HIV Leadership through Accountability

# Advancing the Sexual and Reproductive Health and Human Rights of People Living With HIV

# Key findings from studies in Kenya, Nigeria and Zambia

**April 2010**

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

NEPWHAN

NEPHAK say yes to life

GNP+ GLOBAL NETWORK OF PEOPLE LIVING WITH HIV

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**The Global Network of People Living with HIV (GNP+)**
P.O. Box 11726
1001 GS Amsterdam
The Netherlands

Website: www.gnpplus.net and www.hivleadership.org
Email: infogno@gnpplus.net

# Acronyms

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| **ARV** | Antiretroviral |
| **CCM** | Country Coordinating Mechanism (for delivery of Global Fund interventions) |
| **CEDPA** | Center for Development and Population Activities |
| **CiSHAN** | Civil Society on HIV/AIDS in Nigeria |
| **CSO** | Civil Society Organisation |
| **DFID** | UK government Department of International Development |
| **GIPA** | Greater Involvement of People Living with HIV and AIDS |
| **GNP+** | Global Network of People Living with HIV |
| **IEC** | Information, education and communication |
| **ICW** | International Community of Women Living with HIV/AIDS |
| **LACA** | Local Action Committee on AIDS |
| **LGBT** | Lesbian, gay, bisexual and transgender |
| **MIPA** | Meaningful Involvement of People Living with HIV and AIDS |
| **MSM** | Men who have sex with men |
| **NACA** | National Agency for the Control of AIDS |
| **NAPEP** | National Poverty Eradication Programme |
| **NARN** | Nigeria AIDS Research Network |
| **NDE** | National Directorate of Employment |
| **NEEDS I & II** | National Economic Empowerment and Development Strategies |
| **NEPHAK** | National Empowerment Network of People Living with HIV/AIDS in Kenya |
| **NEPWHAN** | Network of People Living with HIV and AIDS in Nigeria |
| **NIBUCAA** | Nigeria Business Coalition Against AIDS |
| **NGO** | Non-Governmental Organisation |
| **NSF** | National HIV/AIDS Strategic Framework |
| **NYNETHA** | Youth Network on HIV/AIDS in Nigeria |
| **NZP+** | Network of Zambian People Living with HIV/AIDS |
| **PLHIV** | People living with HIV |
| **PMTCT** | Prevention of Mother-To-Child Transmission |
| **SACA** | State Agency for the Control of AIDS |
| **SEEDS** | State Economic Empowerment and Development Strategies |
| **SRHR** | Sexual and Reproductive Health and Rights |
| **UNAIDS** | Joint United Nations Programme on HIV/AIDS |
| **UNGASS** | United Nations General Assembly Special Session on HIV/AIDS |

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"Advancing the Sexual and Reproductive Health and Human Rights of People Living with HIV: A Guidance Package" is one of five evidence-gathering tools being implemented through the HIV Leadership through Accountability programme. The programme combines specific HIV evidence-gathering tools, national AIDS campaigns and targeted advocacy to achieve Universal Access to prevention, treatment, care and support. For more information about the HIV Leadership through Accountability programme please visit www.hivleadership.org.

# Contents

# Introduction

A groundbreaking guidance package entitled, "Advancing the Sexual and Reproductive Health and Human Rights of People living with HIV" was launched in 2009 by people living with HIV and their advocates. Based on input from networks of people with HIV worldwide, the *Guidance Package* explains what needs to be done by global stakeholders in the areas of advocacy, health systems, policy making, and law to support and advance the issues of sexual and reproductive health and rights (SRHR) - and why they matter. Michel Sibidé, Executive Director of UNAIDS, noted that the *Guidance Package*, "will help to ensure that the human rights of people living with HIV, irrespective of their lifestyles, are respected and that they obtain access to the services and information they need to protect themselves and their loves ones."

In a two-year process of research and analysis, the Guidance was developed by the Global Network of People Living with HIV (GNP+), the International Community of Women Living with HIV/AIDS (ICW) and Young Positives in collaboration with EngenderHealth, International Planned Parenthood Federation (IPPF), the Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Population Fund (UNFPA) and the World Health Organization (WHO).

Now GNP+ has taken a next step by collaborating with national networks of people living with HIV to develop social science research instruments and use them gather data on the sexual and reproductive health (SRH) needs and experiences of key constituency groups in their countries. These country-level reports document the barriers and deficits that keep particular groups from being able to access essential information and services to meet their needs and provide recommendations for the development and implementation of programmes and policies.

## Why this process?

The process of engaging national PLHIV networks in capturing, recording and publishing these data serves two purposes. It builds a solid evidence base about *why* removal of these barriers is critical and *how* national health care systems can be strengthened in specific ways to achieve this. This evidence base is needed to inform national-level priority setting and to mobilise advocacy to press governments and policy-makers to meet their commitments in this area.

This particular process also serves to highlight the unique value of using a bottom-up approach to analysing the human costs incurred by the weakness of these health care

systems. It also demonstrates the essential role that civil society, and specifically networks of people living with HIV, can play in helping governments to plan, monitor and evaluate the effectiveness of such services as they are improved.

The following three reports are part of an "HIV Leadership through Accountability" initiative undertaken jointly by GNP+ and the World AIDS Campaign. In this five-year initiative, the two organisations are working with national PLHIV networks in fifteen countries to promote movement toward the goal of universal access to HIV prevention, treatment, care and support services.

GNP+, as a part of its participation, is supporting the development of tools by and for people living with HIV and the use of those tools to collect and analyse evidence on four human rights areas; stigma and discrimination, criminalisation of HIV transmission, human rights violations based on HIV status, and sexual and reproductive health and rights of people living with HIV.

The three reports here are the first to emerge from work on sexual and reproductive health and rights under the HIV Leadership through Accountability programme. They are:

- A Report on the Uptake of Prevention of Mother-To-Child Transmission (PMTCT) Services by People Living with HIV in Nairobi, Kenya

- A Study of the Sexual and Reproductive Health Needs and Rights of Adolescents Living with HIV in Lusaka, Zambia.

- A Case Study of Discordant Couples in Abuja, Nigeria.

## Why these groups?

In many countries, the unique and neglected needs of various sub-groups are becoming increasingly apparent as their quality of life is compromised by lack of the services they need. The networks of people living with HIV in the Kenya, Zambia and Nigeria chose to focus their research on the sub-groups identified above (pregnant women living with HIV, adolescents living with HIV, and couples in long-term sero-discordant relationships) because each identified its selected as being among those in greatest need of improved services in their respective countries.

The decision to focus on specific sub-groups rather than on people living with HIV as a whole was made for two reasons. Pragmatically, the resources available to conduct this research were not sufficient to support an in-depth exploration of the diverse unmet SRH needs of the various populations living with HIV. Since the SRH needs of single men, for example,

were likely to differ markedly from those of women with children or adolescents, it was deemed more productive to select one high-priority group and assess its needs in some depth than to attempt to do a broad scan to assess the needs of a diverse population.

Secondly, the networks recognised that, while the data gathered on the needs of adolescents in Zambia, for example, could not be presumed to reflect those of adolescents in Nigeria, there was a good chance that some of the findings from one country might have relevance to the counterpart sub-groups in the other two countries. Thus, the findings of each study hold the promise of having at least preliminary usefulness for all three countries in that they can at least inform efforts to develop subsequent research.

# What did we learn from the studies?

## In Kenya

The National Empowerment Network of PLHIV in Kenya (NEPHAK) started with a document review of existing documents and interviews with policy-makers and service providers. They found that PMTCT is addressed in the National PMTCT guidelines, the ART guidelines and, to some extent, in the Sexual and Reproductive Health guidelines.

Although awareness of these policies is high among policy makers and service providers, it subsequently proved to be virtually non-existent at the community level. The translation of policies into practice was also found to be very uneven.

They then conducted exit interviews and focus group discussions with clients regarding their experiences accessing PMTCT. The findings revealed long waiting periods to see clinical staff, unsatisfactorily short time with staff and group counselling used where individual counselling would have been more helpful, given the sensitivity of the topics addressed. Under-staffing was reported as the primary cause of these deficits. Although PMTCT services are free of charge, financial barriers still inhibit access because of the expense of essential collateral services such as laboratory tests or ultra sound scans that are not free.

Other barriers identified included lack of documented referral services and poor linkages between service providers and the communities served, very limited access to written materials on PMTCT and no access to materials that clients could take home with them.

The findings indicate progress toward the integration of HIV and SRH services, an area identified as a high priority for the Ministry of Health. Most facilities providing PMTCT in Nairobi now also provide contraception (condom, pills and injectables), STI diagnosis and management, treatment of opportunistic infections and ART. But gaps still exist in diagnostic areas (especially CD4 and viral load testing, X-ray, laboratory tests and scans). Inconsistent

access to ARV supplies and drugs for other opportunistic infections also remains a serious systemic weakness. Frequent stock outs were reported to result in many missed opportunities to implement integrated HIV and PMTCT interventions.

## In Nigeria

After desk review, the Network of People Living with HIV/AIDS in Nigeria (NEPWHAN) conducted focus group discussions among participants in long-term sero-discordant, heterosexual relationships to gather information to inform the development of their study survey instrument. They then administered the survey to a larger group of participants recruited from HIV service provider sites and support groups.

Over half (58%) of the participants reported that sexual intimacy had been negatively affected by learning that one partner was HIV positive while the other was negative, and that this was associated with fears of infidelity and/or abandonment. The negative partner's fear of contracting HIV was cited as the primary reason for decreases in sexual intimacy.

Despite this fear, 40% said they never used condoms and 32% used them only occasionally. Nine tenths of the respondents had never received any form of SHR counselling from a health facility, organisation or even within their support groups. Three fourths said their service provider did not offer information on contraception or fertility options to sero-discordant couples.

Requests for information and questions about SRH issues were reportedly not well received by service providers except in the specific area of PMTCT. Most respondents said that service providers offered PMTCT services to pregnant women, as well as information about the benefits and risks of various modes of childbirth.

The study revealed that the health facilities and service providers lack the skills, knowledge and professional preparation they need to handle the specific needs and concerns faced by sero-discordant couples. No respondents were aware of the existence of any service provider offering integrated SRH/HIV services.

## In Zambia

The Network of Zambian People Living with HIV/AIDS (NZP+) also started their work with desk review and then conducted focus group discussions and in-depth interviews with respondents including adolescents living with HIV and their parents and guardians, service providers and policy makers. The findings indicate that policies and guidelines specifically targeting the SRH needs and concerns of adolescents living with HIV are nowhere in evidence.

The HIV-related stigma and discrimination commonly reported by the adolescents interviewed effectively inhibited both their willingness to disclose their HIV status and their uptake of SRH services. Concerns about privacy and confidentiality within the health facility setting also constituted a barrier for adolescents seeking SRH services. Participants reported getting most of their SRH information and advice from their peers. Although the adolescent participants appreciated the minimal SRH information they received at school, they regarded it as inadequate.

The findings suggest that sexually active participants were not the only ones needing improved SRH services. Adolescent participants interviewed who were not sexually active nevertheless commonly expressed confusion regarding their puberty signs and fears regarding infertility in adulthood due to their HIV status. Living with HIV does not hamper adolescents' future aspirations to found families and having biological children. Many of the adolescents in the study are aware that they have the right to do this.

Parents and guardians of adolescents living with HIV reported that they rarely discuss SRH matters with their adolescent children, saying that this was difficult due to restrictive cultural norms regarding discussion of sex and the fact that they felt their own knowledge of SRH issues was insufficient.

# Cross-Cutting Issues and Recommendations

The recommendations produced from the three studies were remarkably consistent, even though they were expressed in differing contexts. They can be divided into two cross-cutting categories: health system strengthening and service delivery and disclosure.

## Health System Strengthening

The Nigerian study states that, "Poor funding and continued neglect over the years have culminated in a Nigerian health care system that is almost moribund and largely staffed by a de-motivated workforce that is frequently insufficiently trained and unprepared to deal with the multiple emerging health issues confronting them." The weakness of the existing health care structures was recognised in all three studies. Recognising that the limited resources were available to remedy this, the study makes the following cross-cutting recommendations:

### Integrate Services

All three studies recommend investment in service integration (rather than the creation or perpetuation of parallel systems) and the engagement of appropriate community resources (particularly in the form of lay personnel) wherever possible.

The Kenya study, for example, recommends the further integration of PMTCT services into reproductive health and child and newborn health services. Both the Kenyan and Nigerian studies recommend integration of HIV, especially HIV testing and education, at all family planning and SRH provider sites and the provision of SRH services by all providers of HIV care, with emphasis in both settings on the dually protective role of male and female condoms.

Integrating adolescent SRH services into HIV services would likely improve their uptake by adolescents living with HIV. Similarly, HIV counselling and testing programs were urged to provide accurate and timely information on HIV discordance and referrals to programs designed to meet the SRH needs of sero-discordant couples – just as many already provide information on PMTCT to pregnant women who test HIV positive.

The studies indicate that these integration efforts have the best chance of success if they are planned in collaboration with the target groups they are designed to serve. So health

facilities committed to providing youth-friendly services, for example, should involve adolescents living with HIV in the planning and delivery of such services.

The failure to integrate such services appropriately results in loss of SRH rights for clients and increased public health risks for communities overall. Each time HIV transmission occurs that could have been prevented by linkage and access to appropriate services (whether it is transmission from parent to child, from one uninformed or untested adolescent to another or from one married partner to the other), individuals suffer and the health care system over all is further burdened.

All study highlight that advocacy efforts aimed at increasing funding for HIV/SRH program must be sustained and that services integration, as well as the expansion of services to rural and underserved communities, must be emphasised.

## Improve Supply Chain Management

Any expansion of services will likely exacerbate the difficulty of assuring access to essential drugs and commodities. The need to strengthen and improve supply chain management was noted in all countries. In tandem with system integration efforts, supply chain systems serving different programs within each country need to be harmonised in order to remedy current, chronic problems with under-stocking and stock outs.

## Train and Deploy Lay Personnel

Ways of expanding the engagement of lay (non-clinically-trained) personnel to extend the reach and capacity of health care systems were proposed. The Kenyan authors proposed that lay trained counsellors (under the supervision of clinical staff) provide psychosocial support and mentoring to the PMTCT clients on disclosure and during hospital delivery, especially with regard to best infant feeding practices. This could reduce the workload of existing clinical staff somewhat and, thus, expand the amount of time they have to spend with each client.

They also note that, once trained, community health workers could assist in monitoring ARV prophylaxis, thus supplementing the monitoring available from clinical staff.

In Nigeria, it was noted that training HIV discordant couples to serve as peer counsellors on the issue would help strengthen intervention programs and PLHIV support group activities.

## Increase Health System Staffing

Even if supplemented with increased support of lay people, the health care systems in all three countries still need more staff, as well as better-trained, equipped and supervised

staff. Survey respondents in all three countries agreed that understaffing in their health care facilities is a root cause of many other problems.

They also noted the need for better managed and documented referral systems. In Kenya, for example, the need for earlier and better-documented referrals of pregnant women to health facilities offering PMTCT was noted.

### Build Laboratory Capacity and Affordability

Insufficient local capacity to conduct diagnostic testing and monitoring was cited as a barrier to care – as was the fact that these services are often available only to those who can pay for them, even when provided in the context of SRH services that are otherwise free. Expanded lab capacity and funding is needed, in tandem with capacity-building training for health care workers on clinical assessment of ART, so as to use expensive laboratory services as effectively as possible.

### Engage in Monitoring, Evaluation and Further Research

Finally, there is a generalised need to strengthen the supportive supervision of health care staff and to evaluate the effectiveness of service delivery systems, specifically in terms of consumer uptake and satisfaction. Conducting regular exit interviews among clients using targeted and integrated services was recommended.

All studies uniformly recognised the limitations of the research they were able to conduct and recommended additional operational research on the needs of the target populations they surveyed and their counterparts in other areas. The Nigerian authors pointed out that this is essential to ensuring that consumers' first-hand insights into the challenges confronting them are used to inform the design of appropriate intervention activities.

## Service delivery and disclosure

In addition to these systemic recommendations, the reports also recommend changes needed in service delivery at the provider and community level. These necessarily start with reducing stigma and increasing accessibility and uptake of HIV testing – two goals that are so closely related that they must be considered together.

### Address Stigma, Encourage Disclosure and Increase HIV testing

The Kenyan study notes that programmes to assist women in accessing HIV testing and then disclosing their HIV status, if positive, need to strengthened. They recommend the adoption

and scale-up of routine HIV testing with an option to 'opt-out'. This, however, must be accompanied by the offer of couples counselling at all health facilities, as well as targeted efforts to help partners and families become more involved in supporting the woman using PMTCT services, her treatment and her infant feeding decisions. The absence of these supports is a primary barrier to women's willingness to access PMTCT services and follow through with them.

The Nigerian and Zambian studies reveal that fear of family ostracism, partner abandonment and community/peer rejection similarly keep adolescents living with HIV and sero-discordant couples from seeking the SRH services they need. Expansion and improvement of services alone will be insufficient if the issues of stigma and fear of disclosure are not addressed.

## Expand and Strengthen Community Engagement

Community actions (organized in collaboration with the health facilities) to reduce stigma around HIV and to promote uptake of HIV testing and prevention were also recommended. These efforts should visibly include community leaders, clinic and/or community based support groups, and the community health workers charged with providing community and home-based health promotion services.

## Provide More and Better Staff Training and Supervision

These studies also document the fact that, in many provider sites, staff simply do not have the training and professional preparation to deal with the SRH needs of the populations surveyed. High quality, non-judgmental counselling and services or referrals to meet identified SRH needs should be readily available in health care facilities.

Study authors agreed that this is a challenge across provider sites. Creating an enabling environment within health facilities where SRH counselling and services can be offered in a non-judgmental and supportive environment will require not only additional training but also effective supervision to assure that problems in attitude and professional behaviour, as well as knowledge deficits, are detected and corrected promptly and effectively.

# Country specific recommendations

While broad consensus was reflected around the above issues, there were two areas in which recommendations emerged in some studies and not others. This may have to do with differences among the focus countries or it may be related to the target populations addressed in each study.

The Kenya study focusing on PMTCT recommended that the existing policy recommendations be more effectively implemented. The Zambian and Nigerian studies, however, advocate the formulation of supportive policies and laws, and using credible evidence-based research to inform the revision of the relevant policies, protocols and laws currently in place. This points to the fact that the existing policies omit mention of the needs of adolescents living with HIV and sero-discordant couples.

Similarly, the need for staff training was particularly noted in Zambia and Nigeria. PMTCT seems to be one area in which provider staff have received training and have some specific knowledge. It is also possible the task of helping to prevent perinatal transmission of HIV does not elicit cultural disapproval, embarrassment, and/or judgmental behaviour among provider staff to the same extent that acknowledging the SRH needs of either adolescents or sero-discordant couples does. This might also explain why the need for training and supervision to improve the professional conduct of staff was less emphasized in the Kenyan report on PMTCT.

# What next?

These three studies have been created to inform both policy development and implementation directly and stimulate advocacy efforts in support of such movement. The process of conducting this research has enabled networks of people living with HIV in Kenya, Nigeria and Zambia to identify appropriate entry points within their counties for policy change. They are now well positioned to initiate advocacy, through those entry points, to propel movement toward operationalising their recommendations. Through the HIV Leadership Through Accountability programme, GNP+ is supporting national networks of people living with HIV to develop evidence-informed advocacy strategies. GNP+ is, simultaneously, using the findings for advocacy on sexual and reproductive health and rights of people living with HIV at global level.


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