

POSITIVE HEALTH, DIGNITY AND PREVENTION IN NIGERIA:

FINDINGS AND RECOMMENDATIONS FROM STUDIES LED BY PEOPLE LIVING WITH HIV



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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
CS	Civil Society
CSO	Civil Society organisation
CSW	Commercial sex workers
DfID	(UK Government) Department for International Development
HIV	Human Immunodeficiency Virus
GIPA	Greater Involvement of People Living with HIV
GNP+	Global Network of People Living with HIV
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
LTA	The HIV Leadership through Accountability Programme
M&E	Monitoring and Evaluation
MSM	Men who have Sex with Men
NACA	National AIDS Coordinating Agency
NEPWHAN	Network of People Living with HIV and AIDS in Nigeria
Network	National network of PLHIV
NGO	Non-Governmental Organisation
NIBUCAA	Nigeria Business Coalition against AIDS
NSHP	National Strategic HIV/AIDS Plan
NSP	National Strategic Plan
OI	Opportunistic Infection
PHDP	Positive Health, Dignity and Prevention
PLHIV	People Living with HIV
PwP	Prevention with Positives [Preferred terminology is Positive Health, Dignity and Prevention]
PUD	People who use drugs
SRHR	Sexual and Reproductive Health and Rights
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS

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Introduction

The Network of People Living with HIV and AIDS in Nigeria (NEPWHAN) was formed in 1998 to serve as a collective voice of people living with HIV (PLHIV) in the country and to coordinate the various groups and organisations of PLHIV in Nigeria.

NEPWHAN's two principal goals are to:

1. Mobilise and empower PLHIV to join in the national response aiming to reduce and eventually end new HIV infections; and
2. Mitigate the impact of HIV on the lives of PLHIV and their loved ones in Nigeria.

In addition, NEPWHAN also envisions a day when all Nigerian PLHIV are accorded equal rights and privileges as any other member of society.

In order to better accomplish these tasks and realise this vision, NEPWHAN joined the HIV Leadership through Accountability (LTA) Programme, which builds the capacity of national networks of PLHIV to develop an evidence base for advocacy campaigns through research. As a participant in the LTA programme, NEPWHAN implemented several studies, modelled on five evidence-generating tools, developed by the Global Network of People Living with HIV (GNP+) and its partners. The findings and recommendations of this research are informing evidence-based advocacy for policy change in order to enhance the Nigerian HIV response and move towards achieving universal access to HIV prevention, treatment, care and support.

In 2011, after consultations with PLHIV from around the world, GNP+ and UNAIDS also released Positive Health, Dignity and Prevention (PHDP), a policy framework that promotes the rights, health and empowerment of PLHIV to take leadership roles in HIV prevention responses while creating a more conducive environment for HIV prevention efforts. PHDP aligns closely to NEPWHAN's goals and vision to end new HIV infections, to reduce its harmful effects on both the health and well-being of PLHIV, and to promote the human rights of PLHIV and key populations affected by the epidemic.

Advocacy for PHDP requires evidence on several aspects of the HIV response, some of which may have already been collected by the research NEPWHAN conducted for LTA programme. This paper reviews the findings and recommendations of the research pertinent to PHDP in Nigeria, in order to advocate for the health and wellbeing of PLHIV in Nigeria.

Positive Health, Dignity and Prevention

Positive Health, Dignity and Prevention (PHDP) is a policy and advocacy framework that recommends addressing the human rights, health and welfare needs of PLHIV holistically as a critical step to more effectively engage them. In fact, a focus on the health and dignity of people living with HIV also contributes to the health and well being of their partners, families and communities, and in and of itself, should act as significant steps towards HIV prevention.

PHDP is a distinct shift from ‘prevention with positives’ (PwP) projects being rolled out in a number of countries, including Nigeria, which are narrowly targeted at changing the behaviour of people who know that they are HIV-positive, with limited consideration of how failure to meet their needs for social support, human rights and treatment of PLHIV can undermine HIV treatment and prevention efforts.

PHDP calls for programmes to recognise the value of PLHIV as partners, leaders and implementers of the HIV response, including HIV prevention. Programmes should empower and build the capacity of PLHIV and not simply treat them as patients, passive targets or worse, as vectors of transmission. PLHIV should be seen, not as part of the problem, but as an integral part of the solution.

PHDP argues that in order to reach and engage PLHIV in the HIV response, national programmes must address the following points:

1. Establish a legal and policy environment where it is safe to live openly as an HIV-positive person (if he or she so chooses), free from the fear of HIV stigma, discrimination, gender violence, displacement or other human rights violations;
2. Focus on the health and well-being of PLHIV by providing universal and convenient access to essential treatment, care and support services including confidential HIV counselling and testing services. A focus on high quality health services is needed to improve and maintain the well-being of those who test HIV-positive, including timely antiretroviral therapy (ART);
3. Provide the tools and services to enable HIV-positive people to exercise their full sexual and reproductive health rights, while protecting their partners and infants from HIV;
4. Develop policies and support services addressing the social and economic factors that undermine the health and dignity of PLHIV such as poverty, food insecurity, lack of access to educational opportunities or employment, gender inequality and the discrimination and oppression of key marginalised populations at risk of HIV (including men who have sex with men, people who use drugs, migrants, prisoners, young people, women and sex workers);
5. Tailor non-judgmental services to reach out to the underserved key populations.

HIV prevention services need to include PLHIV, including key populations, in conception, design and implementation of the services targeting them. Otherwise, programmes may fail to consider critical fears or needs of the population and may even stigmatise their targeted population and limit the uptake and effect of the service. For instance, prevention initiatives focused solely on the responsibility of PLHIV to prevent passing on HIV to others, may inadvertently send out the message that ‘PLHIV are

solely responsible for HIV transmission’ and lend support to efforts to criminalise HIV-exposure and/or transmission and ‘scape-goat’ key populations. Such an approach can backfire and actually increase the transmission of HIV by chasing the targeted population groups away from HIV testing and health services. HIV treatment and prevention interventions will never achieve their optimal desired results in an environment where the human rights of PLHIV are not respected, or where their social and health needs are not being met, and when they are not engaged in the services that affect them.

The Positive Health, Dignity and Prevention Policy Framework describes some of the core programmatic components that could help create a more enabling environment for the success of HIV treatment and prevention services; and these encompass the full range of health and social-justice issues for PLHIV (see appendix B). Few countries have policies, programmes or services in place performing well enough to reach the goals of PHDP and advocacy is needed on several fronts at once to address the wide range of issues and promote the engagement of PLHIV across the HIV response.

National advocacy should be tailored to address the most significant barriers to PHDP in Nigeria and to take advantage of opportunities that already exist. But tailoring the campaign to the Nigerian context requires being informed by current and accurate information on:

1. The most pressing health and dignity needs for HIV-positive people living in Nigeria; and
2. The strengths and weaknesses of existing national policies, programmes or services including:
 - a. Whether there are key programmatic areas that have been neglected (such as programmes addressing gender inequality).
 - b. Examples of best practice where they exist — such as initiatives demonstrated to improve the health and well-being of PLHIV and their engagement in HIV prevention efforts — that can be scaled-up as part of the national PHDP framework; and
 - c. When and where there are critical gaps in knowledge, such as the absence of data on the Positive Health, Dignity and Prevention needs of marginalised key populations.

However, many of the values and programme components of the PHDP Framework overlap with issues explored by five evidence-gathering tools. Together, their combined findings provide an insight of where Nigeria is with regards to the values and programmatic components for PHDP.

Five Evidence-gathering tools used in HIV Leadership through Accountability Programme

PLHIV should set the agenda for any advocacy that affects them. However, in order to truly improve conditions for people living with HIV in Nigeria, advocacy agendas should be based upon evidence documenting what the local conditions are. This means understanding how Nigerians living with HIV have experienced their lives with HIV, including their experiences of accessing essential services, and what those experiences say about the quality or performance of the Nigerian national HIV response.

NEPWHAN, through the HIV Leadership through Accountability (LTA) Programme (funded by UKAid from DFID) implemented five evidence-gathering tools in partnership with civil society. The research, based on five standardised tools, aims at strengthening evidence in five key areas:

1. The level of involvement of people living with HIV in the Nigerian national HIV response, using the **GIPA (Greater Involvement of People Living with HIV) Report Card**: This tool measures the meaningful engagement of PLHIV in the decisions and programmes that affect them by interviewing key individuals in international NGO's and technical assistance organisations, and in the government and other major stakeholders in the national HIV response.
2. HIV-related stigma and discrimination, using the **PLHIV Stigma Index**. This involved conducting a large survey of PLHIV in Nigeria to measure trends in stigma and discrimination within the social environment, family, seeking employment and the workplace; how stigma, including internalised stigma, and discrimination affect access to health care services, HIV testing and treatment, or having children and internal stigma impact on the lives of people living with HIV; and whether PLHIV in Nigeria are aware of their rights.
3. Documenting and analysing human rights violations against Nigerian PLHIV on the basis of their HIV status or presumed status, with the **Human Rights Count!**.
4. Documenting and analysing the access and quality of services supporting the rights of PLHIV to have healthy, satisfying sex lives and to have children — using the **Sexual and Reproductive Health and Rights Guidance Package**. In the case of Nigeria, NEPWHAN adapted the tool to assess the experiences and needs of sero-discordant couples to sexual reproductive and health services.
5. The **Global Criminalisation Scan** documented and analysed cases relating to criminalisation of HIV transmission and exposure, and of laws that specifically restrict the rights of PLHIV, or of key populations at risk of HIV such as men who have sex with men (MSM), sex workers or people who use drugs (PUD). The methodology involved documenting laws, judicial practices and case studies.

Goals and Methodology

This report reviews the combined findings and recommendations of research conducted by NEPWHAN in order to establish the steps required to achieve Positive Health, Dignity and Prevention in Nigeria.

It explores whether the evidence contained within the five reports published by NEPWHAN to describe the country's progress towards achieving the values of PHDP and to document the existence and performance of the programmatic components (policies, services and initiatives) ready to be integrated into a national PHDP framework, and then highlights recommendations most likely to improve the health and dignity of PLHIV in Nigeria.

A thematic review was performed of the LTA report findings, conclusions and recommendations to search for any significant reference to the key PHDP themes and issues, as described by the PHDP Policy Framework. Observations were made of any topic which was not addressed in the LTA research, or when there was little information regarding a population's health and dignity needs, or when the performance of a programme or service could not be assessed, or could not be determined due to the quality of the available data, or due to limitations in the LTA study methodology.

The desk review also includes references to a few important developments, which have been reported at recent LTA meetings or on the LTA website (www.hivleadership.org) and other published relevant information. The report also identifies some of the limitations of the review when other sources of information may need to be consulted, or additional research needs to be performed in order to provide a more comprehensive evidence base.

The following section of report summarises the key findings of the review, and describes the key barriers and opportunities to advance PHDP as suggested by the thematic analysis and the action steps for PHDP advocacy that can be drawn from the LTA research recommendations.

Meeting the Principles and Values of PHDP

While there have been marked improvements in the meaningful engagement of PLHIV in the Nigerian HIV response in recent years — and the country’s National AIDS Coordinating Agency has adopted a National HIV Strategic Plan that is relatively progressive — NEPWHAN’s LTA research shows that to date Nigeria’s HIV/AIDS Response fails to deliver on any of the key points essential for PHDP.

Perhaps most critically, there is no supportive legal environment to protect people from HIV stigma and discrimination or to provide them with a means of redress when their human rights have been violated. Human rights violations are common.

Although internationally supported HIV testing and treatment services are expanding, the LTA findings suggest one could not characterise the HIV response in Nigeria as being ‘focused on the well-being of PLHIV’ as about half a million PLHIV in immediate need of ART are not on treatment, and the quality and reliability of those health responses are poor (see next section - core programmes).

The LTA reports suggest that government has done very little to support the development of programmes to support PLHIV to help mitigate factors that can negatively affect the health and dignity of PLHIV, such as food insecurity and gender inequality, other than a costly antipoverty campaign of apparently limited effectiveness — and that programme gives no consideration to the HIV specific needs and risks related to poverty.

Nigeria has no programmes targeted to address the stigma and discrimination experienced by key populations such as men who have sex with men. Many are unwilling to live openly — NEPWHAN should do a dedicated study of PLHIV Stigma Index focused on MSM, particularly as only a handful were willing to self-identify in the current national study. It is easy to see why, given that the government recently criminalised same sex relationships or any activity that might be construed as promoting same sex activity, which will make it only more difficult for clinic and projects to develop outreach services for them. What support and outreach services there are, are also primarily funded by international donors and non-governmental implementers and thus of questionable sustainability.

On a positive note, some PLHIV are beginning to be seen as much more than just patients in Nigeria. *“Considerable strides have been made in Nigeria towards the meaningful involvement of PLHIV in decisions affecting them as a group,”* said Peter Nweke, Programme Manager at NEPWHAN at the 3rd LTA Planning and Review meeting recently. The LTA research reportedly increased the level of PLHIV empowerment and capacity development, including involvement in the design and implementation of services. NEPWHAN’s GIPA Report Card study has also identified a best practice case of a successful programme that identifies PLHIV, trains and places them as paid employees in private firms.

While these successes have not yet been seen below the federal level (“The state government does not seem to believe in the GIPA principle,” one respondent said); and there are still charges that much of the PLHIV representation is merely tokenism, there are clearly several PLHIV now actively involved and placed in roles at the policy making level, and they should have at least some positive influence on critical policies and service development.

A case in point is NEPWHAN's growing influence. Many of the recommendations coming out of NEPWHAN's LTA research reports were incorporated into Nigeria's National HIV/AIDS Strategic Plan 2010-2015. Although not described in the LTA studies, the objectives and ambitions of the NHSP Strategic Plan are indeed praiseworthy — and merits mentioning especially because it endorses adopting the PHDP framework. It sets extremely ambitious goals that would address most of the shortcomings of Nigeria's HIV and AIDS response mentioned here and aims to provide 80% of the population with essential HIV-related services by 2015.

The problem is that the national government has never shown any real interest in backing the implementation of these plans, as is evidenced by the total lack of significant domestic funding to support the national HIV response. In fact, the government only contributes 15% of the total HIV funding in Nigeria, whereas 85% comes from donor agencies.¹

“The national response is largely donor dependent and for most part, donor driven,” according to the National HIV/AIDS Strategic Plan.

¹ NACA. National HIV/AIDS Strategic Plan 2010-2015.

Core programmatic components and elements to support PHDP in Nigeria

With the possible exception of PLHIV empowerment, LTA findings suggest that core programmatic components that could support PHDP have either been neglected and underdeveloped in Nigeria — or where they do exist, they are primarily due to the efforts of the civil society, non-governmental organisations and dependent upon international donor support.

However, it should be noted that the scope of the LTA research did not include an investigation of the complete range of possible programmatic elements that could be part of a PHDP framework, or may have used more general terms for the core programme which could include some of these services/element. That being said, the absence of some terms, such as the lack of any reference to elements such as mental health services or treatment literacy suggests there are some critical gaps in the information the five LTA tools research may provide.

PLHIV empowerment

The meaningful involvement of people living with HIV is one programmatic area that is explored in some detail by the GIPA Report Card. As already noted, there have been some advances in PLHIV involvement at the federal policy making level in Nigeria — though not commonly at the level of state or local government. (Some further GIPA results are described in Annex A.) However, the tool provides less information on other elements involved in PLHIV empowerment. The study did indicate that lack of access to education and training among more disadvantaged PLHIV was one of the reasons why there has not been a greater uptake of employable positions available for PLHIV, as part of implementing the GIPA principle, and called for Nigeria's existing poverty elimination campaign to provide vocational training for PLHIV.

Gender Equality

Gender inequality is entrenched in Nigeria, particularly in the north. Economic empowerment is unlikely when young girls are denied basic education. Rates of illiteracy are extremely high which is associated with extremely low levels of knowledge among women about HIV, its prevention and its management. For instance, NEPWHAN's PLHIV Stigma Index study found that some 44.7% (n=203) of HIV-positive women did not receive ART during pregnancy, because they did not know the treatment existed. Women may also receive worse treatment in healthcare settings than men. The SRHR Guidance Package study found that HIV-positive women in sero-discordant relationships are rarely treated in a non-judgemental manner by health care staff. This may explain why only 2% of respondents agreed with the following statement on the study questionnaire 'service providers offer information on legal, medical and counselling support services available to women in the event of sexual and gender-based violence in a sero-discordant relationship'. Approximately 80% strongly disagreed with the statement. NACA does have a policy of gender-mainstreaming, and the NHSP has set a target to make sure that 80% of all health care staff nationwide are 'gender-responsive' by 2015 to improve the treatment women receive. In the GIPA Report Card, a number of women living with HIV reported that their involvement at the policy making level has improved somewhat recently.

Health promotion and access

The extremely poor state of the national health system came up frequently in NEPWHAN's research reports. Many respondents in the LTA reports described the health system as being in a shambles — inadequately funded, staffed and equipped — there are challenges to accessing timely ART, with little access to HIV testing and counselling; too few centralised ART sites; poor supply chain management with problems leading to prolonged stock outs and treatment interruptions; little access to CD4 count monitoring, and PLHIV have to pay for much of their care themselves — such as for the treatment of opportunistic infections (OIs). While the ART programme grew quickly over the last several years, and has ambitious goals for expansion, the programme is almost entirely dependent upon outside funders — unless the Nigerian government finally starts paying for care. The absence of national guidelines, policies and standards in several critical areas (such as ART guidelines) illustrate a lack of dedication and accountability.

Human Rights

At present there is no legislation to specifically protect the human rights of PLHIV and stigma, discrimination and human rights violations continue unabated, which is why NEPWHAN feels the anti-discrimination bill is important. However, the bill would undermine messages regarding the shared responsibility for preventing new HIV infections with the adoption of HIV-specific anti-criminal laws. In addition, the human rights of marginalized key populations are not protected, and new laws oppressing these populations are being adopted.

While prevention programmes are underway in Nigeria (again largely supported by international funders), prevention efforts are likely to have a suboptimal effect in an environment where the human rights of PLHIV are not protected, or where laws criminalising HIV exposure/transmission could be adopted because people prefer to avoid getting tested for HIV. In addition, because of the inadequate access to ART, HIV-positive people qualifying for treatment will find it more difficult to protect their partners (transmission within couples accounts for the largest number of new infections in the country).

Likewise, efforts to achieve an HIV-free generation are stymied in Nigeria by the poor performance and low coverage of the prevention of vertical transmission programme, though this could be changing, as there have been major efforts and advances recently to better train healthcare workers in this area, according to the SRHR Guidance Package. The oppression of groups such as sex workers, people who use drugs and men who have sex with men could steer them away from health services and increase their already disproportionate burden of HIV, nationally.

Sexual and Reproductive Health and Rights

NEPWHAN's SRHR research documented an almost complete lack of services or capacity to support the sexual and reproductive health needs of people in sero-discordant relationships. Furthermore, there were numerous documented cases where people were denied treatment unless they adopted certain birth control methods against their will. The PLHIV Stigma Index reported this too. Access to ART was withheld according to some respondents, conditional on using certain types of contraception for 11.2% (n=28) of men and 6.1% (n=28) of women. 85% of the HIV-positive partners in the SRHR said they did not receive non-judgemental supportive care. The total absence of SRHR services further illustrates the extent of the degree nationwide, that health care staff stigmatise and discriminate against PLHIV.

Social and Economic Support Services

There is a network of grassroots PLHIV support groups in Nigeria, though coverage varies by setting, with poorer access in the North offering psychosocial support. NEPWHAN's research also suggested that other forms of social and economic support for PLHIV are very limited.

It is not clear how effective the national poverty elimination campaign in Nigeria is — 50% of the population still lives below the official poverty line despite huge sums spent on the campaign (corruption could keep funds from reaching their targets), and it is not tailored to the specific needs of PLHIV, to redress the negative economic impact of HIV or the vulnerability that contributed to people becoming HIV-positive in the first place. These consequences often affect women most profoundly, who contracted HIV from their older husbands at a young age, and when husbands die, they are forced to live on the street with their children. NEPWHAN's GIPA Report Card noted that these same economic disadvantages meant that many PLHIV had little access to education, and were thus less likely to develop the sort of skills and experience needed to take advantage of opportunities for employment of PLHIV in the HIV response.

Together, these programmatic shortcomings suggest that in Nigeria, a large proportion of PLHIV are at high risk of not knowing their status and accessing necessary care; there is little to no financial support to cushion them or their families from the economic consequences of HIV, and the lack of protection from human rights abuses, HIV stigma, and discrimination — all of which make it increasingly difficult to live any life with dignity. Without securing the health and dignity of PLHIV, prevention programmes are unlikely to be able to stop new HIV infections in the country.

Key barriers to achieving PHDP in Nigeria

From the review of the LTA tool findings and recommendations, the key barriers to achieving PHDP in Nigeria are:

1. Lack of government commitment/funding for the HIV response
 - a. “Government has not shown enough commitment to universal access. International donor agencies are largely responsible for expanding service outlets for ART, care and support services while government support is minimal,” according to one respondent in the GIPA Report Card.
 - b. Likewise, the Nigerian government shows no interest in developing national campaigns or programmes that could improve the health and welfare conditions of PLHIV countrywide. And it is not because Nigeria’s government is without money.
2. The absence of legal protection or national efforts to eliminate HIV stigma and discrimination
 - a. Stigma and discrimination are commonly experienced by people living with HIV in Nigeria. Three of the Nigerian LTA studies identified the need for anti-discrimination legislation as the single most crucial priority needed in order to improve the lives of people living with HIV. The desperation to have some legal protection and recourse to reduce stigma is so great that NEPWHAN is pushing for the passage of one bill, even though it is based on the HIV model and a law which has a section criminalising HIV transmission.
3. Inadequate and inaccessible HIV testing, treatment, monitoring and care services
 - a. There are three million Nigerians living with HIV. Over 800,000 would immediately qualify for ART if they were in care, however only 300,000 people are on ART. Where are the missing 500,000?
 - b. Part of the issue may be inadequate access to HIV counselling and testing, or stigma and discrimination may keep them from testing or seeking out care. But other health system barriers could also play a part. For instance, 70% of Nigerians pay out of pocket for medical care, and even though ART is freely provided, the cost of accessing other HIV-related care may not be. If they are in care, they may have no access to diagnostics such as CD4 and viral load monitoring.

Finally, ART sites are located at larger centralised health facilities rather than at primary health care clinics in the community. This can make it very difficult for those living in more remote areas to access care in a large country like Nigeria, with poor roads or little access to transportation.
4. A lack of services supporting the sexual and reproductive health rights of PLHIV
 - a. A healthy and satisfying sex life is an important part of health and well-being, and people should be free to have children if they so wish — but people living with HIV need support and access to all the appropriate tools and technology to make informed choices for their own health and to reduce any risks of HIV transmission.

5. Gender inequality and gender-based violence
 - a. Women living with HIV deserve health and dignity just as much as men, but are more vulnerable to abuse, and the LTA research in Nigeria suggests that they are currently provided with little support.
6. An oppressive social and legal environment affecting men who have sex with men and other sexual minorities
 - a. Men who have sex with men have a much higher burden of HIV than the general population, but the policies recently adopted by the Nigerian government may make them virtually unreachable to prevention and care services.
7. Limited social and economic assistance for PLHIV from the government
 - a. People living with HIV have unique economic and social service needs which remain unaddressed.

Opportunities for promoting PHDP in Nigeria

In Nigeria, NEPWHAN's LTA research did not appear to identify national programmes that could be considered for potential incorporation into the PHDP framework, though there are many organisations in Nigeria doing work and providing support services that contribute to the health and wellbeing of PLHIV.

One interesting project providing training, employment and involvement of PLHIV, described in the GIPA Report Card, is the result of a collaboration by the Nigeria Business Coalition against AIDS (NIBUCAA) together with NACA, NEPWHAN, Society for Family Health (SFH) and UNAIDS. It identifies and supports PLHIV to train and then gets them a placement as paid employees referred to as 'GIPA Officers' in private firms. In addition to their primary duties within the firms, the GIPA Officers implement workplace HIV and AIDS interventions. This programme receives support from the Global Fund in Rounds 5 and 9 to scale up further.

Another major opportunity to advance PHDP in Nigeria is the endorsement of PHDP by NACA in the National Strategic Plan:

"The overarching priority of the NSP is to reposition prevention of new HIV infections as the centrepiece of the national HIV and AIDS response. Thus greater focus will be placed on scaling-up HIV-prevention services that enable individuals to maintain their HIV-negative status as well as improve access to quality treatment and care services for PLHIV including positive health, dignity and prevention (PHDP) interventions that reduce their transmitting HIV to others."

In addition, the NSP attempts to address virtually all the critical shortcomings of the ART programme, calling for decentralisation to the primary healthcare level and simultaneously addressing human resources and supply chain management. The plan calls for putting at least 80% of eligible adults (women and men) and 100% of children (boys and girls) on ART by 2015.

It calls for an enhanced focus on poverty and food insecurity with applied research to determine what can be done to strengthen policy and program assistance for affected populations; a comprehensive database and management information system to monitor the HIV programme and its outcomes, using the data to improve quality.

Finally, and crucially, it calls for an increase in funding for care and support services: *"Financial resources for care and support services should be provided through a specific budgetary line."* The question of course is how to pay for all of this, at a point when donor funding is dwindling. The answer is that NACA has set as one of its objectives to lobby the Nigerian government to increase its contribution to the HIV response to pay for at least 30% of the programme by 2015.

In light of NACA's endorsement of PHDP in the national strategic plan, and the activities it recommends that would promote the health and dignity of PLHIV, there is a clear incentive to campaign in support of Nigeria's own National Strategic Plan, to make sure that it is adequately funded by the Nigerian government, and implemented.

Given the real danger of losing some of the international funding support over the next few years, advocating for the Nigerian government to contribute much more has become the most urgent issue for joint advocacy.

Next steps for PLHIV and PHDP in Nigeria

1. Advocacy to increase the Nigerian government's spending and commitment to the HIV response.
2. Advocacy to demand passage of anti-discrimination legislation, importantly, without the criminalisation clause. Once mechanisms and services to seek justice have been established, develop a nationwide educational campaign to develop rights-literacy among PLHIV and inform them about how to access these services.
3. Develop, with full participation of PLHIV, anti-stigma, HIV sensitisation programmes in communities and health care facilities. Public enlightenment campaigns and information on HIV and the need to stop HIV-related stigma and discrimination must be sustained at every level and extended to every community in the country so that rural dwellers especially can understand and fully comprehend all about HIV. Interventions are also needed to address self-stigma among people living with HIV.
4. Intervention programs specifically targeting discordant couples should be designed to provide accurate and timely information on 'HIV discordance' at various HCT entry points. Also, training of HIV discordant couples to serve as counsellors on the issue will further strengthen such intervention programs and activities in support groups of PLHIV.
5. Service providers should be well informed and trained to provide information and services, based on the latest science, on all aspects of sexual and reproductive health to discordant couples in order to address their specific needs.
6. Training bursaries could be provided by interested donors to increase the number of PLHIV who have useful skills to contribute in HIV programming, in addition to their valuable perspective as individuals directly affected by the HIV epidemic.
7. The call for incorporating PLHIV perspectives into poverty planning should be brought to the attention of NAPEP. This step could reduce both poverty and the rate of new HIV infections in Nigeria.
8. Demand that all state and local governments adopt and implement the national workplace policy. Both public and private sector organisations should also be mandated to develop or adopt the national workplace policy.

Conclusion

The review found the LTA research addressed the most critical questions regarding the federal government's HIV response. What was not covered so well were the range of other programmes or services at the state level, or from NGO's, community-based responses that might serve as models of best practice that could be scaled up country-wide.

There was also little information available on underserved populations, including adolescents, people who use drugs, MSM, prisoners, sex workers etc, or a very clear picture of what efforts are underway in the country to address gender issues.

A desk review and survey of the different regional networks, NGOs into local programmes to see whether some of the programmatic elements described in the PHDP report are available anywhere in the country. As NEPWHAN's PLHIV Stigma Index recommends, a further implementation of the PLHIV Stigma Index is needed among MSM and potentially other populations, while the SRHR may also need to be performed in other populations.

At a later stage, as programmes are put in place, it will be important to evaluate their performance and reach. The five LTA research tools are well placed to be part of the monitoring and evaluation of the national strategic plan. The evidence gathered with a bottom-up approach and informed by community responses is a valuable contribution to the evidence-base on how to achieve Positive Health, Dignity and Prevention in Nigeria.

LTA Programme: NEPWHAN's research to develop an evidence base for advocacy

"In the past, civil society has been known to make statements about issues that affect people living with HIV/AIDS. There was only one problem — there was no evidence to back their statements up," said Peter Nweke, of NEPWHAN at a recent LTA programme meeting. *"That's what these five evidence-gathering tools were meant to address — to create an evidence base for advocacy for policy change."*

As already noted, this evidence might also be used as a basis for a campaign for Positive Health Dignity and Prevention.

NEPWHAN began the research after joining the HIV Leadership through Accountability Programme. The research was based on five standardised tools, adapted and translated for use in the Nigerian context. The process and methodology conducting the trials are described in the final reports. The studies reported that Nigeria's response to its HIV epidemic has expanded over the last several years, however, there are still serious challenges confronting people living with HIV in the country and barriers to optimal treatment, prevention and care.

GIPA Report Card

NEPWHAN's research using the GIPA Report Card concluded *"Considerable strides have been made in Nigeria towards the meaningful involvement of PLHIV in decisions affecting them as a group,"* said Peter Nweke in a presentation on the implementation of the GIPA Report Card in his country at the 3rd LTA programme meeting in Nairobi at the end of July 2011. *"It's not perfect, but something real is going on."*

But there were some problems: The GIPA principle was less likely to be applied below the federal level and was operationalised in some states and not in others. Some organisations at the state level 'were uninterested,' and others had good policies but inadequate funding for implementation. In Nigeria, PLHIV tend to be more involved in implementation activities than planning and design in the HIV response.

General findings include lack of awareness among stakeholders and PLHIV about GIPA. In particular, PLHIV networks at the grassroots level lack an understanding of the GIPA principle and its value — which limits GIPA at the local level. There were situations where job positions in the HIV response were open to PLHIV, but no one came forward to fill it. Aside from lack of awareness of GIPA, the major reasons why PLHIV did not take advantage of these opportunities were fear of stigma or related discrimination should they openly represent the PLHIV community of in one of these positions. Poverty is the second worst barrier to GIPA and PLHIV may be particularly at risk of poverty due to the cost of treatment and accessing care, whose livelihoods have been destroyed by stigma or ill-health resulting from their HIV infection. Poverty was a barrier in a number of ways 1) remuneration for some positions was below a living wage, and 2) many PLHIV, especially women, didn't have an opportunity to pursue an education or develop the skills required to fill some of these positions — particularly high level policy setting positions. For this reason, NEPWHAN called for PLHIV to be represented in the national campaigns against poverty, as they are disproportionately affected by it.

The PLHIV Stigma Index

In Nigeria, 710 people were interviewed: 54% experienced food shortages more than four days per month; 44% verbal insults; 31% physical harassment & threats and 9% were denied health services. Most of the stigma was encountered in workplaces, homes and places of worship.

Evidence from PLHIV Stigma Index is already being used as the basis of a broad civil society campaign to ensure the passage of the Nigerian anti-discrimination bill. However, as noted below there is a problem with this bill as it is currently drafted.

The SRHR Guidance Package

NEPWHAN identified the SRHR needs of sero-discordant couples as their key group for this research tool. They found that the respondents had low levels of awareness of SRH, and a complete absence of services for this need — there are no protocols, staff are not trained or supervised to manage such cases. “There are very few trained HCT couple counsellors in Nigeria and even fewer who are trained on managing the specific issues challenging HIV discordant couples. 90% of respondents in the study had never received any form of counselling on sexual and reproductive health rights from a health facility, organization or even within their respective support groups.

The Global Criminalisation Scan

The Global Criminalisation Scan report found a lack of awareness and knowledge of specific laws, which exist in two states in Nigeria, with prosecutions reported. Where these laws do exist, they may be poorly understood. For instance, lawmakers in the two states in Nigeria to have criminalised HIV believed the laws were for the ‘protection’ of people living with HIV. A common reason for this could be because legislation criminalising HIV transmission is woven into the rubric of a ‘model law’ a template that a USAID-funder programme drafted to help countries in Africa quickly pass anti-HIV discrimination legislation.

In fact, the proposed anti-discrimination bill that NEPWHAN is stridently advocating for, contains the same clauses that would criminalise ‘willful’ HIV transmission in Nigeria. This is a serious problem that must be addressed before the bill is passed.

Human Rights Count!

Found that the key areas where human rights violations occurred included workplaces, homes (for women and youth), and churches. The majority of cases (65%) in Nigeria were not reported to authorities and of these, over 70% were either afraid to report the incident or didn’t know how to.

All of these factors limit the potential contribution of HIV-positive individuals in the fight against HIV— in their own lives and in their communities. Taken together, these issues present significant barriers to universal access: potentially reducing the uptake of HIV counselling and testing, as well as access to and uptake of support, care and treatment and prevention services.

Positive Health, Dignity and Prevention

The PHDP framework, emphasising the health and rights of people living with HIV (PLHIV), evolved partly as a response to “Positive Prevention” an earlier attempt by public health officials and prevention specialists to target interventions at HIV-positive people to reduce the risk of onward transmission of the virus. But many people living with HIV felt ‘Positive Prevention’ placed the burden for HIV prevention almost entirely upon those who had tested HIV-positive — as if they were solely responsible for HIV transmission. PLHIV were being treated as a source of infection to be contained, rather than as human beings.

“We held an international technical consultation in Tunisia in April 2009, where people brought examples from various regions, of the kind of messaging that is in their country around Positive Prevention”, said Georgina Caswell of GNP+. “Messages like: ‘PLHIV need to be careful’ or ‘PLHIV should not have sex’.” Such messaging led recently diagnosed people living with HIV to despair, believing they would be unable to be sexually intimate with their partners, their relationships might be at an end, or that they could never conceive children with their HIV-negative partners. In more than one health facility in Africa, the fear of HIV transmission has been taken to extremes: some pregnant women living with HIV have been coerced to terminate their pregnancies— even though higher effective interventions to prevent vertical transmission exist to protect most infants. In other cases, women living with HIV have been sterilised, sometimes without their knowledge.

These human rights violations are in no way associated with Positive Prevention programmes, which were rolled out partly in response to data from some of the more mature HIV epidemics in Africa showing that most of the new HIV infections in countries such as Kenya and Uganda were now occurring among stable partnerships (as opposed to casual partners) when one partner was HIV-positive (sero-discordant couples). In response to the new epidemiological data, with support from PEPFAR and other donors, Positive Prevention programmes were quickly scaled up by international NGOs in a number of countries.

Unfortunately, PLHIV were not really engaged in the inception of these programmes. As noted above, many felt that the subtext of the ‘Positive Prevention’ message was that PLHIV have to be prevented from passing on HIV to others — as though people knew their HIV status were most to blame for the continued high incidence of HIV in most countries.

Around the same time, another US funded endeavour made the situation even worse for people living with HIV by introducing a “model” HIV-specific criminal law, a legislative template that has now been used by 27 countries to draft laws criminalising HIV transmission. The laws vary slightly from country to country. For instance, in Benin, it is now illegal to fail to disclose the result to one’s partner within six weeks of testing HIV-positive. Given the risks of gender-based violence if they should disclose their HIV-positive status to their partner, women living with HIV may be at greater risk of running afoul of this law.

These laws are unlikely to have an effect on HIV transmission — since it is generally HIV positive people who are unaware of their status who are most likely to transmit the virus. Nevertheless, people who know they are living with HIV are increasingly being subjected to arrest and incarceration in countries all over the globe. This could prove counter-productive to HIV prevention efforts because it could discourage people from getting tested for HIV and receiving care and treatment. As Frederica Stines, Africa programme officer at the International Women’s Health Coalition was quoted as saying in one news story: “Who wants to know their status if they could be arrested?”

Many people living with HIV, who have experienced HIV-related stigma and discrimination first hand, fervently want to avoid passing on HIV— and should be given the information they need to protect their loved ones and have

access to the full range of effective HIV prevention tools. PLHIV could become leaders in HIV-prevention efforts, but they are less likely to be effectively engaged by prevention programmes that stigmatise them or treat them as irresponsible and reckless.

At the 2009 technical consultation in Tunisia, PLHIV advocates demanded an end to demeaning treatment, and announced that one of the first things that prevention programmes had to do was stop pinning the entire responsibility for HIV prevention upon PLHIV. Rather, they should emphasise that HIV prevention is a shared responsibility. In other words, HIV-negative individuals have the responsibility to take precautions to protect themselves as well — it is not solely the role of the person living with HIV. In fact, it is in an HIV-negative person's interest to practice HIV prevention consistently since their partner may be unaware of his or her HIV status.

People who are unaware that they are HIV-positive may be more likely to practice high risk behaviours, so the HIV advocates at the technical consultation called for HIV testing and counselling services must be universally available and easily accessible so people so that people have up-to-date knowledge of their HIV status.

However, the advocates noted that prevention campaigns with HIV-positive people would miss their mark, where there is little motivation to get tested for HIV. In other words, people will lack an incentive to test if there is no access to care and treatment needed to preserve one's health, or if it is impossible to disclose one's status to one's partner or to live openly with HIV because of stigma and discrimination, or repressive legal environments. Other people may not wish to get tested if it means that they could no longer exercise their human sexual and reproductive rights, such as having children.

The PLHIV advocates called for a new framework 'Positive Health, Dignity and Prevention' to be drafted with a more holistic approach that prioritises the health, wellbeing, and meaningful engagement PLHIV — if these can be secured, prevention interventions would be much more likely to be effective.

"Positive Health, Dignity and Prevention argues that, if you improve and if you maintain the dignity of the person living with HIV, and if you support the individual living with HIV around their broad health needs, this will result in a range of benefits including a reduction in the likelihood of new infections," said Caswell.

More recently, GNP+ and its partners have released the **Positive Health, Dignity And Prevention: A Policy Framework**, which sets forth the following the strategies guiding principles and values:

We are more than patients

People living with HIV are leaders in the design, programming, implementation, research, monitoring and evaluation of all programmes and policies affecting us.

We will not be treated as vectors of transmission

A human rights approach is the foundation of Positive Health, Dignity and Prevention

We are all responsible for HIV prevention

Preventing new HIV infections is the shared responsibility of everyone irrespective of HIV status.

We have needs and desires to be met

Sexual and reproductive health and rights must be recognised and exercised by everyone regardless of HIV status.

Values

Positive Health, Dignity and Prevention can only be achieved through the following points:

- A supportive and protective legal and policy environment that aims for a world free of HIV-related stigma and discrimination.
- A focus on improving and maintaining the health and well-being of people living with HIV, which, in turn, contributes to the health and well-being of their partners, families and communities.

- The promotion of holistic health and wellness, including universal, equitable access to voluntary HIV counselling, confidential testing, care and support and timely access to voluntary treatment and monitoring.
- Addressing a range of factors that undermine health and dignity, including: poverty and food insecurity; lack of mental and psychosocial support; lack of educational opportunity; social exclusion; gender inequality; and stigma and discrimination based on HIV-positive status, behaviours such as injecting drug use, sex work and/or sex between men, and identities such as being lesbian, gay, bisexual, transgender or intersex.
- Responding to the needs of key populations, including the particular and specific needs of young people and women – not key populations in the same way as marginalised populations actively persecuted, criminalised and driven away from prevention services by society and national governments], and through respectful programmes tailored to specific contexts and the diversity among people living with HIV.

The framework sets out 8 general programmatic components of PHDP, including Empowerment, Gender Equality, Health Promotion and Access, Human Rights, Preventing New Infections, Sexual and Reproductive Health Rights, Social and Economic Support and Measuring Impact. It also describes some of the programmatic elements that might be involved, though these could differ from setting to setting.

I. EMPOWERMENT

- Meaningful involvement of people living with HIV
 - Positive leadership
 - Participation in policy dialogue and advocacy
 - Mentoring of future leaders including women and young people living with HIV
 - Peer support groups
- Education and literacy
 - Treatment
 - Sexual health and comprehensive sexuality
 - Prevention of transmission
 - Reproductive health
 - Family planning
 - Legal and rights
 - Health education for living well (improving nutrition, ceasing smoking, limiting alcohol and drug use, increasing exercise), which helps provide information on health options
 - Building of self-esteem and confidence
 - Age-appropriate and HIV-specific sex and relationships education for children and adolescents born with HIV.
- Capacity building for organizations and networks of people living with HIV
 - Resources for networks and associations of people living with HIV
 - Social mobilisation and community engagement
 - Facilitation of networking opportunities
 - Linking to other social justice and development movements

II. GENDER EQUALITY

- Gender-based violence prevention and management
 - Health-provider training on sexuality, gender, stigma, discrimination and gender-based violence
 - Legal reform and enforcement of laws and mechanisms protecting people from gender-based violence
- Constructive engagement of men in reproductive and sexual health
- Appropriate health services for women living with HIV, including, but not limited to, prevention of vertical transmission of HIV

- Legal advocacy and activism for women’s rights
 - Networking opportunities
- Legal advocacy and activism for rights for men who have sex with men, and for lesbian, gay, bisexual, transgender, and intersex people
 - Networking opportunities
- Economic empowerment of women
- Education
- Support for care-giving
- Social empowerment including equality in decision-making and negotiating skills

III. HEALTH PROMOTION AND ACCESS

- Knowledge of HIV status under conditions of informed consent, confidentiality and good counselling
 - Community-based voluntary counselling and testing
 - Provider-initiated counselling and testing
- Treatment and care access, availability, sustainability, and quality assurance
 - Clinical monitoring
 - Availability and access of timely and appropriate antiretroviral therapy
 - Antiretroviral therapy adherence support
 - Prevention of disease progression and further infections
 - Prophylaxis for tuberculosis (TB) and other opportunistic infections
 - Diagnosis and treatment for TB and other opportunistic infections
 - Diagnosis and treatment for Hepatitis C and other co-infections
 - Research and better understanding about the long-term effects of antiretroviral therapy and HIV, including youth who acquired HIV perinatally
 - Palliative care
 - Facilitated referral systems
- Psychosocial well-being services access, availability, sustainability, and quality assurance
 - Mental and emotional health services
 - Counselling services and support groups

IV. HUMAN RIGHTS

- Confidentiality of HIV-positive status
- Conditions for safe, voluntary, and beneficial disclosure
- Respect for individual autonomy
 - Choosing when, and if, to test, disclose, and/or initiate antiretroviral therapy
- Establishment of an enabling environment, including protective laws
 - Stigma and discrimination reduction
 - Support for advocacy and activism leading to legal and policy reform and implementation
 - A focus on shared responsibility for preventing new HIV infections, including removal of HIV-specific criminal laws

V. PREVENTING NEW INFECTIONS

- Access and availability of tools and technologies that help prevent sexual HIV transmission
 - Male and female condoms and water-based lubricants
 - Male circumcision
 - Antiretroviral therapy
 - Post-exposure prophylaxis

- New prevention technologies, such as pre-exposure prophylaxis and microbicides, as and when they become available
- Access and availability of services that help prevent vertical transmission
 - Primary prevention of HIV infection among women of childbearing age
 - Preventing unintended pregnancies among women living with HIV
 - Preventing HIV transmission from a woman living with HIV to her infant, including breast-feeding information and support
 - Providing appropriate treatment, care and support to mothers living with HIV and their children and families.
- Access to evidence-informed harm reduction for people who use drugs, including opiate substitution therapy
- Serodiscordant couples counselling (including partner and couples testing)
- Prevention, screening and treatment of sexually transmitted infections, including viral hepatitis
 - Human papillomavirus vaccination
 - Hepatitis A and hepatitis B vaccination

VI. SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS

- Sexual health and well-being
 - Age-appropriate, comprehensive sexuality education, including a focus on the specific needs of adolescents born with HIV
 - Prevention and treatment of sexually transmitted infections, including viral hepatitis
 - Counselling and support for a satisfying sex life, including but not limited to improving libido, and treating sexual dysfunction
- Reproductive health
 - Maternal health
 - Family planning, including infertility and contraceptive services
 - Cervical, breast and other related cancer screening and management
 - Access to appropriate, safe and non-coerced termination services
- Sexual and reproductive health and rights advocacy and funding

VII. SOCIAL AND ECONOMIC SUPPORT

- Food and water security
- Social and economic support for caregivers
- Access to financial services
 - Support of productive linkages, including cooperatives
- Employment of people living with HIV
 - Further education and retraining opportunities for adults with HIV
 - Access to full education and employment opportunities for young people living with HIV
- Health and social protection for children and adolescents living with HIV

VIII. MEASURING IMPACT

- Develop monitoring and evaluation systems to measure impact, progress towards PHDP.

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