MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV AND AIDS (MIPA)

ZIMBABWE BASELINE SURVEY (2009)

Zimbabwe AIDS network
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<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immune deficiency syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral (treatment or therapy)</td>
</tr>
<tr>
<td>ASO</td>
<td>AIDS Service Organization</td>
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<tr>
<td>BC</td>
<td>Behaviour Change</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-Based Organization</td>
</tr>
<tr>
<td>DAC</td>
<td>District AIDS Coordinator</td>
</tr>
<tr>
<td>DAAC</td>
<td>District AIDS Action Committee</td>
</tr>
<tr>
<td>DMTWG</td>
<td>District MIPA Technical Working Group</td>
</tr>
<tr>
<td>FGD</td>
<td>Focused Group Discussion</td>
</tr>
<tr>
<td>GIPA</td>
<td>Greater Involvement of People Living with HIV and AIDS</td>
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<tr>
<td>GNP+</td>
<td>Global Network of People Living with HIV/AIDS</td>
</tr>
<tr>
<td>HA</td>
<td>Horizons/Alliance</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-Based Care</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>ICW</td>
<td>International Community of Women Living with HIV/AIDS</td>
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<tr>
<td>IG</td>
<td>Income Generation</td>
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<tr>
<td>IGPs</td>
<td>Income Generating Projects</td>
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<tr>
<td>IEC</td>
<td>Information, education, and communication</td>
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<tr>
<td>IOM</td>
<td>International Organization for Migration</td>
</tr>
<tr>
<td>MAC</td>
<td>Matabeleland AIDS Council</td>
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<tr>
<td>M &amp; E</td>
<td>Monitoring and Evaluation</td>
</tr>
<tr>
<td>MIPA</td>
<td>Meaningful Involvement of People Living With HIV and AIDS</td>
</tr>
<tr>
<td>MoHCW</td>
<td>Ministry of Health and Child Welfare (MoHCW),</td>
</tr>
<tr>
<td>NAC</td>
<td>National AIDS Council</td>
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<tr>
<td>NAP+</td>
<td>Network of African PLWH</td>
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<tr>
<td>NARF</td>
<td>National AIDS Reporting Form</td>
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<tr>
<td>NAP+</td>
<td>Network of African PLWH</td>
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<tr>
<td>NCDPZ</td>
<td>National Council of Disabled Persons of Zimbabwe</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Governmental Organization</td>
</tr>
<tr>
<td>NMTWG</td>
<td>National MIPA Technical Working Group</td>
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<tr>
<td>NUT</td>
<td>Nutrition</td>
</tr>
<tr>
<td>OI</td>
<td>Opportunistic Infection</td>
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<tr>
<td>OVC</td>
<td>Orphans and Vulnerable Children</td>
</tr>
<tr>
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<td>Provincial AIDS Action Committee</td>
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<tr>
<td>PAC</td>
<td>Provincial AIDS Committee</td>
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<tr>
<td>PLWHIV</td>
<td>Person living with HIV and AIDS</td>
</tr>
<tr>
<td>PLWHIV</td>
<td>People Living with HIV and AIDS</td>
</tr>
<tr>
<td>PMD</td>
<td>Provincial Medical Director</td>
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<tr>
<td>PMTCT</td>
<td>Prevention of Mother to Child Transmission</td>
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<tr>
<td>PMTWG</td>
<td>Provincial MIPA Technical Working Group</td>
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<tr>
<td>PPAAT</td>
<td>Public Personalities Against AIDS Trust</td>
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<tr>
<td>PSI</td>
<td>Population Services International</td>
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<tr>
<td>PVO</td>
<td>Private Voluntary Organisation</td>
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<tr>
<td>Acronym</td>
<td>Full Form</td>
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<tr>
<td>SAPWA-</td>
<td>Southern African Network of PLWHIV</td>
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<tr>
<td>SMIPA-</td>
<td>Sustainable Meaningful Involvement of People Living with HIV and AIDS</td>
</tr>
<tr>
<td>STI-</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>TB -</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>TWG -</td>
<td>Technical Working Group</td>
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<tr>
<td>UNAIDS -</td>
<td>Joint United Nations Program on HIV and AIDS</td>
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<tr>
<td>UNDP -</td>
<td>United Nations Development Program</td>
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<td>UNICEF -</td>
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<td>UNFPA-</td>
<td>United Nations Population Fund</td>
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<td>UNGASS -</td>
<td>United Nations General Assembly Special Session</td>
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<td>USAID -</td>
<td>United States Agency for International Development</td>
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<td>VAAC -</td>
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<td>VCT -</td>
<td>Voluntary Counseling and Testing</td>
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<td>WAAC -</td>
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<td>WMTWG -</td>
<td>Ward MIPA Technical Working Group</td>
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<tr>
<td>ZAN-</td>
<td>Zimbabwe AIDS Network</td>
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<td>ZCTU-</td>
<td>Zimbabwe Congress of Trade Unions</td>
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<tr>
<td>ZHAUU -</td>
<td>Zimbabwe HIV and AIDS Activists Union</td>
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<td>ZINERELA-</td>
<td>Zimbabwe Network of Religious Leaders Personally Affected or Living with HIV</td>
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<td>ZNASP-</td>
<td>Zimbabwe National AIDS Strategic Plan</td>
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<td>Zimbabwe National Network of PLWHIV</td>
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EXECUTIVE SUMMARY

In Zimbabwe at the end of 2007, the total for both adults and children living with HIV stood at 1,320,739, adults alone (15-49) were 1,085,671; women (15-49) accounted for 651,402 and children living with HIV (0-4yrs) were 32,938. This left the prevalence rate for adults (15-49 yrs) at 15.6%. The declines experienced in 2005 and 2006 have been attributed to the scaling up of antiretroviral treatment (ART) services.

HIV incidence is the key parameter that prevention efforts aim to reduce, since newly infected persons contribute to the total number of people living with HIV and are a potential source of further transmission. At the national level, there have been various responses to HIV and AIDS. Zimbabwe has a national AIDS policy and sustainable financing for HIV and AIDS programs through a 3% national AIDS levy on all employees that was introduced in 2000 and is administered through the National AIDS Council (NAC). Zimbabwe is implementing a comprehensive multi-sectoral response to HIV and AIDS, known as the ZNASP 2006–2010. The country has also institutionalized the Greater Involvement of People living with HIV (GIPA) now Meaningful Involvement of People living with HIV (MIPA), launched at the Paris AIDS Summit in 1994 and endorsed by heads of 42 States. It aims to recognise the important contribution that People Living With HIV and AIDS (PLWHIV) can and do make, and to create a space for their involvement in all spheres from policy to practice (UNAIDS, 1999). MIPA questions the right of people not living with HIV/AIDS to set the agenda for HIV/AIDS programmes.

In 1994, during the Paris AIDS Summit, 42 national governments, through a declaration that has come to be known as the GIPA declaration, collectively recognized the need for the greater involvement of people living with HIV/AIDS (PLHA) in response to the AIDS pandemic. The GIPA declaration states that the greater involvement of people living with or affected by HIV/AIDS is ‘critical to ethical and effective national responses to the epidemic’.

Taking into consideration that no previous studies have been undertaken to establish information on the knowledge of and implementation of MIPA in Zimbabwe the National MIPA Technical Working Group and NAC proposed a comprehensive study. They commissioned a study to generate insights on current state of MIPA in Zimbabwe.

The Terms of Reference were to:

- Review of existing HIV and AIDS policies and legal frameworks to assess their adequacy to and adoption of the MIPA principle in the different sector responses.
- Determine the existing networks and affiliated support groups in terms of their legal status, membership numbers, affiliations and representation. b) determine the extent to which MIPA is integrated into stakeholders’ human resource and staffing processes, decision making and organizational culture etc.
- To assess the existing competence and capacity of stakeholders to mainstream MIPA into their planning and programming, as well as those of their partners.
- Assess overall needs and skills levels of networks and institutions of PLWH
FINDINGS OF THE SURVEY:

Zimbabwe has committed itself to integrating the principles of MIPA in its HIV and AIDS intervention, though the operationalisation of this commitment has tended to be a big challenge. The existing policy and legal framework attempt to address the issue of MIPA but not emphatically enough and the problem of stigma and discrimination looms large as a barrier to meaningful involvement of PLWHIV. Stigma and discrimination made disclosure isolated rather than common. Seemingly, the existing policy and legal framework requires tightening to ensure that MIPA is approached as a human rights issue in HIV and AIDS interventions. The point of departure would be to sensitise policy makers and stakeholders in the multi-sectoral response framework for them to ensure that there is policy reform addressing MIPA.

Institutional arrangements for the integration and operationalisation of MIPA need to be crafted carefully to ensure that there is a sustainable shift from commitment to action on the issue of meaningful involvement of people living with HIV and AIDS in the national response. Nevertheless it is worth noting that in the pursuit of sustainable MIPA (SMIPA) there are two principal players to ensuring transition from commitment to action, that is, the infected and health service providers or AIDS service organisations. The two parties have mutual obligations where the former ought to demand a role in service design, implementation (provision) and monitoring and evaluation (audit); and the latter has an obligation to craft a product that is always informed by the demand side or target beneficiary (PLWHIV). To this end, the development of a conducive policy framework by NAC is imperative to the attainment of MIPA.

When looked at from the point of view of six levels of involvement proposed by UNAIDS (1999) that is starting with the lowest- target audience, contributors, speakers, implementers, experts and decision makers, most organizations of PLWHIV were found to be at level six of involvement. That was the case when one considered level of participation of PLWHIV in designing, implementation and monitoring and evaluation of the HIV and AIDS intervention programmes. On the other hand, most support groups and their members were a mere target audience of the HIV and AIDS response and very far away from the decision making arena. This situation could be attributed to support groups being generally perceived by programmers as an extension of organisations involved in the national response rather than being an integral part of the operationalisation of the intervention programmes. Most of the design and monitoring and evaluation of programmes was still being done by implementing partners and donors thereby leaving support groups without autonomy over the activities they implemented. This situation pointed primarily to gaps in policy and lack of empowerment in form of capacity development as barriers worth of attention in ensuring the meaningful involvement of support groups in the HIV and AIDS national response.

CONCLUSION

This survey was principally a situational analysis of the state of meaningful involvement of people living with HIV and AIDS (PLWHIV) in Zimbabwe. Essentially the survey sought to establish how far the country had progressed in the fulfillment of MIPA from principle to practice. With reference to this, the most salient findings of the baseline survey were that the existing policy, strategic plan and legal framework guiding NAC, ASOs, CBOs, FBOs and other agencies of the multisectoral response hardly positioned MIPA to be the cornerstone of the entire HIV and AIDS response, that is in prevention, treatment, care and support and mitigation. The overall picture emerging from the survey depicted NAC and other stakeholders being geared mostly for the implementation of GIPA and not MIPA. Under GIPA organizations aimed at ensuring just the participation of PLWHIV in implementation of HIV and AIDS programmes whereas in the latter case emphasis is on empowerment of PLWH to reach the highest level of participation i.e. decision making level. When measured against the six levels of participation, the majority of ‘players’ were far from reaching ‘meaningful’ involvement of PLWHIV which at the highest levels entail involving them in the HIV and AIDS response as experts and decision-makers and not being confined to the lower roles of being a target audience, contributors, speakers or implementers. Most players involved in the HIV and AIDS response were still paying lip service to implementation of the principle of MIPA. Many of them exhibited a very shallow understanding of the concept of MIPA and hence lacked the know-how for operationalising the principle of MIPA. On the other hand,
PLWHIV representing the demand side of the HIV and AIDS response were found wanting in terms of skill-base to participate meaningfully. They lacked a variety of skills that were critical to ensuring their meaningful involvement. Capacity building at various levels depending on one’s experience and educational background is therefore a key step in empowering PLWHIV to be meaningfully involved in the response. Without empowerment there would be no meaningful involvement of PLWHIV to talk about.

In order for MIPA to take root in the HIV and AIDS response in Zimbabwe it is important to make sure that an enabling environment is created. The first step should be to attend to the structural issues which should involve the reviewing of the current policy and legal framework to ensure that they recognize and position MIPA as a cross-cutting theme in the multisectoral response framework. Hence the existing legal and policy framework needs refocusing in order for it to drive the operationalisation process of MIPA. The second step would be to engage in an extensive educational campaign familiarizing stakeholders with the concept of MIPA. The third step in implementing MIPA in the national response is to attend to the training needs of both the demand and supply sides. A lot of resources went into training PLWHIV in basic nursing care especially for HBC. As a result majority of PLWHIV were mostly involved in care and support. However, their involvement did not involve decision-making in anyway but just as implementers of decisions already made. Training in the various areas of need would therefore enable both sides to play their respective roles within the multisectoral response in accordance with the principles and practice of MIPA. Fourth, since the survey revealed that the existing network of PLWHIV organizations was too weak to steer the ‘MIPA-isation’ process owing to lack of capacity and internal strife; there is need for institutional capacity building to enable the organisations of PLWHIV to play their oversight role in implementation of MIPA.

Another finding of the baseline survey and a cause for concern was that stigma and discrimination still existed in Zimbabwe and was the worst enemy of MIPA. It prevented many PLWHIV from opening up about their HIV status because involvement would automatically expose them. This created a big challenge with individuals and organizations asking; ‘how can we involve them when we don’t know them?’ The greatest weapon in fighting this hurdle to the attainment of MIPA is for the government to invigorate the voluntary counselling and testing thrust (VCT). The logic being as many people become aware of their statuses the less they are prone to stigmatizing those who go public about their status since undergoing testing is on its own a humbling enough. More importantly, it is absolutely necessary for the authorities to increase access to ART. This goes a long way in encouraging HIV positive people to be open about their status since contraction of the virus would no longer be stigmatizing as it would no longer be perceived as a ‘death sentence’ but a health problem just as common as other incurable diseases requiring managing.

Recommendations

The recommendations fall under the following themes: policy and legal framework, capacity building and training, coordination and governance, educational and awareness needs, stabilization of network of PLWHIV, sustainable resource mobilization.

Policy and Legal Framework

1. PLWHIV are currently not involved in the entire spectrum of the HIV and AIDS national response hence organisations of PLWHIV should lobby for meaningful involvement of PLWHIV in prevention, treatment, care and support that is in the entire programming cycle from design to evaluation of programmes. Network of PLWHIV should advocate for formulation of MIPA friendly policies and strategic plans that ensure highest form of involvement by PLWHIV.

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1 Please note that ZNNP+ is cited herein to represent all organisations of PLWHIV and assuming that it will take on board the interests of the majority of stakeholders on MIPA.
2. There is need for NAC to revisit the existing policy and strategic plan to ensure that they cater for the specific interests of women living with HIV and AIDS, the disabled, Youths, OVCs, men having sex with men, commercial sex workers and other vulnerable groups.

3. There is need for ZNNP+ and NAC to organize and coordinate a review of the Zimbabwe national strategic plan (ZNASP) 2006-2010’ and Behaviour Change Strategy in order to ensure that PLWHIV are accorded a frontline role in the execution of the plans.

**Existing Networks of Support Groups**

4. The network of PLWHIV should embark on a countrywide support group formation, affiliation and capacity development to ensure meaningful involvement of PLWHIV in the HIV and AIDS national response at their respective levels.

5. There is need for the network of PLWHIV to organize and coordinate training of support groups in communication and negotiation, computer literacy, legal and Human Rights, basic counseling, leadership and internet literacy.

**Capacity Building**

6. There is need for the network of PLWHIV to organize capacity building and training for leaders of organizations of PLWHIV in leadership, organisational planning and development, organisational management, financial management, networking, advocacy, writing proposals for funding, resource mobilization, designing a monitoring and evaluation framework and basic literacy in information technology.

7. There is need for ZNNP+ and NAC to organize training of trainers’ workshops for NAC national and provincial staff and representatives of partners on MIPA. This is in order to ensure that NAC secretariat, partners and sector representatives have an in-depth understanding of the concept of MIPA.

**Coordination and Governance**

8. There is need for ZNNP+ to professionalise the day to day running of the organization by putting in place a secretariat that will implement the decisions of the Board on MIPA.

9. There is need for the network of PLWHIV to constitute MIPA Technical Working Groups that mirror the hierarchy of decentralized governance that is covering the national, provincial, district, ward and village. This is in order to ensure representation at all levels and ensure flow of information both upwards and downwards.

10. There is need for the network of PLWHIV to lobby for the formulation of national workplace policies that promote MIPA in the governance of organisations.

11. There is need for the network of PLWHIV and NAC to embark on the development of a MIPA Strategic Plan/ MIPA National Strategy and a MIPA Monitoring and Evaluation Framework that will help guide the process of translating MIPA from principle to practice.

12. There is need for the network of PLWHIV and NAC to oversee the development of Guidelines on MIPA or MIPA Code of Conduct (MCC) to be adhered to by both employers and employees in Zimbabwe. The MCC will also serve as a tool for fighting stigma and discrimination at workplaces.
Educational and Awareness Needs

13. There is need for the network of PLWHIV and NAC to coordinate the development of materials for a nationwide educational awareness campaign on MIPA. This is necessary for ensuring that the nation’s attention is drawn to the values and essence of MIPA.

14. There is a need for the network of PLWHIV and NAC to oversee the regular documentation of `MIPA Best Practises’ to be published and distributed to the public. The publication of ‘best practises’ is meant to provide corporate entities with MIPA models.

Stabilization of Network of PLWHIV:

15. In order to deal with internal strife in organisations of PLWHIV that undermines realisation of MIPA, NAC and network of PLWHIV should draw up a plan for fostering unity among the various organizations of PLWHIV in Zimbabwe.

16. There is need for the network of PLWHIV and NAC to leverage funding from donors specifically to be used for capacity building of leadership of organisations of PLWHIV.

Resource Mobilization:

17. There is need for the network of PLWHIV and NAC to train the leadership of organisations of PLWHIV in writing proposals for funding to ensure their meaningful involvement in the HIV and AIDS national response.

18. There is need for the network of PLWHIV to lobby for a greater say in the administration and utilisation of the national HIV and AIDS levy.

Unclassified Recommendation

19. There is need for the network of PLWHIV and NAC to lobby the donor community to promote MIPA in Zimbabwe by ensuring that proposals submitted for funding mainstream MIPA as a precondition for approval.
CHAPTER 1: INTRODUCTION

BACKGROUND
An estimated 33.2 million people are living with HIV and AIDS (UNAIDS 2007). Every day over 6800 persons are infected with HIV and about 5700 people die from AIDS. The estimated number of deaths due to AIDS in 2007 was 2.1 million. AIDS remains a leading cause of mortality worldwide and the primary cause of death in sub-Saharan Africa. Sub-Saharan Africa remains the region mostly affected by HIV and AIDS. A total of 22.5 million people are living with HIV in the region with 1.7 million of them infected in 2007 (ibid). According to UNAIDS (2007)’s global view of HIV infection, there were 33.2 million PLWHIV. Of these 30.8 million were adults, 15.4 million were women and 2.5 million were children under 15 years. In the same period new infections were 2.5 million. Of these 2.1 million were adults and 420 000 were children under the age of 15 years.

Almost 61% of people living with HIV in the region were women. Southern Africa alone accounted for almost one third (32%) of all new infections and AIDS deaths globally in 2007.

In Zimbabwe at the end of 2007, the total for both adults and children living with HIV stood at 1,320,739, adults alone (15-49) were 1,085,671; women (15-49) accounted for 651,402 and children living with HIV (0-4yrs) were 132,938. This left the prevalence rate for adults (15-49 yrs) at 15.6%. However declines have been experienced in 2005 and 2006 and have been attributed to scaling up of antiretroviral treatment (ART) services.

HIV incidence is the key parameter that prevention efforts aim to reduce, since newly infected persons contribute to the total number of people living with HIV and are a potential source of further transmission. At the national level, there have been various responses to HIV and AIDS. Zimbabwe has a national AIDS policy and sustainable financing for HIV and AIDS programs through a 3% national AIDS levy on all employees that was introduced in 2000 and is administered through the National AIDS Council (NAC). Zimbabwe is implementing a comprehensive multi-sectoral response to HIV and AIDS, known as the ZNASP 2006–2010. The country has also institutionalized the Greater Involvement of People living with HIV (GIPA) now Meaningful Involvement of People living with HIV (MIPA), launched at the Paris AIDS Summit 1994 and endorsed by heads of 42 States. It aims to recognise the important contribution that people living with HIV/AIDS (PLHA) can and do make, and to create a space for their involvement in all spheres from policy to practice (UNAIDS, 1999). MIPA questions the right of people not living with HIV/AIDS to set the agenda for HIV/AIDS programmes.

The "Greater Involvement of People Living with HIV/AIDS" (GIPA) principle, a global commitment emanating from the Paris AIDS Summit in 1994, is a recognition of the important contributions people infected or affected by HIV/AIDS can make in response to the HIV/AIDS epidemic (Pokharel, 2004).

Several studies attempt to address the issue of GIPA and MIPA (Gooey 2006; Stephens 2004; Magaz et al 2004; Horizons 2002; GNP+ 2002). Gooey (2006) makes a number of observations on barriers to MIPA, service delivery, and capacity building of PLWHIV. On the issue of barriers, he identifies three types; social, institutional and personal. Under social barriers come issues of stigma and discrimination and lack of solidarity amongst PLWHIV. On institutional barriers he identifies lack of workplace policies encouraging involvement of PLWHIV, and patronizing attitudes of staff, boards of directors or donors – discriminating against PLWHIV. According to Gooey (2006) the issue of
policy and reasons for disclosure/non-disclosure constitutes the core of the institutional barrier problem. He observes that, although disclosure is a very individual matter with no hard or fast reasons, the level of responsibility and need of PLWHIV influences disclosure. He further argues that personal barriers to MIPA are mainly subjective; these include fear of stigma and violence, and a lack of confidence or motivation in the ability to contribute.

Gooey, also observes that being meaningfully involved in HIV and AIDS responses provides many therapeutic benefits for PLWHIV - rebuilding self worth, and leading meaningful and fulfilling lives. Many PLWHIV evolve from service users (beneficiaries) to becoming service providers – mostly as counselors, educators and trainers within AIDS organizations, health services and support groups.

Of similar mind set to Gooey on the impact of disclosure on MIPA is Stephens (2004) who contends that stigma and discrimination ranks as a major disincentive to the promotion of GIPA and constitutes a fundamental barrier to PLWHIV involvement. The author observes that a negative link is established between the level of felt and enacted stigma (discrimination) and the ability of PLWHIV to initiate and sustain involvement. He proceeds to articulate some of the benefits arising from PLWHIV involvement on MIPA such as improved policy and programs, creation of greater awareness of HIV/AIDS at all levels of society, and more effective HIV and AIDS communication strategies. At personal level, involvement contributes to a greater sense of personal well-being and assists people to stay active and economically viable. The impact of involvement on reduction of stigma and discrimination is also significant. Stephens argues that the advantages of GIPA at the policy level accrue beyond the immediate concerns of prevention, care, and treatment issues and can improve the capacity of sectors such as education and employment to respond to HIV and AIDS. Involvement also marks ownership. This will create a greater sense of commitment toward the policy or program that is developed, which will help develop trust between the beneficiaries and the project and a greater understanding of the programs and policies on the part of the beneficiaries.

Magaz et al (2004) reveals some drawbacks to GIPA. He avers that increased involvement of PLWHIV per se where strict screening procedures and training schedules do not precede it may result in reduction in quality of service provision for organizations and the country concerned.

A study commissioned by International HIV and AIDS Alliance (Horizons, 2002) recommends the creation of a supportive environment for meaningful involvement of PLWHIV. It stresses the need to avail material support and incentives to unemployed and employed PLWHIV. For the employed, in addition to salary, provisions should be made to facilitate access to care, particularly drugs, counseling and treatment free of charge. Furthermore, when PLWHIV are involved in HIV and AIDS activities incentives in the form of meals should be extended.

The study also examines the level of involvement and participation of PLWHIV in managing HIV and AIDS organisations. It observes that with few exceptions, visible PLWHIV are not involved in NGO management, policymaking and strategic planning (“strategic” and “governance” levels of decision making). The study identified two “types” of non-involvement: tokenism and exclusion. Tokenistic involvement is where PLWHIV are assigned management positions because they are HIV positive but do not have access to the decision-making process. They may, for example, be appointed to the board of an organization but have no influence on policy, programming or financial issues. Tokenism also includes visibility; for example, where PLWHIV attend meetings and conferences but only give testimony and are not allowed to speak on behalf of the organization with which they are involved.
Exclusion is where a person who identifies himself or herself as HIV positive, or is identified as HIV positive by an NGO, cannot access the services provided by the organization and cannot take part in the activities of the organization in any way.

In the area of capacity building Stephens again points out that capacity building entails engaging PLWHIV with experienced and skilled policymakers. However he warns that this requires a level of expertise that many PLWHIV who have come forward do not possess owing to the fact that the majority of PLWHIV who have revealed their status are from low socioeconomic strata with only basic education.

In order to achieve capacity building, GNP+ recommends more systematic training and capacity building in proposal writing, project development, budget, and implementation and monitoring of implementation skills for PLWHIV.

Horizons (2002): Policy Project; narrates the impact of PLWHIV involvement in service delivery and management on NGOs. Data from the study highlight that PLWHIV involvement in service delivery helps to improve care and support services by making them more relevant and personalized. Involvement in service delivery also enhances credibility of NGOs and its service. PLWHIV also get a platform from which they are able to raise staff awareness of their issues from a PLWHIV perspective.

At this juncture, it seems necessary to put the concept of MIPA into context by revisiting its origins. The early stages of MIPA then loosely referred to as Greater Involvement of People Living with HIV (GIPA) can be traced back firstly to the Denver Conference: (which gave birth to the so called Denver Principles). Below are the Denver Principles.

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**THE DENVER PRINCIPLES (1983)**

There is no better way to cite the history of the PLWHIV self-empowerment movement than to quote the principles articulated in Denver in 1983. They are as relevant and powerful today as they were then.

**THE DENVER PRINCIPLES**

(Statement from the advisory committee of the People with AIDS) We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

**RECOMMENDATIONS FOR ALL PEOPLE**

1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

**RECOMMENDATIONS FOR PEOPLE WITH AIDS**

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviours for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.
In 1994, during the Paris AIDS Summit, 42 national governments, through a declaration that has come to be known as the GIPA declaration, collectively recognized the need for the greater involvement of people living with HIV/AIDS (PLHA) in response to the AIDS pandemic. The GIPA declaration states that the greater involvement of people living with or affected by HIV/AIDS is ‘critical to ethical and effective national responses to the epidemic’.

On the basis of the Denver Principles, UNAIDS (1999) suggests a pyramid of six levels of PLWHIV involvement, viz. involvement as Target Audiences, Contributors, Speakers, Implementers, Experts and Decision Makers.
Horizons/Alliance (2002) has come up with its own interpretation of the Denver Principles in order to operationalise them. Their study provides a similar evidence-based framework that helps to clarify what meaningful involvement is in practice. The study identifies four categories of involvement. These are summarized in the table below

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2 The UNAIDS (1999) ‘key material’ From principle to Practice, Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)
CATEGORIES OF INVOLVEMENT

**Access to services:** This level of involvement is defined as PLWHIV taking part in NGO activities as beneficiaries of services. It was most typically observed among the 17 NGOs that took part in the study.

**Inclusion:** Inclusion is characterized by PLWHIV acting as support staff for HIV/AIDS NGOs and as volunteers in HIV/AIDS service delivery. The research found that PLHA involvement at this level is not formally supported by structured training or wage remuneration.

**Participation:** Participation moves PLHA involvement into a more structured and recognized role within NGOs. In this category, PLHA expertise is recognized and work is financially rewarded.

**Greater Participation:** Greater participation is defined as the most advanced stage of PLHA involvement. This level is characterized by PLWHIV working in management and as significant policy and strategic organizational actors. At this level, PLWHIV may also have a significant representative role outside the NGO.

The UNAIDS and Horizons/Alliance (2002) guides to meaningful involvement of people living with HIV and AIDS will serve as a very important analytic tool of the baseline data. It provides some semblance of indicators with which to assess Zimbabwe's position in MIPA.
CHAPTER 2: METHODOLOGY

Taking into consideration that no previous studies have been undertaken to establish information on the knowledge of and implementation of MIPA in Zimbabwe the Technical Working Group and NAC proposed a comprehensive study. They commissioned a study to generate insights on current state of MIPA in Zimbabwe. The insights will be used to formulate a National MIPA Strategic Plan. The terms of reference of the study were:

MAIN OBJECTIVE OF THE STUDY

Conduct a baseline study on current trends on MIPA within NAC and key Implementing Agencies in the Multi-lateral Response for the development of MIPA strategic interventions.

Specific Objectives

The specific objectives of the baseline study are to:

• To determine the existing PLWH networks and major support groups in terms, legal status, membership and representative-ness.

• To outline and collate information on the approaches that have been adopted in the national legislative and policy frameworks to ensure meaningful involvement of PLWH in the responses to HIV and AIDS.

• Highlight how NAC and other key implementing agencies have integrated GIPA and MIPA principles in their administrative structures, policies, procedures, programmes and in executing their mandate.

• To show how different key stakeholders in the national response (ASOs, private, public and uniformed forces sectors) have integrated the GIPA and MIPA principles in their interventions ranging from their administrative systems and policies to their programmes.

• To examine the extent to which PLWH are represented in various HIV/AIDS structures of the Multi-lateral response.

• To identify the challenges, barriers, gaps, and opportunities to greater and meaningful involvement of PLWH in the multi-sectoral national response.

• To determine the overall needs and skills levels of networks and institutions of PLWH.

• To make recommendations for, the development of a strategy document and a monitoring and evaluation framework for improved multi-sectoral integration of GIPA and MIPA principles in responses to HIV and AIDS.
UNDERSTANDING AND INTERPRETATION OF THE ASSIGNMENT

The assignment entails:

- **Legal and Policy review** - A detailed review of existing HIV and AIDS policies and legal frameworks to assess their adequacy to and adoption of the MIPA principle in the different sector responses.

- **Institutional Assessments** - (a) determine the existing networks and affiliated support groups in terms of their legal status, membership numbers, affiliations and representation. b) determine the extent to which MIPA is integrated into stakeholders’ human resource and staffing processes, decision making and organizational culture etc.

- **Programmatic and technical skills assessments** - to look at existing competence and capacity of stakeholders to mainstream MIPA into their planning and programming, as well as those of their partners.

- **Assessment of overall needs and skills levels of networks and institutions** of PLWH.

The consultant(s) were required to describe the cross-sectoral situation of MIPA in national responses to HIV and AIDS. Specifically, the consultant(s) were expected to assess the extent to which the principle of MIPA was being integrated or factored theoretically and practically into responses to HIV and AIDS by leading AIDS Service Organisations (ASOs) e.g. NAC, ZAN etc, private and public sector and uniformed forces sectors i.e. army, prisons and police. The main tasks of the consultant were to review existing policies and legal frameworks for mainstreaming of MIPA principles, institutional assessments for integration and, operationalisation of MIPA principles; and assessment of programmatic and technical skills of institutions for mainstreaming MIPA.

METHODOLOGY FOR THE BASELINE SURVEY

The baseline study adopted both quantitative and qualitative research. The former was deemed necessary for capturing statistical data on a variety of parameters such as number of support groups in NAC districts and provinces; membership, membership distribution by sex etc. The qualitative approach was also adopted for capturing data on people’s opinions or perceptions on the state of MIPA within the HIV and AIDS multi-sectoral response framework. The specific data collection techniques to be used are the review of literature, interviews, focus group discussions and questionnaire.

Data Collection

*Review of Literature*

The consultants among others reviewed the following literature or documents:

- The National HIV and AIDS Policy
- Zimbabwe National HIV and AIDS Strategic Plan,
- National HIV and AIDS Behaviour Change Strategy
- Workplace HIV and AIDS policies
- Zimbabwe HIV and AIDS National Strategic Plan Monitoring and Evaluation Framework 2006-2010
- Zimbabwe NAC Act
Interviews
Primary data collection was carried out in six provinces using interview schedules which guided interviews with selected stakeholders. The provinces selected for the fieldwork to represent cultural and geographical variations were Manicaland, Matabeleland North, Masvingo, Bulawayo, Mashonaland East and Harare. Most interviews in these provinces were held with individuals in their capacity as representatives of their organizations. Most of the key informant interviews were held in Harare since most Head Offices of AIDS Service Organisations (ASOs) were located in the capital (see annex for a full list of people and organisations involved in the survey).

Focus Group Discussions
The consultants held seven (7) focus group discussions with support group members at district level in order to get a close up picture of the state of MIPA in the HIV and AIDS response at grassroots level from the point of view of beneficiaries. The group discussions were in 5 Provinces and principally covered urban and peri-urban areas.

Sampling Procedure
Combinations of random and purposive sampling methods were used to obtain units of analysis which included focus group members, key informants and implementers. Random sampling was ideal for selecting representative support groups for analysis out of the many units and the purposive sampling was used to target people who were deemed to be potential sources of information on the MIPA situation in their respective constituencies.

Data Analysis
Quantitative data was analyzed using frequency tabulations and qualitative data was categorized according to themes and analyzed thematically.

PROBLEMS ENCOUNTERED
The survey did not succeed in interviewing representatives of Government Departments and representatives of uniformed forces. However, in Bulawayo the researchers managed to interview the Regional Health Director for Prisons. All the efforts made to fix appointments for interviews by phone or calling in person at respective workstations of target senior government respondents did not yield any positive results.
CHAPTER 3: REVIEW OF EXISTING POLICY AND LEGAL FRAMEWORK FOR MAINSTREAMING OF MIPA PRINCIPLES IN ZIMBABWE

INTRODUCTION

Policies guide the interventions and operations of stakeholders on defined issues for uniformity, consistency and delivery of quality services by the service providers to the populace of a country. An analysis of the HIV and AIDS policies in Zimbabwe is necessary for ascertaining the policy provisions in relation to MIPA. Below is an outline of Zimbabwe HIV and AIDS policies and their provisions for MIPA.

POLICY FRAMEWORK

▪ *The Declaration of Commitment of the United Nations General Assembly Special Session on HIV and AIDS (UNGASS, 2001).*

▪ *The Zimbabwe National Strategic Plan (ZNASP) 2006-2010*; acknowledges the centrality of MIPA as a guiding principle to the multi-sectoral response to HIV and AIDS.

▪ *The Zimbabwe National Guidelines on HIV Testing and Counselling (2005)*; called for the involvement of PLWH in the planning and implementation of counselling and testing services, and for PLWH to provide linkages between counseling and testing and post test support services.

▪ *The Government of Zimbabwe HIV and AIDS Care Plan for the Nationwide Provision of ART 2005-2007* – strategic objective 3 calls upon the Ministry of Health and Child Welfare to expand treatment and care including ART with MIPA and to develop national criteria for determining free access to ART services by community volunteers and non-health personnel.

▪ *The National Behaviour Change Strategy* - highlights the importance of involvement of PLWH in behaviour change and prevention Programmes

▪ *National Aids Policy* - states that the strategy to intervene on HIV and AIDS calls for a multi-sectoral response through the proposed National AIDS Council (NAC) including support groups for people living with HIV and AIDS. There is a guiding principle on protecting and promoting human rights and dignity of PLWHIV. Discrimination against PLWHIV is stated to be counter productive as it increases vulnerability to HIV infection and undermines efforts in response to the epidemic.

Strategies that speak to involvement of PLWHIV to be employed under the policy include:

▪ Promotion and enforcement of legislation which protects individuals against human rights violation and discrimination in respect of HIV and AIDS

▪ Implement educational and information interventions aimed at changing the attitudes of the general public and specific target population groups in support of respect of human rights and avoidance of discrimination of PLWHIV.
▪ Confidentiality of medical information about people living with HIV infection is important because of the risk of stigma and discrimination in respect of HIV and AIDS.

▪ Give information and offer counseling to HIV positive women and their partners in order to enable them to make informed decisions about planning pregnancy

▪ Increase general public’s access to IEC on options for HIV positive women to reduce the risk of mother to child transmission of HIV.

▪ Encourage all breast feeding women whether HIV positive or not to use barrier protection methods to prevent early conception and HIV infection or re-infection

▪ Provide appropriate information for PLWHIV to enable them to make informed decision about breast feeding

▪ Support PLWHIV on appropriate, safe and affordable breastfeeding options

▪ Mobilize and support communities and support communities and families to deliver HBC and utilize existing community structures

▪ HIV positive mothers who request for VCT of their children will access it when their babies reach an age at which the tests are likely to be accurate.

▪ Zimbabwe National Reproductive Health Policy- The policy focuses on prevention of primary infection in the reproductive age group and its complications in those who are HIV positive. There is an objective of reducing the risk of complications in HIV infected people and extend their lifespan. Strategies to be employed include the provision, accessibility, affordability of ARV and other drug support therapy to PLWHIV in public and private sectors.

(No MIPA provisions)

National Action Plan for OVCs- Children living with HIV are considered to be vulnerable children. There is no MIPA in the child protection committees at provincial, district and community level that ensures the implementation of MIPA.

Zimbabwe National Strategic Framework for the Private Sector Response to HIV and AIDS 2007 to 2009- This is a framework for guiding and coordinating strategic HIV and AIDS programming in the private sector, small and medium enterprises and the informal sector to protect PLWHIV against stigma and discrimination at workplaces.

One of the key principles guiding the development of the strategic framework is full adherence to the principles of greater and meaningful involvement of PLWHIV. In the event that PLWHIV’s work becomes demanding and compromising on their health, the employee and the employer will decide together transfer to a more suitable position. PLWHIV were also stated to be awarded opportunities for participation in the development and implementation of HIV and AIDS policies and programmes within the workplace.

The policy guides stakeholders in their contributions to behaviour change promotion. It speaks to the need to reduce stigma and discrimination associated with PLWHIV and involvement of PLWHIV as
role models on faithfulness, HIV status sharing. The policy also focuses on strengthening behaviour change messages for PLWHIV.

On the guiding principles, policy provisions note that it is essential to combat stigma associated with HIV and AIDS as well as prevention services and meaningful involvement of PLWHIV in HIV prevention. Regarding the components of the BC strategy, there is an acknowledgement of the challenges that there is limited involvement of PLWHIV in HIV and AIDS response. PLWHIV are recognized as behaviour change (BC) agents and target groups on interventions on uptake of services and addressing stigma.

District level BC action plans in accordance to the policy state that there shall be:
- Establishment of district BC forums including PLWHIV
- Support to Ward AIDS Action Committees (WAAC) in identifying potential homes for post test support groups and PLWHIV support group.
- Promotion of participation of PLWHIV and establish district systems to monitor their discrimination and exclusion.

The policy has an objective on reducing stigma discrimination and increase number of PLWHIV openly discussing their status and be involved in programme on HIV prevention. This objective focuses on
- Creation of an enabling environment for PLWHIV to be secure and comfortable to share and discuss on their status.
- Support to employers to develop HIV and AIDS workplace policies and clarifying the organizational support and health care benefits for PLWHIV.
- Training of health and other service providers to address attitudes on stigma and discrimination.
- Male and female condom promotion for discordant couples, and PLWHIV during the VCT and post test interventions.

On the objective of increased behaviour change promotion targeting PLWHIV, the policy states that there is to be
- Development of messages and support to assist PLWHIV to avoid passing on of HIV.
- PLWHIV involvement in and targeted through testing and counseling, post test support groups, ASOs, HBC and health service provisions.
- PLWHIV shall be involved in prevention efforts at all levels, including as employees of ASOs, experts, and volunteers in leading positions will be increased.
- Representation of PLWHIV in AIDS Action Committees at all levels, including in leading positions will be increased.
• Public awareness programmes led by PLWHIV who are willing to share their status.

For Behaviour Change Strategy dissemination and implementation, it is stated that there will be engagement of all stakeholders from umbrella bodies, PLWHIV, FBOs and CBOs. The BC strategy on the results matrix acknowledges that the role of PLWHIV is still marginal and therefore among some of its planned activities intends to:

- Mainstream gender and meaningful involvement of PLWHIV in all community action planning processes
- Organise training of trainers for PLWHIV in prevention, stigma and discrimination
- Establishing of focal points for monitoring and exposing discrimination against PLWHIV such as exclusion from meetings.
- Involvement of PLWHIV in prevention programmes at all levels including as staff, experts and volunteers.
- Training of selected members of PLWHIV and post-test support groups in positive prevention.
- Promotion of contraceptives and dual protection among the PLWHIV.

**MIPA Gaps in HIV and AIDS Policy**

- Levels of MIPA are not stated in the policy provisions
- Role of MIPA in reducing trans-generational relationships and the development of IEC and documentation materials is not stated.
- There is no binding provision securing the position of PLWHIV as legitimate participants in policy and decision making.
- No provision highlights on the empowerment of PLWHIV in their human rights, policies only emphasise protection from discrimination and stigma.

**The Legislative Framework**

- The constitution of Zimbabwe- guarantees every individual's right to privacy, association and assembly, and freedom from discrimination but does not guarantee the right to health.
- The National AIDS Council Act 15:14 identifies PLWHIV as being a special class of persons in the response to HIV AND AIDS.
- The Labour Act – provides for the prevention of discrimination against PLWH in the employment sector.
- The Public Health Act,
- The Sexual Offences Act- outlines sexual offences and criminalises the willful transmission of HIV and AIDS.
CONCLUSION

Zimbabwe has committed itself to integrating the principles of MIPA, though the operationalisation of this commitment has tended to be haphazard and discretionary. A number of policies speak to issues of MIPA but the implementation of such provisions is still lacking as evidenced by stigma and discrimination in most HIV and AIDS reduction interventions and processes. There is need for policy reforms to ensure that MIPA becomes a human rights issue requiring urgent attention for sustainable interventions of addressing the HIV and AIDS interventions. Sensitizing policy makers and stakeholders working on HIV and AIDS is also instrumental to ensuring that policy reform addresses MIPA gaps.
CHAPTER 4:
INSTITUTIONAL ARRANGEMENTS FOR INTEGRATION AND OPERATIONALISATION OF MIPA PRINCIPLES BY NAC AND OTHER IMPLEMENTING AGENCIES

INTRODUCTION
Institutional arrangements are pivotal in the translation of MIPA from principles to practice. Without them, the concept of MIPA and its principles will remain at rhetorical level. When this is allowed to happen, the casualty is the quality of national response to the HIV and AIDS epidemic. It is worth re-stating that a nation’s response to the epidemic in prevention, treatment, care and support hardly attains optimum effectiveness without the active involvement of people living with HIV and AIDS in the entire programming cycle of planning, implementation, monitoring and evaluation. This section looks at institutional arrangements for the integration and operationalisation of MIPA principles by NAC and other implementing agencies. But before delving into the arrangements themselves there is need to be clear about conceptualization of the term ‘institutional arrangements’.

In this report institutional arrangements shall be held to refer generically to (1) rule configurations or policy and legal framework that guide the implementation of MIPA (2) the human, financial, technical and material resources put in place for driving the implementation process and; (3) structures set up to engage in decision making necessary for ensuring the operationalisation of MIPA at various levels. On the other hand, integration shall be deemed to refer to the accommodation of the MIPA thrust within existing operational frameworks. In order to obtain insight into the integration and operationalisation of MIPA by NAC and other implementing agencies, this section specifically focuses on legal and policy provisions for MIPA, coordination and implementation structures and the monitoring and evaluation framework.

LEGAL AND POLICY PROVISIONS FOR MIPA
Legal and policy provisions are essential for ensuring that the concept of MIPA is implemented precisely in the way it is prescribed at law and by policy. More importantly, the provisions make the implementation of the concept binding to all players involved in the HIV and AIDS multi-sectoral response. In order to have an insight into the legal and policy provisions for MIPA there is need to review briefly the NAC ACT, ZNASP (2006-2010), Zimbabwe National Behavioural Change Strategy (2006-2010) and the Zimbabwe HIV and AIDS National Strategic Plan Monitoring and Evaluation Framework (2006-2010), the NAC Activity Report Form (NARF) and the Zimbabwe Public Service Commission HIV and AIDS Policy.

National AIDS Council of Zimbabwe Act
The National AIDS Council of Zimbabwe Act (1999) under Board of Council stipulates that (1) “There shall be a board of the Council which, subject to this Act, shall be responsible for formulating the general policy of the Council and controlling its operations”. Section 5(2) e stipulates, *inter alia*, that the Board shall consist of “organizations that protect the interests of persons infected with HIV and AIDS”. At the time the baseline survey was conducted two organizations of PLWHIV were in the Board of Council to represent the interests of their constituency and the Board had provision for a minimum of 11 members and maximum of 14 members.

Zimbabwe National HIV and AIDS Strategic Plan
The Zimbabwe National HIV and AIDS Strategic Plan [ZNASP] (2006-2010) under section 3.4 on ZNASP embraces the principle of meaningful involvement of people living with HIV and AIDS and commits itself to “fully operationalise the principles of greater and meaningful involvement of people living with HIV and AIDS (MIPA) throughout components of the strategy”. Under the same section the strategic plan also made the following observations on MIPA:

- Stigma remains very high
- Persons openly and positively living with the virus are not yet fully represented in political and programme structures and committees.
- Capacity of key PLWHIV networks needs strengthening
- PLWHIV are still considered more as victims, or programme beneficiaries, than full partners in the national response.
- People living openly and positively with HIV have enormous potential to contribute and drive the implementation of the ZNASP, particularly with regard to prevention messages and interventions and socio-economic mitigation initiatives.
- Active engagement of PLWHIV in strategic planning, implementation and M & E will be sought wherever possible.

Again in the ZNASP (2006-2010) under section 4 on ‘Key Strategies and Targets’ the issue of integrating MIPA is hinted at in the statements that:

- Persons living openly with the virus will be encouraged to become strong advocates for prevention, benefiting from full and meaningful involvement in prevention and treatment program and project design, implementation, monitoring and evaluation.
- The representation of PLWHIV in AIDS Action Committees at all levels, including in leading positions, will be increased.
- Where possible, public awareness programmes including treatment literacy should be led by PLWHIV who are willing to share their experiences.

**Zimbabwe National Behavioural Change Strategy**

The Zimbabwe National Behavioural Change Strategy (2006-2010) crafted for prevention of sexual transmission of HIV addresses the issue of MIPA in its guiding principles by stating in clause (b) that:

> It is essential to combat stigma associated with HIV and AIDS as well as HIV prevention services and meaningfully involve PLWHIV in HIV prevention.

Under objective 2.4 “Increase behavioural change promotion targeting HIV positive persons” the Strategy stipulates that; “persons living with HIV and AIDS shall be involved in prevention efforts at all levels including as employees of AIDS service organisations, experts and volunteers”. In addition, it is further stated that “public awareness programmes should be led by PLWHIV who are willing to share
their experiences”. The planned activity with reference to this was the involvement of HIV positive persons in HIV prevention programmes.

Zimbabwe HIV and AIDS National Strategic Plan Monitoring and Evaluation Framework

It is noteworthy that the Zimbabwe HIV and AIDS National Strategic Plan Monitoring and Evaluation Framework (2006-2010) is completely silent on the issue of MIPA. The policy adopted by NAC to have each thematic area develop its own M&E framework ensured that the M&E for the concept of MIPA was addressed in the Zimbabwe National Behavioural Change Strategy (2006-2010) under the various outcome areas.

The Public Service Commission being one of the largest employers in Zimbabwe also deserved having its HIV and AIDS Policy scrutinized for compatibility with the concept of MIPA. Among its Involvement of People Living with HIV” which stated that “people living with HIV and AIDS should be involved in the planning, implementation and monitoring of HIV and AIDS programmes so as to give AIDS a human face” (HIV and AIDS Policy [Zimbabwe Public Service Implementation Strategy], 2005). Under policy objective and strategy 5.16 which seeks to “give HIV and AIDS a human face by involving people living with HIV and AIDS” Public Service parties are mandated to:

1. Involve people living with and affected by HIV and AIDS in sharing testimonies of their life styles, food and where to access assistance; and

2. Involve people living with and affected by HIV and AIDS in planning and implementing HIV and AIDS programmes in the workplace.

In the same policy document are two indicators relevant to MIPA, namely:

- Number of workplace-based support groups for people living with HIV and AIDS
- Number of reported incidences of stigmatization and discrimination

MIPA COORDINATION AND IMPLEMENTATION STRUCTURES

The MIPA coordination and implementation structures were the Technical Working Groups and lead provincial Behaviour Change organisations, respectively.

Structure and Composition of MIPA Technical Working Group

The operationalisation of MIPA is driven by MIPA Technical Working Groups at three levels, that is, national, provincial and district. Each Technical Working Group (TWG) on MIPA was to be composed of 8-12 key stakeholders involved in the multi-sectoral response to HIV and AIDS. The Groups were to be predominantly composed of representatives of member-organizations of the PLWHIV Forum. The NAC National MIPA Coordinator, Provincial AIDS Coordinator and District AIDS Coordinator would serve as the secretariat for the national, provincial and district TWGs respectively. The Provincial and District TWGs were in the process of being constituted at the time the baseline survey was conducted.

The National MIPA Technical Working Group was chaired by the Zimbabwe Network of People Living with HIV and AIDS (ZNNP+) with representatives from The Centre, Public Personalities Against AIDS
Members of the Provincial and District TWGs were to be derived from members of the multi-sectoral response to HIV and AIDS at provincial and district levels respectively.

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<th>Functions of the National MIPA Technical Working Group</th>
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<tr>
<td>(1) To coordinate and superintend the integration of MIPA principles and concepts in all the National HIV/AIDS Programmes and interventions.</td>
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<tr>
<td>(2) To oversee a comprehensive review of current MIPA approaches in the various organisations, programmes as well as structures and recommend interventions and responses.</td>
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<td>(3) To present the findings to key stakeholders.</td>
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<td>(4) To direct the process and efforts aimed at producing a National MIPA strategy and operational plan.</td>
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<td>(5) To provide technical support on MIPA to the programme, policy makers and implementers dealing with HIV/AIDS in the country.</td>
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<td>(6) To advise on the development and implementation of a MIPA strategy.</td>
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<td>(7) To develop a common and coordinated approach to programming.</td>
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<td>(8) To facilitate the development of a standard framework and guidelines on meaningful involvement of PLWHIV.</td>
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<td>(9) To develop MIPA and PLWHIV advocacy strategy.</td>
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<td>(10) The development of a resource mobilisation strategy</td>
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<td>(11) To monitor the implementation of Programmes, trends and issues arising out of MIPA interventions.</td>
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**MIPA and Lead Provincial Behaviour Change Organisations**

On the ground to implement the concept of MIPA is the District Officer for Meaningful Involvement of People Living with HIV and Positive Prevention. The District Officers for MIPA were to become automatic members of their respective District TWGs and are employed under selected lead provincial Behaviour Change (BC) organisations. The District Officer for MIPA and Positive Prevention reports to the District Officer Behaviour Change Programme, who in turn reports to the Behaviour Change Programme Manager. The terms of reference of the District Officer for MIPA and Positive Prevention are presented below:
TOOLS FOR MONITORING AND EVALUATION OF MIPA

The monthly NAC Activity Report Form is a critical tool for measuring progress in the HIV and AIDS response, and among others, in the translation of MIPA from principles to practice. In the strategic area of prevention under the programme area of VCT, indicator code VCT5 and VCT6 refers to number of HIV positive clients referred for medical care this month (OI, ARV therapy) and total number referred for psychosocial support this month, respectively. Under the strategic area of “Mitigation and Support for Affected” in the programme area of “Income Generation (IG)” indicator code IG1 refers to “number of persons participating in IG projects specifically for persons affected by and infected with HIV started by this organization this month”. Indicator code IG2 talks of “number of new IG programmes specifically for persons affected by and infected with HIV started by this organization this month”. IG3 refers to number of persons in this organization newly trained to manage IG projects specifically for persons affected by and infected with HIV by a nationally recognized institution this month”.

In the strategic area of care for Infected and the programme area of People Living With HIV and AIDS NARF requires information on number of new support groups for PLWHIV established by an organisation per month (Indicator Code PLWHIV 1). The Form also asks for number of new members joining existing PLWHIV groups established by the organisation per month (Indicator Code PLWHIV 2). Indicator Code PLWHIV 3 also requires information on number of persons at the organisation newly trained to provide psychosocial support to PLWHIV by a nationally recognised institution per month. The last indicator on the strategic area of “Care for Infected” solicits for information on number of PLWHIV who received support from the organisation per month, by type that is in the areas of psychosocial support, food and nutrition, shelter/housing, counseling, medical assistance, material support, agricultural inputs and others (Indicator Code PLWHIV 4).
In the programme area of ‘Nutrition’ under the strategic area of ‘Mitigation and Support’, the NAC Activity Report Form requires information on whether an organisation provided nutritional support for persons living with HIV and AIDS per particular month (Indicator Code NUT 3). Another indicator is on number of health workers and caregivers at the organisation newly trained in dietary management for PLWHIV per month (Indicator NUT 2).

REFLECTIONS ON CURRENT STATE OF INTEGRATION AND OPERATIONALISATION OF MIPA

This section reflects on the institutional arrangements for the integration and operationalisation of MIPA by principally reviewing the existing legal and policy framework, organizational structure for implementation of MIPA and the monitoring and evaluation framework for MIPA.

Existing Legal and Policy Framework

The existing legal and policy framework is inadequate for laying a foundation for the integration and operationalisation of MIPA. It is not broad and focused enough to guide the translation of the concept of MIPA from “commitment to action”, to use the theme of the ZNASP (2006-2010). The Act needs to accord PLWHIV a frontline position in the national HIV and AIDS response by making a bold and prescriptive statement on mandatory involvement of PLWHIV in the decision making structures of all organisations participating in the HIV and AIDS multi-sectoral response framework. In addition, the Act also needs to acknowledge that MIPA cuts across the spectrum of HIV and AIDS response, that is, prevention, treatment, care and support and mitigation. Implicitly, the NAC Act should provide for the involvement of PLWHIV in decision making at various levels and structures of all facets of the HIV and AIDS national response.

In order to make changes to the existing Act, it is worth noting that the ‘mother’ Act for NAC provides for a less costly route to revising the content of the Act at any point in time by empowering Minister responsible for administering the NAC Act to cause the undertaking of any modifications to it when deemed necessary. Section 20 of the NAC Act titled: Minister may give Board directions on matters of Policy in subsection (1) reads:

Subject to subsection (2) the Minister with the approval of the President, may give the Board such directions of a general character relating to the policy which the Council is to observe in the exercise of its functions, as the President and the Minister consider being requisite in the national interest.

At policy level, the major weakness in integrating and operationalising MIPA lies in that the National Behavioural Change Strategy only provides for involvement of persons living with HIV and AIDS in certain sections of the plan and not in all. For instance out of the 17 objectives on behavioural change in the BC strategy only one objective was to be implemented with the involvement of PLWHIV. This is objective 2.4 which talks about “increased adoption of safer sexual prictises among HIV positive persons”.

Again in the National Behavioural Change Strategy, the monitoring and evaluation framework contained therein also fails to give due recognition to the significance of involving PLWHIV in most if not in all the outcome areas under the overarching goal of “reduced number of new HIV infections”. Out of a total of 21 outcome indicators, only two (2) focus on measuring the issue of meaningful involvement of people living with HIV. The ideal situation should be one where almost all the outcome areas have indicators on involvement of PLWHIV.
**Existing Structure for Integrating and Operationalising MIPA**

The existing structure for integrating and operationalising MIPA through Technical Working Groups are at three levels, that is, the national, provincial and district needs to be interrogated for functionality, inclusiveness and integration. *Functionality* herein refers to the ability of the structure to achieve set goals or tasks as measured through given indicators. On the other hand, *inclusiveness* herein refers to the extent to which the Group accommodates most of the stakeholders who are key to the attainment of set tasks or objectives. Lastly, there is a need to reflect on *integration* which refers to degree of compatibility and blending with existing structures for national HIV and AIDS response. In essence, the TWGs should score highly on all three elements in order for them to pass as appropriate institutions for integrating and operationalising MIPA.

**Functionality**

The MIPA Technical Working Group has a mandate to; coordinate integration of MIPA principles, oversee review of existing MIPA approaches, direct efforts for producing national MIPA strategy, provide technical support on MIPA, advise on development and implementation of MIPA strategy, develop a common and coordinated approach to programming, facilitate development of standard framework for MIPA, develop MIPA and PLWHIV advocacy strategy, develop resource mobilisation strategy and monitor implementation programmes. The National MIPA TWG by design should be able to discharge its responsibilities cited above effectively and efficiently with the assistance of the NAC secretariat which coordinated implementation of decisions of the group. However, it is important to note that the terms of reference of the National MIPA TWG needed to be followed up with the development of indicators for monitoring and evaluation of its activities.

**Inclusiveness**

The point of departure is to ask; which stakeholders are key to the attainment of the goals of the national MIPA Technical Working Group? Obviously, members of the national HIV and AIDS multi-sectoral response should constitute the TWG. Unfortunately the public service and business sector are not represented in the Working Group. The representation of these sectors is vital to ensuring flow of information and the implementation of MIPA principles in the respective sectors.

**Integration**

The existing structures for coordinating the national multisectoral HIV and AIDS response are the PAAC, DAAC, WAAC and VAAC. The MIPA thrust brought in new structures to operate at national, provincial and district levels, namely, the National Technical Working Group, Provincial MIPA Technical Working Group (PMTWG) and the District MIPA Technical Working Group (DMTWG). The question is how functional is it for the TWGs to operate independent of the existing institutions of the national multisectoral HIV and AIDS response? How radically different are the mandates of the two structures or institutions to warrant separate existence?

The MIPA Technical Working Groups ought to be seen as prime instruments in the national HIV and AIDS multisectoral response. Hence to separate them completely from the already existing HIV and AIDS multisectoral response framework would be to overlook the synergistic value of linking the two institutions.
We therefore propose that MIPA TWGs be connected to existing institutions through making chairpersons of MIPA TWGs ex officio members of PAAC, DAAC, WAAC and VAAC. District MIPA Officers should be ex-officio members of the District MIPA Technical Working Groups. In essence, this set up makes the MIPA Technical Working Groups sub-committees of AIDS Action Committees from village level to province. It is further proposed that the chairperson of the National MIPA Technical Working Group (NMTWG) be an ex officio member of the NAC Board. The existing arrangement prior to the baseline survey connected MIPA Technical Working Groups to NAC field staff through the Provincial AIDS Coordinator (PAC) and District AIDS Coordinator (DAC) serving as the secretariat of the Provincial and District MIPA Technical Working Groups, respectively. This arrangement should be maintained.

Institutional Arrangements for Integration and Operationalisation of MIPA in the Multisectoral HIV and AIDS Response Framework
There are two new proposed structures, that is, the Village MIPA Technical Working Group and the Ward MIPA Technical Working Group. A strengthening of Support Groups should see chairpersons of support groups forming the Village MIPA Technical Working Groups (VMTWG), then the chairpersons of VMTWG elects from their ranks one or two people to represent them in the Ward MIPA Technical Working Group (WMTWG).

**Monitoring and Evaluation Framework for MIPA**
The monthly NAC Activity Report Form is the monitoring and evaluation tool. A close analysis of the spectrum of indicators in it indicates that MIPA is hardly catered for. There are a few indicators relating to MIPA. The ideal situation should be one where almost all the outcome areas in the HIV and AIDS response captured in the NARF have indicators on the involvement of people living with HIV and AIDS. Hence there is a need for NAC and other implementing agencies to revisit the NAC Activity Report Form and include indictors on MIPA.

**Conclusion**
The institutional arrangements for integration and operationalisation of MIPA need to be crafted carefully to ensure that there is a sustainable shift ‘from commitment to action’ on the issue of meaningful involvement of people living with HIV and AIDS in the national response. Nevertheless it is worth noting that in the pursuit of sustainable MIPA (SMIPA) there are two principal players to ensuring transition from commitment to action, that is, the infected and health service providers or AIDS service organisations. The two parties have mutual obligations where the former ought to demand a role in service design, provision and audit; and the latter has an obligation to craft a product that is always informed by the demand side or target beneficiary. To this end, the development of an appropriate policy framework by NAC is imperative to the attainment of MIPA. Nevertheless, it is worth noting that the best policies; frameworks, and will from NAC will be ineffective if PLWHIV are not ready to provide meaningful input to the response.
INTRODUCTION
This chapter focuses on the existing competence and capacity of stakeholders to mainstream MIPA into their planning and programming, as well as those of their partners. Specifically, the chapter examines the extent to which PLWHIV are involved in the programming cycle and the skill-base they have to enable them to be meaningfully involved in the HIV and AIDS response. The chapter also assesses the extent to which MIPA is currently mainstreamed into the stakeholders’ planning and programming of the HIV and AIDS response.

MAINSTREAMING OF MIPA
Mainstreaming means making an issue feature as a common thread in all the programmes or initiatives. With specific reference to MIPA it means considering the issue of MIPA in all the facets of the HIV and AIDS response.

Nationally, UNFPA funded the employment of MIPA officers to work under lead Behaviour Change (BC) organizations in various provinces as a way of mainstreaming MIPA. The responsibility of MIPA officers was the formation of support groups which would be involved in various forms of advocacy on behalf of PLWHIV. MIPA officers also worked with Behaviour Change Facilitators in conducting training in HIV and AIDS. At the time of the survey there were MIPA officers in Manicaland under FACT-Mutare, in Matabeleland North under Matabeleland AIDS Council and in Mashonaland East under ZChire. However, there were challenges to using MIPA officers as pointed out by one BC Programme Manager:

Mainstreaming using MIPA officers poses certain challenges. For example, are the MIPA officers activists or professionals because there is a chance of getting lost into activism? GIPA involved more of activists and it seems MIPA is involving more of professionals. The overall goal should be reduction of new infections. People should therefore not lose sight of behaviour change as a result of prioritizing MIPA. We want to learn from PLWHIV but without losing focus on behaviour change. A MIPA officer should therefore fuse plans with other officers especially behaviour change facilitators. They need to engage in integrated planning.

At the national level, there is a MIPA coordinator housed at the National AIDS Council. The coordinator is responsible for coordinating all MIPA activities in the country and derives his mandate from the National MIPA Technical Working Group whose role was visioning for the implementation of MIPA.

Some organisations tried to mainstream MIPA by involving PLWHIV in planning meetings. NAC and Zimbabwe AIDS Network (ZAN) structures ensured that PLWHIV were involved in planning meetings. In ZAN, PLWHIV were involved in chapter meetings. ZAN had a provincial executive committee and national membership council which had representatives of PLWHIV elected by Zimbabwe National Network for People Living with HIV (ZNNP+) members. In Bulawayo, at the provincial level, the committee had 7 members and one of them was living with HIV. At national level (the national membership council) there were three representatives of PLWHIV. These representatives participated in planning and decision making.
Within NAC, PLWHIV were represented in structures that included the Provincial AIDS Action Committee (PAAC), District AIDS Action Committee (DAAC) and the Ward AIDS Action Committee (WAAC). Respondents from the NAC structures in the various provinces argued that NAC involved PLWHIV in planning because these structures were planning structures and planning was bottom up. Furthermore, NAC structures were governance structures. In this regard, they argued that these structures were mini-boards so PLWHIV were involved in decision making. When consolidating district plans to provincial plans, there was a provincial representative of PLWHIV. Implementation was then guided by integrated plans that would have been developed in planning meetings. As one PAC pointed out,

Most of the heavyweights or decision makers like Governor; PMD; PAC; representatives from Ministry of Education in most cases the Provincial Education Director among others are members of PAAC. The Governor is the patron of PAAC. PLWHIV are represented. However, usually representatives of PLWHIV find it difficult to articulate issues at the same level with other members of PAAC.

The issue of some PLWHIV failing to operate at same level with other decision makers was reiterated by a DAC in Matabeleland North province who pointed out that some representatives of PLWHIV to NAC structures could not even read or interpret a circular, it was therefore alleged that they retarded progress in meetings. Members of one support group in Masvingo stated that their representatives to NAC structures operated at different levels of understanding with other members of committees so this posed as a challenge for MIPA. Furthermore, PLWHIV argued that their representatives to NAC structures were not effective enough because they were outnumbered by other representatives. Other respondents observed that people who came for DAAC meetings actually represented themselves. They did not consult their constituencies before coming for meetings and also lacked the resources for reporting back.

Some organizations brought in PLWHIV to give testimonies, do dramas and offer entertainment during training workshops on HIV and AIDS. In Matabeleland North, Environment Africa involved PLWHIV during training workshops to do drama and present message songs. Also in the city of Bulawayo in Matabeleland North province, some PLWHIV who had basic training in counseling were employed at Mpilo Referral Hospital as counselors and paid for the services they offered.

**INVolVEMENT OF PLWHIV IN PROGRAMMING**

For MIPA to be effective and successful, PLWHIV have to be included at all levels of programme planning and implementation. Their views have to be solicited at every stage and they have to be included in the team that plans the objectives and activities. Including them in the monitoring and evaluation is also essential. Programming is the art of identifying needs and problems and the ability to plan and implement a set of given objectives for solving those problems. For one to say they are programming one should have the skills to identify the problem, identify the required intervention, influence action, monitor and evaluate progress and provide indications on mobilization of resources.

Most ASOs argued that it is through baselines that PLWHIV are involved in planning before any programs are introduced. It was at this stage that PLWHIV were consulted to find out what they expected of the programmes. PSI’s New Life programme involved PLWHIV through workshops where they aired their views. The New Life programme itself started as a result of consulting PLWHIV in workshops who then indicated there was a gap after VCT. Furthermore at PSI, PLWHIV participated in the development of the Protocol for Adherence Counseling. PSI as a research based organization,
involved PLWHIV all its interventions so the views of PLWHIV influenced the design and shape of programmes. PSI worked with feedback from clients.

Some ASOs considered PLWHIV as key partners in all planning processes and gave them the chance to bring their own plans that were then incorporated for implementation. For example, through monthly meetings PLWHIV were involved in planning for Matabeleland AIDS Council activities. Here programmes approved by donors were put on table then PLWHIV were asked on how they wanted them implemented. MAC’s food relief pack initially included cooking oil and soya blend but PLWHIV requested that it include peanut butter and cash in addition and MAC responded accordingly.

Respondents at the Zimbabwe Red Cross Society indicated that PLWHIV were involved in planning meetings where at most two representatives of PLWHIV were invited from the project areas. These representatives were PLWHIV and clients of the Zimbabwe Red Cross Society. Furthermore the representatives were affiliated to ZNNP+. They came up with their programmes in meetings. In project areas there were also care facilitators and members of support groups who assisted with information for planning. Implementation of the programmes was mostly done by volunteers under the supervision of Zimbabwe Red Cross Society officers. While treatment monitoring was done by Home Based Caregivers (HBC) using handbook tools in which they recorded whether the patient completed the course, took the tablets on time, took food before tablets and whether the patient went for review on given dates. However, overall monitoring was done by Zimbabwe Red Cross monitoring and evaluation staff. Evaluation of the programme was mainly done by Zimbabwe Red Cross staff with little assistance from the volunteers.

For Hope Humana, management mobilized PLWHIV to discuss with them the programmes they wanted to be implemented in their areas. However, the final decision on which programme to be implemented lay with management as well as key stakeholders such as ACT, ADRA, Plan International, Mavambo Trust, Children’s Rehabilitation Unit, Africa Young and New Hope. Monitoring was done by field officers with the assistance of HBC. HBC gave reports to field officers who also provided feedback to the management staff. Evaluation was mainly done by management but at times PLWHIV were included to give their own views on the success, weakness, opportunities and strengths of the project(s) or activities.

In Masvingo urban, PLWHIV formed advocacy committees. Advocacy committee members were elected from the PLWHIV. They were trained in advocacy by Batanai. It was these committees that provided information on gaps in current programmes that was then used when donors came in the area. Needs assessments, targeting and problems of double dipping were dealt with by PLWHIV through their advocacy committee. PLWHIV were involved in food distribution committees to deal with problems of double dipping. In this regard, PLWHIV in advocacy committees helped in planning, implementation and monitoring of programmes.

Most ASOs said they tried to involve PLWHIV in programming as implementers and beneficiaries or clients for projects. As one respondent commented, ‘they are usually more comfortable as beneficiaries and not as active participants.’

Faith Based Organisations (FBOs) have not done much in terms of MIPA. Churches such as Brethren in Christ, Seventh Day Adventist, Baptist church and Methodist Church formed support groups but the church role was mainly in awareness campaigns, pastoral care and addressing stigma and
discrimination. Few people in various church-based support groups disclosed their HIV status. One representative of the FBOs pointed out that the non-disclosure of HIV status by most of the church-based support groups was probably due to the fact that HIV and AIDS issues were still regarded as moral issues hence people were not willing to disclose their status.

In all the six provinces included in the baseline survey, most PLWHIV complained of exploitation. One respondent in a focus group discussion in Mashonaland East argued aptly observed that “vanhu vari kuita mari ne status yedu. Isu tisu maladder anoshandiswa nevari muma office kuti vakwire kumusoro”

**SKILLS FOR MAINSTREAMING OF MIPA**

Availability of PLWHIV with skills to participate effectively is a precondition for successful mainstreaming of MIPA. The majority of PLWHIV who disclosed their status lacked skills necessary for meaningful involvement. Generally respondents concurred that PLWHIV had life coping skills and general experience of living with HIV which were also important for MIPA. Nevertheless, since the majority of those that disclosed their status had low educational qualifications and no professional base, their involvement was generally peripheral. PLWHIV pointed out that they needed to be exposed to a variety of skills if they were to be meaningfully involved. One respondent summed up the concerns of most PLWHIV with a poor educational background, ‘Vanotisiya nokuti vanoti hatina kudzidza’ (They leave us out because they say we are not educated).

Some organizations trained PLWHIV in a number of areas. For example, the Zimbabwe Red Cross Society trained PLWHIV in support group formation and logistics, how to work effectively as a group, planning group action, income generation activities (i.e. identifying and accessing markets), accessing and managing support group resources, communication skills and advocacy work.

Nevertheless, capacity development needed for mainstreaming of MIPA fall into three categories: personal, institutional and network. The skill requirements for mainstreaming MIPA at personal level would have to focus on developing the individuals’ capacities to discharge their responsibilities in the HIV and AIDS intervention effectively and efficiently. Most members of organisations of PLWHIV lacked capacity to do the work they were supposed to do and this affected access to donor funding. People in the network did not have the skills they needed for the jobs they were doing so donors could not fund their programmes. Some PLWHIV have been activists for long and could not leave their jobs because they lacked qualifications and skills to engage in alternative forms of livelihood. They continued holding on to their jobs and positions in their respective organisations of PLWHIV despite the lack of relevant qualifications.

Ideally, at institutional level capacity development required for mainstreaming MIPA especially for organisations of PLWHIV would principally be for facilitating information flow both horizontally and vertically among stakeholders. In addition, networking skills are also essential for mainstreaming MIPA ‘globally’ or among partners and stakeholders. In the case of ZNNP+ it was meant to be a network of support groups or PLWHIV and its strength lay in facilitating information flow. ZNNP+ could not be expected to build an effective network of PLWHIV without infrastructure for communicating with its membership. The survey noted lack of basic communication infrastructure at the national offices of ZNNP+ in Harare. Without the communicative capacity of not only ZNNP+ but

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3 Literal Translation: Some people are getting rich using our HIV status. We are ladders used by officers to climb to the top.
of most organisations of PLWHIV in Zimbabwe it would be difficult to promote the mainstreaming of MIPA at various workplaces.

The survey indicated that PLWHIV required training in a number of areas such as advocacy, administration, governance and coordination skills. PLWHIV were implementers in their formations but they needed to guide implementation through advocacy. They required skills on how to identify issues they wanted to advocate for so that they knew how to put across their issues in the structures they were represented. According to one NAC M&E Officer,

As a result of lack of advocacy skills PLWHIV tend to use emotions. They feel HIV is a ticket to take them anywhere. As a result, there used to be lots of demonstrations by PLWHIV. Presently, these emotions come in meetings and end there, they are not taken to the streets. We have made great strides in terms of their representation. But do they have the capacity to identify issues in those organizations and present them without emotional statements?

Furthermore, respondents concurred that PLWHIV were confrontational and aggressive. Statements like, “Mari ndeyedu, munikudya mari yedu” (The money is ours) are very common in meetings with PLWHIV. This mindset had to be addressed if MIPA was to succeed. It was alleged that in meetings representatives of PLWHIV tended to be emotional and vindictive. Capacity development therefore needed to focus on communication skills. Most PLWHIV were not good communicators so they needed communication skills.

In Masvingo, due to training in advocacy and communication by Batanai, support group members were active and had realized success. The advocacy committee has had a number of achievements which included successfully lobbying for a quota system on stands allocation from the city council, ensuring reliability in operation of CD4 count machine, ensuring Cotrimoxazole availability and free hospital service for PLWHIV. The advocacy committee managed to identify the loopholes in the referral system which necessitated PLWHIV to sell HIV results to those that were negative in order for them to access food packs from organizations that provided food to PLWHIV. The referral system has since been revised.

PLWHIV need to have administrative, governance and coordination skills. A number of organizations would want to support organized structures of PLWHIV. In their various formations PLWHIV had a weakness of being poor administrators as one respondent observed. It was argued that they wanted to be autonomous, with their boards being predominantly constituted of PLWHIV but their conduct of business was said to be “chaotic”. A number of cases were cited such as The Centre which was closed from 31st March 2008 to November 2008 due to governance problems. The same applied to ZNNP+ which also suffered from governance problems. It was further argued that most PLWHIV who were founders of organizations of PLWHIV served both as directors and board members at the same time, dominating decision-making at both levels. They appointed the board members themselves usually not on the basis of merit but patronage. This scenario resulted in poor performance by the organisations in question since decision-making centred on one individual-the founder.

Furthermore, if PLWHIV are to be meaningfully involved, they need skills in programming, project proposal development and management, monitoring and evaluation, strategic planning, documentation skills (i.e. report writing, minutes writing and record keeping). Additionally, they need training in resource mobilization.
There are leadership wrangles in support groups. The majority of people who disclosed their HIV status were less educated and did not have understanding of leadership issues. They therefore needed training in leadership and governance. Training should therefore focus on the fact that programmes and organizations should not be personalized but should be run professionally for purposes of sustainability. Professionals were shut out of support groups because of leadership wrangles. This also calls for training in conflict resolution and management.

DISCUSSION
An assessment of the existing competence and capacity of stakeholders to mainstream MIPA into their planning and programming, as well as those of their partners revealed a number of insights. ZAN and NAC were in the forefront of mainstreaming of MIPA. Both of them ensured that PLWHIV were represented in their national and provincial governance structures. However the same could not be said of most of the AIDS service organisations. They hardly involved PLWHIV in the governance of their organisations except in the execution of various aspects of some of their HIV and AIDS initiatives. However, it is worth noting that although NAC and ZAN involved PLWHIV in the governance of their organisations the practice could not easily pass for MIPA in the strictest sense of the principle. There were numerous concerns raised by some respondents on the effectiveness of some of the representatives of PLWHIV in the governance structures in question. Their contributions in the decision-making process were in some instances described as below par in relative terms. This was mostly attributed to either a lack of a sound educational background or decision-making experience. The real problem is that meaningful involvement requires that one be actively involved in the deliberations and not just be physically present. Hence involvement in decision-making must be beyond one’s physical presence.

The mainstreaming of MIPA by some ASOs was generally frustrated by a situation where some PLWHIV did not want to be open about their HIV status making it difficult for some AIDS service organisations to involve them in planning and programming. What did not help the situation was that others who were more open about their HIV status lacked skills to be meaningfully involved in the planning and programming of HIV and AIDS response. As a result of this problem, most ASOs only involved PLWHIV in some and not all aspects of planning and programming HIV and AIDS response, depending on their perception of the competencies of PLWHIV available. However, there were some ASOs which mainstreamed MIPA and deserved to be a model for others. For instance Matabaleland and Masvingo AIDS Councils acquitted themselves very well in terms of their skills for mainstreaming MIPA. The Masvingo Council even went further to equip some of the PLWHIV with the necessary skills for their participation in planning and programming.

With reference to skills for mainstreaming MIPA, majority of organisations involved in the HIV and AIDS response were nor familiar with the concept of MIPA. Practises as simple and minor as inviting representatives of PLWHIV to give a testimony on HIV and AIDS before an audience was regarded by most ASOs as an act of MIPA. For other ASOs involving PLWHIV in peer education and provision of home-based care services were perceived as acts of MIPA. In sum, there was widespread ignorance of what constituted MIPA and hence the skills for mainstreaming MIPA were generally scanty. How could organisations be expected to have skills for mainstreaming MIPA, a concept they were hardly familiar with? Seemingly, some of the few organisations that were mainstreaming MIPA at the time of the survey achieved it by accident rather than by design.
CONCLUSION
The challenge of mainstreaming MIPA in the stakeholders’ planning and programming in the HIV and AIDS response lies in fostering a common understanding of the concept of MIPA. The cases of mainstreaming of MIPA witnessed during the survey were not an artifact of a thorough understanding of the six levels of involvement as conceptualized under the UNAIDS scale. Instead, the mainstreaming was informed more by the concept of GIPA whose basic requirement is the participation of PLWHIV in the implementation of HIV and AIDS programmes. Theirs was a case of excelling in GIPA which elevated them to mainstreaming MIPA. Capacity development for stakeholders that is ASOs and PLWHIV is a pre-condition for mainstreaming meaningful involvement of people living with HIV.
CHAPTER 6: REVIEW OF EXISTING NETWORKS OF PEOPLE LIVING WITH HIV AND AIDS (PLWHIV) AND SUPPORT GROUPS

INTRODUCTION
From the onset, it should be noted that meaningful involvement of people living with HIV and AIDS (MIPA) responds to the experiences of individuals, households and communities affected by HIV and AIDS through the existence of networks of PLWHIV and support groups. It can be argued that support groups are at the epi-centre of the HIV and AIDS response since the groups are a forum in which members can share problems and concerns, brainstorm solutions, give each other advice and form friendships. More so, support groups participate in the implementation of HIV and AIDS programmes such as food distribution, psycho-social support and counseling, condom distribution, promoting voluntary counseling and testing (VCT), supporting home based care (HBC), peer education and livelihoods through income generating activities. As such, it is therefore vital for any HIV and AIDS programme to have the contribution of support groups in decisions, policies as well as programmes. It is also equally important to note the inter-linkages between existing networks of PLWHIV such as Zimbabwe National Network of People Living with HIV and AIDS (ZNNP+), Youth Engage, The Centre, Zimbabwe HIV and AIDS Activists Union (ZHAUU) and Public Personalities Against AIDS Trust (PPAAT) with support groups since support groups are building blocks of networks of PLWHIV. This chapter will therefore review the existing networks of PLWH and support groups in terms of legal status, membership and representativeness.

Before looking at the network of organizations of PLWHIV it seems worthwhile to present data on support groups from five provinces and distribution of membership by sex.

PROFILE OF SUPPORT GROUPS

MIPA Related Activities and Structure of Provincial Support Groups
Six provinces were consulted to ascertain the affiliation of PLWHIV to support groups by sex and province; and their activities related to the national HIV and AIDS multisectoral response.

Support group membership was heavily skewed towards females living with HIV as indicated in the quadrant below (Manicaland, Masvingo, Mashonaland West, and Midlands Provinces: Fig 1 to 4). The situation is also similar to district profiles where all districts in the respective provinces were dominated by female membership except for Matabeleland North province. Empirical evidence points to the fact that women living with HIV are more likely to disclose their status than their male counterparts. The following graphs are illustrative of the uneven distribution of membership by sex in the support groups.
The picture of male dominance in support groups in Matabeleland North is quite unusual. The explanation suggested was that many women could have passed away after suffering from HIV and AIDS and left widowers. The reason being many men take a long time to notify their partners of their HIV status thereby prejudicing the other party of seeking attention in time.
Mashonaland West and Midlands Provinces have a concentration of NGOs emphasizing delivery of care and treatment services in support groups (Fig 6 and 7). Adherence counseling and education on ART compliance comprise the main activities in treatment literacy. NGOs committed technical and financial resources towards capacity building for PLWHIV in income generating projects and attitudinal training related to living with HIV and AIDS, including coping skills in the two provinces.
LEGAL STATUS OF EXISTING NETWORKS OF PLWHIV
Legal status provides the fundamental basis of operational guidelines, accountability, and powers of an organization or support group. More so, legal status of a support group is necessary for the purpose of growth and helps reduce inequalities between organizations and support groups. As such this section will highlight the legal status of existing networks of PLWHIV such as Youth Engage, ZHAAU, The Centre, PPAAT, ZNNP+ and support groups.

ZNNP+
It was founded in 1992 and has been officially registered as an NGO under the Private Voluntary Organisation (PVO) Act Chapter 17:05 as stated by the ZNNP+ Constitution of 1999. By registering under PVO, ZNNP+ had:

(i) the recognition that it is providing all or any of material, mental, physical/social needs of persons/families, rendering charity to persons/families in distress and provision of assistance in/or production of activities aimed at uplifting the standards of living of persons/families.

(ii) legal basis to commence/continue to carry out its activities, seek financial source from any source and collect contributions from the public as per requirement of Chapter 17:05 Section 1 and 2 of the Private Voluntary Organisation Act (The Statute Law of Zimbabwe, 1995)

(iii) entitled to receive grant from the state as stated in Chapter 17.05 Section 6:4 of the PVO Act (The Statute Law of Zimbabwe, 1995)

Constitution: ZNNP+ also has a constitution which has sections on among other things, interpretation, name, statement of purpose, objectives, powers of ZNNP+, membership, annual assembly, National Executive Committee and advisory board, Finance and Assets, affiliations, interpretations, amendments or dissolution.

Support Groups: According to Chamisa, ZNNP+ Harare Provincial Coordinator, the organization has 1095 registered support groups. They are affiliated to ZNNP+ which means that they have already been represented by ZNNP+ in the official registration of PVO. The national assumption of ZNNP+ is that support groups create their own constitution using national guide lines. However, in one case a focus group discussion (FGD) with Hope Fountain support group in Umguza District revealed that while the group is affiliated to ZNNP+ it does not have any constitution.

YOUTH ENGAGE
The Organisation was registered with the Notarial Deed of Trust for the purpose of recognition and accountability. It has a constitution which also has sections on interpretation, name, statement of purpose, objectives, powers of Youth Engage, membership, annual assembly, National Executive Committee and advisory board, Finance and Assets, affiliations, interpretations, amendments or dissolution.

PPAAT
The organization was registered under the Notarial Deed of Trust. The legal status of Support Groups affiliated to it is based on the assumption that they are all legal because PPAAT is a legally registered organisation.
THE CENTRE
It was registered under the Notarial Deed of Trust on the 23rd of November 1994 and does not have a constitution but uses the Notarial Deed of Trust document to guide its activities. The document has sections on, among other things, interpretation, appointment of Trustee(s), proceeding of the Trustee(s), Name of the Trust, Settlement of assets on the centre, Powers, Accounts, personal liability, amendment, Termination and Acceptance.

ZHAAUU
The organization was registered in 2005 under the PVO Act (Chapter 17:05), 2007 under the Companies Act (Chapter 24:05) and 2008 under the Notarial Deed of Trust (MA338/2008). It also has a constitution which guides its operations. Legal registration provided legal representation of the organisation and clients, facilitated representation on Anti Retro Virus (ARVs), user fees, CD4 counts and access to nutrition. ZHAUU does not have registered support groups in the organisation. People affiliate as individuals and the organisation uses those people indirectly to refer to them as their support group.

MEMBERSHIP
To ascertain the meaningful involvement of PLWHIV, it is equally important to consider the membership. This section will consider membership in terms of who is eligible, requirement for registration, application for membership of support groups, registration of members and collection of forms for registration.

ZNNP+
People Eligible for Membership:

(i) Support Groups of PLWH
(ii) Individuals with keen interests in PLWH Support groups.
(iii) Institutions, affiliate organizations (e.g. New Dawn of Hope, Hope Humana, Inerela, The Centre, Youth Engage, Mashambanzou, Red Cross Society, Batsirai, and companies with PLWHIV intervention programmes. Currently ZNNP+ has a total membership of 50 000 (Tendai Mhaka) with 1095 support groups (Chamisa).

Eligibility of Membership by Support Groups:
According to the ZNNP+ Constitution Amended in 1999, all applicants for membership of support groups are made in writing to the district committee. An applicant will receive provisional membership with full membership rights while the District National Committee is assessing status and suitability of the prospective member. The district committee will respond within two months from date of application. Once satisfied the district committee will grant full membership to the applicant or alternatively reject the application. A formal letter will notify applicants accordingly. When confirmed, a provisional member would assume full membership rights upon payment of joining fee. If not approved an applicant shall be accorded an appeal before an appeals committee of the District National Executive committee which shall vote with a simple majority vote of members present deciding the appeal. Membership of the support group and association shall and if a support group resigns by giving one month notice in writing to the secretary of the association violating provisions of code of conduct, support group dissolves, support group has acted in a way likely to harm the interest of the organisation, support group fails to attend three consecutive general meetings without
warning/reasonable excuse, if after one year from the acceptance of a support group as a member there is little/no evidence of any progress in carrying out support programmes. (Constitution)

Collection of Forms for Registration
Provincial representative collects the forms from the national representative. He distributes to district representative who forwards them to the ward representative. The ward representative distributes to support group executive committee. Members not in support groups get forms from support group executive representative and forward them to ward until they reach the district representative for approval.

Requirements for Individual Members:
(i) Being HIV positive
(ii) Proof of status
(iii) National identity card and voluntary participation. Registration form requires the following, date of registration, name of member, physical address, postal address, telephone number, amount paid, card number, name of district representative, group chairperson, contact address and telephone number, sex, orphans, year group was formed, list of your activities (if any), additional information and declaration.

It should also be noted that offices in the operational structure of the organization are acquired through elections, popularity and being HIV+

Youth Engage
One can be a member of Youth Engage if he or she is living with HIV, has been personally affected by HIV through loss of parents, sister, brother, close relative and one can join as a friend. It should be noted that the members can be organizations or individuals who support the objectives of the organisation.

PPAAT
Membership is open to anyone who feels can make a contribution whether infected or affected (youths, adolescence adults both church going/not). Every member has a membership card. The organization does not have support groups directly affiliated to it.

THE CENTRE
The organization has a membership of 400 PLWHIV and these are clients who come for ART. The Centre has 15 – 20 support groups but all not registered directly with the organisation. According to a senior member of staff of the Centre, “The registered support groups have their own constitution for registration which is very independent from The Centre. They register through the social welfare’. The organisation does not register support groups because they want to maintain their confidentiality. Membership stretches from The Centre to Rugare, Kambuzuma, Hatcliffe, Mabvuku, Tafara, Highfield, Glen Norah and Mufakose.

ZHAAU
Currently the organization has 4 000 PLWHIV (1500 in Zvimba, 1025 Harare and the rest in Bulawayo). The organization provides individual registration and not Support Groups. Further to, registration forms are obtained from area coordinators in Mabvuku, Mbare and ZHAAUU Head Office in Harare city centre and some selected low density suburbs.
Requirements for Registration: HIV positive status and disclosure of one’s HIV+ status and any other information like surname, forename, Date of birth, ID number, marital status, number of dependents, business/occupation and declaration are some of the requirements for registration. Elections also form basis of acquiring positions in the operational structure of the organization.

REPRESENTATIVE-NESS
Representative- ness of existing networks of PLWHIV with support groups is a major component of MIPA. As such this section will consider representative- ness in meetings or workshops, in the national response to HIV and AIDS (prevention, treatment care and support) paying particular attention to design, implementation, monitoring and evaluation of programmes.

ZNNP+
It has 100% representation of PLWHIV since the organization is wholly of PLWHIV. More so the organization represents its members in national, regional and international meetings.

National representation: ZNNP+ participates in:
(a) National AIDS Council (NAC) chapters and Technical Working Groups on MIPA
(ii) Advocacy at Zimbabwe AIDS Network (ZAN) and NAC meetings
(iii) Represent support groups at Ward AIDS Committee (WAAC), District AIDS Committee (DAAC) and Provincial AIDS Committee (PAAC).
(iv) Government led programmes that include World AIDS Day
(v) International Women’s Day
(vi) Parliamentary Health Portfolio Committee

Regional Networks
(i) Southern African Network of PLWHIV (SAPWA)
(ii) Regional Board Networking of South African PLWHIV
(iii) Network of African PLWH (NAP+)

Global Networks
(i) Global Networks of PLWH (GNP+)
(ii) International Community of Women living with HIV

ZNNP+ representative-ness can also be measured by the fact that the organisation:
(i) Disseminates relevant information on HIV and AIDS related issues to PLWH (and the information cascades from the National Executive until it reaches the support groups and family and household
(ii) Lobbies and advocates on issues of treatment, care, support for the human and legal rights of PLWH
(iii) Facilitates mobilization of resources for support group and members.
(iv) Supports and builds capacity for PLWH
(v) Facilitates networking and shares information at different levels.
(vi) Facilitates positive living.
Support Groups
Those registered with ZNNP+ had members elected, to WAAC, DAAC and PAAC. Unregistered support groups had no representation at all in ZNNP+. For instance there were a number of support groups such as Fynex and others who expressed ignorance of the above mentioned NAC structures.

Design of Programmes
It is done by the secretariat after getting information on needs from membership through consultation which starts from family/household committees to village/support group levels to ward, to district, to provincial committees who forward to the secretariat. The secretariat uses its own discretion when approving or designing programmes.

Mobilization of Resources for Livelihoods
This is the responsibility of ZNNP+ secretariat and partners such as Voluntary Service Organizations, Institute of Cultural Affairs, Mashambanzou, Africare, Pact etc and donors such as Irish AID and Hivos. For partners and donors the design of programmes is done by them whilst support groups are recipients and implementers.

Monitoring and Evaluation
It is done by the Provincial and National Coordinators and Partners. Support groups are left out because they lack basic skills necessary for monitoring and evaluation.

Skills Training
It is done by Provincial Coordinator, programme officers and partners. They also hold workshops for training of trainers and information from such workshops will be cascaded to the support groups.

Youth Engage
The organization represents its membership through participation in forums supported by NAC such as the MIPA Technical Working Group. However it has no representative in the NAC board. Capacity development of Support group members is done in Hatcliffe, Epworth and Chitungwiza by group leadership.

PPAAT
The organization has 40% of the board with PLWHIV. It is represented in NAC meetings but does not produce IEC materials (e.g. brochures, posters, books, documentaries). The Organisation is also represented in the MIPA Technical working group and in ZAN.

THE CENTRE
It presents reports to NAC office, participates in CCM meetings and is a member of ZAN.

Treatment
The Centre gets supply of ARVs from SIDACTION of France which are then prescribed to clients. It also has doctors who visit The Centre once a week/month, who prescribe medication and manage OI infection.
Care
The organization provides HBC through psychosocial counseling networks with secondary caregivers and provides capacity building for HBC. It has primary caregivers in Kambuzuma, Mbare, Rugare, Hatcliffe, Mabvuku who are both recipients of services and implementers of the programme.

Support
The Centre is a Drop In place for both adults and children from all over the country.

Training
Provides training on nutrition, basic counseling, palliative care and positive living free of charge for ‘support groups’ but charge a fee for organizations.

Livelihoods
Does not provide income for IGPs, but sensitize people to develop livelihoods programmes using their ‘organic’ environment.

Monitoring and Evaluation
Undertaken by the organisation but not effective enough. Plans were under way to develop a stronger monitoring and evaluation framework.

ZHAAU
Attends NAC meetings and is part of MIPA Technical Working Group and attends CCM meetings.

Design of Programmes
The organization monitors opportunistic infections (OI) clinics and educates communities on ARVs and is involved in treatment advocacy, human rights advocacy for PLWHIV and income generation projects. It should be noted that design of programmes is done by the Head Office President, vice President and Secretary General. Support Groups are used for needs identification only.

Implementation of Programmes
This is done by area coordinators and regional committees.

Monitoring and Evaluation
M&E is done by the Head Office President, Vice President and Secretary General – National Coordinator. It should be noted that membership of the so-called ‘support groups’ are just recipients of ‘benefits’.

DISCUSSION
Results seem to suggest that organizations of PLWHIV are operating at the sixth level of involvement as has been facilitated by legal registrations which make them participate in decision making or policy making bodies and their inputs are valued with all the other members of these bodies. On the contrary, support groups are at level one where they are target audiences as they only receive services and provide feedback or just serve as mere source of information. The aforementioned can be justified after analyzing the previously highlighted legal status, representative- ness and membership of existing networks of PLWHIV and support groups as shall be shown in this section.

Legal Status
While legal registration of existing networks of PLWHIV facilitates the provision of operational guidelines, accountability, it should be noted that it places organizations at the sixth level of MIPA. However, the fact that those support groups affiliate to organizations such as ZNNP+ means that they have already been indirectly represented by ZNNP+ in the official registration of the PVO Act. While they are target audience of ZNNP+ at least one can conclude that they have autonomy (though controlled by national structures) to run activities as compared to the so called ‘support groups’ in ZHAAU, Youth Engage and The Centre who are not registered at all. While Chamisa stated that support groups create their own constitution it should be argued that support groups’ constitutions are guided by national guidelines. More so some support groups do not have a constitution which makes them passive participants without legal codes of conducts. Furthermore, it will be very difficult for support groups to mobilize and distribute resources to facilitate meaningful full involvement.

Membership
Elections, HIV+ status and bureaucratic processes of registration can be stumbling blocks to meaningful involvement for support groups. The procedure for membership application as highlighted above can block access, inclusion, participation and involvement of PLWHIV. In principle it is said approval takes two months but however, in practice support group members argued that it may take up to a year before approval and during this period some prospective members would die before having access to medication.

The fact that organizations of networks of PLWHIV emphasize on elections for office bearers can mean that appropriate, effective and hardworking people can be left out in the access, involvement, participation and inclusion to run the offices. More so, elections do not come up with best candidates. People are elected on the basis of HIV+ status and popularity and may not be the best in terms of qualifications to run programmes. This has been substantiated by one DAC in Matabeleland North Province who stated that ZNNP+ members lack professionalism as evidenced through their involvement as stakeholders in DAC meetings. The office bearers at that time according to this DAC had problems of even interpreting a simple circular. They could not even speak in English. Furthermore they lacked advocacy skills. As such, there was need for ZNNP+ to revise its constitution to indicate the calibre of the people to be elected to office.

The call for membership basing on HIV+ status only left support groups being made up of people who were old and lacking formal education and formal training. As argued by another in DAC, while the chairpersons of support groups were enthusiastic, it should be noted that some of them had not received formal training on leadership and how to run support groups. Surely this discredited their participation, inclusion and involvement in HIV and AIDS response.

Representative-ness
MIPA in support groups has to be assessed in the lenses of information dissemination, design and implementation, monitoring and evaluation of HIV and AIDS programmes, advocacy and treatment on human rights, mobilization of resources and capacity building.

While the organisations of PLWHIV could be said to be level six of MIPA in terms of representative-ness, it should be noted that the situation was very different for support groups. The fact that the organisations disseminated relevant information on HIV and AIDS related issues to PLWHIV’s in support groups meant that there was a ‘top-down’ approach to communication. This was clearly substantiated by the operational structure of ZNNP+ and ZHAAU. Such operational structures put
support groups on level of target audience who only received instructions. While one coordinator from MIPA organisation, argued support groups were consulted in the operational structure it should be noted that they only provided important feedback which in turn could influence or inform sources of information.

It should be noted that the design of programmes was done by the secretariat after ascertaining needs from membership. Consultations started from family, support group, ward, district, provincial up to the secretariat level. While consultations might have been necessary for uniform running of activities it could be argued that the time lapse before approval could be a hindering block for PLWHIV to assess services or resources, participate and be included in activities.

While all organizations of PLWHIV advocated for treatment of PLWHIV it should be argued that some members in support groups had no access to treatment. This was substantiated by ZNNP+ Bulawayo Provincial Coordinator who stated that there was a long waiting list for those that were to be commenced on ART. Resultantly people end up not seeing the need for testing and disclosure. Ndlovu ZNNP+ Provincial chairperson of Victoria Falls also stated that the CD4 count machine was down. People took time to get commenced on ARVs. Even results showed that the viral load was very high. At that time there was no second line treatment so people were defaulting.

On human rights some people are paying as much as R600 to bribe nurses to be commenced on ART. Support groups provide people for condom distribution and counseling while the design of programmes would have been done by the secretariat. ZNNP+ was doing advocacy for human rights training in Bulawayo, Harare, Mutare and Mashonaland Central in partnership with Zimbabwe Lawyers on Human Rights. However it should be noted that advocacy was being done on behalf of support groups who later became recipients of services. More so, while there was advocacy for human rights, Chamisa still noted that there was still stigma and discrimination of PLWHIV at work places as some people were losing their jobs because they were HIV+. Opportunistic Infection clinics had also been said to be discriminatory mainly because they were located from the main hospital, there was a red sign for Opportunistic Infections clinics and a red ribbon.

While ZNNP+ facilitated resource mobilization for PLWHIV income generating projects, it should be noted that the design of the programme was done by ZNNP+ through the secretariat and implementing partners and donors. What should be clear about IGPs from partners and donors is that they are donor-driven. Support groups participated in food `partitioning` and distribution, piggery, peanut butter making, managing herbal and nutritional gardens and poultry, depending on the needs of the donor. However, what should be borne in mind is the fact that participation of support groups in such activities was at level one of involvement. Support groups received donations and the type of feedback they provided influenced and informed the sources of donations. Support groups were just recipients and implementers of projects designed by ZNNP+ secretariat, partners and donors.

More so, the fact that monitoring and evaluation of support groups was done by provincial and national coordinators, partners and donors leaving out support group members clearly revealed that support groups were just used as patients and also revealed that they were incapable of monitoring and evaluation.

All organizations of networks of PLWHIV had a mandate to provide support and build capacity in PLWHIV in support groups because support groups were building blocks of the organisation. This
was also another clear indication of skills retardation among PLWHIV and support groups. It should also be noted that skills training for support groups was done by provincial coordination programme officers and partners. They could also facilitate training of trainers. From the abovementioned one can therefore deduce that support groups were target audience who were only recipients of services. Even though they would share the information with members within their group, the fact that training had cascaded downwards highlight professional incapability and skills deficiency in support groups. Whilst ZNNP+ pointed out that it supported and built capacity for support groups of PLWHIV, such an assertion should be taken with a pinch of salt because PLWHIV and support groups highlighted that ZNNP+ was doing nothing at the time the baseline survey was conducted because of lack of resources. More so, ZNNP+ Bulawayo Provincial Coordinator stated that people do not have confidence any more in ZNNP+ because it is not doing anything for its membership. A senior member of ZNNP+ clearly stated that “zamu raamai harina mukaka4.” ZNNP+ used to do capacity development for leadership for support groups but this was then very limited due to limited funds. It can be argued that such financial scarcity had a staggering blow to inclusion, participation, involvement and getting access to service by PLWHIV and support groups.

CONCLUSION
Organizations of PLWHIV could be said to be at level six of involvement if one considers legal status, membership and representativeness as compared to support groups who were merely target audience or patients in level one. MIPA in this case was hindered by the fact that some support groups were not registered and more so, they were passively represented in the initial registration of organizations either in PVO or Notarial Deeds of Trust. Further more, emphasis on elections for office bearing in organizations of PLWHIV, the bureaucratic process of registration and HIV+ status also contributed to level one participation of support groups. The fact that information was cascaded from the top to support groups, design, monitoring and evaluation of programmes was still done by secretariat, implementing partners and donors means that PLWHIV in support groups had no autonomy over the activities they implemented. This also highlighted the need for skills training in support groups. Furthermore, there was still need for advocacy on treatment and human rights and also resource mobilization in support groups in order for them to have meaningful contributions in activities they were involved in.

4 Literal translation: The mother’s breast has no milk
CHAPTER 7: OVERALL NEEDS AND SKILLS LEVELS OF NETWORKS AND INSTITUTIONS OF PLWHIV

The most common response from respondents on why most organisations of PLWHIV were not effective enough to discharge their mandates as expected was that: PLWHIV LACK CAPACITY. This statement obviously defined people’s position on how to relate to leaders of organisations of PLWHIV. However, it is worth noting that capacity is acquired and not an in-born attribute associated with some people and not others. The best form of empowerment for PLWHIV to meaningfully participate in the HIV and AIDS national response is to attend to their capacity building and training needs.

CAPACITY BUILDING FOR ORGANISATIONS OF PLWHIV AND NETWORKS

The following areas were identified by respondents as critically important for the effectiveness and ‘survival’ of organisations of PLWHIV and their networks:

- Organisational Planning and Development
- Organisational Management
- Financial Management
- Networking
- Advocacy
- Proposal Writing
- Resource mobilization
- Designing monitoring and evaluation framework

SKILLS BUILDING AND TRAINING NEEDS

Skills building and training leads to self-reliance. The following areas were identified by support group members as significant for their empowerment:

- Effective communication and negotiation
- Language and Computer Literacy
- Legal and Human Rights
- Train-the-Trainer
- Counseling
- Leadership
- Community-Based Research
- Internet Literacy and Information Technology
This baseline survey revealed a number of challenges, barriers, gaps and opportunities to the integration and operationalisation of MIPA in the multisectoral national response. Below are some of the issues which surfaced from the numerous interviews held with stakeholders.

**CHALLENGES**

There were a number of challenges to operationalisation of MIPA in Zimbabwe. Some of them were; disclosure of status, stigma and discrimination, access to treatment, capacity development, advocacy, internal strife in formations of PLWHIV, male involvement and livelihoods for PLWHIV.

**Disclosure, Stigma and Discrimination**

The greatest challenge to MIPA and worth mentioning first is the issue of disclosure. The commonest argument from the majority of respondents representing health service providers was that; “How can we involve them when we don’t know them?” In essence, the argument was that there was lack of a critical mass of people who had come in the open about their status to warrant considering their involvement or representation in the decision making process or governance structures. But then the issue of disclosure cannot be viewed in isolation. The findings of the survey indicated that there was a direct correlation between disclosure at workplace and the level of stigma and discrimination prevailing in an organisation. The more an organisation was perceived to have potential to stigmatise and discriminate against PLWHIV, the less the infected staff would want to disclose their status. Remember perception is reality until the perception gained is contradicted by reality again. The issue of decision to disclose one’s HIV status is not just a knee-jerk scenario but a rationale process undertaken over time based on a cost-benefit analysis. The socio-economic environment of the organisation determines whether an infected person will come in the open or not about his or her status. The critical question becomes; Is the tariff of incentives for disclosure attractive enough to offset one’s personal, social or institutional concerns potentially to arise therefrom?

The survey found out that of the few infected people who disclosed their HIV status at the workplace, the disclosure was usually made to the significant other only-the ‘Boss’ or one’s immediate superior and not to the rest of staff. The boss had to swear to secrecy or confidentiality as a precondition for one to proceed and reveal his or her status. The lesson one learns from this situation is that infected persons will disclose their status to people they perceive as of strategic importance to their wellbeing. If one has to decide to disclose to a group or to the entire staff of an organisation they are working for, the decision will be made on the basis of the group’s significance to the well-being of the infected person. Some infected persons disclosed to their immediate superior so that the boss would have a better understanding of the fluctuations in health or absenteeism that could be resulting from the challenges of living with the virus. Hence before disclosure of one’s HIV status, ‘in the beginning’ must be a perception of the existence of worthwhile benefits of the contemplated disclosure. The entry point then in promoting disclosure by infected people at workplaces or any other form of social groupings is to put in place a contingent of meaningful and sustainable benefits to serve as a carrot for people to disclose their status. Stephens (2004) contends that stigma and discrimination ranks as the major disincentive to the promotion of GIPA and constitutes a fundamental barrier to PLWHIV involvement.
Concerned about the prevalence of stigma and discrimination of PLWHIV the national response has appointed District MIPA Officers attached to behaviour change organisations. According to one of the NAC officials:

MIPA officers are trained and there to provide technical assistance and spearhead fighting stigma and discrimination of PLWHIV. This is one of their key result areas.

To achieve MIPA, according to Mr Amon Mpofu NAC M&E Director;

What we must fight first is the stigma. It is a long process and we must continue to fight it. Stigma limits access to services and participation in general.

However, one needs to warn that unless the fundamentals of fighting stigma and discrimination that is access to VCT and treatment are not addressed, and then promoting MIPA becomes a daunting task.

Access to Treatment
Unfortunately for Zimbabwe it is now 24 years since the first HIV infection was recorded in the country but stigma and discrimination still abounds in both covert and overt forms. This situation is aggravated by lack of access to treatment or ARVs. The national record has 1.8 million who are HIV positive. Of the 365 000 who are in need of ARVs only 152 000 (40%) are enrolled for ART. For those that are on ART there is still no guarantee of getting the ARVs regularly due to a number of factors such as the charging of US$5 as service fee each time one goes for refill and that most ART centres are located far away from beneficiaries making it difficult for one to get to the dispensing sites. According to a senior member of Zimbabwe HIV/AIDS Activist Union (ZHAUU) this state of affairs means 41% of infected people “who are in need of ARVs are on death-row”. The occurrence of a cholera outbreak in Zimbabwe in late 2008 stole the limelight in terms of priority of funding thereby resulting in the country drifting further and further away from meeting the access to treatment target. Cholera became the fourth force after Malaria, TB and HIV to demand financial attention by the Global Fund and other donor communities.

According to one ZNNP+ official of the Bulawayo Province:

There is a long waiting list for those that are to be commenced on ART, people end up not seeing the need for testing and disclosure. Some people are paying as much as R600 to bribe nurses to be commenced on ART

Access to treatment was a very thorny issue which really warranted the involvement of PLWHIV. Below is a graphic narration of the experiences of PLWHIV trying to access treatment services provided by people not living with the virus:\5:

Staff that are not PLWHIV do not understand what PLWHIV go through. Drugs sometimes disappear, nurses sometimes get drugs and sell them in streets. There is a very viable market at the railway station and in Luveve for ARVs that are stolen from the hospitals. There is need for nurses who are living openly with HIV to be employed at these hospitals. Dispensing of drugs should also be done by PLWHIV.

\5\ Installment from Victim Support Group of Bulawayo Province
Outside the realm of employment, access to treatment is a very powerful incentive for people to undergo VCT and disclose their statuses freely. The issue of access to treatment is pivotal to combating stigma and discrimination as there will be nothing to fear or be ashamed of since infected people who at worst were bed-ridden end up living normal lives. The success in treatment helps to portray HIV as any other common and non-stigmatising health complex such as hypertension (high blood pressure), sugar diabetes and others.

Empirical evidence from areas where HIV infected people have easy access to ART such as in the Global Fund districts, indicates that many people are willing to test and disclose their status to the public in general. They have many models and living testimonies of once infected and dying people resurrected from the dead through enrolment on ART. A brief visit made to Murambinda Mission Hospital witnessed HIV infected people queuing up for either refilling or initial supply of ARVs talking openly about their status and even making a joke about it. In the words of one infected person, “HIV neflu hazvina musiyano. Chinonyadzisa ipapo chii? Inongouya ichienda ichisiya uripo.” Hence the more people who undergo VCT and gain access to treatment, the less stigma and discrimination is experienced by PLWHIV. In terms of MIPA, the more access people infected with HIV have to treatment, the more they are likely to be actively involved in the HIV and AIDS response. In sum, as long as access to treatment is a problem in Zimbabwe, stigma and discrimination shall remain very difficult to eradicate and meaningful involvement of PLWHIV shall remain difficult to achieve.

**Capacity Building**

Capacity is both a challenge and a barrier to implementation of MIPA. On the challenge of capacity development or empowerment a representative of ZNNP+ authoritatively stated that, “There is no MIPA without empowerment”. The baseline survey noted a consensus view among all players in the HIV and AIDS multilateral response that the issue of capacity stood as a monumental challenge and barrier to meaningful involvement of PLWHIV. The capacity deficiency was notable at both personal and institutional levels in the areas of advocacy, financial management, managerial skills, programming, leadership skills, proposal writing, resource mobilisation, organizational development, governance and others.

The survey found, inter alia, that most PLWHIV were not empowered for MIPA. They lacked the necessary skills to play a meaningful role in the HIV and AIDS national response. There was therefore a need to empower PLWHIV through training them to be “experts in their own rights and remunerated as experts” This is a precondition for the views of PLWHIV to be respected at whatever level they are making a contribution. According to a UNAIDS official the issue of capacity was quite key to both PLWHIV and organisations of PLWHIV:

> People open the door to ZNNP+ only as a professional partner and not for having HIV virus as a qualifier. For me it’s about providing much more support to develop their capacity as a professional network

So serious to MIPA was the issue of lack of empowerment through capacity development that a senior national official of ZNNP+ observed that:

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6 There is no difference between HIV and flu virus. What is shameful about contracting it? It comes and goes away and leaves you alive.
Most of the so called representatives for PLWHIV are bench warmers. They do not have the capacity to contribute meaningfully. I've been here for 7 years, no one from NAC or ZAN has ever asked us whether there is any training we need to run the organisation effectively. We can't respond effectively and appropriately without empowerment but we have volunteered to respond to the pandemic going public about our status as a way of helping the fight against the HIV and Aids epidemic.

Due to lack of capacity development majority of PLWHIV cannot experience meaningful involvement. It is for this reason that the survey found out that most infected people who opened up about their status and were members of support groups were just at the entry point of the continuum of involvement using the Horizons (2002) scale, that is, at access to services and inclusion where PLWHIV take part in NGO activities as beneficiaries of services and act as support staff for HIV and AIDS NGOs, respectively. Using the UNAIDS (1999) levels of involvement, support groups and their members at grassroots' level would be located at the levels of target audience, contributors, speakers and implementers where activities are conducted for them (PLWHIV), where activities involve them only marginally, where they are used as spokespersons in campaigns and where they carry out real but instrumental roles in interventions, e.g., as careers, peer educators etc, respectively.

At institutional level PLWHIV organisations such as ZNNP+ and others require capacity building in areas that enable them to become vibrant and autonomous and achieve MIPA. Contributing to the significance of empowering organisations of PLWHIV one Provincial AIDS Coordinator in reference to ZNNP+ warned that:

ZNNP+ can't challenge NAC if they are heavily dependent on NAC. They need to be independent and this can only come through appropriate empowerment capacity building in governance and coordination, advocacy and resource mobilisation.

In the case of ZNNP+ again, the issue of access to communication infrastructure is crucially important. According to a ZNNP+ senior official, “ZNNP+ is meant to be a network which means its strength is derived from information flow. ZNNP+ can not build these networks without infrastructure to communicate with members.” Indeed, a visit to ZNNP+ offices by researchers revealed that the organisation was literally dysfunctional, with no access to land line, fax line, photocopier nor internet facility.

However, a sobering suggestion on how to go about planning capacity development came from a UNICEF, HIV and AIDS Specialist who argued that:

Capacity development should start at the family/household level because most of the problems that PLWHIV are facing in terms of MIPA start in the family. How is the family/household dealing with MIPA? MIPA should take a bottom up approach rather than a top down approach. Funding policy should therefore be directed at the family/household in terms of capacity development.

Lynde Francis, founder of The Centre, added her voice to the issue of capacity development arguing that, “MIPA is not only about employing HIV positive people but meaningfully involving people who have the capacity to input”.
Poor Advocacy Skills

Advocacy is the mainstay of pressure groups and ZNNP+ and other organisations of PLWHIV are not an exception. Nevertheless, advocacy is a real challenge in the sense that it entails attempts to win the sympathy of the other party or parties to an extent where it galvanizes those parties to take action in the desired direction. But then winning the support of the desired parties requires tact, skill and resources. This is where most support groups and other organisations of people living with HIV are found wanting. Logically tact and skills must be in place before resources are marshaled to implement the advocacy plan or strategy. The findings of this survey were that most of the PLWHIV and their representative organisations tended to take militancy as the cornerstone of advocacy on any issue. Indeed it is a well known phenomenon that confrontation begets confrontation and hence PLWHIV miss out on opportunities that present themselves for successful advocacy by being unnecessarily militant in approach. Seemingly it would not be fair to judge PLWHIV harshly on adopting militancy as an approach. In the absence of formal capacity building or training on advocacy skills the belligerent mode may continue to prevail to nobody’s benefit. In the words of one social commentator: *when the only tool you have in your hands is a hammer, everything around you looks like a nail*” (---------Park Design is a Puzzle: Doctoral Thesis).

According to a senior Matabeleland North NAC official:

In their various formations PLWHIV require skills on how to identify issues they want to advocate for so that in the structures they are represented they know how they can put across their issues. We have made great strides in terms of their representation. But do they have the capacity to identify issues in those organizations and present them without emotional statement.

Another voice on the importance of training PLWHIV on how to present their grievances or issues for consideration comes from a UNICEF, HIV and AIDS Specialist who observes that:

It is important that the leadership of organizations representing PLWHIV be capacitated because a majority of them are not professional in their approach to work. In meetings, they just burst because they use emotions. They are vindictive.

The above statements point to the need to train leaders of PLWHIV organisations in advocacy and communication. An inappropriately communicated message is usually resisted by the target recipient.

According to a ZAN senior provincial official:

PLWHIV do not understand that they are constrained academically; they view themselves as all knowing. They should however know that, ‘living with HIV is not a qualification, but a condition.’ PLWHIV short in engagement. They are too confrontational so they need communication skills. They also need a general understanding on HIV because they do not know much.

It is also unfortunate that HIV and AIDS is no longer viewed by the local media as worth of their attention. This really compounds the problem of advocacy and makes formal training on advocacy imperative if MIPA is to be achieved. Without the media alongside you one has no public voice.
A senior ZHAUU official observed that: “The media is an issue. HIV/AIDS doesn’t create much interest any more. Media people even ask, ‘what’s there that is attractive to deserve coverage.’ The best practice in advocating for MIPA may be provided by Masvingo urban where PLWHIV have formed Advocacy Committees. The committees provide information on gaps in current programmes that is used when donors come in the area. Needs assessments, targeting and problems of double dipping are dealt with by PLWHIV. Advocacy committee members are elected from the PLWHIV. They were trained in advocacy by Batanai.

Internal Strife in Formations of PLWHIV
The saying ‘united we stand and divided we fall’ does not sound prudent enough for some of the formations of PLWHIV. There are leadership wrangles in support groups and other PLWHIV organisations are also pre-occupied with attacking others in a battle for recognition and frontline leadership of the community of PLWHIV. There are accusations and counter-accusations tossed back and forth on ZNNP+ by other bodies of PLWHIV. Some of the accusations directed at ZNNP+ by rivalry formations are that it claims to be ‘mother’ of support groups and yet it does not have any support groups practically affiliated to it, it is also accused of colluding with government and NAC to undermine the unity of genuine organisations of PLWHIV, seen as a government front for weakening organisations of PLWHIV and others. This internal strife does not bode well for the cause of MIPA. According to ZNNP+ official “the cake is small but partners are many.” Instead of forming a robust common front for articulating the interests and concerns of PLWHIV with one voice, some organisations of PLWHIV spent their energy and resources fighting others. In the words of a ZAN Provincial official, “Energy is spent on fighting for leadership posts. And the fighting is not about getting involved but what to get out of the leadership”.

The main loser in this irrational territorial contest is always the ordinary PLWHIV whose human rights are violated every day and whose access to treatment and care is denied everyday without a representative force to come to one’s rescue. It is unthinkable that MIPA can be achieved in an environment where those who are supposed to be the main players in the empowerment thrust of PLWHIV are busy undermining each other. Hence ZNNP+ and other formations of PLWHIV ought to put their house in order as quickly as possible to create a conducive environment for rolling out MIPA from the top to the bottom and vice versa.

Even the extra-territorial and reckless attacks directed at organisations involved in coordinating the national HIV and AIDS response do not help much to further the cause of MIPA. One of the leaders of one organisation of PLWHIV said: “Even people who are in the NAC board do not deserve to be there. ZAN, NAC and government do not want HIV positive people. Sometimes NAC and ZAN do not invite people. These two organizations manipulate people and organizations”

Male Involvement
Throughout the 6 provinces visited for fieldwork male under-representation in support groups was highly noticeable. This is a major challenge. HIV does not discriminate on grounds of sex. It infects both males and females but there are very few men involved in the HIV and AIDS response. Given that there are few discordant couples, the number of men disclosing and participating in support groups should have been almost equal to that of men. Perhaps one factor which might explain poor male involvement is that it was noted that there were more women disclosing their status than men. Disclosure usually precedes or occurs concurrently with the decision to join a support group, especially for the infected. As long as fewer men are prepared to disclose their status men shall continue to be poorly represented in organisations of PLWHIV. As a result of this scenario MIPA is dealt a telling blow as it misses out on the contributions of infected
males “invisible” and sitting on the fence. The nation therefore needs to conduct a countrywide comprehensive study to find out the reasons why fewer men than infected disclose their status. The study should investigate issues of what would motivate more men to disclose and become actively involved in the national HIV and AIDS response.

Livelihoods for PLWHIV
Support groups should be kept going. However, PLWHIV need Income Generating Projects to empower them economically. Most women were still relying on men so this put them at risk especially when negotiating safe sex. Women needed control and power over resources. In general PLWHIV need empowerment because most of them lost jobs due to ill health. Without realizing meaningful economic returns from one’s involvement in a Support Group, over time the probability of one withdrawing are high. They had pinned most of their hopes on Support Groups to provide them with a livelihoods base such as poultry, herbal or nutrition gardening.

The survey on livelihoods condition of PLWHIV in the 6 provinces of Harare, Bulawayo, Matabeleland North, Masvingo, Manicaland and Mashonaland East, revealed that most of them were struggling to make ends meet. Those that had received support from certain NGOs and had constant monitoring and mentoring were doing relatively well. But those that were supported and weaned tended to be viable in the short term but went under soon after. The greatest challenge of the pre-survey livelihoods situation of PLWHIV was hyper-inflation in Zimbabwe. Huge sums of Zimbabwean dollars realized from operations did not make any sense in United States dollar or South African Rand terms.

PLWHIV Wanting to Control Everything
During the baseline survey, some representatives of PLWHIV criticized `non-HIV infected’ people who coordinated the affairs of PLWHIV viciously. The sentiments expressed were generally indicative of concern with invaded territory. The feeling was one of `Them and Us’. Those PLWHIV attacking non-infected people holding positions of decision making in ASOs overlooked the fact that the non-infected had a stake also in response to HIV and AIDS as much as the infected and affected. It is an unfortunate attempt to personalize the HIV and AIDS epidemic and at the same undermine the constellation of forces that should work hand in glove with PLWHIV in the fight against the virus. The seemingly ‘hate relationship’ prevailing between the infected and non-infected players in the HIV and AIDS response can only serve to undermine the integration, mainstreaming and operationalisation of MIPA in Zimbabwe. In fact, increased involvement of PLWHIV in the day to day running of ASOs through MIPA will help eliminate the prevailing atmosphere of mistrust.

Scarcity of ASOs on Workplace Programmes
There is a general scarcity of AIDS Service Organisations focusing on workplace programmes on HIV and AIDS. Hence workplace programmes have not yet realized the desired impact. Most employers claim not to have experts or expertise to rely on in their HIV and AIDS response. At most workplaces especially in the private sector PLWHIV make contributions at most when invited to give testimonies. According to Sinatra Nyathi (NAC Bulawayo PAC):

There are very few AIDS Service Organisations specializing in HIV and AIDS workplace programmes. This explains why companies contact NAC directly thereby compelling us to provide the service. And we do this by identifying some PLWHIV to go and give testimonies. Before presentations NAC discusses the testimonies of PLWHIV to try and bring out the MIPA issues.
The point is most organisations have HIV and AIDS workplace policies but these are hardly implemented. Implicitly then most organisations’ HIV and AIDS interventions remain at rhetorical level. Hence under these circumstances there are no grounds at all on which to talk about MIPA.

GAPS
There are two areas where there are serious gaps in planning and programming of MIPA. These are the special needs of the women, the disabled, youths and OVCs.

Women Living with HIV and AIDS
Women living with HIV and AIDS are not just one of those people living with HIV and AIDS. Women have special needs requiring special attention in programming of MIPA. Most of the people interviewed on whether they gave special consideration to the plight of women in decision making on the HIV and AIDS at the workplace gave a very casual response. The most common view was that women were already over-represented in support groups. The worry then should have been with men because they hardly featured in support groups. There was therefore general admission that women were not being given due consideration in planning HIV and AIDS intervention. The workplace HIV and AIDS policies reviewed hardly addressed issues of gender inequality, access to PMTCT, power imbalances at workplaces which exposed women to sexual harassment, women’s participation in the development of workplace policy, participation in the entire programming cycle, which is from designing, implementation, monitoring and evaluation. The representation of women living with HIV and AIDS in key decision making bodies on HIV and AIDS intervention at workplaces ought to be regarded as a priority.

Disabled, Youths and OVCs Overlooked
Without having to labour the point, the plight of disabled people living with the virus is as serious as that of women if not worse. There are so many issues that are unique to the physically challenged which cannot be imagined and planned for by someone who has never been in that condition. Issues to do with mobility, access, protection from abuse and many others deserve special recognition and representation of the disabled in the programming cycle. Most of the respondents conceded to not having considered the disabled people as requiring special attention and representation in planning. The same applied to the case of OVCs and youths. They were never seen as a special case in planning, implementation and monitoring and evaluation. Some respondents were arguing that ‘children are children’ their interests were represented by adults. For instance the youths are not represented in the NAC Board.

Lack of Government and Donor Support to MIPA
Of all the financial support being provided by the donor community to the HIV and AIDS response none is being targeted at programmes for promoting MIPA. The general argument from donors is that their money comes targeting the funding of specific areas and if MIPA does not fall within it then it is left out. Indeed it would be very useful for the donor community to adopt a policy that ensures funding only programmes that mainstream MIPA. In an interview held with Lynde Francis she criticized government and donors very strongly for doing virtually nothing to promote MIPA:

Most difficult in operationalising MIPA are donors. They just pay lip service and still perceive PLWHIV as beneficiaries, recipients and victims.

She noted further that:

Government has a ‘yes’, ‘yes’ approach to MIPA but actually do nothing. It took many years for us to have somebody sitting on the NAC Board and today we are still battling to have PLWHIV represented in Senate.
Lack of Legislation on MIPA
As noted earlier on, the legislation on HIV and AIDS in Zimbabwe is not tight enough to enforce compliance by all actors. There is a lot of laxity for instance in implementation of HIV and AIDS workplace policies to an extent where literally nothing is being done by some stakeholders. This is a serious gap in operationalisation of the HIV and AIDS response which inevitably will militate against efforts to operationalise MIPA. There is therefore need for specific legislation to connect institutions on MIPA.

BARRIERS TO MIPA
The issues presented below may be loosely perceived as barriers since they are fundamental to triggering the roll out of MIPA. These are lack of HIV and AIDS workplace policies promoting MIPA, ignorance of the concept of MIPA, resource mobilisation, founder member complex, weak network and lack of ZNNP+ structures at district level.

Lack of Workplace Polices Promoting MIPA
Of all the AIDS Service Organisations, FBOs and CBOs visited for the survey none had workplace policies that made it compulsory for the organisations to mainstream MIPA. In addition, the organisations hardly had anybody representing interests of PLWHIV in their structures of governance. Tinkering with the existing workplace HIV and AIDS policies to ensure that they mainstream MIPA in programming is an essential step in integration and operationalisation of the concept. The significance of addressing the regulatory framework first lies in that it empowers PLWHIV to demand implementation of the promise of involvement. Anything written down becomes legally binding once adopted.

A Zimbabwe AIDS Network official spoke his mind on the significance of having a workplace policy on HIV and AIDS and MIPA. He pointed out that:

A lot of ASOs do not have workplace policies meaning that to them, “HIV and AIDS is about them (PLWHIV) and not us.” Some of the policies are not implementable, they are just concepts.

The following narrative from Victory Support Group, Bulawayo Province illustrates the necessity for a workplace policy on MIPA otherwise MIPA will be substituted by abuse of PLWHIV. The Group pointed out that:

Peer counselors in OI clinics in Bulawayo have helped a lot in dealing with the long queues that were characteristic of these places. These peer counselors do pre and post test counseling and lessons on drug adherence but they do all this for free. They are actually being used. When there are staff meetings at these hospitals where peer counselors are engaged, they say peer counselors should not attend meetings, they say we want professional counselors only in meetings.

Ignorance of the Concept of MIPA
Lack of understanding of the concept of MIPA can be a serious barrier to the operationalisation of MIPA in Zimbabwe. Many of the stakeholders interviewed seemed very ignorant of the concept of MIPA. As for Support Groups it was the first time they were hearing about the term MIPA. Most representatives of other AIDS Service Organisations also found it very difficult to explain the concept of MIPA. At most they thought MIPA referred to involving PLWHIV in the implementation of HIV and AIDS programmes and at worst some simply explained what the acronym stood for. Some NAC and Behavioural Change Organisations staff were also found wanting in terms of their understanding of MIPA. In essence then, it is impossible to
operationalise MIPA countrywide in an environment where potential drivers of the programme are not knowledgeable about the issue. It is therefore incumbent upon National MIPA Technical Working Group to mount an educational campaign programme to educate stakeholders on the concept of MIPA. This exercise should be preceded by the development of Guidelines on MIPA in Zimbabwe.

**Resource Mobilisation**

An effective countrywide campaign for mainstreaming of MIPA in the HIV and AIDS response will require mobilisation of resources for that purpose. The resources required, that is, human and financial are for the purpose of:

(a) Financing the development of a Zimbabwe MIPA Strategic Plan
(b) Financing the development of Guidelines on Implementing MIPA in Zimbabwe
(c) Development of M & E Framework for MIPA in Zimbabwe
(d) Training of outreach staff on mainstreaming of MIPA
(e) Training of Trainers on MIPA for partners in the multisectoral response framework
(f) Workshop on MIPA for organisations of PLWHIV and ASOs.
(g) Financing IEC material for MIPA at workplaces
(h) Transport for community mobilisation on MIPA
(i) Transport and funds for monitoring and evaluation
(j) Support Group educational awareness meetings on MIPA
(k) Funding a study to document best practices on MIPA in Zimbabwe.

**Founder Member Syndrome**

There are some organisations and members of some Support Groups likely to experience difficulty in implementing MIPA due to what is termed the ‘founder member syndrome’. In most cases, the founder member complex manifests itself in personalizing an organisation. There is a perception that, ‘because I started the organization, all information should come to me and real involvement for benefits should be for me only.’ When ASOs are run by founder members this presents a major hurdle to implementation of MIPA at the workplace. In any case the only constant factor at the organisation will be the founder member and the rest of staff will be a variable as they could be could be fired from the group or organisation any time.

According to Mr Kachote (Acting Director of The Centre):

Most support groups started by individuals do not have constitutions. The constitutions are in the heads of their founders. As a result most of the benefits accruing to the group are enjoyed by either their families or friends. Cognisant of this when The Centre invites leaders of the founder-based support groups for training we ask them to bring one or two more other members of the group. This is in order to bring to surface group members with potential usually overshadowed by the founder.

**Weak Network**

The network of PLWHIV headed by ZNNP+ was very weak at the time the baseline survey was conducted. According to Mhaka (ZNNP+ Provincial Coordinator):

PLWHIV attempt to network at support group level but not much is being done because PLWHIV are divided. They seem to have no network at all. When Red Cross comes with assistance they say they belong to Red Cross, the same with Oxfam. PLWHIV have identity crisis because ZNNP+ has no resources. They tend to identify with organizations that somehow support them. There is need for empowerment at the grassroots level. They do not view ZNNP+ as theirs. They say ‘ZNNP+ iri kuHarare’.
Another important point raised by Mhaka was that ZNNP+ staff worked on a volunteer basis and the question then was; “how do you make a volunteer accountable (for the state of the network)?”

Generally ZNNP+ was perceived by stakeholders as lacking anchor at district and village level, which are the critical levels for implementation of any programmes. This made the involvement of PLWHIV in the HIV and AIDS response weak. According to one NAC official:

The challenge is we don’t have a vibrant ZNNP+. People who come to our DAAC meetings actually represent themselves. They don’t consult their constituencies before coming. They also don’t have the capacity for reporting back or a platform for sharing with their colleagues.

OPPORTUNITIES

There are a number of opportunities presenting themselves for the integration and operationalisation of MIPA in Zimbabwe. Some of them are:

▪ The positive political atmosphere generated by the setting up of an inclusive government opens up more doors for donor funding of programmes designed to strengthen and scale up the national HIV and AIDS response through MIPA.

▪ The Zimbabwe National AIDS Council Act empowers the Minister to authorize policy changes as deemed fit for national interest at any point in time. This enables NAC to deal speedily with structural issues necessary for integration and operationalisation of MIPA.

▪ Donors who provided funds to Zimbabwe for the first time to deal with the cholera outbreak could be persuaded to consider taking part in a basket funding of MIPA programme as an add-on obligation after the decommissioning of the mission for cholera.

▪ Most organisations have experience in mainstreaming HIV and AIDS hence the same skill-base will be utilized for mainstreaming MIPA.

▪ Again most organisations have HIV and AIDS workplace polices which could be revised to accommodate MIPA with a bit of tinkering. A significant number of organisations had not even finalized their HIV and AIDS workplace policies hence they could easily include MIPA issues.

▪ Resources available, the high calibre of staff at ZNNP+ could be empowered to join hands with NAC in driving the MIPA implementation processes in the provinces.
CHAPTER 9: DISCUSSION AND CONCLUSION

This section uses two (2) main tools, that is, UNAIDS (1999) Levels of Involvement and the Horizons/Alliance (2002) Categories of involvement to discuss and draw a conclusion on the findings of this baseline survey on MIPA. The three tools constitute the basis on which to ‘score’ the findings of the survey. Each of the values in the three tools will be ticked against the various facets of the HIV and AIDS response, namely, prevention, treatment, care and support; and mitigation, on which it was being operationalised. At this point it is worth noting that the two tools were derived or distilled from The Denver Principles of 1983 (see Introductory Chapter). But before presenting the matrix it is necessary to show a template with the elements of the various values and number those values in order for them to correspond with the numbers at the top of the matrix. The values are presented in ascending order with the lowest being represented by the value 1 and highest by 4 (on Horizons/Alliance scale) and by 6 (on the UNAIDS scale).

**Templates for Scoring Meaningful Involvement of People Living with HIV and AIDS**

<table>
<thead>
<tr>
<th>HORIZONS/ALLIANCE CATEGORIES OF INVOLVEMENT</th>
<th>UNAIDS LEVEL OF INVOLVEMENT:</th>
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<td>1. Access to Services</td>
<td>1. Target Audiences</td>
</tr>
<tr>
<td>2. Inclusion</td>
<td>2. Contributors</td>
</tr>
<tr>
<td>3. Participation</td>
<td>3. Speakers</td>
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<tr>
<td>4. Greater Participation</td>
<td>4. Implementers</td>
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<td>5. Experts</td>
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<td>6. Decision makers</td>
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**SUMMATIVE SITUATIONAL ANALYSIS REPORT OF MIPA IN ZIMBABWE: SUPPORT GROUPS**

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<tr>
<th></th>
<th>Horizon/Alliance Levels of Involvement</th>
<th>UNAIDS Levels of Involvement</th>
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<td>Prevention</td>
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<td>Treatment</td>
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<td>Care and Support</td>
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<td>Mitigation</td>
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The accompanying narrative to the two matrices focuses on levels of involvement in each facet of the response, that is, prevention, treatment, care and support; and mitigation.

**Prevention**

In prevention and support groups, the Horizons/Alliance assessment tool indicates that the participation of PLWHIV was in form of inclusion only. Most PLWHIV were operating as support staff to NGOs distributing condoms and IEC material on prevention. The same activity when assessed using the UNAIDS scale thrust people living with HIV into level (3) where most serve as ‘speakers’ in

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7 Please note that the scoring represents the situation in which the majority of PLWHIV are and not for the minority.
campaigns to effect behaviour change. On the same response of prevention leadership of organisations of PLWHIV fell on level 2 also in the Horizons/Alliance scale, which is mere inclusion in the activity. The UNAIDS scale placed the leaders on level (3) and (4), that is being used as speakers in the promotion of behaviour change and as ‘implementers’ distributing condoms and IEC material.

FINDINGS OF SITUATIONAL ANALYSIS OF MIPA AND LEADERSHIP OF PLWHIV ORGANISATIONS

<table>
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<th></th>
<th>Horizon/Alliance Levels of Involvement</th>
<th>UNAIDS Levels of Involvement</th>
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<td>Mitigation</td>
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**Treatment**

On the issue of treatment, the participation of support groups fell into level 1 and 2 of the Horizons/Alliance (HA) scale, which is a matter of access to services (ART, psychosocial counseling and adherence counseling etc) and also being ‘included’ (in treatment literacy, counseling etc) respectively. In the same area of ‘Treatment’, leadership of PLWHIV organisations fell on the 3rd and 4th levels of the UNAIDS scale. These levels are for PLWHIV who were being used as ‘speakers’ and also participated in the treatment response as psychosocial and adherence counselors and other roles.

**Care and Support**

The participation of Support Groups in the care and support response placed them at level 2 of the Horizons/Alliance scale-inclusion. They were included in the provision of home based care services. On the UNAIDS scale the support groups fell on level 4 of implementers again on the basis of participating as carers and peer educators. On the same HIV and AIDS response of care and support, the HA Scale places the participation of leaders of PLWHIV on level 2 which as in the case of support group members is also inclusion. They served various NGOs as volunteers. On the other hand, the UNAIDS Scale of involvement puts the leaders at level 4 of implementers, respectively. Most of the leaders were also involved as care givers and peer educators.

**Mitigation**

Most support groups were just beneficiaries of mitigation programmes. According to the HA Scale, this places them on level 1 of access to services. In most of the interviews held in the 5 provinces, members of support groups had received various forms of mitigation benefits such as agricultural inputs, implements, materials and seedlings for nutrition gardens. When one uses the UNAIDS Scale of involvement, the participation of leaders of PLWHIV is placed at level 4 which is earmarked for implementers. Like support groups, the leaders also expected to be considered for various forms of mitigation such as food relief, agricultural inputs and others.

**Empowerment**

The issue of empowerment is central to MIPA and resonated throughout the survey. According to Mr Chiduku, the National MIPA Technical Working Group Chairperson:
MIPA without empowerment is meaningless. Empowerment can be technical, financial or structural. Unfortunately our involvement as PLWHIV and organisations of PLWHIV does not have that form of commitment from our partners. There is need to train PLWHIV to be experts in their own right and remunerated as experts. PLWHIV providing services according to Maslow's hierarchy of needs, need to be paid better and better and empowered to offer their services professionally. When PLWHIV contribute as experts their views will be respected at whatever level they are making a contribution.

The place of empowerment in MIPA was summed up by a UNAIDS official who argued that “without empowerment, there is no MIPA to talk about”.

CONCLUSION
This survey was principally a situational analysis of the state of meaningful involvement of people living with HIV and AIDS (PLWHIV) in Zimbabwe. Essentially the survey sought to establish how far the country had progressed in the fulfillment of MIPA from principle to practice. With reference to this, the most salient findings of the baseline survey were that the existing policy, strategic plan and legal framework guiding NAC, ASOs, CBOs, FBOs and other agencies of the multisectoral response hardly positioned MIPA to be the cornerstone of the entire HIV and AIDS response, that is in prevention, treatment, care and support and mitigation.

The overall picture emerging from the survey depicted NAC and other stakeholders being geared mostly for the implementation of GIPA and not MIPA. Under GIPA organizations aimed at ensuring just the participation of PLWHIV in implementation of HIV and AIDS programmes, whereas in the latter case emphasis is on empowerment of PLWHIV to reach the highest level of participation i.e. decision making level. When measured against the six levels of participation, the majority of ‘players’ were far from reaching ‘meaningful’ involvement of PLWHIV which at the highest levels entail involving them in the HIV and AIDS response as experts and decision-makers and not being confined to the lower roles of being a target audience, contributors, speakers or implementers. Most players involved in the HIV and AIDS response were still paying lip service to implementation of the principle of MIPA. Many of them exhibited a very shallow understanding of the concept of MIPA and hence lacked the know-how for operationalising the principle of MIPA. On the other hand, PLWHIV representing the demand side of the HIV and AIDS response were found wanting in terms of skill-base to participate meaningfully. They lacked a variety of skills that were critical to ensuring their meaningful involvement. Capacity building at various levels depending on one’s experience and educational background is therefore a key step in empowering PLWHIV to be meaningfully involved in the response. Without empowerment there would be no meaningful involvement of PLWHIV to talk about.

In order for MIPA to take root in the HIV and AIDS response in Zimbabwe it is important to make sure that an enabling environment is created. The first step should be to attend to the structural issues which should involve the reviewing of the current policy and legal framework to ensure that they recognize and position MIPA as a cross-cutting theme in the multisectoral response framework. Hence the existing legal and policy framework needs refocusing in order for it to drive the operationalisation process of MIPA. The second step would be to engage in an extensive educational campaign familiarizing stakeholders with the concept of MIPA. The third step in implementing MIPA in the national response is to attend to the training needs of both the demand and supply sides. A lot of resources went into training PLWHIV in basic nursing care especially for HBC. As a result majority of PLWHIV were mostly involved in care and support. However, their involvement did not involve decision-making in anyway but just as implementers of decisions already made. Training in the various areas of need would therefore enable both sides to play their respective roles within the multisectoral response in accordance with the principles and practice of MIPA. Fourth, since the survey revealed that the existing network of PLWHIV organizations was too weak to steer the ‘MIPA-ization’ process owing to lack of capacity and internal strife; there is need for institutional capacity building to enable the organisations of PLWHIV to play their oversight role in implementation of MIPA.

Another finding of the baseline survey and a cause for concern was that stigma and discrimination still existed in Zimbabwe and was the worst enemy of MIPA. It prevented many PLWHIV from opening up about their HIV
status because involvement would automatically expose them. This created a big challenge with individuals and organizations asking: ‘how can we involve them when we don’t know them?’ The greatest weapon in fighting this hurdle to the attainment of MIPA is for the government to invigorate the voluntary counselling and testing thrust (VCT). The logic being as many people become aware of their statuses the less they are prone to stigmatizing those who go public about their status since undergoing testing is on its own a humbling enough. More importantly, it is absolutely necessary for the authorities to increase access to ART. This goes a long way in encouraging HIV positive people to be open about their status since contraction of the virus would no longer be stigmatizing as it would no longer be perceived as a ‘death sentence’ but a health problem just as common as other incurable diseases requiring managing.
The recommendations fall under the following themes: policy and legal framework, capacity building and training, coordination and governance, educational and awareness needs, stabilization of network of PLWHIV, sustainable resource mobilization.

**Policy and Legal Framework**

4. PLWHIV are currently not involved in the entire spectrum of the HIV and AIDS national response hence organisations of PLWHIV should lobby for meaningful involvement of PLWHIV in prevention, treatment, care and support that is in the entire programming cycle from design to evaluation of programmes. Network of PLWHIV should advocate for formulation of MIPA friendly policies and strategic plans that ensure highest form of involvement by PLWHIV.

5. There is need for NAC to revisit the existing policy and strategic plan to ensure that they cater for the specific interests of women living with HIV and AIDS, the disabled, Youths, OVCs, men having sex with men, commercial sex workers and other vulnerable groups.

6. There is need for ZNNP+ and NAC to organize and coordinate a review of the Zimbabwe national strategic plan (ZNASP) 2006-2010’ and Behaviour Change Strategy in order to ensure that PLWHIV are accorded a frontline role in the execution of the plans.

**Existing Networks of Support Groups**

4. The network of PLWHIV should embark on a countrywide support group formation, affiliation and capacity development to ensure meaningful involvement of PLWHIV in the HIV and AIDS national response at their respective levels.

5. There is need for the network of PLWHIV to organize and coordinate training of support groups in communication and negotiation, computer literacy, legal and Human Rights, basic counseling, leadership and internet literacy.

**Capacity Building**

6. There is need for the network of PLWHIV to organize capacity building and training for leaders of organizations of PLWHIV in leadership, organisational planning and development, organisational management, financial management, networking, advocacy, writing proposals for funding, resource mobilization, designing a monitoring and evaluation framework and basic literacy in information technology.

7. There is need for ZNNP+ and NAC to organize training of trainers’ workshops for NAC national and provincial staff and representatives of partners on MIPA. This is in order to ensure that NAC secretariat, partners and sector representatives have an in-depth understanding of the concept of MIPA.

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Please note that ZNNP+ is cited herein to represent all organisations of PLWHIV and assuming that it will take on board the interests of the majority of stakeholders on MIPA.
Coordination and Governance

8. There is need for ZNNP+ to professionalise the day to day running of the organization by putting in place a secretariat that will implement the decisions of the Board on MIPA.

9. There is need for the network of PLWHIV to constitute MIPA Technical Working Groups that mirror the hierarchy of decentralized governance that is covering the national, provincial, district, ward and village. This is in order to ensure representation at all levels and ensure flow of information both upwards and downwards.

10. There is need for the network of PLWHIV to lobby for the formulation of national workplace policies that promote MIPA in the governance of organisations.

11. There is need for the network of PLWHIV and NAC to embark on the development of a MIPA Strategic Plan/ MIPA National Strategy and a MIPA Monitoring and Evaluation Framework that will help guide the process of translating MIPA from principle to practice.

12. There is need for the network of PLWHIV and NAC to oversee the development of Guidelines on MIPA or MIPA Code of Conduct (MCC) to be adhered to by both employers and employees in Zimbabwe. The MCC will also serve as a tool for fighting stigma and discrimination at workplaces.

Educational and Awareness Needs

13. There is need for the network of PLWHIV and NAC to coordinate the development of materials for a nationwide educational awareness campaign on MIPA. This is necessary for ensuring that the nation’s attention is drawn to the values and essence of MIPA.

14. There is a need for the network of PLWHIV and NAC to oversee the regular documentation of ‘MIPA Best Practises’ to be published and distributed to the public. The publication of ‘best practices’ is meant to provide corporate entities with MIPA models.

Stabilization of Network of PLWHIV:

15. In order to deal with internal strife in organisations of PLWHIV that undermines realisation of MIPA, NAC and network of PLWHIV should draw up a plan for fostering unity among the various organizations of PLWHIV in Zimbabwe.

16. There is need for the network of PLWHIV and NAC to leverage funding from donors specifically to be used for capacity building of leadership of organisations of PLWHIV.

Resource Mobilization:

17. There is need for the network of PLWHIV and NAC to train the leadership of organisations of PLWHIV in writing proposals for funding to ensure their meaningful involvement in the HIV and AIDS national response.

18. There is need for the network of PLWHIV to lobby for a greater say in the administration and utilisation of the national HIV and AIDS levy.
Unclassified Recommendation

19. There is need for the network of PLWHIV and NAC to lobby the donor community to promote MIPA in Zimbabwe by ensuring that proposals submitted for funding mainstream MIPA as a precondition for approval.
REFERENCES


Magaz, P and Hardee K. 2004: Implementing GIPA: How USAID Missions and their Implementing Partners are Fostering Greater involvement of People Living with HIV and AIDS.


ZNNP+ PVO2/99 Amended Constitution
### LIST OF PEOPLE INTERVIEWED

<table>
<thead>
<tr>
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<td>Mr Yekeye</td>
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