisations and the armed forces. About 40% of violations took place in the context of the family and were perpetuated by siblings and spouses, especially husbands, as well as extended family such as in-laws and aunts. In these cases the government failed to implement measures to prevent the violations or to adequately investigate the violation or punish the perpetrators.

Graphic 2



Stigma and exclusion

> **There was a funeral of my late brother. I was not informed about it [and] when I asked they said I had nothing to contribute, the church would not want me there anyway and hence there was no reason to inform me about it.** (Female, rural area)

In the *PLHIV Stigma Index* study, respondents were asked about their experiences of stigma and discrimination in the previous 12 months and some of the results are depicted in the graphic below. Other highlights include:

- Of those respondents who had had experienced stigma and/or discrimination for reasons other than their HIV status, many belonged to key populations.

- Respondents whose household members had been subjected to stigma by association at least once was higher in large towns/cities (50.7%) than rural areas (39.6%) or small towns or villages (33.5%).
- **Due to internal stigma, over 70% of respondents irrespective of income group, made the decision not to have children. Furthermore, over 30% opted to abstain from sex or marriage.**

Women's rights

Gender inequality compounds the degree of violation that HIV-positive women face as compared to HIV-positive men. The lower status of women correlates to the type of violations experienced by women and the gender of the perpetrators of the violations.

Women who participated in the *Human Rights Count* study faced a number of gender-based inequalities. UNAIDS (2005) points out that women are more likely to be blamed as sources of infection and less likely to be accepted by society. A number of women in this study faced this bias. For example one HIV-positive woman was blamed for the death of her spouse while an HIV-positive man was rejected by his family for having married a 'wayward' woman who had transmitted HIV to him. At least two HIV-positive women reported being denied access to medication by their husbands, while one woman had her medication hidden from her and yet another one was unable to travel to get a refill of medication because her husband refused to give her transport money.

The demographics of the respondents of this study also give an indication of the gender inequalities that may exist in the society of the respondents. For example, the female respondents had lower levels of education with no female respondent having a university qualification. Additionally, of the respondents that reported being unemployed, there were more females (57.1%) than males (42.9%). Women are often unable to leave relationships where their rights are not respected because of their economic reliance in the relationship.

Women, on the other hand, were more likely than men to report violations of their human rights. Although at face value this was a positive indication, it could also be a reflection of the general lack of support-seeking behaviour noted among men.

Traditional and cultural practices were also identified as playing a role in the type of violations experienced and whether or not these violations were reported. For example, four of the eight violations reported from Southern Province involved women whose rights were violated by their spouses or in-laws. Southern Province is known to culturally accept the practice of polygamy and this may in itself diminish the influence of women in a marriage relationship especially when the man intends to marry another woman.

Key populations

In line with the PLHIV Stigma Index study's objective of identifying the different experiences of population groups with regard to stigma and discrimination, respondents were asked with which 'key population' they identified. About 70% indicated that they did not belong to any of the categories listed while the remainder identified as belonging to key populations: ex-prisoner (14.5%), sex workers (6.6%), migrant workers (3.7%), internally displaced people (2.5%), members of indigenous group (0.7%), people who use drugs (0.6%), men who had sex with men (0.6%), transgender people (0.6%), refugee or asylum seeker (0.2%) and gay or lesbian (0.2%).

Despite the relatively small percentages, these findings are important evidence of the existence of men who have sex with men, gay men, lesbians and people who use drugs among people living with HIV in Zambia. It was also a learning point for NZP+ who realised that the sampling should have taken into account the stigma experienced by key populations and designed the sampling and the way that it reached out to key populations.

Over half of respondents indicated none of the reasons other than being HIV-positive applied to them. Of those respondents who had had experienced stigma and/or discrimination for reasons other than their HIV status, many belonged to key populations e.g. sex workers, internally displaced person or ex-prisoner, men who have sex with men or people who use drugs.

One quarter of respondents reported that children who have been orphaned due to AIDS live in their household with 1-2 orphans per household most frequently reported.

Empowerment of people living with HIV - the GIPA Report Card

What is Greater Involvement of People living with HIV (GIPA)?

The GIPA principle was endorsed by 192 United Nations member states in 2006. The origins of the GIPA principle started in 1983 in Denver (US), when people living with HIV first voiced and demanded that they should be included at every level of decision-making. This became known as the Denver Principle, and it states that:

> *"PLHIV be involved at every level of decision–making; for example, serve on the boards of directors of provider organizations, and participate in all AIDS-related meetings with as much credibility as other participants, to share their own experiences and knowledge" (UNAIDS 1999).*

In the PLHIV Stigma Index study, **more than half the respondents indicated that they had not heard of the UN Declaration of Commitment on HIV and knowledge of national policies that provide protection for people living with HIV show a similar pattern.** Other findings on empowerment include:

- Among respondents, 40.7% reported being a member of a support group and/or network of people living with HIV with older respondents more likely to be members,
- Nearly 70% of respondents reported that they had not been involved as volunteer or employee in a programme or project providing assistance to people living with HIV in the previous 12 months; while 30.9% had.
- Involvement in HIV legal and policy reform was minimal with only a tenth of respondents reporting being involved in efforts to develop legislation, policies or guidelines relating to HIV in the previous 12 months.
- There was a clear difference in legislative or policy level participation between members and non-members of support groups (17.9% and 2.1% respectively).
- With regards to respondents feelings of being able to influence policies, laws and programmes, 40% mentioned local projects to benefit people living with HIV less than one in five feeling that they had any influence at the national programmatic level or on local or national policies; while over one third felt unable to influence any of the areas.

The *GIPA Report Card*[12]

Despite key policy documents in the national HIV response making broad statements of commitment to the GIPA principle, there is little detail on how this will be implemented or monitored and the participation of people living with HIV in the HIV response in Zambia remains low.

The National AIDS Plan

The national plan was seen to be accommodating people living with HIV through NZP+ but implementation as well as participation by people living with HIV is still at low levels. There also is a lack of funding to implement the GIPA principle and few funds are raised specifically for that purpose. For example,

[12] GIPA Report Card Zambia Country Assessment 2009, NZP+, January 2010

the Zambia National AIDS Spending Assessment technical report did not report any money spent on implementing or supporting the GIPA principle in the response, although the National Chairperson of NZP+ was on the Quality Assurance Team that contributed to the report.

GIPA at State and Provincial levels

The GIPA principle was said to be implemented with the participation of people living with HIV at national, provincial, district and community levels in planning, implementation and monitoring. However, it is not always consciously recognised to be the GIPA principle.

Policy Development

People living with HIV are represented on most national HIV planning teams, however participation was seen as below expectation due to stigma and discrimination; lack of capacity by people living with HIV to contribute effectively; and because policy development is usually at the centralised level of NZP+ or TALC. Often, involvement was more at the level of implementation rather than at the policy-making, planning and design stages of programme development. It was noted that observance of the GIPA principle might be tokenistic, sometimes in support of fundraising efforts.

Universal Access

National targets for universal access have been set in areas such as voluntary counselling and testing (VCT), the prevention of vertical transmission and also the provision of ARVs. It was generally felt that people living with HIV were not consulted about the targets, but merely informed. One of the barriers identified to achieving universal access was poor coordination of HIV programmes, with a lack of adequate consultation and involvement of people living with HIV.

Representation of Networks of People Living with HIV

It was generally felt that people living with HIV are represented on various decision-making bodies at national, provincial and district levels. However, representation of networks was said to be less effective than it might be because of limited information flow across the national, provincial and district networks due to lack of funding; lack of quality control, and also because only a small number of people living with HIV involve themselves in network issues.

Women's Networks

As well as the involvement of some in the new Zambian Women's PLHIV network COZWHA+, women have been involved as representatives of NZP+, although some felt they are not doing enough to encourage women's involvement.

Barriers to Involvement

The most prominent barrier to involvement in the GIPA principle was reported to be poverty. Stigma and discrimination also create barriers, as do low knowledge levels about issues such as the GIPA principle. These affect access to some of the facilities accessible to people living with HIV as well as the activities that they could be involved in. Other barriers that were cited included differences between people living with HIV, low levels of skills, inadequate staffing and inadequate funding.

Opportunities for Involvement

Zambia's political environment is conducive to support dialogue, advocacy and legislation in favour of people living with HIV. This is complemented by the existence of an HIV policy, strong commitment and necessary structures. There is opportunity for NZP+ to do more to increase the involvement of people living with HIV, and for government to be proactive in inviting people living with HIV to participate in the response to HIV. More training for the various stakeholders about the GIPA principle would be useful.

Prevention, Treatment and Care

Testing and counselling: Among the respondents in the PLHIV Stigma Index, the proportion of men and women who reported taking an HIV test just to know their status is similar to that of men and women who tested because of HIV-related symptoms (24.4% and 34.8% compared to 22.2% and 34.3%, respectively). With nearly one quarter of men and more than one third of women being symptomatic at time of diagnosis, this suggests that more investment should be made in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.

Most respondents irrespective of age group reported receiving both pre- and post-HIV test counselling. However, human rights violations associated with involuntary HIV testing and being tested without any counselling[13] remain a challenge, as do the cost, time and distance in accessing HIV testing services. **Although there is a national HIV policy that clearly states that HIV testing should be voluntary, 7.8% (73 of 839 respondents) reported testing under coercion.**

Disclosure of status: Self-disclosure by respondents of their HIV-positive status was highest to health care workers. And two thirds of respondents had disclosed to their husbands, wives or partners, while 5.3% indicated that their sexual partners were not aware of their HIV status. However, many reported their status was revealed without their consent. Friends and neighbours was the category most frequently informed without the respondent's consent (24.4%), followed by work colleagues (11.1%). The impact of this was felt most in rural areas, where 27% of respondents reported very discriminatory reactions among friends and neighbours, more than double that of respondents residing in a large town or city.

Access to health services and medicines: In the *PLHIV Stigma Index* study, 8.4% of respondents reported being denied health services (including dental services) in the past 12 months. With the sample being almost exclusively drawn from among people attending health centres providing ART it was not surprising that access to ART was not identified as a problem, with nearly 90% accessing ART. Furthermore, over 70% of respondents indicated that they were taking some medication to prevent or to treat opportunistic infections.

Over two thirds of respondents reported having had a constructive discussion on HIV treatment options. Treatment-related challenges mentioned by respondents mostly related to side-effects, pill burden and the duration of treatment, suggesting that more investment in treatment literacy could improve adherence and health outcomes.

> **'The time of taking the drugs is too long. It would be better if some cocktail could be formulated to be taken may be once per month.'** (Male, rural area)

> **'Stavudine[14] is giving a lot of problems. My legs are becoming swollen. I feel like stopping taking ARV's.'** (Male, small town)

[13] More than 10% of young people and people over 50 years of age reported having been tested without any counselling at all.
[14] Stavudine is also known as Zerit (brand name) or d4T.

Respondents in the GIPA Report Card study felt that even though supply constraints occur, ARVs are generally accessible. Zambia was said to have been recognised as having one of the best ART management and supply chain systems. However universal access has not been reached due to problems of poverty, infrastructure, facilities, qualified health personnel, timely and proper dissemination of information, coordination, funding, stigma and discrimination, as well as low involvement of people living with HIV.

The quality of services at government-run health institutions was perceived to be poor compared to private institutions. For instance, those who go to government clinics have to stand for a long time in queues for medicines before they can be attended to. People in rural areas were perceived as more negatively impacted and some reported having to travel to urban centres just to collect the medicines.

Sexual and Reproductive Health and Rights

In the *PLHIV Stigma Index* research, **some 9.7% of the respondents asked, reported having been denied family planning services as a result of their HIV status, while 11.8% indicated that they had been denied sexual and reproductive health services.**

Reproductive health counselling plays an important role in the effectiveness of HIV prevention strategies, particularly those focusing on vertical transmission and HIV-discordant couples. Of those who felt this applied to them, 38.5% of men and 30.3% of women reported never having received counselling on reproductive options

Female respondents were asked to indicate if they had experienced coercion from a health care professional in relation to termination of a pregnancy (abortion) in the previous 12 months. Of the 309 women who felt the question applied to them, 5.2% had experienced pressure to terminate a pregnancy.

Female respondents were also asked about access to services to prevent vertical HIV transmission. Surprisingly, more respondents from rural areas (61.2%) reported receiving interventions to prevent vertical transmission compared to 52.6% of respondents residing in large towns/cities and 41.4% of those living in small towns or villages. Furthermore, nearly a quarter of women from rural areas (23.9%), and small towns or villages (24.1%), along with 7.7% of women from large towns/cities did not know that such services exist. Clearly, more needs to be done to improve knowledge of and access to prevention of vertical transmission services in all settings.

IN FOCUS: Sexual and reproductive health needs and rights of adolescents living with HIV

Despite not having the status of a binding international instrument, the Guidance Package on Advancing the Sexual and Reproductive Health and Rights of People Living with HIV released in 2009 is one of the most comprehensive guidelines covering sexual and reproductive health (SRH) issues for adolescents living with HIV. In advocating a more responsive policy environment, the package states:

> **"...National frameworks and curricula need to do more to address the SRH concerns of young people who are already living with HIV, including forming relationships, practising safe, pleasurable sex and disclosing their status. Existing programmes tend to ignore the needs of young people who have been HIV positive since birth because until recently, HIV infected infants were not expected to survive to adolescence. Guidelines should be revised to specifically address the situation of young people who were born HIV positive as well as those infected at a later stage." (GNP+ et al, 2009:35)**

In 2009, NZP+ conducted an exploratory qualitative study[15] to examine the SRH needs, concerns and barriers to accessing related services for adolescents aged 10-19 years living with HIV in Lusaka, Zambia.

About 82,000 out of the estimated 1.4 million Zambians living with HIV are children (NAC, 2008). According to the 2007 Zambia Demographic and Health Survey, the HIV prevalence in 15-19 year olds in the country is 4.7%. At 5.7% the prevalence among girls in this age group is higher than that for boys, which stands at 3.6%.

Missing from national policies

The review of available policy documents and service protocols relating to adolescents in Zambia revealed that no national policies specifically address the adolescent SRH needs. The National Policy on HIV and AIDS lacks any specific mention of adolescents living with HIV or their SRH needs. Although the recently adopted National Reproductive Health Policy refers to some of the challenges adolescents face in accessing SRH services and information, no interventions specifically for adolescents living with HIV are mentioned.

> **"Adolescents living with HIV are not being specifically targeted in Zambia unless within programmes addressing sex work, migrant populations and human trafficking. Even in these programmes the targeting is for both negative and positive adolescents. There is no specific study conducted to identify and target this particular group.**
>
> **The health system does not adequately address adolescent SRH concerns in the RH service provision. Most of the health facilities do not have a conducive environment, space and equipment for providing quality adolescent SRH services. There are some restrictions in the provision of some RH commodities such as condoms to sexually active adolescents and youths. This hinders those who may be in need of these commodities (for prevention of STI/HIV and unintended pregnancies) from accessing". Policy influential, UNFPA**

[15] An Exploratory Study of the Sexual and Reproductive Health Needs and Rights of Adolescents Living with HIV in Lusaka. Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV. NZP+, March 2010

The research suggests that the SRH needs and concerns of adolescents living with HIV in Zambia are assumed to be addressed through the existing policies targeting youth, people living with HIV, children or key populations. Interviews with adolescents highlighted the need for specific policies and interventions that responded to their needs and concerns.

Fear of being different

Stigma and discrimination related to living with HIV emerged quickly as a key issue in the majority of the interviews conducted in this study. For some of the adolescents, the knowledge that HIV was primarily a sexually transmitted infection evoked feelings of shame and bitterness, especially for those who reported having acquired the infection perinatally.

> **"We are sometimes treated in a strange way at school. It's unfair because some of us have never had sex. We were just born with it."** FGD, 10-14 years old female adolescents

Younger adolescents in particular identified the fear of mocking by friends as one of the main reasons they avoided playing with their peers in the neighbourhood.

> **"My guardians have told everyone in the neighbourhood that I'm HIV positive. When I have a difference with playmates, my status is often brought up. It hurts me. I don't feel free when I'm playing."** FGD, 10-14 year old male adolescents

One of the study criteria for inclusion was that all adolescent participants had to be aware of their HIV-positive status. Interestingly, in Chinyanja, a local language, the term "nimamwa mankwala" is consistently used to denote HIV-positive status, although its literal translation is "I drink medicine". Some adolescents living with HIV exhibit self-stigma as evidenced in the remark of a 15 year old female adolescent: *"I won't get married when I grow up since I drink medicine (I'm HIV positive). I would rather be a nun."*

Waiting for disclosure

An overwhelming majority of the adolescents interviewed disclosed that they learnt about their HIV-positive status from health care providers and not their parents.

> **"It's a very big problem. A majority of our adolescents here are on treatment without the parents telling them why. We try as much as possible to help the parents to disclose the status to the child since HIV is talked about in schools, on TV and other places and we don't want the child to learn about their status from a different source. Our message to parents is not to tell lies to their children."** Service provider, faith-based facility

The observation of the service provider quoted above is supported by the response by a female adolescent:

> **"The nurse at the clinic told me that I am HIV positive. I know I was born like this. I'm still waiting for my mother to tell me."** 16 year old female adolescent

Observations by some parents and service providers interviewed suggest that many parents may not know how to handle the challenge of telling their children how they came to be living with HIV and may refrain for fear of possible adverse reactions from the child.

> **"It is taboo for me as a father to discuss such things (SRH) with my daughter."** Father, 15-year old female adolescent

> **"I think as parents, we lack information. What can I teach my child if I don't know myself? We need to be empowered with information"** Father, 14-year old female adolescent

In contrast, some of the parents were of the opinion that the HIV-positive adolescents had unique SRH needs which could best be addressed by the parents themselves.

> **"As a parent, I will do it myself. I don't think any other person would understand my daughter's problem. She has special needs"** Mother, 13-year old female adolescent

> **He (son) is still young. I share with him stories on HIV now. When he is old enough, I will tell him everything. It will be easier for him to understand then. It is challenging at the moment** Mother, 10-year old male adolescent

Demanding information

A number of the younger adolescents stated that the FGD provided their first opportunity to ask questions about sexuality and reproduction in a friendly atmosphere. When asked what they considered the appropriate age for the provision of SRH information and education, the female adolescents indicated younger ages than did the males. Equally evident was the variation between the younger and older adolescents regarding the specific SRH issues about which they sought more information and education. This is indicative of the evolving SRH needs and concerns across the life cycle.

The need for SRH information was echoed by a service provider who also cast some light on some of the questions frequently encountered:

> **"They face a lot of challenges. They ask questions like, "Am I ever going to get married now that I'm HIV positive?" "If I have sex with my partner, am I going to infect them?" Some concerns that they normally have relate to puberty. Even when a child is 16, they could be looking like a 10 year old. When they start experiencing the (puberty) changes on their bodies, they tend to wonder what is happening."** Service provider, faith-based facility

In Zambia, cultural norms in most communities dictate that discussions relating to sexuality be shrouded in secrecy. Additionally, any discussion of matters relating to SRH between parents and their children is generally considered taboo. Thus, it is not surprising that only 10% of the adolescents interviewed indicated parents as their main source of SRH information and advice. For more than half of the respondents, friends were cited as the main source of SRH information and advice. The clinic was also identified as another important source of information especially for those adolescents on ART.

> **When I go to get medicine from the hospital, we have a meeting with other young people and the nurse talks about such things (SRH matters).** FGD, 10-14 year old female adolescents

Although the Ministry of Education has incorporated sexuality education in the school curricula at various levels, the extent to which teachers discuss SRH matters during lessons is not clear. While some of the respondents stated that they obtained their information on SRH from school, others were of the opinion that their teachers did not provide sufficient information on the subject.

> **"Our policies on SRH and HIV issues for learners are very good. The problem is implementation at school level...Since the topics are non-examinable; some teachers do not bother to present them in class. In some cases, there are not enough reading materials for every learner."** Policy influential, Ministry of Education

A notable finding of this study is the prominent place peers hold in the provision of SRH information for most of the adolescents interviewed. Part of the explanation lies in the quest for independence from

parental control that is often characteristic of adolescence. For some of the respondents, turning to peers was a coping strategy and friends provided them with information (albeit not uniformly accurate) that they could not obtain from their parents or guardians.

Seeking services and care

During the FGDs and the in-depth interviews, adolescents were asked if they had experienced an SRH-related condition and their motivations for selecting the service provider they opted to consult. Those who had experienced such a condition reported having taken the following steps: use of traditional medicine provided by a relative, self-treatment with medication from private drugstores, and not seeking any help at all. Remarkably, a large number of respondents opted not to seek help at all; convinced that the condition was simply a result of their HIV positive status. The health seeking behaviour (or lack thereof) exhibited by the respondents suggests a serious lack of access to accurate information tailored to the SRH needs of adolescents living with HIV.

According to some providers, STIs were prevalent among adolescents living with HIV. Syphilis, in particular, was identified as the most common STI for which they sought medical attention. Contraceptives and pregnancy testing were also mentioned among the services and commodities usually asked for.

Adolescents face many barriers in accessing health care services. These include: legal barriers such parental or spousal consent requirements, or age limits for providing contraception. Although most SRH services are ostensibly free in public health facilities in Zambia, the indirect costs associated with accessing these services can deter adolescents from seeking appropriate help when in need. Some of the respondents mentioned the cost of transport to the health facility as the reason they did not collect the free condoms they knew were available in government-run clinics.

For some of the respondents on ART, the long travel times they experienced when collecting their monthly supply of drugs discouraged them from seeking psychosocial help at the clinic for their SRH concerns. One sexually active male adolescent described the lack of youth-counsellors at the local clinic as the main reason he could not go there to obtain SRH information and advice.

The need for integrated HIV and SRH services was also evident among some of the parents and guardians interviews.

Our fertility desires

Nearly all the adolescents in this study indicated that they would like to have wives or husbands and their own children in future. Partner notification and choosing a partner who was also HIV-positive (sero-sorting) were mentioned as coping strategies for HIV-related stigma.

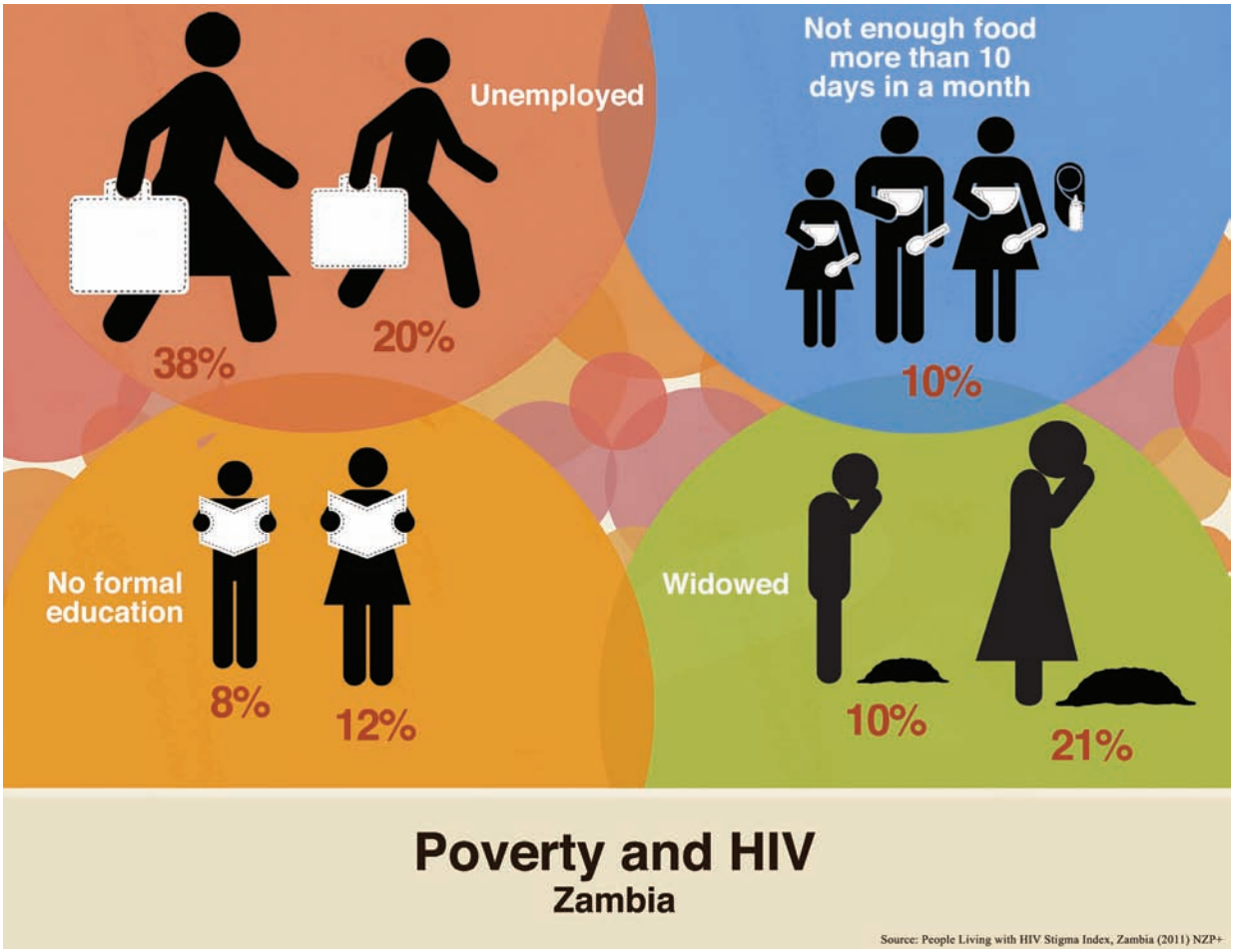
> **A woman makes a home. When I grow up, I will marry and have two children. We talk about it with my friends at school.** FGD, 10-14 year old male adolescents

Younger and older adolescents alike viewed engaging in relationships and bearing children as among their human rights that should be respected. The findings suggest that being HIV positive does not have much influence on the adolescents' attitudes towards relationships and childbearing in adulthood. Also, the fertility intentions are perhaps a reflection of the socio-cultural factors that underpin the reproductive decisions of many Zambians.

Furthermore, female respondents in particular exhibited a high degree of awareness of prevention of vertical transmission as way of reducing the risk of passing the infection to one's child(ren).

> **"Everyone is free to marry and raise a family. Even an HIV positive couple can bear HIV negative children"** FGD, 10-14 year old female adolescents

Graphic 3



Poverty and unemployment

Poverty Reduction Strategies

Poverty can increase the risk of contracting HIV, particularly for youth and women, while HIV can result in a slide into poverty through bereavement, ill-health and incapacity to work, loss of employment opportunities through stigmatisation, and elevated costs of medical care. People living with HIV who live in poverty have more difficulty in adhering to treatment (partly because irregular food intakes can make ARV treatment intolerable) and thus experience higher mortality rates and greater infectiousness. Thus in a country such as Zambia which is experiencing a generalised HIV epidemic with very high rates of infection in the general population, these dynamics must be addressed as part of effective poverty interventions.

While respondents in the *GIPA Report Card* study were mainly agreed that Zambia has a poverty reduction plan, views were mixed on whether people living with HIV had been involved as such in developing it, and a small majority felt that people living with HIV had not had adequate input in adjusting for gender differences in impacts of HIV. However, people living with HIV were reported to have been involved in

the development of the current Fifth National Development Plan that includes the aim of reducing the impact of HIV on the population in general and on people living with HIV in particular.

Employment

While respondents in the *GIPA Report Card* study assumed that people living with HIV were represented by NZP+ during the development of employment legislation, this was not actually the case. Not many organisations have a policy that mandates employment of people living with HIV, but many encourage people living with HIV to apply and may prefer to hire them. Where designated positions exist, many are to subordinate positions, though some organisations did reserve high-level roles (but unpaid positions such as Board members) for people living with HIV. The most reported barrier related to employment was stigma and discrimination. This was said to reduce employment chances even for people living with HIV who are highly qualified professionals.

In the *PLHIV Stigma Index* study, over one quarter of respondents across all locations were unemployed with higher levels reported in rural areas (nearly 35%), and unemployment was more pronounced among women than men (37.6% and 20.4% respectively). Similarly, more men than women reported being in full-time employment (21.9% compared to 8.4%).

As highlighted above in ***Graphic 2***, evidence from the PLHIV Stigma Index study demonstrates the very real existence of HIV-related stigma and discrimination in the workplace.

> **"I was demoted from work, when I was found to be HIV-positive. The public service commission helped to resolve the issue upon reviewing the case, and I was reinstated and promoted at the same time." (Male, large town)**

> **"My friends at the market wanted to chase me because I was HIV-positive. Other people living with HIV and the market leadership helped resolve the issue." (Female, large town)**

Nutrition and food security

Overall food insecurity was prevalent amogst respondents in the *PLHIV Stigma Index* study, ranging from 83.8% in large towns/cities through to 95.2% in small towns or villages. However, severe food insecurity was more common among large town/city residents (64.6%) than in small towns (32.3%) or rural areas (43.4%). The results suggest that challenges to access aduquate nutrition are common in all locations.

Education

- With regard to education opportunities, 8% of respondents in the *PLHIV Stigma Index* study reported having been dismissed, suspended or prevented from attending an educational institutional on account of HIV status.

In the *Human Rights Count* study, results indicated that among the females that participated in the study, none had attained a university level education whereas 7.1 % of males had. On the other hand, there were more women than men who reported having attained primary and secondary education.

Recommendations

Reform of laws/policies

- The government must take the lead in creating a policy and legal environment that will safeguard the rights of people living with HIV and specifically address HIV-related stigma and discrimination.
- NAC must support the active participation of people living with HIV in the development of laws, polices and guidelines.
- NZP+ will engage government and in particular members of parliament to broaden understanding of the legal and policy implications of criminalisation in HIV transmission cases.

Addressing human rights violations, discrimination and stigma

- NZP+ must intensify efforts to build the human rights literacy of PLHIV and raise awareness of positive health, dignity and prevention
- Given the low level but consistent pattern of denial of rights to people living with HIV in health care settings, NAC should review and update pre- and in-service training curricula to enhance the capacity of health providers to provide non-judgmental and non-discriminatory services to people living with HIV.
- 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.
- Civil society organisations should develop monitoring tools that will allow for ongoing tracking of HIV related abuses. Government departments should monitor HIV related complaints and responses to these complaints.

Prioritising women and other key populations

- PLHIV should also be involved in monitoring the effects of HIV and AIDS programming in affected communities and in helping health and development professionals to ensure their efforts achieve maximum effectiveness for the health and welfare of the Zambian people.

Respecting sexual and reproductive rights

- Scale up the provision of correct information and appropriate options for the sexual and reproductive health for people living with HIV, including prevention of vertical transmission programmes and services across all locations.
- At the health facility level, high quality, non-judgemental counselling and related services should be more readily available. This requires the provision of adequate SRH supplies, commodities and service providers trained to address the unique SRH needs of adolescents living with HIV.
- Service providers and community members should promote the establishment of adolescent support groups. This would enhance the accuracy and accessibility of peer-provided SRH information.
- Interventions should also equip parents and guardians with the knowledge and skills they need to provide such information to their HIV-positive adolescents.

Access to comprehensive healthcare

- Invest more in promoting voluntary counselling and testing as an entry point for timely diagnosis to enable treatment, care and support to start at the earliest opportunity.

Promoting economic and social rights

- The Government must develop HIV-related social protection measures and other economic empowerment schemes to that ensure people living with HIV have access to education, employment, and jobs in order to mitigate the impact of poverty.

Notes

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