

GIPA Report Card Zambia

Country Assessment 2009

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



GLOBAL NETWORK OF
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Zambia

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Acronyms

ARV	Antiretroviral
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)
CHEP	Copperbelt Health Education Project
CIDRZ	The Centre for Infectious Disease Research in Zambia
COZWHA+	Coalition of Zambian Women Living with HIV/AIDS
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
GRC	GIPA Report Card
IEC	Information, education and communication
ICW	International Community of Women Living with HIV/AIDS
ILO	International Labour Organisation
JICA	Japanese International Cooperation Agency
MIPA	Meaningful Involvement of People Living with HIV and AIDS
NZP+	Network of Zambian People Living with HIV/AIDS
NAC	National AIDS Council
NGO	Non-Governmental Organisation
NSP	National HIV/AIDS Strategic Plan
NUNV	National United Nations Volunteer Project
PALS	Positive and Living Squad
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
SHARe	Support to the HIV and AIDS response
TALC	Treatment, Advocacy & Literacy Campaign
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UNV	United Nations Volunteer Project
ZNAN	Zambia National AIDS Network

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The GIPA Report Card is one of five evidence-gathering tools being implemented through the HIV Leadership through Accountability programme. The programme combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy to achieve Universal Access to prevention, treatment, care and support. For more information about the HIV Leadership through Accountability programme please visit www.hivleadership.org.

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Executive Summary

Sample

Representatives were interviewed from 29 organisations active in the HIV and AIDS response in Zambia. Some were PLHIV, some professionals working on HIV and AIDS, and some were both. The GIPA Report Card was developed to assess the level and type of involvement of PLHIV in the current response, with a view to informing future efforts to increase their meaningful involvement in future programming.

1.1 GIPA Knowledge

Overall, respondents showed substantial knowledge of the GIPA principle. Meaningful involvement of PLHIV was perceived to imply participation in the HIV response at all levels and in all matters including planning, implementation, monitoring and evaluation.

1.2 The National AIDS Plan

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

1.3 GIPA at State and Provincial levels

The GIPA principle was said to be implemented with PLHIV participation at national, provincial, district and community levels in planning, implementation and monitoring. However, it is not always consciously recognised to be the GIPA principle in the formal sense. It was hoped that the level and quality of PLHIV participation in the HIV and AIDS response could be improved. The concept of the GIPA principle was new to some of the respondents.

1.4 United Nations General Assembly UNGASS Special Session on HIV/AIDS

Some respondents had no knowledge about UNGASS and others knew little about it, reportedly due to lack of involvement in the UNGASS process. The latest UNGASS country report was an improvement over the previous one, mainly because meaningful involvement by NZP+ had increased. While UNGASS reflects the true picture of the HIV response in Zambia, more needs to be done in terms of following up the gaps identified in the report.

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1.5 Policy Development

PLHIV involvement in national-level policy development was seen as meaningful because PLHIV are represented on most national HIV planning teams. Participation was however seen as still below expectation due to stigma and discrimination; lack of capacity by PLHIV to contribute effectively; and because policy development is usually at the centralized level of NZP+ or TALC. Often, involvement was more at the level of implementation rather than earlier, at the policy-making, planning and design stages of programme development. The GIPA principle is still in its infancy in Zambia and there is need to widen participation structurally and systematically right down to the grassroots. It was noted that observance of the GIPA principle may be tokenistic, sometimes in support of fundraising efforts.

1.6 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. Women living with HIV were reported as not doing enough themselves to get involved in national HIV policy because of cultural limits on socially appropriate roles.

1.7 Universal Access

National targets for universal access were reported to have been set in such areas as VCT, including PMTCT and also ARVs. Even though supply constraints occur, ARVs are generally accessible. Access has been negatively affected by 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 PLHIV. Take-up of PMTCT was reported to have fared better. Nevertheless, civil society organizations (CSOs) were reported to have enjoyed some success in meeting their individual targets.

1.8 Representation of Networks of People Living with HIV

It was generally felt that PLHIV 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 PLHIV involve themselves in network issues.

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1.9 Research and Sexual and Reproductive Health

PLHIV are involved in mainly operational research such as male circumcision, PMTCT, herbal remedies, vaccines and microbicides for women. Respondents reported that no clinical trials are being carried out in Zambia. A substantial number of the respondents were not sure if PLHIV are involved in research. Some of the research was seen as unethical, with concerns expressed about the potential effects on some research participants.

1.10 Poverty Reduction Strategies

Zambia has a national poverty reduction plan that includes PLHIV, although not in a very specific manner. The current Fifth National Development Plan aims to reduce the impact of HIV on the population in general and PLHIV in particular. Some of the poverty reduction strategies are implemented through the NAC by CSOs which are involved in poverty reduction for PLHIV. While the country was felt to be on the right path, there still is need to increase the levels of PLHIV participation. Women were particularly seen to be more vulnerable to HIV-related poverty, as more women than men were living with HIV.

1.11 Employment

Respondents reported that PLHIV were represented by NZP+ during the development of employment legislation. Not many organisations have a policy that mandates employment of PLHIV, and an objection to doing so on equal opportunity grounds was expressed. Most encourage PLHIV to apply and may prefer to hire them, but without any formal allocation of positions for PLHIV only. Where designated positions exist, many are to subordinate positions, though some organisations did reserve high-level roles for PLHIV. The most reported barrier related to employment was stigma and discrimination. This was said to reduce employment chances even for PLHIV who are highly qualified professionals.

1.12 GIPA-related materials

A few organisations were reported to have developed some materials, mostly IEC. Many were however reported to not having developed any materials on the GIPA principle, though some used materials developed by others. In many cases, GIPA did not fall within the organisations' primary mandate, and there was often no budget for such materials.

1.13 Financial Support

Most institutions were reported to be providing financial support to PLHIV in the same way that it was provided to those who were not PLHIV, based on such factors as qualifications, position, salary scales, and sometimes on the basis of explicit equal opportunity principles.

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One major complaint revolved around remuneration for voluntary work: there was a common feeling that PLHIV may be expected to volunteer to help others, but even expenses for transport are not always reimbursed. Costs for child-care are an issue; some organisations cover these but others do not.

1.14 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 PLHIV as well as the activities that they could be involved in. Other barriers that were cited included differences among PLHIV, low levels of skills, inadequate staffing and inadequate funding.

1.15 Opportunities for Involvement

Zambia has had many success stories relating to HIV, and there is opportunity to build on these successes, especially in the light of the current increase in funding. The political environment is conducive to support dialogue, advocacy and legislation in favour of PLHIV. 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 PLHIV, and for government to be proactive in inviting PLHIV to participate in the response to HIV and AIDS. More training for the various stakeholders about the GIPA principle would clearly be useful.

Introduction: the GIPA Principle

In order to realise the rights and responsibilities of people living with HIV to self-determination and meaningful participation in decision-making processes that affect their lives, it is important that PLHIV not just take part in affairs that affect them but take part in a meaningful way. It is with this in mind that the principle of “Greater Involvement of People Living with HIV and AIDS” (GIPA) was envisaged. Application of the GIPA principle promotes and strengthens the involvement of PLHIV and ultimately enhances the quality and effectiveness of HIV responses.

As part of an international effort to increase the involvement of people living with HIV (PLHIV) in addressing the issues which affect them, the Global Network of People Living with HIV (GNP+) is undertaking an international study of the level and type of involvement of PLHIV in HIV and AIDS programming. It is seen as a means of monitoring and evaluating governments’ and organisations’ application of the GIPA principle, particularly in light of the 2001 United Nations General Assembly’s Special Session on HIV and the Declaration of Commitment.

A standard assessment tool, the GIPA Report Card (GRC), has been prepared to support national and international advocacy for GIPA, following a PLHIV Think Tank Meeting in 2005. A questionnaire has been developed to gather data for the GRC, which is completed in each country by a selection of key informants working on PLHIV issues, and supported by a literature review.

The objectives of the GIPA Report Card are to:

- Provide information on the current level of application of the GIPA principle, which will serve as a baseline against which future application of the GIPA principle can be measured;
- Hold governments, NGOs, United Nations agencies, donors, organisations of PLHIV and other stakeholders accountable to their commitments relating to the application of the GIPA principle;
- Increase and improve the meaningful participation of PLHIV in different sectors within the broader national response to the HIV epidemic in a country;
- Assist in developing indicators to monitor and evaluate the quality and impact of PLHIV engagement; and
- Provide follow-up recommendations to enhance stakeholders’ (governments, NGOs,

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United Nations agencies, donors, organisations of PLHIV) identification of opportunities and entry points for the application of the GIPA principle within their organisation or institutions and in their policies and programmes, including cost estimates.

The GIPA Report Card is to be owned, developed and implemented by PLHIV through a bottom-up process, including broad and diverse consultation.

This report presents the GIPA Report Card for Zambia.

Policy and Literature Review

2.1 HIV and AIDS in Zambia

Zambia, like other Sub-Saharan countries, has one of the world's highest HIV general prevalence rates. Zambia's first AIDS case was reported in 1984. One year later 17.5% of hospital patients in the capital city of Lusaka tested HIV-positive. In 2002, the National AIDS Council (NAC) was established and in 2004, the late President Patrick Mwanawasa declared HIV and AIDS a national emergency.

According to the Zambia Demographic Health Survey (ZDHS, 2007), the national HIV prevalence among adults ages 15 to 49 is at 14%. This represents a decline from the 2002 estimate of 17%. The proportion of people living with HIV rises from 5% among those aged 15-19 years to 24% among those aged 35-39 years. The prevalence of HIV is twice as high in urban (23%) as in rural areas (11%). HIV rates in Zambia are higher among wealthier people and the better-educated.

Women have a disproportionately higher HIV infection rate at 16% compared to 12% for men. The majority, about 80%, of transmissions are heterosexual while the remaining 20% is mainly as a result of mother to child transmission (PMTCT). Life expectancy has also fallen from 52 to 42 years¹. The epidemic in Zambia is feminised and in the age group 15-24 years, the prevalence for women is four times higher than for men.

The Zambian government developed a strategic plan for addressing HIV and AIDS as early as the mid-1980s. By the 1990s, it was estimated that 20% of the population had become infected with HIV. This rapid rise in prevalence led the World Health Organization (WHO) to develop a National AIDS Advisory Council in Zambia³.

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2.2 History of the GIPA principle in Zambia

In 1996, Zambia had one of the first noted examples of the GIPA principle in practice with the United Nations Volunteer (UNV) project titled “UNV project to support people living with HIV and AIDS.” Zambia was one of the two countries first selected to implement a two-year pilot project to test the National UNV (NUNV) model as a possible mechanism for increasing GIPA in the national response⁴. UNV has enhanced GIPA-related efforts through community-oriented pilot projects.

The first site in Zambia for the application of the GIPA principle through UNV volunteers was the Copperbelt Health Education Project (CHEP), an NGO that is involved in the provision of information, education and communication (IEC). CHEP management appointed the NUNV as Coordinator of PALS programmes (Positive and Living Squad, which carries out peer education), in order to give him/her greater responsibility and to broaden its own comprehension of the involvement of PLHIV in HIV and AIDS activities. CHEP has also funded three workshops in which the NUNV has been a resource⁴. Following piloting in Malawi and Zambia, the initiative expanded to include more than 15 countries.

2.3 The GIPA Principle and NZP+

The Network of the Zambian People living with HIV/AIDS (NZP+) was established in Lusaka in 1996 as a national organization of PLHIV. It aims to improve the quality of life of PLHIV by pursuing three objectives: support of, communication with, and representation of the people living with HIV/AIDS. The support group is the fundamental unit of NZP+ constituted by PLHIV who live in the same locale or work in the same place. NZP+ has representation in all of Zambia’s 72 districts.

NZP+ represents and encourages PLHIV to participate actively and be involved in decision-making processes through lobbying, campaigning and raising awareness at all levels of government. NZP+ sits on the National AIDS Council (NAC) as a representative of PLHIV and other civil society organizations. In 2008, there were 28 district level policy dialogues involving local governance municipal authorities, PLHIV (NZP+) and other stakeholders. This provided opportunities for GIPA in local governance structures and shows promise for the GIPA Principle in the planned decentralized HIV response.

NZP+ is a member of the national AIDS Response which has many partners. The UNGASS taskforce team consists of 6 civil society representatives, including a PLHIV¹⁵. Within the Zambian 2008 and 2009 National Multi-Sectoral AIDS Work plan, there are six key areas of intervention including GIPA, and NZP+ is a lead or contributing partner in all areas of multi-sectoral workplans^{16,17}. Along with utilizing their seats on various boards, NZP+’s current

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GIPA-related activities include training of support group facilitators in advocacy and conversations to promote civic awareness⁵. The organizations' strategic plan has outlined the projected implementation of training and capacity enhancement services to help facilitate an increase in the realisation of GIPA⁶. Lessons learned however suggest that there is a need to scale up support for PLHIV in all of its six thematic areas of:

- Intensifying prevention,
- Expanding treatment, care and support,
- Mitigating the socio-economic impact,
- Strengthening the decentralised response and mainstreaming HIV and AIDS,
- Improving the monitoring of the response, and
- Integrating advocacy and coordination of the multi-sectoral response¹⁸.

2.4 The GIPA Principle Today in Zambia

The national HIV/AIDS/STI/TB policy aims to address the problem of HIV in Zambia through a multi-sectoral and multi-dimensional approach. In order to reduce the rate of new infections and to mitigate the effects of the epidemic, the policy aims to promote partnership and ensure that all sectors of society including all line-ministries, non-governmental organizations, and bilateral as well as multilateral partners are actively involved in the design, implementation, review, monitoring, and evaluation of the national response to HIV and AIDS. The policy highlights the formation of NZP+ and the role PLHIV play by *"participating in the design, development, and implementation of HIV/AIDS-related policies and programmes."* According to the policy brief, government line-ministries and agencies are expected to include NZP+ members in the formulation of HIV and AIDS-related programmes and activities⁷.

Despite these positive strides, key policy documents in the national HIV response still do not address the GIPA principle. Although one of the guiding principles of the National HIV and AIDS Strategic Framework is *"...the greater and meaningful involvement of PLHIV (GIPA) at all levels of the response"*⁹, it does not address how it will include the GIPA principle in HIV programming, and PLHIV participation in the HIV response in Zambia remains low.

Apart from broad statements of commitment to support employees and individuals living with (or affected by) HIV^{8,14}, the national HIV/AIDS/STI/TB policy does not explicitly make the GIPA principle key to the realisation of its goals and objectives. Even though it highlights partnership with NZP+, the National HIV/AIDS/STI/TB Monitoring and Evaluation Plan does not state how it will monitor/evaluate this partnership in the formulation of HIV/AIDS-related programmes and activities¹⁰.

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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 report¹².

Discussions have suggested that there is still a need for the UN to advocate and promote greater and meaningful involvement and participation of PLHIV. The GIPA principle also needs to be integrated into all aspects of AIDS interventions nationally and at the grassroots in all districts¹¹. Throughout 2007, the NAC Civil Society Unit focused primarily on identification and capacity support for key self-coordinating structures, including NZP+. PLHIV and groups working on gender issues are now routinely included in the NAC consultation process. The NAC work plan for 2007 mentions one of the outcomes as being *“an effective NAC that is able to achieve its mandate”*. An important component of this will be to extend support for enhancing institutional leadership capacity within NZP+ at all levels: to provide effective leadership in all areas of governance, strategic thinking and planning, programme development, advocacy, and monitoring and evaluation. A key country programme output would be a national framework to support capacity development within key institutions using the GIPA principle, with NZP+ as a collaborating/implementing partner¹³. However, this needs to be consolidated in a practical manner and if the commitment is to turn into a reality, it must be clearly articulated in the NAC Work plan.

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Methodology

The methodology used follows that set out in the GIPA Report Card User Guide 2009.

A purposive randomised sampling approach was used to recruit the PLHIV respondents. For the leadership cohort, the study used a snowball approach. The PLHIV cohort was recruited through the e-forum list sponsored by Partners Zambia, the Treatment Literacy Campaign and the World AIDS Campaign. Invitations to participate in the GRC were also made at two partner workshops for PLHIV. Results were disaggregated by gender.

Clusters were planned to be representative of the Zambia National AIDS Strategic Framework sector wide approach. Each cluster had 2-3 PLHIV respondents with a corresponding 1-2 leadership grouping in that sector. This was purposely done in order to capture both views towards the GIPA principle. The rationale for this approach was mainly so that the GIPA principle would be measured and understood in light of the national HIV response. Respondents were broken down as private, public bilateral/ multilateral donors, UN system, faith-based, civil society organisations (CSO), and networks of PLHIV.

A total of 29 interviews were conducted in July and August 2009. Of these, 2 respondents self-administered the GIPA Report Card Questionnaire, 3 respondents were interviewed as a group and 24 were one-on-one interviews. One respondent was only able to respond to questions 1 to 4 due to time constraints.

GIPA Report Card Results

4.1 Profile of respondents

Characteristics of Individual Respondents

A total of twenty nine adults were interviewed, of age ranging from 27 years to 54 years as follows:

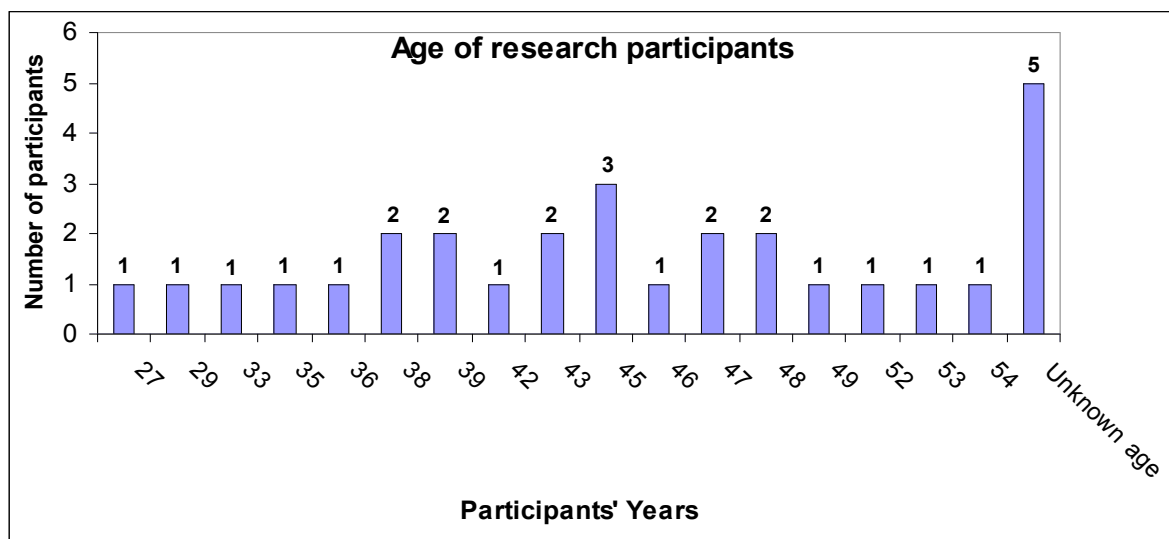


Figure 1: Age range of respondents

Of the people interviewed, 14 were female and 14 male; the gender of one person was not indicated.

Organisations that took part in the interviews

The 29 respondents came from 21 organisations, as follows:

1. Network of Zambian People Living with HIV/AIDS (NZP+) (4 respondents)
2. Treatment, Advocacy and Literacy Campaign (TALC) (2 respondents)
3. Support to the HIV and AIDS Response (SHARe) (2 respondents)
4. Centre for Infection diseases Research in Zambia (CIDRZ)
5. National Museum Board Secretariat
6. Ministry of Education (4 respondents)
7. Times of Zambia
8. Zambia National Commercial Bank

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9. Zambia Revenue Authority
10. Standard Chartered Bank
11. Academy for Education Development
12. United Nations
13. UNAIDS Zambia office
14. NZP+/COZWHA+(Coalition of Zambian women living with HIV/AIDS)
15. DfID (UK government Department for International Development)
16. Japan International Co-operation Agency (JICA)
17. Zambia National Aids Network (ZANAN)
18. Zambia Centre for Communication Programmes
19. Zambia Business coalition on HIV/AIDS
20. National HIV/AIDS/STI/TB Council (NAC) (2 respondents)

Budgets for organisations in the sample

When respondents were asked to state their organisations' annual budget, slightly over half (15) of the respondents did not know or were not sure and therefore did not mention the budget. Of those that mentioned the budgets, the figures ranged from US\$ 130,000 to US\$ 5million per annum, as follows:

1. K 700,000,000 (US\$ 130,000)
2. K 900,000 (US\$ 170,000)
3. US\$ 250,000
4. US\$ 200,000- 250,000
1. US\$ 350, 000 - 400,000
2. 2 billion Kwacha (US\$ 370,000)
3. US\$ 500,000
4. US\$ 1.1million
5. US\$ 2million
6. US\$ 2-3 million
7. \$ 3.5 million
8. US\$ 4million
9. K 25,000,000,000 (US\$ 4.6 million)
10. US\$ 5million

Employees living with HIV

Twenty of the twenty-nine organisations were reported to have employees who were living with HIV. Altogether, there were 1,103 employees living with HIV: 13 organisations employed 1-4 PLHIV, six had 9-30, and one organisation had 1,000 employees living with HIV. In one organisation, the respondent did not reveal the number of PLHIV for purposes of

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confidentiality while in another, the respondent did not know the number of PLHIV in that organisation citing that not many want to come out in the open due to stigma and discrimination. Seven organisations reported having no employee who was living with HIV.

Table 1: Organisations with Employees who are living with HIV

													Total
Number of employees who are PLHIV	1	2	3	4	9	11	16	27	30	1,000	Not known	None	103
Number of organisations	3	6	3	1	2	1	1	1	1	1	2	7	29

PLHIV volunteers

Among the sample, no respondent reported being a volunteer. Ten of the respondents reported not having PLHIV volunteers in their organisation, while another stated that PLHIV volunteers were a mainstay of their organisation's activities:

"Most work done here is being implemented by volunteers and there are about fifty PLHIV doing voluntary work in our organization country-wide"

The numbers of volunteers living with HIV according to organisations that reported having such members of staff came to a total of 2,232, broken up as shown in the figure below:

Table 2: Organisations with volunteers who are living with HIV

												Total
Number of volunteer PLHIV	1500	360	200	>100	50	12	7	2	1	Don't know	Nil	>2232
Number of organisations	1	1	1	1	1	1	2	1	3	2	15	29

One respondent was not sure if there are any PLHIV volunteers in their organisation because not many are able to disclose their serostatus. Another did not reveal how many PLHIV volunteers were in their organisation as this was regarded to be confidential. Thirteen respondents reported not having any such volunteers in their respective organisations.

Designated paid positions for people living with HIV

Out of 29 organisations, only 6 had positions that were deliberately reserved for PLHIV. One organisation had designated two positions; those of Office Messenger and Office Cleaner. Another organisation designated around 1,082 positions including 1 Council member, 9

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Provincial members; 72 District members, and about 1,000 Community members. One organisation had initially designated the position of “National Coordinator” but this seemed to be no longer the case. The position of Executive Director was not designated in any organisation. In another organisation, 6 positions had been designated and included those of Board Member, Coordinators, Office Cleaner, Driver and Chairperson. A third organisation reserved the positions of Peer Educators, Supervisors, and Programme Coordinators for PLHIV.

The majority of the informants reported that their organisations did not specifically reserve any positions for PLHIV:

“We do not have such conditions as a ministry”

Two of the organisations reported that rather than deliberately designate some positions for PLHIV, they encourage them to apply for such positions and give them priority. Another organisation reported not wanting to designate any positions because doing so would be discriminatory.

“PLHIV are given priority affirmed in Terms of Reference (ToR) and Job adverts”

“No designation, but employment of PLHIV is encouraged”

“For the position of Executive Director, PLHIV are encouraged to apply”

“We do not want to be discriminatory”

Implementation of internal discussion about the GIPA principle

The majority (21) of the informants reported that their organisations had internally discussed the GIPA principle. Discussion in some cases was brief and not regular.

“Yes, we have been doing that and it's one of our principles that we have undertaken, most of the people working for this organization are PLHIV including our chairperson”

“To some extent GIPA [is] shared after briefing by other coalition members”

“Not formally, but supportive of coordinator's HIV work”

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Primary locations where projects are implemented

A substantial number (7), of the organisations stated that their projects were implemented throughout the country. Two of the organisations implemented their programmes in rural areas and one implemented their activities not only in Zambia but also in a neighbouring country. Most of the organisations did not indicate the primary locations of their projects.

Type of population(s) served

Almost all of the organizations served two or more types of populations and only one of them served only one target group. The populations that were being served by most of the organizations were PLHIV, particularly women, young people aged 10-25 years, the elderly, and men, and several non-PLHIV groups, such as child-headed households, orphans and vulnerable children, prisoners, sex workers and displaced people. Some of the respondents interviewed were not sure about the type of populations that their organizations were serving. The respective populations that were reported as being served by the different organisations are shown in the table below:

Table 3: Target groups of PLHIV organisations

Population served	Number of organisations serving this population
People living with HIV, of which:	8
Women	8
Young people (10-25 years of age)	7
Elderly	6
Men	5
Orphans and vulnerable children	5
All of the above	4
Child-headed households	3
Migrant labourers and/or other mobile populations (including deportees)	2
Prisoners	2
Sex workers	2
Refugees, internally displaced people or asylum seekers	1
Injecting drug users	0
Men who have sex with men	0
Transgender people	0
Other	6

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4.2 Mission Statements of the Organisations

The organisations that were part of the sample had various missions, addressing the problem of HIV and in some cases other goals. The missions ranged from advocacy for more accessible treatment to the promotion of leadership, as well as wider coordinated participation in the HIV response by stakeholders including Public Service, Civil Society and PLHIV. Some missions related to poverty reduction and empowerment of PLHIV and general improvement of the quality of life for PLHIV including discouragement of stigma and discrimination. Other missions concerned financial as well as technical support; voluntary counselling and testing; care and support as well as encouraging the implementation of HIV workplace programmes including in the private sector.

- The mission of NZP+ was reported as *“envisaging an improved quality of life for PLHIV who are empowered and productive members of a well informed HIV/AIDS competent community free of stigmatization and discrimination”*.
- The Treatment, Advocacy and Literacy Campaign (TALC) advocates for equitable access to affordable, cost effective, comprehensive and complete continuum of treatment, care and support for people living with HIV and AIDS and those affected.
- Support to the HIV/AIDS Response in Zambia (SHARe), was reported to aim to provide support to the HIV response in Zambia, through organizational and capacity strengthening policy environment regulation and delivery of HIV and services. SHARe also strives to ensure a well coordinated HIV response and to support the National AIDS Council (NAC) in its day-to-day programmes including other partners like NZP+.
- The mission for the Centre for Infectious Diseases Research in Zambia (CIDRZ) is to get as many people as possible tested, able to access treatment, and able to speak openly about HIV status, and to fight stigma and discrimination.
- UNAIDS’s mission is to help the world prevent new HIV infections, care for those already infected, and mitigate the impact of the epidemic by supporting, strengthening and coordinating an expanded response that engages the efforts of many sectors and partners in the UN system, governments, civil society, donors, the private sector and others.
- The mission of the Zambia National AIDS Network (ZNaN) is to promote and facilitate liaison and coordination among HIV/AIDS services organizations and

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provide assistance in strengthening the capacity of member organizations to respond to the challenges of HIV/AIDS in Zambia.

- At the Zambia Business Coalition on HIV/AIDS, the mission is to organise the private sector to begin to do something about HIV/AIDS for their organizations and to provide technical support to workplace programmes in member companies for HIV workplace activities to take off.
- The UK Department for International Development (DfID) was reported as wanting to reduce poverty through technical assistance to the public sector and to civil society.
- The mission of the Japanese International Corporation Agency (JICA) is to improve the lives and health of people in Zambia by supporting government and communities with technical capacity-building to enhance self-sustainability of Zambian people.

Some of the mission statements that emerged from the respondents dealt with issues quite apart from HIV and AIDS:

- The National Museum's mission is to collect movable heritage for preservation, education and research for present and future generations.
- The Ministry of Education's mission is to provide quality education to all.
- The Zambia Revenue Authority's mission is to collect enough revenue for the government.

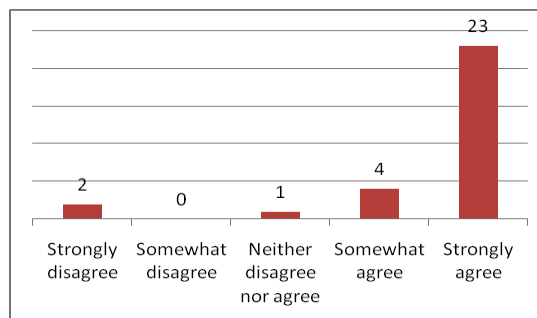
Organisations reported different means for achieving their goals. From a structural point of view, one organisation reported decentralised structures from the national down to district and further down to community levels. Another reported that in order to achieve their mission, the organisation was *"guided by a strategic plan that has been put in place by the organization"*. From the perspective of policy, some of the organisations reported being mandated by an act of parliament while others aimed either to develop or to advocate for development of appropriate policy. Others achieved their goals through monitoring, evaluation and resource mobilisation as well as by linking PLHIV to appropriate treatment, and financial services and support. Some respondents did not provide information related to their organisation's mission statements while other interviewees did not know the mission statements of their employers.

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4.3 GIPA Knowledge

When asked to what extent they agreed or disagreed with the statement below, respondents indicated the following:

I know that the GIPA principle means meaningfully involving PLHIV in the programmatic, policy and funding decisions and actions that impact on our lives by ensuring that we participate in important decisions.



The vast majority of the interviewees strongly agreed with the statement.

When asked what the meaningful involvement of PLHIV meant to them, respondents described the following:

Respondents reported the need for involvement of PLHIV in matters that concern them at national and decentralised levels of the community and in all aspects of the process including planning, implementation, monitoring and evaluation. This includes consulting them; availing them of appropriate support including information and funding, and effecting affirmative action that designates some positions for PLHIV. It also means that PLHIV should also support each other through support groups during illness and other difficult times.

Meaningful involvement was also reported to encompass provision of information to discourage stigma and discrimination. It was reported that where PLHIV are accepted and availed of equal opportunity, there are more accounts of disclosure of seropositive status.

PLHIV should be provided with the opportunity to influence workplace policy in their own employment. Similarly, national leadership should put in place measures that allow for purposeful and positive involvement rather than tokenism. Others saw meaningful involvement as having HIV programmes that are more coordinated and which have more funding from various sources.

“Being actively involved in all aspects of intervention that would affect the person living with HIV/AIDS, this should include planning, implementing, monitoring and evaluation all these stages should involve PLHIV”

“It means working with people who are HIV at all levels, such as decision making. They should be part of the agenda at all levels”

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When asked “Please describe the current situation in your country, state and/or community regarding the involvement of people living with HIV in the response to HIV”, respondents described the following:

It was generally felt that much positive change had taken place in Zambia over the last few years, both in rural and urban areas. This has been partly because of support from the government through the NAC, as NZP+ is involved in all NAC activities including policy formulation, and is recognized as a key partner. This includes membership of the CCM. This participation is seen as a way of protecting the rights of PLHIV.

PLHIV have continued to share information and to form support groups, some of which are very effective despite lack of funding and inadequate capacities in certain areas. They are now able to talk about their situation more freely.

“NZP+ has an institutional seat (at NAC) and is widely recognized in the country. It receives issues from other PLHIV organizations such as TALC and brings these to the forum where it is mandated to”

“I believe we have so many HIV positive people contributing to the HIV response, in one way or another, and their status doesn't really concern me as long as their contribution is there”

While acknowledging successes, respondents reported that there was a lot more that could be done because the GIPA principle was still in its infancy. Involvement of PLHIV was reported as predominantly during implementation, rather than earlier, when planning is done. It was hoped consultation of PLHIV could be systematically widened and decentralised so that more are able to participate and also so that information could flow right down to the grassroots.

The GIPA principle's success has also been seen as inhibited by stigma and discrimination, for instance in the workplace. Some respondents felt that the GIPA principle was not receiving the seriousness that it deserved, especially at implementation stage when it was felt PLHIV were not being provided with the “space” for them to be appropriately involved. There is still need to further encourage PLHIV to appreciate and participate in HIV programmes both in communities and at workplaces. Despite the existence of policy that could enhance the GIPA principle, execution of such policy was reported as still weak.

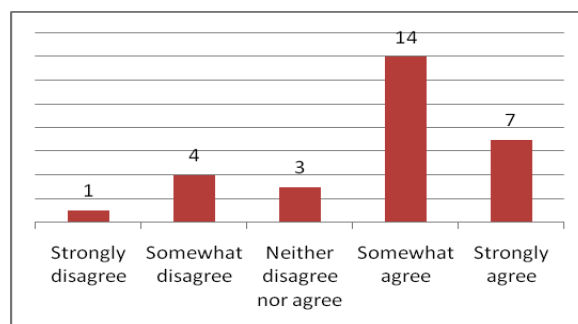
In some cases, PLHIV were seen as merely being used to raise funds and were forgotten about as soon as such funds were obtained. Quite a lot of the money purported to be for improving the lives of PLHIV was also seen as being unnecessarily used for workshops.

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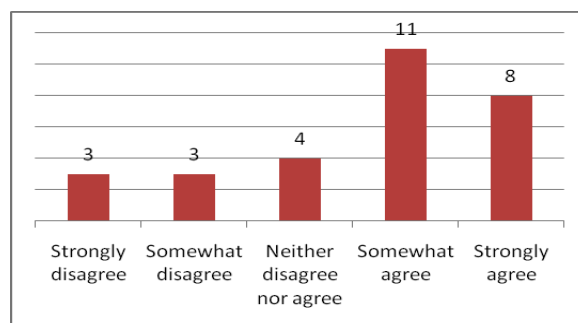
4.4 National HIV and AIDS Plan

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

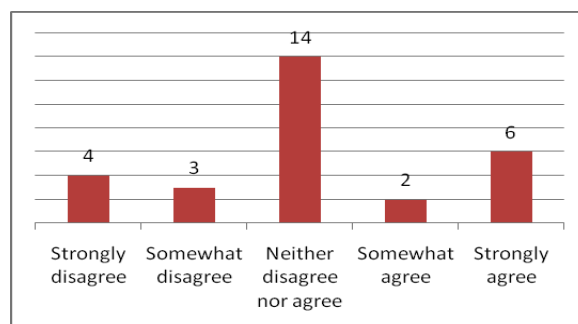
The GIPA principle is fully included in the National AIDS Plan.



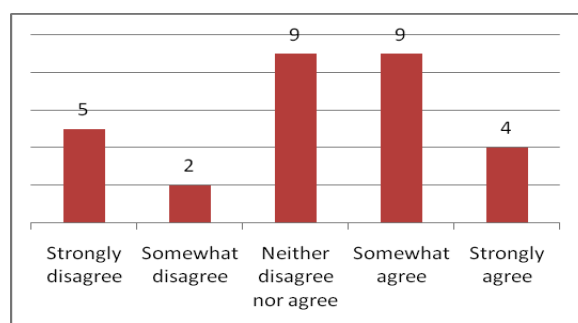
People living with HIV were meaningfully involved in developing the National AIDS Plan.



In my country, there have been studies done looking at the GIPA principle.



The GIPA principle has been adequately included in the National AIDS Plan monitoring and evaluation framework.



Zambia

Does your country have a National GIPA Plan, National GIPA Guidelines or equivalent?

Yes (21)

No (8)

In the view of respondents, GIPA has affected the National AIDS Plan, but more remains to be done.

When asked “Are the National AIDS Plan and/or National GIPA Plan adequate? Do they have allocated budgets? How have they been put into action? How could they be improved?”, respondents made the following comments:

The national plan was generally seen as adequate mainly because it caters for PLHIV, particularly through NZP+ who are best placed to represent the GIPA agenda. However, it was reported that although NZP+ is part of some of the NAC meetings, PLHIV do not have a permanent office at NAC.

Some respondents understood that substantial amounts of monies are disbursed for the implementation of HIV programmes but felt that the national plan budget was inadequate for work on the GIPA principle. Others felt that there are no funds that are either specifically allocated or specifically raised for implementing the GIPA principle.

It was felt that the national plan allows for the establishment of the NAC through which a number of programmes have been planned for and implemented. This includes HIV/AIDS Task Forces, established at national, provincial and district levels, for which United Nations Volunteers have been recruited as coordinators at the respective levels. A respondent argued that while PLHIV have been involved, it has not been to an extent that could be considered effective, because of various factors including bureaucratic reporting procedures. NZP+ was also seen as contributing to lack of involvement in the plan because of bickering and lack of financial accountability.

“The greatest enemy for GIPA is NZP+ because of continuous fighting and scrambling for material things... Accountability problems, embezzlement... remain barriers”

It was viewed that the GIPA principle was not fully being implemented and hence the need to adopt GIPA guidelines, come up with policy statements, more specific budgets, more specific activities and budgets. Similarly, NZP+ plans and activities should be streamlined more towards the GIPA principle.

“After the formation of National Aids Council (NAC), a number of programmes have been put in place. Every district is actively involved in the fight against HIV/AIDS

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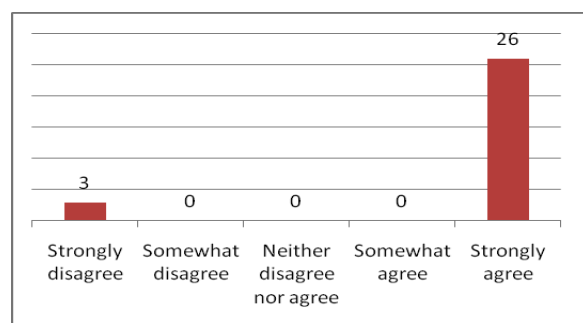
through the UN volunteers who are coordinating these activities in all those districts”

“PLHIV do not have a desk at NAC. Therefore, when we talk about involvement, it's just PLHIV sitting in the meetings”

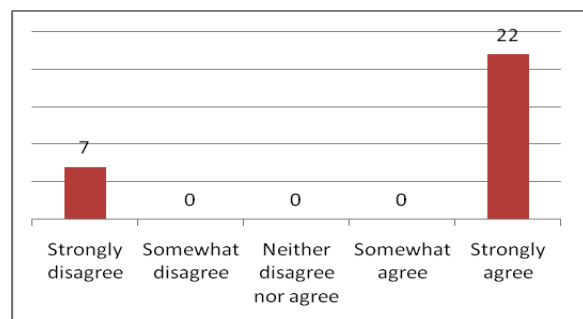
4.5 GIPA at State and Provincial Levels

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

The GIPA principle has been adequately implemented in state or provincial level HIV planning.



People living with HIV were meaningfully involved in developing state or provincial-level HIV policy.



Almost all the respondents strongly agreed with this statement, except for a few who strongly disagreed.

Respondents indicated the following comments on the application of the GIPA principle at the state or provincial level:

Communities in the districts were reported to have effective GIPA structures and were practicing the GIPA principle such as being involved in caring for the sick, although these were not being recognised as the GIPA principle. District and provincial task forces were reported to be planning, implementing and monitoring their own HIV programmes and have their own chapters for which they select representation. The United Nations Volunteers (UNVs) were also reported as being involved in GIPA at provincial and district levels.

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Government was cited for encouraging civil society to collaborate with NZP+ to promote the GIPA principle. Government was also reported to be ensuring greater and cost-free access to treatment including access to ARVs. Aspects of the GIPA principle have also been included in workplace policies.

Some respondents complained that although PLHIV have been consulted, they often have not received feedback and in some cases, PLHIV recommendations have not been considered at all. Other respondents felt that the GIPA principle has not been applied partly because its application had been generally left to the discretion of individual district or community networks. It was hoped that the level and quality of participation of PLHIV who sit on various planning committees at different levels could be improved.

“The United Nations Volunteers UNVs are doing everything possible to tackle the involvement of GIPA at a provincial level” (Female 38 years, Programmes Manager)

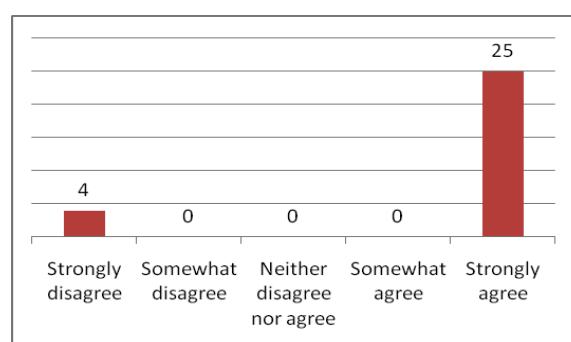
“District communities have GIPA structures which work very well, without remuneration; they are not recognised as GIPA; for example, caring and transporting patients. GIPA is a guide, it's up to the network to develop checklists at implementation to see weaknesses that exist. The strength is all up to the network” (Male 43 years, M and E Technical Advisor)

Some of the respondents did not comment because the GIPA concept was new to them. Some expressed the desire to learn more about this principle.

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

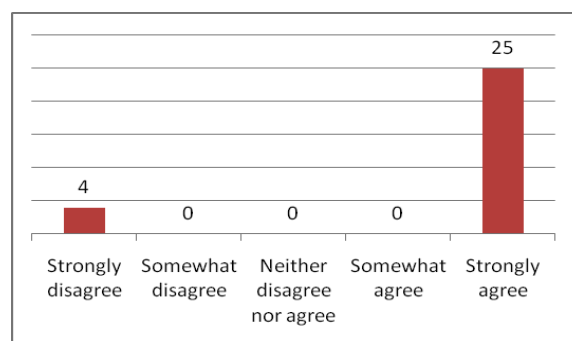
When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

I am familiar with UNGASS and my country's international commitments to the HIV response.



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Organisations or networks of people living with HIV are meaningfully involved in developing the report to UNAIDS on progress towards reaching UNGASS targets.



Again, almost all respondents strongly agreed, while a handful strongly disagreed.

Respondents provided the following comments on the above questions:

Respondents revealed that the UNGASS process in Zambia was inclusive and involves civil society including NZP+, which was described as being

“part of the planning team, part of the delegation, part of the steering committees and part of data collection process”

UNAIDS was said to receive reports from other organizations. In contrast with past experience, more meaningful involvement by various stakeholders including NZP+ in the UNGASS process from start to finish was perceived as having contributed to improvement in the previous UNGASS country report, which was said to reflect a true picture of the country’s HIV response activities. PLHIV reported even having accompanied the Minister of Health to New York where the report was presented.

A number of respondents reported knowing little about UNGASS even when they had heard about it. Therefore, they advocated for more information about it. Another respondent complained of the lack of regular meetings to take stock of HIV-related programmes. As a result, some of what was reported about HIV-related activities was alleged to be untrue. One respondent complained that reports such as that from UNGASS lacked seriousness and were merely meant to make an impression. This is because report findings were not followed up in order to improve future performance and ensure that targets are met.

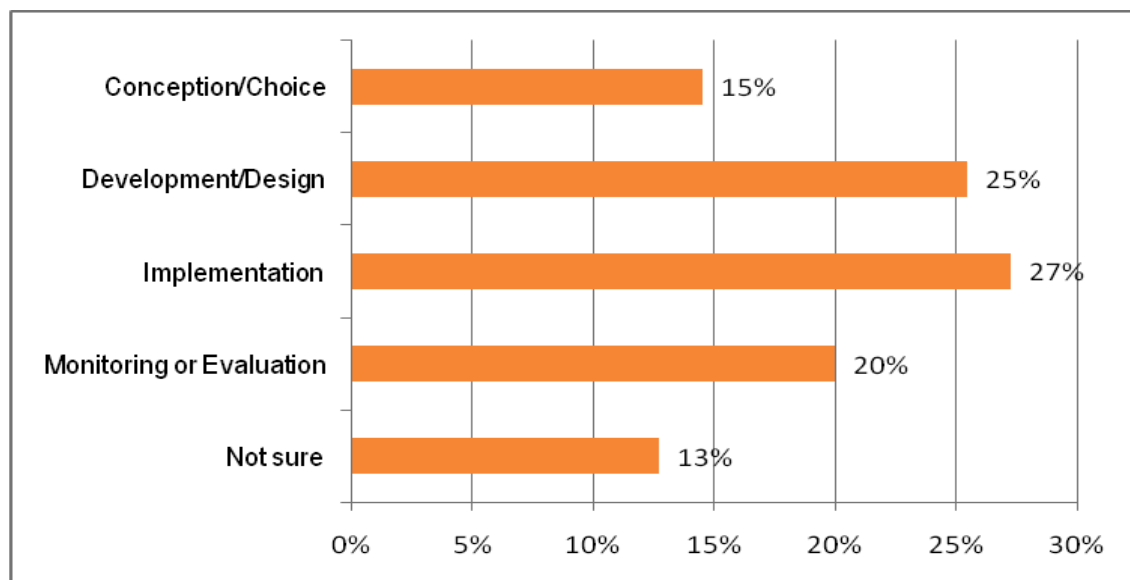
“We need to do a lot of education continuously; I do not have enough information concerning UNGASS”

“As a country we do not take stock and convene; we’re not organized. Only when we have to report to UNGASS are we likely to give a true reflection or picture”

Zambia

4.7 Policy Development

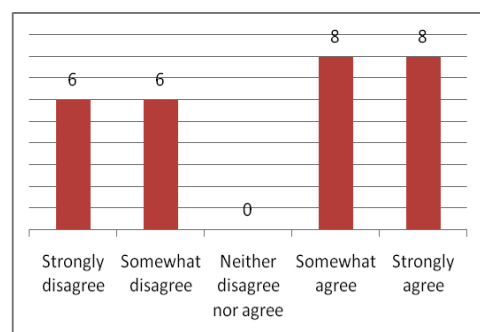
When asked “At what point are people living with HIV most often first involved in national level policy development?”, respondents indicated the following:



Overall, respondents considered that PLHIV input is most under-represented at the conception stage, and also that their involvement in monitoring and evaluation of policy execution and impact could be greater. PLHIV are most likely to be involved at the implementation stage, but have less chance to influence the creation of new initiatives or the identification and correction of problems arising in its execution.

When asked “To what extent do you agree or disagree with the following statement?, respondents indicated the following:

Overall, I would consider the degree of PLHIV involvement in national level policy development to be meaningful”



Opinion on this statement was almost evenly split, with no respondent neutral.

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Respondents provided the following examples and comments on the above questions:

A few of the respondents talked to believed that the degree of PLHIV involvement in national level policy development was meaningful. This was mainly because PLHIV are represented on most national HIV planning teams, especially under the auspices of NAC. One participant also commented that there exists a strong advocacy group that has played a role in the provision of ARVs. In some cases, PLHIV were said to participate in the planning process as consultants or as independent reviewers of policy documents. It was nevertheless hoped that PLHIV participation would be scaled up.

“PLHIV have representation in NAC, which is a policy-making body for the country”

However, respondents commented, in various ways, that there was low meaningful involvement of PLHIV in national HIV policy development. Few were said to be willing to come out in the open about their serostatus due to stigma and discrimination among some policy makers. Additionally, not all among those who are able to disclose their serostatus have the capacity to contribute effectively. This was said to lower the quality of involvement; it also emphasizes the need for training. Rather than at the level of planning, PLHIV were reported as

“mostly involved at the implementation level. The technocrats do a lot at the conception, development and designing level”

One respondent cited her own experience, saying:

“My workplace policy was developed by management and only invited comments from PLHIV afterwards, and this is what also happens at the national level”

Participation of PLHIV in planning was said to be done by consultation although they do not always receive feedback about their contributions. Another respondent complained that

“There is a tendency to involve people's inputs, but what people say is not always reflected”

At another level, involvement by PLHIV was reported to be low because

“The level of implementation is only limited to NZP+ and if you are not a member, you are left out. The [only] other organization that gets involved is Treatment Advocacy and Literacy Campaign (TALC). I feel the representation by NZP+ is not full representation, especially that we do not have a mother body for all that are affected”

Zambia

Participation of PLHIV towards the realization of GIPA targets was said to be sometimes impeded by negative cultural practices as well as their own ignorance. When they are invited, sometimes PLHIV lack technical capacity to contribute effectively.

Two respondents asserted that PLHIV are sometimes invited as observers rather than participants or may be invited only for formality's sake as rubber stamps:

"We are invited mainly for statistical purposes only"

"Decision makers do not involve PLHIV at decision making levels; they are not involved in policy development. When they do, then they are silently involved. This doesn't help us at all"

The HIV/AIDS Policy was said to inhibit PLHIV involvement in national level policy development because it does not legally prescribe their inclusion. As a result,

"The degree of involvement is not certain because it often depends on discretion rather than [being] legally binding" (Male adult, Research Manager).

When asked

- **"Have women living with HIV, and HIV positive women's networks and organizations, been involved in national level HIV policy development?**
- **Has this involvement been effective?"**, respondents said:

Some respondents said there has been no effective HIV positive women's organization that has affected the country response because women living with HIV have not been involved in national HIV policy development apart from at lower levels in the community. Many of the respondents asserted that they had not dealt with an organization for women living with HIV during their course of work. One respondent argued that women living with HIV are themselves not doing enough to get involved in national HIV policy because of cultural inhibitions¹. Involvement has mostly been from a generic perspective because they have been involved as representatives of generic organizations such as NZP+:

"There has been no effective HIV positive women's organization that has affected the country response. Involvement of women living with HIV has been mostly as representatives of people living with HIV"

¹ For instance, attendance at "kitchen parties". These are social gatherings where, among other thing, women are prepared for marriage. Participants implied that some of the gender stereotypes inculcated in these events serve to limit women's interest in activities outside the home, including involvement in women's networks.

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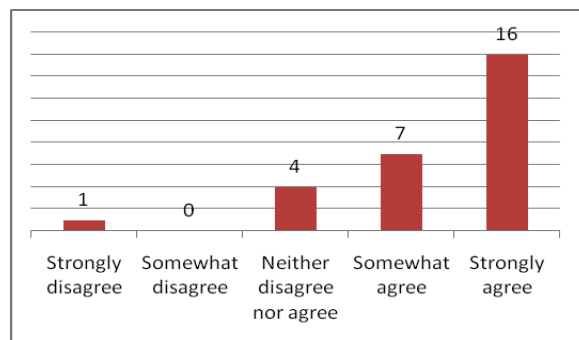
The lack of female networks for PLHIV was said to be attributed to the belief that women were ably represented by the existing organizations for people living with HIV or because NZP+ is not doing enough to encourage women's involvement:

"We do not have any (women's network of PLHIV) in Zambia. I believe it is deliberately done [because] women living with HIV are already well represented"

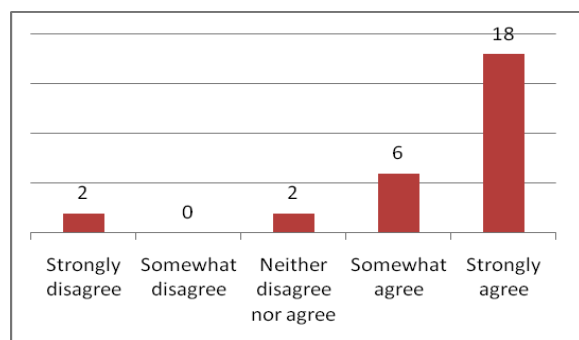
4.8 Universal Access

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

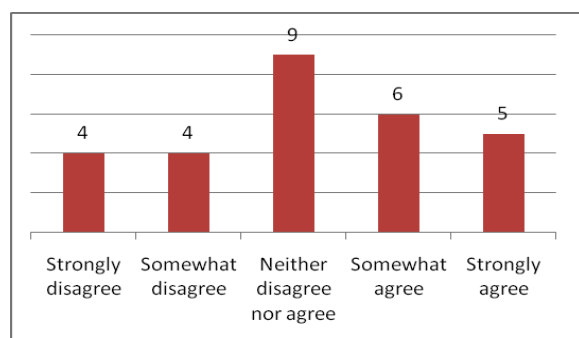
I am familiar with universal access commitments and targets.



My government sets universal access targets, including how many people living with HIV will receive antiretroviral therapy by 2010.



People living with HIV were meaningfully involved in the universal access target setting process.



Most knew of the country's universal access targets, but a sizeable minority did not feel that PLHIV had been meaningfully involved in setting them.

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When asked “Please comment on the above questions and the following questions:

- **What are barriers to achieving targets?**
- **What would help to achieve those targets?**
- **What is working well?**
- **Also please include information on drug quality and regularity of supply”,**
- **respondents gave the following comments:**

Information on universal access was reported to have been obtained from the media including television, radio, magazines, as well as through Ministry of Health provision of information about ARVs. Respondents reported that national targets for universal access had been set and government was doing everything possible to achieve them; however, performance towards meeting these targets was not to expectations. For instance, not as many people as targeted have gone for VCT and not all of those who are on ARVs want to take them regularly. PMTCT was reported to be doing better in terms of meeting targets.

It was generally felt that PLHIV were not consulted about the targets, but merely informed.

Various barriers were cited as contributing to the problem of universal access. Lack of adequate infrastructure was said to have made it difficult to deliver drug supplies and services closer to the people. Other factors preventing universal access were reported to be poverty, stigma, inadequately qualified health personnel, as well as a lack of timely and widely accessible information. Myths and misconceptions were reported to have contributed to the problems in achieving universal access.

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 drugs before they can be attended to. Rural areas were perceived as more negatively affected than in urban areas. Shortage of CD4 count machines delays the start of treatment for some.

Other barriers identified were poor coordination of HIV programmes, with a lack of adequate consultation and involvement of PLHIV. Respondents argued that involvement of PLHIV right from the planning stage would assist in ensuring that all needs are addressed. Government was also seen as having set targets that were difficult to attain, while funding for HIV activities was also seen as inadequate. Meeting nutritional needs of PLHIV was a challenge.

On the other hand, some respondents felt that the dissemination of information has been quite successful because some targets, especially those for civil society organisations, have

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been met. Despite some problems, the supply of drugs is fairly good, following an increase in the number of clinics both in rural and urban areas; this was made possible by efforts from cooperating partners. The fact that most ARVs are distributed through government health institutions has generally increased access:

“The drugs are available; the Government is working hard to make them available”

Routine testing for HIV has been initiated among pregnant women although testing among the general public is still relatively low and most people do not know their serostatus.

Zambia was said to have been recognized as having one of the best ART management and supply chain systems. Some of the drugs were reported to be problematic because of side effects such as “paralysis of the legs”. However, the drug responsible for this side-effect has now been removed from first-line treatment. The distribution of ARVs through government health institutions was reported to be increasing trust in their quality. There is a perception that the country does not receive patented drugs, and may thereby be prone to receiving poorer quality drugs.

Another complaint was that not everyone is able to access their medication, especially in the rural areas. In these areas, some people were reported to travel to urban areas just to collect the drugs. In the words of one respondent;

“The targets are being achieved in urban areas, but not in rural areas, because I have seen people travel to urban areas to acquire drugs which are not always available in their rural clinics”.

Another respondent reported:

“The supply has not been very good. We have had a number of stock-outs in public institutions where drugs are being administered”

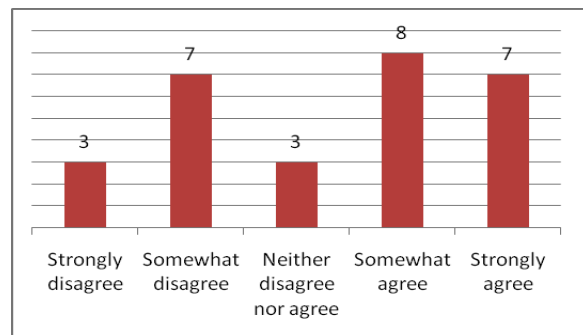
One respondent blamed some of the side effects of the drugs on the clients because they were combining them with traditional herbs.

Zambia

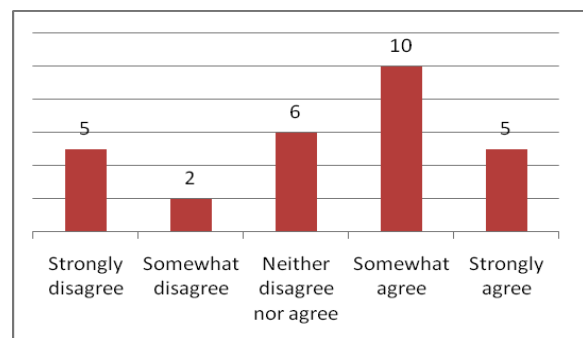
4.9 Representation & Networks of People Living with HIV

When asked to what extent they agreed or disagreed with the below statements, respondents indicated the following:

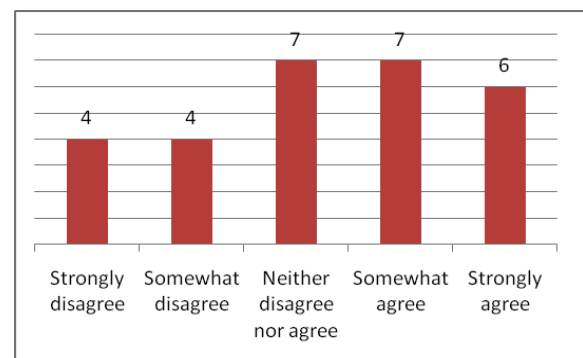
Formal PLHIV representation positions on decision-making bodies work to ensure accountability to PLHIV in my country.



The mechanisms for the representation of PLHIV in formal decision-making bodies are effective in representing the needs of PLHIV (e.g. board positions, committee seats, CCM representatives).



National, regional and state level PLHIV networks communicate effectively with their constituents.



Views on these statements were extremely mixed: some are happy with existing mechanisms for representation, while others are quite dissatisfied.

Respondents included the following comments on the above questions:

The general feeling of the respondents was that PLHIV were represented on various decision-making bodies. For instance, NZP+ is represented at both national and at provincial

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(state) level planning meetings. The networks are able to communicate and coordinate effectively with each other at the various levels, and as representatives, they communicate effectively on behalf of their colleagues. It was stated by a respondent that

“the involvement of PLHIV has helped in achieving good representation and has helped in the formulation of friendly policies for such people”

Some respondents however believed that networking has not been effective partly due to lack of financial support necessary. As a result, the flow of information across the national, provincial and district networks has been negatively affected. While the mechanisms for representation were seen as effective, the calibre of representation was said to be a challenge to effective representation. They have lacked the capacity to contribute adequately to the deliberations in an informed and qualitative manner. Another problem about the representation was said to be that only few PLHIV involve themselves in network issues thereby limiting the number of people that representation could be selected from. This has weakened the impact on PLHIV welfare. One respondent urged PLHIV to make better use of opportunities of GIPA by being

“‘specific and issue-based’. PLHIV haven't been very focused. It would help to be more focused on PLHIV issues in all fora ”

At the same time, some of those who are not living with HIV but work on the issue do not have genuine goodwill to promote the welfare of PLHIV. In some cases, contributions from PLHIV representatives have been disregarded. There is suspicion among some people that some of those organizations who claim that they exist for the good of PLHIV are in actual fact there to promote their own interests. Therefore,

“there is need for more willingness by various policy makers to ensure effective involvement of PLHIV”

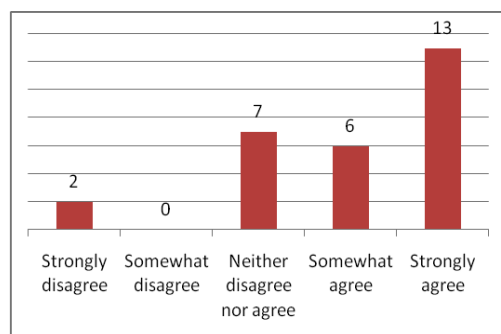
One respondent argued that there was need to move from “token” representation to meaningful representation and to encourage PLHIV to have wider participation and coverage, because just the presence of PLHIV organizations in meetings helps to remind the other participants that they should always be sensitive to PLHIV needs. Therefore, representation should begin to be beyond just NZP+.

Zambia

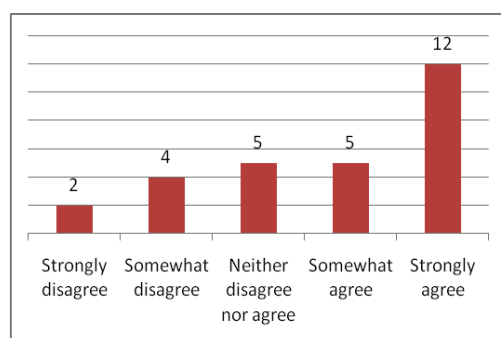
4.10 Research & Sexual and Reproductive Health

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

My country has a national sexual and reproductive health plan.



Policies have been introduced or incorporated into existing plans to address the sexual and reproductive health needs of women and men living with HIV.



There was awareness of national attempts to address sexual and reproductive health issues, though some were of the view that this was not occurring.

When asked “Are people living with HIV involved in conducting research in your country e.g. in clinical trials and in the research and development of new prevention technologies?”, respondents said:

Most of the responses reported that PLHIV are involved in research. In most cases, it was not mentioned what type of research they were involved in, with some respondents admitting that while they were aware that PLHIV are involved in research, they do not know the type of research this was. A substantial number of the respondents were not sure if PLHIV are involved in research. Those who were aware of such work said that PLHIV are involved in research on topics including male circumcision, PMTCT, herbal remedies, vaccines and microbicides.

One respondent argued that whatever research is conducted, PLHIV are not involved at the planning stage. Another reported that

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“there are no clinical trials going on in Zambia; only operational research which tends to be project-oriented. PLHIV are involved in monitoring and evaluation, and in NAC’s Joint Annual Programme Reviews”

Two of the respondents asserted that PLHIV

“are normally used as guinea pigs and that hasn’t worked very well. They have not produced any positive results”

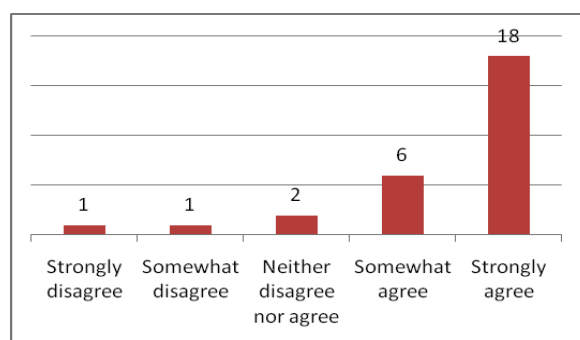
A respondent described some of the research as *“unethical”* while another felt that PLHIV are often *“objects”* of the research, or victims of the side-effects of such research. PLHIV were urged to consider the effects that the research may have on them before agreeing to be part of the trials.

PLHIV were seen to be invited to be involved in research only because, and when, organizations needed them to complete their reports.

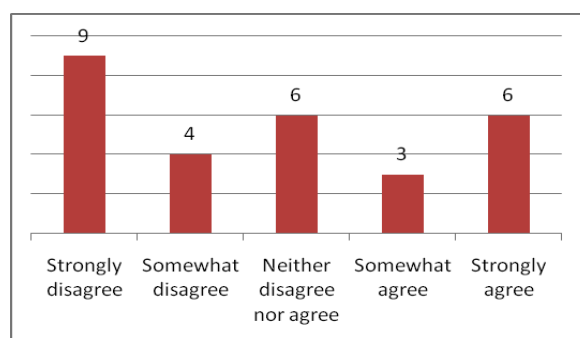
4.11 Poverty Reduction Strategies

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

My country has a poverty reduction plan and/or strategy in place.

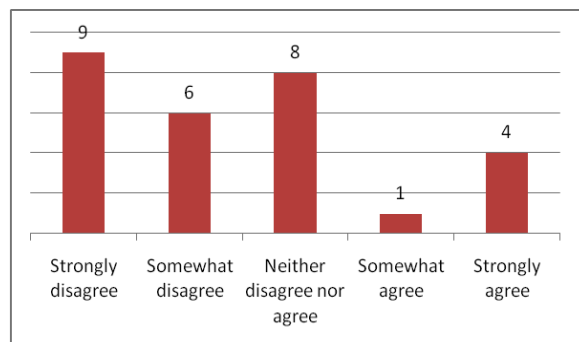


The poverty reduction plan and/or strategy were developed with input from people living with HIV.



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The poverty reduction plan and/or strategy has been adequately reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men.



While respondents were mainly agreed that Zambia has a poverty reduction plan, views were mixed on whether PLHIV had been involved as such in developing it, and a small majority felt that PLHIV had not had adequate input in adjusting for gender differences in impacts of HIV and AIDS.

Respondents provided the following additional comments:

Respondents reported that Zambia has a national poverty reduction plan that is not necessarily specific to HIV but which seeks to reduce poverty in the country as a whole:

“We have a poverty reduction plan done by the government”.

“It is a government policy not (necessarily) related (specific) to the HIV sector”

Respondents reported that the “Millennium Development Goals” and “Zambia Vision 2030” were part of the national poverty reduction plan. From a specific point of view, the national poverty reduction plan was reported to include PLHIV and some of the strategies are implemented by the National AIDS Council and other NGOs including the Zambia National AIDS Network (ZNaN) which disburses funds to smaller NGOs that may be involved in poverty reduction for PLHIV.

Other respondents were not sure about such a strategy and had only vague information about it.

“Have not heard of anything addressing specifically PLHIV, but I know that there has been talk of poverty reduction; In terms of targeting PLHIV , I am not clear if it affects them as well”

“I have heard of the government putting in place poverty reduction strategies, but never heard of PLHIV being part of the process”

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One respondent asserted that PLHIV were consulted at the planning stage, but were however left out from the monitoring process.

“When developing we are there, when it comes to monitoring we are not there”

Respondents argued that consultation was not wide and PLHIV specifically were not consulted. Two respondents felt that the lack of consultation was because the strategy was a general government one and not specific to PLHIV. Another saw the lack of consultation as due to the fact that it was drawn up by technocrats. An example was cited about the government’s ‘Citizens Economic Empowerment Commission which had to make “a lot of assumptions” about PLHIV since it had been designed by technocrats without the involvement of PLHIV. Therefore, the poverty reduction strategy was seen as not specifically meant to meet the needs of PLHIV.

“At the time when the poverty strategy plan was being made, very few people participated and I do not think there was any consultations from PLHIV”

“Poverty reduction programmes have been there but not involving PLHIV. Those are government programmes”

“This (involvement of PLHIV) has not happened, as formulation of the poverty reduction plan was done by technocrats without the involvement of people living with HIV”

With regard to reassessment, it was mentioned that the challenge was the treatment of HIV as a medical/health issue and not a development issue. There was said to be poor linkage between the Poverty Reduction Strategic Plan (PRSP) and the HIV response.

Implementation of the Plan was also reported to be weak. Generally, the country was seen to have had few success stories with regard to empowering women.

“The policies are there on paper, but not working. I think the Government has issues of priority and weakness. We do not have strong implementation plans in place. We only plan, but we do not implement”

However, there also was mention that the current Fifth National Development Plan includes the aim of reducing the impact of HIV on the population in general and on PLHIV in particular. PLHIV were reported to have been involved in its development. This plan was said to be managed through the HIV strategic framework and further, through the impact

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mitigation theme. Some of these strategies were said to have been developed before or at the same time as GIPA came into effect.

“Some of the strategies were developed when or before GIPA took root. Generally we’ve started on the right path including strategies that cover PLHIV. [However], strategic areas should increase to have adequate PLHIV influence in decision making”

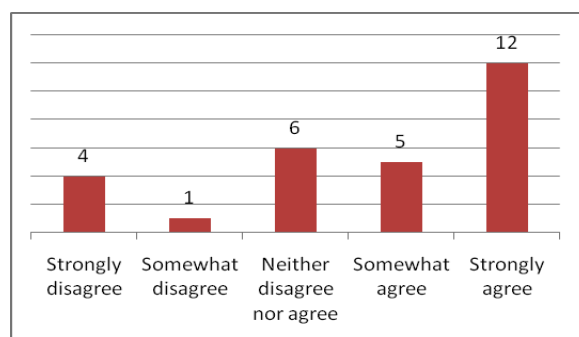
“Government needs to involve and engage PLHIV in poverty reduction that affects PLHIV. Because HIV is now a life-long ailment, PLHIV need to have some input in poverty reduction, so as to decide their own fate, how to survive with HIV”

“Zambia has since moved to the National Plan and people living with HIV/AIDS were involved in the 5th National Development plan. It has a chapter on AIDS. AIDS is also mainstreamed in all other sectors”

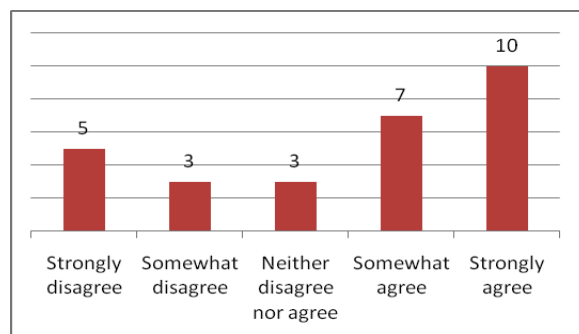
4.12 Employment

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

My government has enacted legislation in line with the International Labour Organisation Code of Practice on HIV and the World of Work.

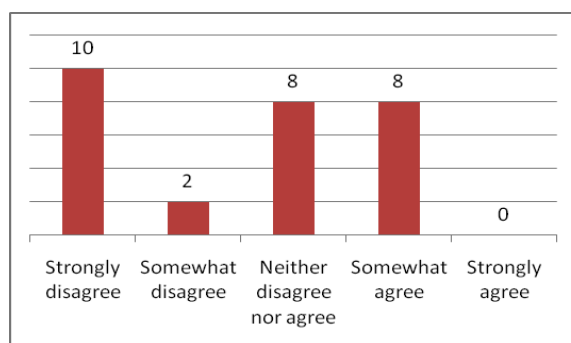


My country has enacted progressive legislation on the workplace rights of people living with HIV.



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People living with HIV were meaningfully involved in the development of this legislation.



While a small majority agreed that action has been taken to address workplace HIV policies and rights, over a third strongly disagreed that PLHIV were meaningfully involved in the process. However, in excess of a quarter agreed somewhat that there was appropriate involvement.

When asked “If you were in agreement with the above question, how were people living with HIV involved in the development of this legislation?”, respondents provided the following comments and specific examples:

Respondents reported that PLHIV were represented by NZP+ during the development process of the legislation. This includes representation on the NAC. Districts, through various support groups, were also said to have been asked to provide information towards the legislation. It was also reported that the legislation process was still ongoing and had reached ‘bill’ stage. The International Labour Organisation was said to have also been involved.

While some respondents reported being represented by organisations that deal in HIV matters, others contended that such organisations are not headed by PLHIV and therefore, it could not be said that PLHIV were represented by such organisations.

“Organizations doing HIV programmes sit in these meetings for consultations”

“We have organizations that involve PLHIV such as ZARAN, ZNAN, but they are not headed by PLHIV. We do not have a greater involvement”

Some respondents were not unsure, and a substantial number of respondents did not provide any response to this question.

“I do not have specific examples, but I assume they are supposed to be involved”

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When asked “does your organisation or Ministry have any policy regarding the mandated employment of people living with HIV as staff? If so, is there a budget allocation for this policy?”, respondents described the following:

A number of respondents reported not having such a policy at their workplace while one reported that the number of staff in their organisation were too few for them to have such a policy. In some cases, employment of PLHIV was supported in an informal manner.

“We do not have an HIV policy, but PLHIV are encouraged to apply whenever there is a vacancy though mostly positions are for non-professionals”

Some respondents reported such a policy at their workplace, which among other things, made provisions for equal opportunity and against the discrimination of PLHIV. Participants reported their workplace policies, variously, as giving preference to PLHIV with regard to employment; providing medical needs to PLHIV; excluding HIV testing as part of mandatory medical testing before employment; and the use of peer educators at the workplace.

“People are not discriminated against on grounds of being HIV positive. Everyone has got equal opportunities”

“My organization does not discriminate against any one, therefore PLHIV are employed on their capacity to perform”

In some instances, respondents reported having a budget allocation for the workplace policy, while others reported ignorance about whether or not there was any such budget allocation. In one organisation, there being no budget allocation, the money for their medical scheme was reported to come from staff contributions.

“We have a workplace HIV policy that totally talks about discrimination and people not to be employed based on their status, yes, the budget is there and a fully fledged scheme”

When asked “Are you a person living with HIV who is employed in a NGO, the government or United Nations organisation? If YES, what are some barriers you have encountered, and if applicable, what has contributed to overcoming these barriers?”, respondents described the following:

The most reported barrier was stigma and discrimination. A respondent complained that he was not being recognised as a highly qualified professional despite possessing the necessary credentials and that in this, he was discriminated against even by his fellow PLHIV. Another

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reported of being overlooked by his manager when it came to involvement in work-related activities. Despite the existence of HIV workplace policy, stigma and discrimination was said to be still in existence and was contributing to the small numbers of workers who have disclosed.

A respondent argued that organisations no longer implement programmes against stigma and discrimination. Poverty and inadequate funding for HIV programmes was also seen as reason for the stigma and discrimination, as this situation diverts the few available resources to focussing on other priorities.

Some PLHIV have not encountered any stigma and discrimination at their workplace, and reported receiving much support. Continuation of awareness programmes in workplaces was suggested as one of the means for overcoming this barrier.

“My work is not affected in any way. I have a very supportive boss”

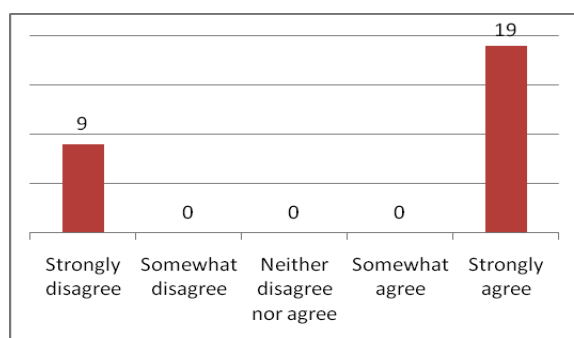
“I am a person living positively. I have not encountered any barriers in terms of employment. The Ministry have been sponsoring me and many more others for further studies”

“Coming out in the open helped people to understand that I have the same capacities to take up the same responsibilities as anyone else in an NGO”

4.13 GIPA-related Materials

When asked to what extent they agreed or disagreed with the statement below, respondents indicated the following:

My organisation has developed materials focused on the GIPA principle and the meaningful involvement of people living with HIV.



The response was strikingly split, with two-thirds claiming that their organisations definitely had GIPA materials, and the other third equally clear that theirs did not have. Awareness of the issue was high, with no-one unsure or even “somewhat” agreeing or disagreeing.

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Respondents were asked:

"If in agreement with the above, are these materials being used by the government or other organisations? Please elaborate and provide specific examples of success below.

If not in agreement with the above, why has your organisation not been involved in developing materials on the GIPA principle and the meaningful involvement of people living with HIV?"

The following responses were indicated:

Some organisations/institutions reported having developed materials focussing on the GIPA principle, including newsletters, books and other IEC materials. Others were reported to have conducted interviews and presentations. One organisation representing PLHIV commented on the need to involve them in related activities as a way of scaling up access to treatment, as well as providing a forum for dialogue with policy makers at district level. One international organisation reported having established a website for information-sharing.

Of those disagreeing, most provided reasons for not having developed materials on the GIPA principle. For instance, it was observed by some respondents that developing such materials was not their primary mandate although GIPA is still promoted in the course of their work. Others asserted that they have not developed such materials either because they do not have a budget specifically for such production or because it was seen as costly to do so.

Others felt that nothing had been done to produce such materials because very little is known about the GIPA principle. One respondent asserted that their programme does not look at GIPA in a specific way but at HIV in general. In relation to this, another respondent said that GIPA was introduced to their organisation in an informal manner and their organisation was

"not too keen to institutionalize GIPA principles".

One organisation was said to be aware and appreciative of the GIPA principle but was currently busy mobilising funds for the sustenance of their organisation and would in future consider developing GIPA materials.

"The GIPA concept has been taken on board, but at the moment the organization is busy mobilising resources and is focused on survival"

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When respondents were asked to provide examples of materials on the GIPA principle that their organisations had produced, the following resources and materials were described:

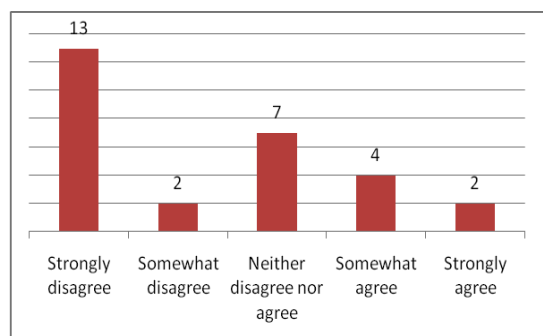
Not much detail was provided about examples of the materials that had been developed. Among the materials developed were mostly printed materials but included an easily accessible website; documents on representation; booklets; newsletters; brochures; posters, pamphlets; and pictures. Others include learning modules, a research study, and management guidelines.

Other organisations reported they do not develop their own materials but depend on those that have been developed by other organisations.

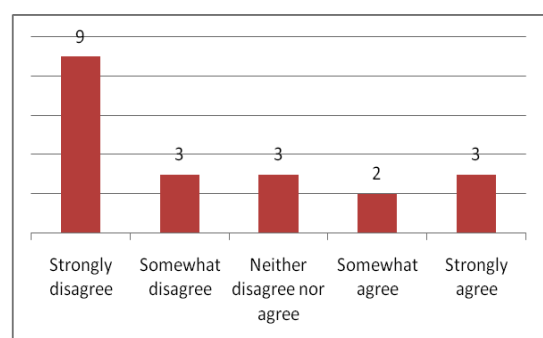
4.14 Financial Support

When asked to what extent they agreed or disagreed with the statements below, respondents indicated the following:

People living with HIV who participate in a government body, have their costs such as travel, accommodation, child care and food fully reimbursed.



As a person living with HIV, I am adequately paid for my involvement in the HIV response.



There was clear dissatisfaction with mechanisms to compensate PLHIV for the costs they incur in working for the good of their peers, and to provide fair pay for the work they undertake.

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Respondents provided the following comments on the above questions:

Generally, respondents felt that PLHIV were not being financially provided for appropriately. Some organisations were reported to be providing shared accommodation when on duty, while transport was reportedly not catered for by some other organisations. While some organisations were reported to cover costs for child-care, others do not. One respondent reported that PLHIV are not provided with meals that are suitable for their situation.

A number of respondents reported that they are not paid for the work that they do; arguing that some people expect PLHIV to provide free services as volunteers and yet they too have obligations to meet such as school and medical fees. One respondent commented about her own situation:

“Apart from my regular work, I am an advocate and activist who speaks for, and represents my organization. but I am not paid extra for these services including weekends”

Some of the respondents were happy about how their organisations were paying them, including their general conditions of service for their involvement in the HIV response. Some respondents reported that their organisations provide working conditions based, not on one’s serostatus, but on such factors as qualifications, position, and salary scale; and also that they were not paid for tasks outside the regular job, with PLHIV were treated just like everyone else. One respondent commented that most PLHIV

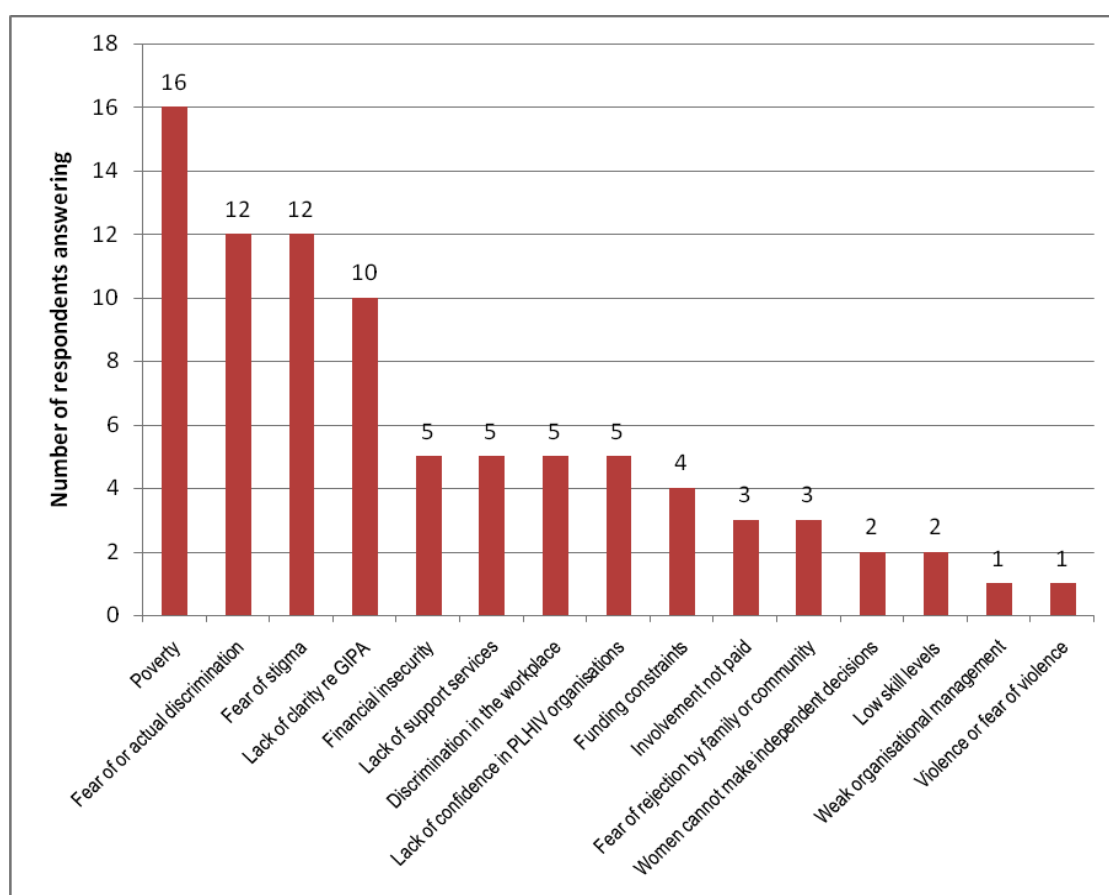
“always want to receive favours because of their HIV status”.

Some respondents reported that they could not respond to the question either because they were not knowledgeable about the issues or because they were not PLHIV.

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4.15 Barriers to involvement

When asked to check off what are the three greatest barriers to the greater involvement of people living with HIV, respondents selected as follows:



Respondents provided the following comments on the above question:

Poverty was prominently reported as a barrier to the greater involvement of people living with HIV, with inability to work unremunerated also named specifically by a few.

Issues around stigma and discrimination were also clear deterrents to being involved in GIPA work. PLHIV are also afraid of disclosing their status for fear of losing their job or their clients/customers in the case of those who are running businesses, and for fear of negative reactions for those in all circumstances: many have had unpleasant experience of such stigmatisation and resulting discrimination. Some PLHIV were reported as disclosing their status

“only when they are sick and when they are in need of food”

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Ultimately, this reduces their access to medication and other support services. The failure to get involved is also attributed to the fact that some of the services were not visibly evident to them. Problems of obtaining visas by PLHIV were quoted as restricting international travel.

Differences among PLHIV in the networks were said to affect the members' confidence in the leadership, which has affected their involvement in the HIV response. These factors are compounded by low skill levels among PLHIV as well as inadequate staffing and funding for the district chapters. PLHIV were reported as not involved because they lack information, *"understanding and clarity"* about GIPA.

4.16 Opportunities for involvement

When asked "What are the three current best opportunities for the greater involvement of people living with HIV in your country?", respondents described the following:

Zambia was said to have a number of CSOs with success stories relating to HIV that others could learn from. The political environment was said to be conducive to GIPA as government was open and supportive to PLHIV. There is opportunity to engage the government, and other stakeholders such as the media, in dialogue to discuss and advocate for further legislation to protect the rights of PLHIV. The fact that an HIV policy, political commitment and certain structures are already in place all provide opportunity for increasing the meaningful involvement of PLHIV.

Being recognised by both government/NAC and civil society as officially representing PLHIV, there also was opportunity for NZP+, to be more proactive in championing the welfare of PLHIV. Therefore, NZP+ must be seen to participate more actively in the forthcoming 2011-2015 national strategic framework. Similarly, government could be proactive and invite PLHIV to participate in the HIV response, including in the development of policy.

District NZP+ chapters could expand participation and engagement on the district GIPA agenda. PLHIV should be seen as a resource in this. Respondents also argued the need for readily available and accessible information, as well as support for those who are discriminated against. This provides opportunity to provide more information and training on the GIPA principle and what it is all about.

Respondents also hoped to see more dialogue and cooperation between NZP+ and TALC, as had been the case with the women of these organisations who had come together to form a coalition of Zambian women living with HIV (COZWHA+) which includes professional women living with HIV. Respondents prominently stated that there had been an increase in donor funding and this had enabled more people to be reached. It was urged however that these funds be distributed in a more efficient way to improve the results.

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Conclusion

The GIPA Report Card for Zambia presents a wealth of feedback on the implementation of the GIPA principle in Zambia and on a number of other important issues, contributed by a varied group of informants who are working in the field and/or are themselves living with HIV.

Meaningful Involvement of People Living with HIV and AIDS

Respondents were well aware of the GIPA principle, and enumerated input by PLHIV at various levels, from contributions to the national plan and UNGASS reporting, through to many local initiatives. However, many barriers to effective involvement were identified, inter alia:

- actual discrimination, or the fear of it;
- a general bias towards involving PLHIV at implementation stage, rather than at the stage of policy analysis and project conception when their priorities might usefully drive the agenda for change, and during monitoring and evaluation when PLHIV might lend a corrective critique from the grassroots. This bias may lead to programming being recognised nationally as “successful” because planned outputs are made, when mis-targeting may mean that they fail to maximise impact on the lives of the beneficiaries;
- PLHIV are often expected to contribute their time and effort unpaid; sometimes they may not even be reimbursed for their expenses. This limits the contribution that many can make, particularly in view of the fact that they may have higher living costs, less income and more responsibilities than their non-PLHIV neighbours;
- tokenism: some organisations involve PLHIV as a show of “best practice” but do not wish their priorities to be swayed by any meaningful involvement of their beneficiary group. Some current spending has little impact: for instance, workshops may not be the most cost-effective of interventions;
- although the prevalence of HIV among Zambian women is higher than among men, and although women carry a disproportionate share of the caring work for PLHIV who suffer serious illness, they are under-represented among those who work in the

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response to HIV and AIDS in Zambia. This relates to social expectations of proper roles for women, and possibly also to the lower economic status of widows which makes it harder for them to spare time to volunteer;

- inadequate skills among those who can find time to contribute and who are willing to risk the stigmatisation that can follow disclosure of serostatus. Training in management, health promotion, community development and research would be particularly useful to increase the impact of their contributions.

Other issues which deserve attention

Zambian PLHIV have contributed to the roll-out of ARV treatment, alongside many other projects, and progress towards universal access is clear. However, it is of concern that respondents reported that stock management, financial constraints, personnel shortages and other problems interrupt the continuous supply of ARVs, particularly in remote rural areas. Because of the problems of drug resistance which swiftly arise when adherence to daily treatment is poor, it is urgent for both humanitarian and cost reasons to organise infrastructure and systems to ensure continuity of supply to all those on treatment.

Concern was expressed about the involvement of PLHIV in research, which usually involves them as subjects but not as those driving the research agenda or staffing projects. At very least it seems that more effort is required to enlighten research subjects about the potential impact of the research on their health and lives; this should be occurring as part of the informed consent process under international conventions of research ethics.

While Zambia has a strategy to address poverty and a programme devoted to reducing hardship, it is unfortunate that the perspectives of PLHIV have not been included in planning in this domain. Poverty can increase the risk of contracting HIV, particularly for youth and women, while HIV and AIDS 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. PLHIV 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.

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The way forward for more effective interventions to combat HIV and AIDS

The impact of money spent on the HIV and AIDS response in Zambia could be elevated considerably by capacity building to allow PLHIV to contribute more fully, and adequate budgets to recompense PLHIV suitably for the work they do. In addition to providing a volunteer workforce for implementing projects, they could play a significant role in targeting funds for the many different initiatives addressing HIV and AIDS in a cost-effective fashion by involvement in policy drafting and programme design. 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.

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