



HIV Leadership Through Accountability

**Liaison Meeting of Focal Points from
Networks of People Living with HIV**

Hilton Hotel, Addis Ababa, Ethiopia, 3-4 December 2011

Acronyms

AIDS	Acquired Immune Deficiency Syndrome
AFRICASO	African AIDS Services Organisations
CATAG	Central Africa Treatment Action Group
CS	Civil Society
CSO	Civil Society organisation
CS Platform	National civil society advocacy campaign platform
DFID	(UK Government) Department for International Development
HIV	Human Immunodeficiency Virus
JOTHI	National network of PLHIV in Indonesia
GBP	Great Britain Pound
GNP+	Global Network of People Living with HIV
GTF	Governance and Transparency Fund (of DfID)
HIV	Human Immunodeficiency Virus
ILO	International Labour Organisation
M&E	Monitoring and Evaluation
MANET+	Malawi Network of People Living with HIV/AIDS
MANASO	Malawi Network of AIDS Organisations
MoU	Memorandum of Understanding
MOV	Means of Verification
MSM	Men who have Sex with Men
NACOPHA	National Council of People Living with HIV/AIDS in Tanzania
NAPWA	National Association of People Living with HIV/AIDS in South Africa
NAC	National AIDS Council/Commission
NEP+	Network of Networks of HIV Positives in Ethiopia
NEPHA	National Empowerment Network of People Living with HIV/AIDS in Kenya
NEPWHAN	Network of People Living With HIV/AIDS in Nigeria
Network	National network of PLHIV
NGO	Non-Governmental Organisation
NZP+	Network of Zambian People Living with HIV
PCB	UNAIDS Programme Coordinating Body
PHDP	Positive Health, Dignity and Prevention
PLHIV	People Living with HIV
PUD	People who use drugs
RÉCAP+	Le Réseau Camerounais des Associations de Personnes Vivants avec le VIH (Cameroonian Network of Associations of People Living with HIV)
RNP+	Réseau National des Personnes Vivant avec le VIH/SIDA du Sénégal (Senegalese Network of Associations of People Living with HIV)
SRHR	Sexual and Reproductive Health and Rights
SMART	Specific, Measurable, Attainable, Relevant and Time-bound
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS

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Day One: LTA programme update

The HIV Leadership through Accountability Programme “has empowered many people living with HIV and built our capacity to research and to identify the issues which need advocacy”

Dereje Alemayehu (Executive Director, NEP++)

Welcome

Dereje Alemayehu (NEP+) welcomed the participants to Ethiopia and to ICASA 2011. He thanked GNP+ and the country network delegates for working on LTA, stating that the LTA *“is a good programme, which has empowered many people living with HIV and built our capacity to research and to identify the issues which need advocacy.”* He called on the participants to use ICASA as an *“opportunity to share [the LTA] experience”* and to *“knock on the closed doors of the donor countries who did not fund the Global Fund”* because ***“a country can survive as a system but as human beings we cannot survive without treatment.”*** He noted that in many countries, the treatment is funded by Global Fund and the situation is especially serious for countries that do not receive PEPFAR funds.

Introduction

GNP+ began the meeting and introduced the goals of the two day sessions – to learn from each other’s experiences with the LTA tools and to strategically think about how to use the evidence gathered for advocacy.

Georgina Caswell (GNP+) noted that the evidence gathered with the different LTA tools will help the networks effectively advocate for social justice and access to treatment, among other key issues, even as the financial crisis limits the amount of funding available to core HIV programming. In addition all the sessions, during the meeting, provide an opportunity to further support newer colleagues.

Lessons Learned Session

The participants broke into three small working groups, by sub-region, to discuss the different programmes and tools and to identify and share the networks’ successes and challenges since beginning the LTA programme and to share best practice. Particular attention was paid to providing insight to newer participants who are just beginning the work. The country groupings were as follows: (1) Cameroon, Nigeria, a few from Ethiopia; (2) Zambia, Malawi, and South Africa; and, (3) Tanzania, Kenya, and remaining Ethiopian colleagues. At the end of these

discussions, the group reconvened to hear from each network about lessons learned, successes and challenges, and strategies for moving forward, as outlined below:

MANET+, Malawi

Eddie Banda spoke on behalf of MANET+, the Malawian PLHIV network.

Getting Started

MANET+ began the process at the Nairobi meeting in July 2011. At that time, MANET+ committed to review and sign a Memorandum of Understanding and to identify the steering committee for the LTA programme, develop terms of reference for the steering committee, and identify the focal point for the programme.

After the Nairobi meeting, the MANET+ staff agreed by consensus that the M&E programme officer would be the focal point because he had already served as the programme coordinator for the PLHIV Stigma Index and was familiar with the tools. They also agreed that three other programme officers would each also be in charge of different tools that MANET+ would implement to avoid placing responsibility for all the tools with one person. They did this after learning of the challenges the other countries had faced when only one individual was responsible for the entire LTA programme and that one person would have to struggle to balance the programme needs with their other duties.

Eddie noted that the staff spent a good amount of time initially reading the materials, reaching out to GNP+, and discussing the concept behind the LTA programme before everyone felt ready to run with it. The support of GNP+ was invaluable during that early stage. Having already just completed the PLHIV Stigma Index national roll out, MANET+ has worked with GNP+ to decide upon the way forward with the findings and recommendations and developed a concept note for further action.

For the other evidence gathering tools, MANET+ allocated responsibility as follows: SRHR Guidance package is the responsibility of the programme officer responsible for PHDP; Human Rights Count! is the responsibility of the programme officer responsible for gender mainstreaming; the programme officer responsible for research and advocacy took responsibility for the Global Criminalization Scan and the GIPA report card is the responsibility of programme officer doing research and advocacy; and finally, the stigma index remained the responsibility of the M&E programme officer, who will also be responsible for the overall LTA programme.

Eddie noted that they had technical support from GNP+ to complete the tracking tool, workplan, and budget. GNP+ also supported MANET+ as they held their first activities, identified what needed, and bought appropriate equipment (scanner).

Where Are MANET+ Now

MANET+ is implementing the first tool – they held a planning meeting for roll out of the GIPA report card, identified data collectors, identified and hired a consultant who trained the data collectors, and currently in the process of collecting the data.

As part of their process, MANET+ held a civil society meeting to introduce the LTA programme and discuss with their partners the different tools and solicited input from civil society in relation to who should be included in the interviews, which has helped them to identify the key organisations to interview.

Challenges

Although there are no major challenges yet, Eddie explained that they anticipate delays in implementation because they gave themselves too little time to do data collection. The data collectors have to keep reminding people to read the GIPA questionnaire, the interviewers have had trouble accessing individuals to interview. They have found that people do not want to take time to sit in an interview and prefer to fill out the questionnaire on their own time but that leads to delays and missed opportunities as the collectors often have to be there to guide them through the questionnaire and explain it to them.

Also, they are still waiting for a review of the PLHIV Stigma Index report from GNP+.

Successes

The initial funds were disbursed timely by GNP+; the programme planning went well; the internal communication and coordination is going well; and they held a successful press briefing to explain the LTA programme to stakeholders. As a result, UNAIDS already pledged to support them to continue activities and MANET+ have received positive media attention.

RNP+, Senegal

Calorine Kenkem (RéCAP+) reported, as the cross-country technical support provider to the Senegalese network, because Ibrahima Ba (RNP+) was unavailable due to a delayed flight.

Where Are RNP+ Now

RNP+ has moved forward quickly with the LTA programme. Immediately following the Nairobi meeting, RNP+ shared the Nairobi Liaison meeting report within RNP+: chose Ibrahima as the LTA programme Focal Point; discussed how to work with the different tools; chose the officers for the tools; held a meeting to complete the workplan; discussed the programme with key partners and met with the consultant for the GIPA report card. They also have met with some research groups who will support them in the roll out of the PLHIV Stigma Index and selected the interviewer for the GIPA report card. They are currently working on terms of reference for

the training for GIPA report cards. In addition RNP+ have identified persons for the steering committee and held the first steering committee meeting last week.

Challenges

It has not been easy to find a consultant for the PLHIV Stigma Index, they reached out to a lot of organizations but some of them were not available and some assumed there would be a lot of money and so demanded high fees. They are still bargaining with potential consultants. They have not yet applied for ethical approval for the PLHIV Stigma Index because the focal point tried to do it on his own, which took some time, and he is now working with a research institute to complete the process.

NACOPHA, Tanzania

Lillianne presented on behalf of NACOPHA, the Tanzanian PLHIV network. NACOPHA, an umbrella of Tanzanian PLHIV networks, has been going through a period of re-organisation. They currently have 4 officers and are looking for a capacity building officer. There are also quite a few volunteers, most of whom are college and university students who are living with HIV. This is quite exciting as they are a new generation of scholars who are coming out and living openly with HIV.

Where Are NACOPHA Now?

They have not yet begun to work on any of the tools except the PLHIV Stigma Index. For the Stigma Index, they have approached the Tanzania University for Health as a potential research partner and they are trying to get steering committee selected. For the steering committee, they are reaching out to legal focal points, UNAIDS, people living with HIV, human rights groups, and others. They will have a technical working group soon.

Challenges

The ethical clearance originally submitted to the university has expired and they are going to have to renew it. This is their priority action!

In addition, managing the different member networks is a challenge because the networks are used to having their own support and without it they are all coming to the umbrella organization with their needs. The networks are still learning how to work well together. Tanzania is a huge country, and has one focal person in each district who is living with HIV who is supposed to be supported by the district council but not all district councils doing it.

NACOPHA is depending a great deal at the moment on GNP+ and Rahab (NEPHAK) for support with the tools, and developing a workplan and budget. In particular, after learning about the work NEPHAK has done with the informal work sector in Kenya, Lillianne explained that they also have trouble getting people to devote hours to formal trainings and would like to learn

from the NEPHAK model where they used performance art and performers to reach employers in the informal sector (markets, small shops, etc.) with messages.

NEP+, Ethiopia

Wubayehu (NEP+) is the focal point for the Ethiopian civil society campaign platform, she presented on behalf of NEP+.

Where Are NEP+ Now?

They have completed the PLHIV Stigma Index. The key findings to date include the following: (1) 95% of women living with HIV and 93% of men living with HIV are living below the extreme poverty level; (2) people living with HIV are denied family planning and sexual and reproductive health services because of their sero-status; (3) high levels of vertical transmission of HIV; (4) people living with HIV experience human rights violations because of their HIV status; (5) people living with HIV have better confidence in health personnel than any other group of service providers; (6) people living with HIV are stigmatized differently in different areas and places.

Successes

NEP+ has finalized all the LTA tools. As a result, they have developed a sense of ownership, developed their own capacity, and developed partnerships with partners inside and outside Ethiopia. They have assigned an LTA country project support officer.

Challenges

There is insufficient budget linked to the LTA programme, and there was a delay in the transfer of funds for all tools, except the Stigma Index. Ethiopia is a big country and needed a lot of funding in order to get a representative sample. In addition the tracking tool/reporting templates were not manageable, and took much too much time to complete. The LTA programme did not start on time, largely because the programme implementation was started when NEP+ was heavily committed to Global Fund work, and responsibility for it shifted from one Focal Point to another Focal Point. There was an initial experience gap but NEP+ has learned by doing it and feel that they are now increasingly capable of conducting research.

Way Forward

NEP+ will map the civil society organizations for a national platform before establishing a national platform to develop implementation action plans with a strong M&E system.

NAPWA, South Africa

Mluleki Zazini presented on behalf of NAPWA.

Where They Are Now?

NAPWA has finalised the Human Rights Count! report and presented the finding and recommendations, together with summaries of the other four tools, to the Eastern Cape civil society campaign platform. In addition, Human Rights Count! is being scaled-up and supported by UNDP for further research across the Eastern Cape and Gauteng provinces. NAPWA has identified focal points and sent invitation letters for a steering committee and UNDP has transferred the first instalment so that NAPWA can start. They are still struggling to get a consultant, however, for Human Rights Count! scale up due to the limited resources.

For the PLHIV Stigma Index, NAPWA conducted training for interviewers and within a week NAPWA identified that most of the interviewers were making mistakes so NAPWA decided to do a follow up workshop for the interviewers. NAPWA requested Kenly Sikwese (cross country technical support) to come assist them with this additional training. The trainers told NAPWA that the interviewers improved their understanding and skills after the workshop¹ and they are now doing data collection.

The national scale up for the PLHIV Stigma Index is moving forward, following on from the work in OR Tambo District in the Eastern Cape. The national steering group has been established, supported by SANAC (South African AIDS Council), but they are waiting for results from the current study in the Eastern Cape.

For both the GIPA Report Card and the SRHR tool, the interviews have been conducted and the consultant is writing the reports. The reports were supposed to be complete by now but the consultant appears to be overwhelmed having to write two reports to write.

For the Global Criminalization Scan, NAPWA's partners didn't think the issue of criminalisation was important so, NAPWA changed its approach from asking partners to complete questionnaires to desk researching the information in relation to criminalization. NAPWA have developed a draft report and are currently waiting for the final version from GNP+.

Successes

The South Africa National Strategy Plan for HIV and AIDS (2012 – 2016) was launched on World AIDS Day 2012 and the PLHIV Stigma Index is included a part of it guidelines. UNAIDS and other partners, were interested in having the PLHIV Stigma Index included in the national strategy and pushed for its inclusion with the Ministry of Health².

¹ The group agreed that this is a very good lesson from the South African model and others might want to do a "pilot" like this in order to identify the problems. Eddie noted that in Malawi, they had a similar approach where they had a training for the data collectors and then called them back together after a short time to allow them to ask questions that might not have occurred to them during the first training.

² This was a good reminder to the group that it is in UNAIDS interest to have the Stigma Index used and publicized as they are a partner and UNAIDS PCB has voted to support the Stigma Index rollout. UNAIDS has a budget for the Stigma Index and it is a useful tool for country's to incorporate into their M&E so networks should feel comfortable seeking UNAIDS support when rolling out the Stigma Index in country.

NZP+, Zambia

Kuniyima Banda presented on behalf of NZP+.

NZP+ is already using the evidence gathered in advocacy. For example, NZP+ used it to influence the National AIDS Strategic Framework and worked with the Zambia Federation of Employers to incorporate both the PLHIV Stigma Index and the GIPA Report Card into assessment tools for their members. They are also using the Stigma Index in developing the National Workplace Policy (ILO, Trade Unions, and the Zambia Federation of employers, and NZP+).

NZP+ has also secured funding to develop PHDP guidelines and GIPA guidelines because there is confusion about how PHDP is different from GIPA. NZP+ is also using the evidence for reviewing the national gender policy because gender inequality was raised as an issue during the Stigma Index. Currently, the gender policy doesn't say anything about HIV so it is a good opportunity to work on the issue.

NZP+ presented the PHDP concept to the National Prevention Convention and as a result they have support from 2 organizations to further develop the adult and adolescence SRH programme plus one other programme (to be determined). UNESCO intends to support SRHR for adolescents living with HIV, based on the SRHR study.

NZP+ is also working with CATHOD to roll out the PLHIV Stigma Index with religious leaders. They trained Catholic in data collection, for example, and implemented two surveys, the first for people living with HIV and the second for people affected by HIV, particularly, priests, pastors, nuns, and doctors in the area. Data collection began at the end of November 2011 and is happening in Kenya and Ethiopia as well. Priests living with HIV are interviewing other priests, ministers, and other pastors.

NEPHAK, Kenya

Rahab Mwaniki (NEPHAK) reported. NEPHAK is also involved with the project to capture stigma in religious settings. The CATHOD paid for a 3 country study (Kenya, Ethiopia, and Zambia).

Updates

Workplace policy: NEPHAK has been creatively engaging the workplace, including the informal sector, using humour and street performers.

Successes

NEPHAK is secretariat to All Parliamentary Group on HIV issues. This means that all civil society issues are channelled through NEPHAK, who then arranges meetings with the Parliamentarians. NEPHAK also sits on the technical working group for PMTCT, which is in the process of developing a country action plan.

October 2010 – NEPHAK with support from joint UNAIDS team convened a women living with HIV meeting in order to recognize the women who have done community work, document what they have accomplished, and then publish and circulate the report.

RéCAP+, Cameroon

The network was created in 2000 and they now have 86 associations in ten regions of Cameroon.

Where They Are Now

Global Criminalization Scan – RéCAP+'s objective is to understand the context and impact of criminalization on universal access, they have finished the implementation of the tool and the consultant has finished the final report.

GIPA Report Card – RéCAP+ hoped to learn if people living with HIV are deeply involved in the processes concerning their lives, they have finished and have the result and are now trying to disseminate the results and decide how to use the report card for advocacy.

Human Rights Count! – RéCAP+ is collecting evidence.

SRH tool – RéCAP+ have not done it because they had decided to focus on the needs of MSM and due to the extremely intolerant climate towards MSM (individuals have been sent to prison) the consultant who was helping said he wouldn't help anymore.

Stigma Index – RéCAP+ have already finished the interviews, with a total of 1300 questionnaires, and are now only awaiting input from GNP+ into the final report before disseminating results. These results included a pattern of stigmatization of people living with HIV in both the healthplace and workplace. For example, 50% of people said they had faced stigmatization in the workplace and about 20% of people had already lost a job or been refused a job because of their HIV status. Another striking result was that less than 20% of those interviewed imagine that a law could protect their rights.

Moving Forward

RéCAP+ have already obtained significant result from the LTA tools and they plan to use it well, to share results with broader civil society, and to work with civil society to lobby the government to address the evidence.

NEPWHAN, Nigeria

Peter Nweke shared that so far the LTA programme is running smoothly. They have been able to conduct all the studies. They submitted the final report on the PLHIV Stigma Index at the end of November and are beginning to think about dissemination efforts. They had initially agreed to do normal dissemination but they now think they need to be more creative to achieve more. They have decided a visual report will prompt immediate action. One of the challenges with a

printed report is that people don't have time to really analyze or understand the reports. So they have spoken with TV producers and are trying to mobilize the resources to do a short video. They believe a video will allow a wider reach because they can air it on TV.

Group Discussion

The group discussed the problems Charles had raised in reaching out to MSM where there are punitive laws and cultural intolerance. Rahab noted that in Kenya it is illegal to do prevention work among MSM or sex workers, so groups who work with these key populations register as other entities and do the work anyway. Charles noted that in Cameroon, they had decided it was better to persist to overturn homophobic laws but it was challenging. Peter shared that it is the same in Nigeria and that the problem with being too confrontational is that the government may respond with force so groups in Nigeria will also change the name of the project to hide it and be strategic. At the same time, MSM who are living with HIV want a space to talk, an organization, because the networks are not meeting their needs.

DAY TWO: AIDS2012 & LIVING2012

On the second day, the group focused on lessons learned from the 2010 International AIDS Conference and began to brainstorm how to maximize the impact and participation of people living with HIV at the 2012 conference. Rahab shared her experiences and insight from attending the 2010 Conference and Marsel gave an overview of the application process and timeline for both Living 2012 and the 2012 International AIDS Conference, which will be in Washington, DC in July 2012. The group then broke into small groups to brainstorm possible abstracts.

Abstracts for AIDS2012

Group 1 (Kenya, Nigeria, and Ethiopia) proposed the following abstracts:

- 1) Country leadership – Tanzania, Nigeria, Ethiopia, Kenya – GIPA and Stigma Index
- 2) Stigma Index with Religious leaders – Zambia (done), Kenya (ongoing), Ethiopia (ongoing)
- 3) Abstract linking Human Rights Count and the law – Nigeria and Kenya

Group 2 (South Africa, Malawi, and Zambia) proposed the following:

- 1) Three-country abstract on the Stigma Index focusing on internal stigma and comparing data from three countries
- 2) An abstract focusing on the reason to test and why people do or do not delay or seek out testing
- 3) An abstract on GIPA in the workplace, in particular, the private sector, comparing three country GIPA report cards – South Africa, Malawi, and Zambia

Group 3 (Senegal and Cameroon) proposed abstracts on:

- 1) the reduction of stigma and discrimination in the health center,
- 2) the impact of punitive laws against people living with HIV, and

- 3) methods to ensure GIPA in broader NGOs and civil society.

Two Things in Two Weeks

All the participants agreed to:

- 1) Register for AIDS2012 and apply for a scholarship
- 2) Provide a written report (150-200 words) on how they used or presented evidence gathered or knowledge gained from their LTA work at ICASA 2011



The LTA Focal Points - Meeting in Addis Ababa, December 2011

Appendices:

LTA Focal Point Liaison Meeting Agenda

Saturday 3 December : LTA Programme Review

The objectives of the day are:

- To re-engage with one another and agree on objectives and the agenda of the meeting;
- To assist each other with programme planning and implementation and next steps;
- To review key evidence results and recommendations and how these will be used for advocacy;
- To explore the overall LTA programme M&E;
- To organise ourselves around advocacy opportunities at ICASA 2011.

Time	Item	Facilitators
08.45	Welcome (<i>Dereje Alemayehu, NEP++</i>) and Logistics (<i>Marsel Kuzyakov, GNP+</i>)	Tigabe Asres (NEP++)
09.00	Session on current status of programme planning and implementation (three sub-region working groups discussing current successes, challenges and next steps)	
11.00	Coffee	
11.15	Presentations on status of programme planning and implementation – 5 minute presentations and 10 minute discussion (MANET+, RNP+ & NACOPHA)	
12.00	Discussions to clarify any programme issues and input into next steps (All)	
12.30	Lunch	
13.30	Challenges, successes, key findings from Round 1 and 2 countries and how this evidence will be used in advocacy – 5 minute presentations and 10 minute discussion (NEP++, NAPWA, RéCAP+, NEP+HAK, NEP+WHAN & NZP+)	Kunyima Banda, (NZP+)
15.00	Discussion about LTA M&E based on findings of baseline data analysis (All)	
15.30	Tea	
15.45	Advocacy opportunities at ICASA2012 (Georgina Caswell, GNP+)	
16.15	Wrap up Day 1	
16.30	Close	

Sunday 4 December: Towards LIVING2012 and AIDS2012

The objectives of the day are:

- To familiarise PLHIV Networks with the application processes and deadlines in relation to AIDS2012 to be held in Washington DC, USA 22-27 July 2012
- To familiarise PLHIV Networks with the LIVING2012 process
- To brainstorm on key priorities on the way to LIVING2012 and beyond
- To agree on immediate next steps

Time	Item	Facilitators
09.00	Recap Day 1 (Peter Nweke, NEP+WHAN) and Introduce Day 2 (Marsel Kuzyakov, GNP+)	Peter Nweke (NEP+WHAN)
09.15	AIDS2012 conference at a glance (Marsel Kuzyakov, GNP+ to present, Rahab Mwaniki, NEP+HAK to share experience from AIDS2010)	
09.45	How to create a conference profile, apply for a scholarship, submit an abstract (Marsel Kuzyakov, GNP+ and Rahab Mwaniki, NEP+HAK)	
10.15	Discussion on the way forward for abstracts: themes, timelines, collaborations and capturing the process (All)	
11.00	Coffee	
11.15	LIVING2012: history, format and consultative process overview (Marsel Kuzyakov, GNP+)	
11.45	Consultation for LIVING2012 (consultation format tbd)	
12.30	Two Things in Two Weeks and Wrap-up Day 2	
13.00	Lunch	