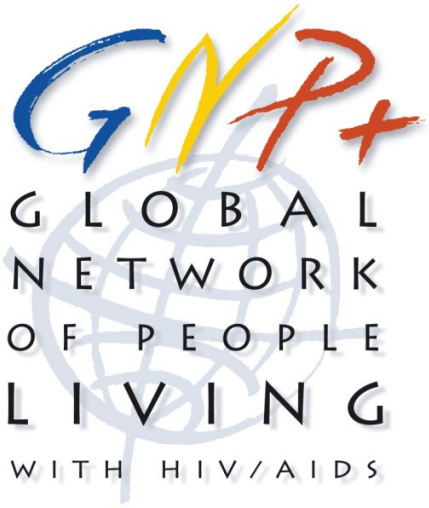

GIPA REPORT CARD

PILOT PHASE REPORT

Kenya, India, Lesotho, and Trinidad and Tobago

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Suggested citation: GNP+. 2008. *GIPA Report Card Pilot Phase Report: Kenya, India, Lesotho, and Trinidad and Tobago.* Amsterdam, GNP+.

Acknowledgements

Christoforos Mallouris, Tanne de Goei, Kate Thomson, Dawn Foderingham, Yolanda Simon, Mike Angaga, Rodrigo Pascal, Andrew Doupe, Erasmus Morah, Jacqueline Makokha, Henry Tabifor, Anand Timari, Denis Broun, the Asia Pacific Network of People Living with HIV (APN+), the Caribbean Regional Network of People Living with HIV/AIDS (CRN+), the Delhi Network of Positive People (DNP+), the Network of African People Living with HIV (NAP+), Community Action Resource (CARe), the International Community of Women Living with HIV/AIDS (ICW) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) and many thanks to all the people living with HIV who shared their experiences and stories in order to make this report possible.

The GIPA Report Card pilot was financially supported by UNAIDS.

Contents

List of Acronyms

APN+	Asia-Pacific Network of People Living with HIV/AIDS
ART	Antiretroviral Therapy
ARV	Antiretroviral
AZT	Azidothymidine
CARe	Community Action Resource, Trinidad & Tobago
CCC	Community Care Centers, India
CCM	Country Coordinating Mechanism
CRN+	Caribbean Regional Network of People Living with HIV/AIDS
CSO	Civil Society Organisation
DNP+	Delhi Network of Positive People, India
GDP	Gross Domestic Product
GNP+	Global Network of People Living with HIV/AIDS
ICW	International Community of Women Living with HIV/AIDS
ILO	International Labour Organisation
INGO	Implementing NGO (Non-governmental Organisation)
INP+	Indian Network of People living with HIV/AIDS
ITPC	International Treatment Preparedness Coalition
KNASP	Kenyan National HIV & AIDS Strategic Plan
LENEPWHA	Lesotho Network of People Living with HIV/AIDS
MNP+	Manipur Network of Positive People, India
NAC	National AIDS Commission, Lesotho
NACC	National AIDS Control Council, Kenya
NACO	National AIDS Control Organisation, India
NACP-III	National AIDS Control Programme phase III, India
NAP+	Network of African People Living with HIV
NCA	National Council on AIDS, India
NGO	Non-Governmental Organisation
NSP	National HIV & AIDS Strategic Plan 2006-2011, Lesotho
PLHIV	People Living with HIV
PMTCT	Prevention of Mother-To-Child Transmission
PWN+	Positive Women Network, India
SACS	State AIDS Control Societies, India
SIP+	South India Positive Network Chennai, India
SRH	Sexual and Reproductive Health
TOWA	Total War Against AIDS, Kenya
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS
UPSACS	Uttar Pradesh State AIDS Control Society, India

EXECUTIVE SUMMARY

About the GIPA Principle

The Greater Involvement of People Living with HIV and AIDS (GIPA) is a principle that aims to realise the rights and responsibilities of people living with HIV to self-determination and meaningful participation in decision-making processes that affect their lives. By promoting and strengthening the involvement of people living with HIV (PLHIV), the GIPA principle enhances the quality and effectiveness of HIV responses.

GIPA Report Card Objectives

The GIPA Report Card is an advocacy tool, which aims to increase and improve the programmatic, policy and funding actions taken to realize the greater involvement of people living with HIV in a country's HIV response. The objectives of the GIPA Report Card are to:

- Provide information on the current level of application of the GIPA principle, which will serve as a baseline against which future application of the GIPA principle can be measured;
- Hold governments, NGOs, United Nations agencies, donors, organizations of PLHIV and other stakeholders accountable to their commitments relating to the application of the GIPA principle;
- Increase and improve the meaningful participation of PLHIV in different sectors within the broader national response to the HIV epidemic in a country;
- Assist in developing indicators to monitor and evaluate the quality and impact of PLHIV engagement; and
- Provide follow-up recommendations to enhance stakeholders' (governments, NGOs, United Nations agencies, donors, organizations of PLHIV) identification of opportunities and entry points for the application of the GIPA principle within their organization or institutions and in their policies and programmes, including cost estimates.

GIPA Report Card PILOT Objectives

The pilot was envisioned as a testing phase for the tool, provide preliminary data, and to better understand the feasibility of measuring how and to what extent the GIPA principle is applied through the use of a report card questionnaire. The pilot phase was deliberately designed to be limited in scope, with future phases to be further developed.
The objectives of the pilot phase of implementation are:

- Implement the GIPA Report Card in 4 (four) countries and provide results using pilot questionnaire.

- Test the feasibility of the GIPA Report Card, i.e. can we measure what the GIPA Report Card is meant to measure?
- Document lessons learnt in country implementation: what worked and what did not?
- Evaluate the GIPA Report Card tool, looking for areas of improvement and to ensure effectiveness toward further phases.
- Provide details on success factors for future implementation of the GIPA Report Card.

This report does not aim to focus on the application of the GIPA principle in countries, although there are country specific results included. Rather, this report is primarily a discussion of the GIPA Report Card questionnaire tool and how to ensure its effectiveness in further roll-out. Findings on the pilot process and recommendations derived from lessons-learnt throughout the implementation of the pilot are included to assist with future phases of the GIPA Report Card; in 2009 – 2010 GNP+ plans to facilitate the implementation of the GIPA Report Card in 10 countries. Overall, the GIPA Report Card questionnaire tool garnered valuable information and was able to provide a picture of if, how, and in what ways the GIPA principle is being acted upon in the pilot countries.

A total of 47 interviews were conducted with 11 in Kenya, 12 in Lesotho, 12 in India, and 12 in Trinidad and Tobago. 39 of the respondents are PLHIV who represented a diverse sample including representatives of PLHIV networks, staff in government ministries and development agencies, staff and volunteers in CSOs and also representatives on CCMs. Those respondents not living with HIV were UNAIDS Country Coordinators (or other where not possible), and a representative of the national AIDS coordinating body in the countries.

GIPA REPORT CARD IMPLEMENTATION PROCESS FINDINGS

Despite a number of logistical challenges, overall, the pilot of the GIPA Report Card succeeded in implementing the GIPA Report Card in 4 countries and provided results using the pilot questionnaire. Initial pilot goals were to test the feasibility of the GIPA Report Card; document lessons learnt on country implementation; and evaluate the GIPA Report Card questionnaire tool focusing on improvement and effectiveness toward further phases and to provide details on success factors for future implementation of the GIPA Report Card.

Implementation was coordinated through GNP+ who contracted Alex McClelland, based in Canada to project manage the country pilots. 5 country consultants were hired who oversaw the implementation of the GIPA Report Card in their countries. Country consultants were selected with support from regional and national PLHIV networks and in some cases UNAIDS country offices as well. The following are condensed findings on the process in the countries studied as collected from all the pilot consultants:

PILOT LOGISTICS

- Initially it was very challenging to identify consultants living with HIV with time, capacity and access to appropriate infrastructure (i.e. internet, phone etc.) to facilitate pilot implementation.
- In some cases, awareness from partners in-country regarding the GIPA Report Card process was limited. This caused some communication problems, delays and lack of responses.
- Working with one consultant per country was ideal; in Trinidad & Tobago confusion and communication issues occurred often and were mainly caused due to working with two consultants, who completed two different reports.
- There were a large number of responses from PLHIV, and national AIDS coordinating bodies were also very responsive when contacted by the consultants to participate in the interviews.

RESEARCH CAPACITY

- An outcome identified by the country consultants as a result of implementing the pilot, was that they developed and built upon skills in interviewing and implementing a research project.
- Developing the final country GIPA Report Card out of the questionnaire results was a challenge for the country consultants who identified a difficulty in summarizing responses and deriving conclusions based on the data. Initial reports lacked detail captured in the interviews, and were also lacking comprehensive data analysis. This resulted in all of the reports being co-written by the project manager who reviewed all the data.
- In some cases, the country reports were inaccurate and did not reflect what was described in the interviews; consultants sometimes presented their own opinions in their reports instead of conclusions that should have been based on what was in the interview data.

KNOWLEDGE OF THE GIPA PRINCIPLE

One major finding throughout the pilot process was the overall lack of knowledge regarding the concept of the GIPA principle among respondents, especially among the PLHIV interviewed. Many respondents had various understandings of GIPA, and a large number of respondents had no knowledge of the principle at all. Most of the country consultants had to spend time orienting interviewees to the meaning of GIPA, as explained by consultant Ellen Scout of Lesotho: *"I had to have a meeting of a few PLHIV in Nyeri to clarify issues on the questionnaires as the one assigned to answer did not really understand what GIPA meant and thus could not contextualise."*

This posed a challenge for collecting data, as many respondents needed information, definitions, orientation and other support to complete the questionnaire. Loon Gangte, country consultant for India provided the following comment based on his observations during the interview process:

"My personal comment is that when we talk GIPA a meaningful/effective GIPA, we need to clearly define and understand "representative" and "communication". If I represent my state or my country in a certain committee at the state/national level, I must take effort to consult and get inputs from my community what are the issues they want to flagged or push, then after the meeting I must make equal effort to disseminate information of the outcome of the meeting. And also I felt that often times we the community/network doesn't take effort to choose/elect the right representative for a certain committee or meeting, it's often at discretionary of a certain individual."

Country consultants identified that through the interview process they felt they built awareness and knowledge among the PLHIV that were interviewed regarding the GIPA principle.

Country consultants also identified that the practice of doing the GIPA Report Card meant that organisations such as the UN, governments and PLHIV networks now know that someone is closely watching and monitoring what is and is not being implemented.

IMPLEMENTATION METHODS

- Over the course of the pilot implementation various methods of collecting data in the questionnaires were used: one-on-one interviews, small group interviews, and sending the questionnaire via email. The most effective method in gathering data was one-on-one interviews, during which the consultant was present to guide the respondent through the questionnaire and ensure that comments were captured.
- Receiving completed questionnaires electronically ensured the best way to collect and analyze data, as with handwritten responses illegibility was an issue. Additionally, emailing the file in PDF format to interviewees raised difficulties, as it was not user-friendly for inputting responses.

GIPA REPORT CARD TOOL FINDINGS

A primary objective of the pilot was to evaluate the effectiveness of the GIPA Report Card questionnaire tool itself, i.e. can we measure what the GIPA Report Card is meant to measure in the questionnaire that was used? The pilot GIPA Report Card results do provide an illustrative picture of how GIPA practice and policy implementation is or is not taking place in the countries examined.

The first objective of the GIPA Report Card tool was to provide information on current application of the GIPA principle, which can then serve as a baseline against which future GIPA implementation can be measured. The GIPA Report Card tool succeeded in meeting this primary objective, however there were a number of challenges which should be addressed in order to make the advocacy tool as effective as possible. When asked if the GIPA Report Card could actually measure how GIPA was being applied, all 5 consultants in Kenya, Trinidad and Tobago, Lesotho and India said "yes", but that much more work was needed to build a greater understanding of the GIPA principle first among those being interviewed. The following are the key issues which arose regarding the GIPA Report Card questionnaire tool throughout the pilot process:

- The format of the GIPA Report Card was a challenge in gathering qualitative data. If detailed information was not provided, then there was no context to the checked-off responses, making it very difficult to derive conclusions from just the check boxes.

- The GIPA Report Card assumed previous knowledge so if respondents were unaware of certain commitments or policies addressed in the questionnaire then they were not able to provide responses.

- There were no other ways to gather data, or to translate local experience into relevance on a larger scale. Often, many respondents had state level experience, but not national level experience, however the questionnaire focused only on the national level. It was often identified that there were missed opportunities to gather input regarding regional or state policy and the application of the GIPA principle in practice and policy.

- The language used in the questionnaire was often identified as difficult, too wordy and overly complicated by many respondents. In the face-to-face interviews, questions often had to be posed numerous ways by the consultants for the respondents to understand the desired intent. There were also a number of grammatical errors in the card which caused confusion.

- The questions on universal access, gender, poverty, sexual reproductive health and rights (SRHR), and psychosocial factors garnered valuable information, but these sections lacked an explanation or explicit connection to the GIPA principle and posed some confusion.

- The country consultants found summarizing narrative sections of the questionnaire results to be a challenge. A great deal of support was needed from the project manager to complete the data synthesis and final country reports.

- There were varied methods of filling out the questionnaire, either by hand or electronically, and either by the consultants or by the respondent. Overall, having questions filled-out electronically assists with reporting/legibility of answers, those that were handwritten were difficult to transcribe. It was difficult to discern if consultant or respondent filled-out questionnaires had an impact on the responses.

GIPA REPORT CARD COUNTRY FINDINGS

A total of 47 interviews were conducted with 12 in Kenya, 11 in Lesotho, 12 in India, and 12 in Trinidad and Tobago. 39 of the respondents are PLHIV, who represented a diverse sample including representatives of PLHIV networks, staff in government ministries and development agencies, staff and volunteers in CSOs and also representatives on CCMs. Those respondents interviewed who were not living with HIV were UNAIDS Country Coordinators (or other UNAIDS representative, where not possible), and a representative of the national AIDS coordinating body in each country.

There is no intention at this stage of the GIPA Report Card to compare countries or analyze differences between them in regards to the application of GIPA principle through practice or activities. What are presented in this report are general themes that arose throughout all four country reports. The GIPA Report Card explored the application of the GIPA principle at institutional, organisational and individual levels, including understanding barriers and opportunities for engagement, involvement in policy development and country application of the GIPA principle in key thematic areas.

Although many PLHIV respondents in the 4 pilot countries addressed progress in levels of participation, involvement is still often described as tokenistic and a majority of PLHIV respondents do not feel that the application of the GIPA principle is being adequately addressed, implemented, monitored or funded in their countries. The following below is a compilation of results from all countries and all interviews, collecting commonalities, addressed gaps and key issues.

"When a policy is developed, PLHIV networks are involved in a consultation meeting, but their voices are not taken or heard, only for the sake of involvement are they invited"- Male PLHIV, India

"Most PLHIV are paid "tokens" or they are viewed as volunteers, not facilitators"-Female PLHIV, Lesotho

One important finding is that the application of the GIPA principle is included and indicated in national, regional and organisational policy documents as a guiding principle (national AIDS plans,

implementation documents, strategic plans, and by-laws). In policy, the benefits and rational for the application of the GIPA principle are often acknowledged, but respondents feel that it is not adequately translated programmatically, and as a result the application of the GIPA principle is not often directly budgeted for. A majority of the pilot countries national AIDS programmes noted that PLHIV were consulted in the development of national HIV policies, and in most cases PLHIV networks noted the same.

Some national AIDS coordinating bodies' held a view when interviewed during the GIPA Report Card process that if PLHIV networks are funded, then the application of the GIPA principle is taken care of. For example, in Lesotho when asked about GIPA being adequately addressed in the Lesotho's National HIV/AIDS Strategic Plan, the representative of the National AIDS Commission responded *"LENEPWHA is fully funded to address GIPA issues".*

Often by national AIDS coordinating bodies, the implementation of GIPA was seen solely as an employment provision and as a guiding principle in policy documents. A number of countries also employed PLHIV in 'GIPA positions'. One of the PLHIV interviewed for the Report Card employed by the government in such a position in Kenya indicated that she is only there as an example for others, her skills are not utilized as a technical officer and often she is only asked to present her "story". In India, the national AIDS plan mandates PLHIV 'GIPA coordinators' in 21 states. While this was hailed by a number of those interviewed in India, others were cautious and addressed the need for more training and greater support for those staff, as it was addressed that some of these mandated PLHIV positions were being held by people not living with HIV.

Multiple barriers to achieving the greater involvement of PLHIV were identified by all 47 respondents including stigma and discrimination, which were identified overwhelmingly. Respondents very often identified poverty, low level skills and lack of confidence in PLHIV organizations as a barrier to the application of the GIPA principle.

A majority of the pilot countries were in the process of enacting anti-discrimination policies or legislation and in some cases had mechanisms in place to address instances of discrimination, such as in Trinidad and Tobago which has a Human Rights Desk that acts as an ombudsperson.

A key issue which arose, often in relation to the respondents, and was identified as barriers to the meaningful involvement of PLHIV was the lack of knowledge regarding what the GIPA principle is and the role that PLHIV can and should play in the HIV response. PLHIV not affiliated with PLHIV networks had significantly less knowledge about the GIPA principle, and PLHIV not engaged at a national level had very little knowledge of the GIPA principle. A number of PLHIV respondents, who were not associated with PLHIV networks, expressed that they felt alienated from the GIPA principle and that it seemed to be applied only for those in the PLHIV networks. For some of the respondents, the first time they had heard about the GIPA principle was through the Report Card interview, regardless of whether they were in a PLHIV network. In other words, GIPA was seen as a project and activities but not an underlying principle with shared responsibility for application.

Another barrier contributing to the involvement of PLHIV was appropriate remuneration, as a majority of PLHIV respondents felt that they are not adequately remunerated for their participation in the HIV response. One PLHIV female respondent from Kenya noted *"PLHIV are not paid for their involvement and it is deemed part of their contribution to the national cause".*

Multiple opportunities for PLHIV involvement were identified across the 4 countries including involvement in national policy development, engagement of PLHIV in monitoring and evaluation, and participation in networks of PLHIV. Most countries identified training opportunities for PLHIV.

Other issues covered in the GIPA Report Card look at a supportive enabling environment which could support the greater involvement of PLHIV including universal access, poverty reduction strategies, SRHR, psychosocial support. Findings on these questions can be found in the country reports included in this report.

BACKGROUND

The need for developing a GIPA Report Card was identified at a Think Tank Meeting in 2005, which brought together a small group of people living with HIV in their personnel capacities to review the current status of the global people living with HIV movement and to make recommendations on how it could be revitalized, with an emphasis on effective support to HIV-positive people in their countries[1].

The process for developing this GIPA Report Card involved a literature review of available documents; telephone interviews with male and female people living with HIV who are either working in organizations and networks of people living with HIV, or for nongovernmental organizations, donor agencies or United Nations agencies, or who have previously worked extensively on the application of the GIPA principle. Subsequently, the draft GIPA Report Card was developed and these were circulated to this group and their networks for comment and input. The GIPA Report Card is the result of this consultative process.

The GIPA Report Card was seen as a means of monitoring and evaluating governments' and organizations' level and type of involvement of PLHIV in response to HIV and AIDS, particularly in light of the 2001 United Nations General Assembly's Special Session on HIV and the Declaration of Commitment, and to assist people living with HIV in articulating, "What do we mean by GIPA?"; "Why do we need it?" and "How can we achieve it?" The GIPA Report Card provides an opportunity for key stakeholders to provide information and their views on GIPA implementation in country. The report will provide unique insights into the operation of GIPA in country and be a tool to promote the meaningful involvement of PLHIV in national responses. GNP+ plans to facilitate the implementation of the GIPA Report Card in 10 countries over 2009 – 2010.

[1] Think Tank Meeting (2005). *Revitalizing the Global Movement of People Living with HIV*. Nairobi, Kenya, 28–30 November 2005.
www.gnpplus.net/cmsdownloads/files/Nairobi_meeting_report.pdf

AIMS & OBJECTIVES

GIPA Report Card PILOT Objectives

The pilot was envisioned as a testing phase for the tool, to provide preliminary data, and to better understand the feasibility of measuring how and to what extent the GIPA principle is applied through a report card questionnaire. The pilot phase was deliberately designed to be limited in scope, with future phases to be further developed.
The objectives of the pilot phase of implementation are:

1. Implement the GIPA Report Card in 4 (four) countries and provide results using pilot questionnaire.
2. Test the feasibility of the GIPA Report Card, i.e. can we measure what the GIPA Report Card is meant to measure?
3. Document lessons learnt in country implementation: what worked and what did not?
4. Evaluate the GIPA Report Card tool, looking for areas of improvement and to ensure effectiveness toward further phases.
5. Provide details on success factors for future implementation of the GIPA Report Card.

GIPA Report Card Objectives

The GIPA Report Card is an advocacy tool, which aims to increase and improve the programmatic, policy and funding actions taken to realize the greater involvement of people living with HIV in a country's HIV response. The objectives of the GIPA Report Card are to:

- Provide information on the current level of application of the GIPA principle, which will serve as a baseline against which future application of the GIPA principle can be measured;
- Hold governments, NGOs, United Nations agencies, donors, organizations of PLHIV and other stakeholders accountable to their commitments relating to the application of the GIPA principle;
- Increase and improve the meaningful participation of PLHIV in different sectors within the broader national response to the HIV epidemic in a country;
- Assist in developing indicators to monitor and evaluate the quality and impact of PLHIV engagement; and
- Provide follow-up recommendations to enhance stakeholders' (governments, NGOs, United Nations agencies, donors, organizations of PLHIV) identification of opportunities and entry points for the application of the GIPA principle within their organization or institutions and in their policies and programmes, including cost estimates.

Costing the involvement of people living with HIV is crucial to the application of the GIPA principle i.e. what levels of support do people living with HIV organizations need in order to be involved,

and what does that cost? Finally, the GIPA Report Cards will serve as one way to bring different organizations together on specific issues.

The GIPA Report Card is to be owned, developed and implemented by people living with HIV through a bottom-up process, including broad and diverse consultations.

GIPA Report Card Outline

It is envisaged that ultimately the GIPA Report Card questionnaire will cover a broad range of the issues relating to the various stakeholders: governments, NGOs, multilateral organisations, United Nations agencies, organizations of people living with HIV and other stakeholders. It is proposed that the GIPA Report Card addresses the following three levels:

1. Macro (institutional level such as UNGASS follow-up processes and programmes, and institutions such as CCMs,)
2. Micro (organizational level, focusing on government ministries, NGOs and organizations of people living with HIV)
3. Personal (barriers to involvement of individual PLHIV)

Macro (Institutional level): There must be laws and policies for protecting PLHIV who become involved, including access to affordable health care such as access life prolonging medication should the need arise, and capacity building as required.

Micro (Organizational level): Pre-conditions for safe involvement include: sensitivity training for colleagues; information about the opportunities for GIPA; appropriate training for the tasks to be undertaken and optimal use of existing skills.

Personal (Individual level): It has to be a personal initiative to be involved, and should be accompanied by a safe space for disclosure, counselling and support, clarification on why one is getting involved and strategies to deal with stigma, discrimination and burnout.

However, in this first pilot round, the GIPA Report Card will use a limited questionnaire, which is to facilitate the rapid commencement of this project, with a focus on the macro and personal levels.

PILOT METHODS

For each pilot country the GIPA Report Card pilot phase methodology consists of:

1. A literature review and analysis of documents, including national and district strategic plans, organization by laws, etc. on people living with HIV involvement at local and national levels. (To be summarized on front page of report card and fully referenced).
2. Written responses to questionnaire from some 10 (ten) key people living with HIV.
3. Interviews and discussions with the UNAIDS Country Coordinator and National AIDS Programme Manager (note that in further rounds the number and types of Interviewees will be expanded).

Project Management

GNP+ in consultation with UNAIDS and national people living with HIV organizations and networks from each of the four pilot countries identified people living with HIV with the appropriate skill set to undertake the review and report writing process. Each of the four countries in which the pilot was conducted was managed by a local independent consultant who was affiliated with a local or regional people living with HIV network. A project management consultant supported country consultants in implementing the GIPA Report Card. There was a breakdown of tasks and responsibilities among all the consultants implementing the GIPA Report Card. For a detailed breakdown of tasks please see Annex II.

Pilot Countries

The pilot took place in 4 countries: India, Kenya, Lesotho, and Trinidad and Tobago. The selection process for countries was based on the presence of a UNAIDS country office, attempts to represent different regions, and practical considerations, including contacts with people living with HIV networks and consultants to undertake the work.

Interviewees

In the pilot phase, interviewees were limited primarily to people living with HIV, except for the UNAIDS Country Coordinator and the National AIDS Programme Manager (or equivalent). A total of 47 interviews were conducted with 12 in Kenya, 11 in Lesotho, 12 in India, and 12 in Trinidad and Tobago. 39 of the respondents are PLHIV who represented a diverse sample including representatives of PLHIV networks, staff in government ministries and development agencies, staff and volunteers in CSOs and also representatives on CCMs.

Subsequently, it is envisaged that in future, interviewees will include representatives from government ministries, United Nations agencies, NGOs and donors.

Criteria were developed to help guide interviewee selection for the pilot phase of the GIPA Report Card. Selection criteria is included as Appendix I.

PILOT COUNTRY RESULTS SUMMARY

The following section presents the overview of country results and also identifies a number of cross-cutting themes from all three countries and the 35 respondents interviewed over June-August 2008. For more detail of results please see each country GIPA Report Card. Results are included by country and included in three sections: findings on the GIPA Report Card implementation process, findings on the GIPA Report Card tool itself, and findings on GIPA in-country.

GIPA REPORT CARD: *INDIA*

GIPA REPORT CARD IMPLEMENTATION PROCESS FINDINGS: INDIA

Initially, due to the close timing in proximity to the 2008 International AIDS Conference, it was very challenging to identify a PLHIV consultant with time, capacity and access to appropriate infrastructure (i.e. internet, phone etc.) to facilitate pilot implementation. Once confirmed, after a two month search, Loon Gangte commenced work on the project and the 12 prospective respondents were identified to ensure diversity and experience.

Even with time constraints there were overwhelming responses to participate amongst PLHIV, and a very positive response from national AIDS coordinating bodies. However, in certain instances it was difficult to get the attention of some prospective interviewees; very persistent follow up by email and phone was required. Personal working relationships helped to secure interviews from respondents, so if there was not a working relationship, getting responses for participation was more of a challenge from certain prospective interviewees.

Each informant was telephoned individually and the GIPA Report Card process was explained to them verbally. They were each asked to participate either in a face-to-face interview or to complete the Report Card via email, depending on where they were and according to logistical constraints; it was only possible for the consultant to travel to certain regions within the time and budget allowance. Once key respondents agreed to participate in the process they were each sent via email the GIPA Report Card questionnaire, consent form and the GIPA Report Card Information sheet.

Out of 12 key respondents in India, 5 face-to-face were conducted and 7 were done via email. Efforts were made to ensure that face-to-face interviews were done with key respondents from INP+ and UNAIDS. Face-to-face interviews were done in Chennai, Delhi and Mumbai. Interviews via email were done in Manipur, Assam, Utter Pradesh, and Delhi. Each participant was provided with an honorarium of $50.00 US dollars and signed the informed consent form indicating that they understood the purpose of the pilot project, the methods that would be used, and that participation was voluntary. In some cases, it was difficult to stay in contact with a number of prospective interviewees.

Face-to-face interviews were found to garner more information and it is recommended that this be done for all interviews in the future. Also, although a voice recorder was not used during the interviews it would have been helpful and could have supported the overall answers with quotes and further information, which was difficult to record by hand. For those interviews that were conducted done via email the PDF file format posed a problem.

The project manager conducted a literature review of key policy documents, looking at national, state and organisational policies and by-laws. Information from the review and the results of the interviews were inputting into the final report.

Nearly all of interview questionnaires were filled-in electronically which made for legibility, and a timelier final reporting process. The final filled-in questionnaires were sent to the project manager to be synthesized and inputted into the final report.

Gagnte identified that the practice of doing the GIPA Report Card meant that people in the UN, government and PLHIV networks now know that someone is closely watching and monitoring what is and isn't being implemented.

Overall, data synthesis for the final county report posed a challenge, Gangte addressed that summarizing results was somewhat difficult and the initial country report lacked detail captured in the interviews, and was also lacking comprehensive data analysis. The final country report had to be written by both the country consultant and project manager. The final filled-in questionnaires were sent to the project manager to be synthesized and inputted into the final report along with Gangte's report.

FINDINGS FROM THE IMPLEMENTATION OF THE GIPA REPORT CARD: INDIA

The GIPA Report Card in India garnered valuable information and upon completion of the project, Loon Gangte the county consultant reported that the tool be valuable in regard to advocacy efforts, and was able to evaluate the application of the GIPA principle in the country. However, Gangte identified that the success of the tool relied heavily on ensuring careful selection of interviewees with relevant knowledge, i.e. selection criteria must be developed to guide the process. It was recommended that this be a strong focus upon wider implementation of the tool.

The following is a list of key issues that arose in regards to the GIPA Report Card tool in India:

- Gangte indentified that there were often missed opportunities to gather input regarding regional or state policy and the application of the GIPA principle Had the question been designed to also cater the gather state level information there would have been a greater amount of information collected.
- The language used in the questionnaire was identified as difficult, too wordy and overly complicated by many respondents. In the face-to-face interviews, questions had to be posed numerous ways by the consultant for the respondents to understand the desired intent.
- Most of the interviewees' responses were inputted electronically into the questionnaire, either by the respondent or by the consultant. This made for simpler analysis over those which were handwritten and a greater ease in reporting. Having questions filled-out electronically assists with reporting/legibility of answers, those that were handwritten were difficult to transcribe.
- Throughout the data analysis it became obvious that more data was garnered when the questionnaire was done with an interview in-person, versus via email.
- The country consultant addressed summarizing narrative sections of the questionnaire results to be a challenge.
- The format of the card was a challenge in gathering qualitative data. If more info wasn't filled out there was no context to the checked off response, making it very difficult to derive conclusions from just the check boxes.
- Emailing the file in PDF format to interviewees caused issues, as it was not user-friendly for inputting responses. Therefore word 'protected' formats would be more useful.
- The questions on universal access, gender, poverty, SRH, and psychosocial factors garnered valuable information, but these sections lacked an explanation or connection to GIPA and posed some confusion.

GIPA IN-COUNTRY FINDINGS: INDIA

10 PLHIV were interviewed representing national, and state PLHIV networks, as well as a number of care and support organizations and NGOs. The UNAIDS Country Coordinator and the Additional Secretary/ Director General of the National AIDS Control Organisation (NACO) were also interviewed, for a total of 12 interviews.

Respondents noted that India has quite a developed 'GIPA landscape' in regards to national policy. There is a National GIPA Strategy, national GIPA Implementation Plan and various state implementation plans, as well as mandated GIPA coordinators in a majority of states. India's national AIDS plan, the National AIDS Control Programme phase III, 2006-2011 (NACP-III) works to support GIPA in a number of ways including increasing the capacity of networks of PLHIV to be

effective partners. However, most respondents do not feel that these policies, implementation plans and programs are effectively being communicated, as one respondent stated, "*GIPA guidelines are not clearly understood by many service providers or PLHIV or all the stakeholders".* It was also felt that India's strategy in regards to GIPA is top-down, therefore often alienating many PLHIV who are not involved at the national level. Respondents from state and regional PLHIV networks had less knowledge of GIPA, and it was noted that GIPA is not widely known or practiced on a state and district level.

In the NACP-III, while there is no explicit GIPA budget line, there are a number of expenditures that work towards GIPA, specifically the GIPA coordinators within 21 states. While a number of respondents addressed the GIPA Coordinator's position, a few felt GIPA was being interpreted solely as an employment provision and that more of a focused and planned capacity building process for meaningful involvement of PLHIV at all levels was needed. It was also addressed that the state GIPA Coordinator activities toward mobilizing community understanding of involvement of PLHIV may be limited. A number of respondents indicated that some of the GIPA Coordinator positions at State AIDS Control Society (SACS), which are reserved for PLHIV, were actually filled with HIV negative people.

Additionally, when there has been involvement at the national policy development level (as indicated by a majority of respondents who stated that PLHIV are involved from the development phase of policy development), PLHIV respondents noted that participation is still tokenistic, representation mechanisms were not always transparent, and recommendations from PLHIV are often not included or reflected accurately in final documents. PLHIV networks were also addressed as not practicing GIPA adequately, lacking transparent representation and identified as being elitist.

Multiple issues regarding networks of PLHIV were addressed in India and the networks themselves were highlighted as having a number of barriers. One informant said *"the definition of GIPA has to be changed to Greater Involvement of PLHIV Networks, not people living with HIV, so as to avoid favouritism and individualism".* However another informant said the *"PLHIV network doesn't practice GIPA",* while another informant provided more details about perceived barriers within PLHIV networks saying *"some individual in the network overburden work responsibility and burnout, but are still not willing to share their responsibility. The possible reason could be job security"* and another comment indicated *"PLHIV networks focus mostly on healthy PLHIV, often we don't address the issues of the people who are dying or sick of HIV related diseases."*

When asked to indicate the greatest barriers preventing the greater involvement of PLHIV, lack of confidence in PLHIV organizations and/or networks, lack of understanding and clarity on what GIPA is, and fear of or actual discrimination were identified as the main barriers to the meaningful participation of PLHIV in India.

GIPA REPORT CARD: *LESOTHO*

GIPA REPORT CARD IMPLEMENTATION PROCESS FINDINGS: LESOTHO

Initially it was a challenge to identify a consultant living with HIV who could had the capacity to implement the project. But with the help of project partners' in-county and globally, Ellen Scout was identified and began work on the consultancy in June 2008. The consultancy commenced with Scout working to secure appropriate interviewees.

Communication between the project management team and Scout was difficult as regular internet access and electrical outages for Scout were an ongoing challenge. This posed difficulty initially, but overall orientation for Ellen was done through a series of email communications and Skype chats. Scout collected the literature review documents, as many of them were not available online, and they were couriered to the project manager who developed the literature reviews.

Transferring contracted payments to Scout also posed an issue, as there was no secure way for the funds to be sent. This took a number of months and numerous attempts by GNP+ to sort out until she was finally remunerated for all her work on the project.

The interview schedule was from 19-24 June, 2008. Interviews were done individually face-to-face. Scout had to work to orient her interviewees to understand the GIPA principle, as many lacked sufficient understanding to complete the questionnaire. "*It was not easy as most of the respondents did not understand the GIPA principle, many respondents also lacked knowledge about national HIV/AIDS policy*" Scout reported.

The translation of the questionnaire into Sesotho was another great challenge. Most of the respondents in Lesotho did not understand the questionnaire or issues in English, so the questionnaire had to be translated on-the-spot by Scout during the interviews.

Scout also reported "*there was a general complaint that it took a long time to complete (the questionnaire) yet they understood that the information was important; others were happy as they could express themselves with a hope that someone is interested.*"

Reponses to the questionnaires were all hand-written, which made it difficult for legibility upon developing the final GIPA Report Card Pilot Phase Report. Overall, data synthesis for the final county report posed a challenge, Scout addressed that summarizing results was somewhat difficult and the initial country report lacked detail captured in the interviews, and was also lacking comprehensive data analysis. The final country report had to be written by both the country consultant and project manager. The final filled-in questionnaires were sent to the project manager to be synthesized and inputted into the final report along with Scout's report.

GIPA REPORT CARD TOOL FINDINGS: LESOTHO

Overall, the GIPA Report Card tool garnered a great deal of valuable and relevant data in Lesotho. This was contingent on, Ellen Scout, the country implementation consultant, orienting each interviewee to the meaning of GIPA and then translating the tool/questionnaire into Sesotho. Only 3 of the respondents could self administer the questionnaire, meaning that others needed support from Scout. Upon completion of the project, Scout reported that accompanied with information on GIPA, the Report Card will be a valuable tool and was able to evaluate GIPA implementation in Lesotho.

A number of key issues arose during implementation in regards to the GIPA tool in Lesotho:

- If respondents were unaware of certain commitments or policies addressed in the questionnaire then they were not able to really input responses. There were no other ways to gather data, or to translate local experience into relevance on a larger scale. Also, there were no questions on regional commitments or policy.
- Handwritten responses were very difficult to transcribe, and some information was lost due to illegibility.
- The country consultant addressed summarizing narrative sections of the questionnaire results to be a challenge.
- The format of the card was a challenge in gathering qualitative data. If more information was not filled out there was no context to the checked off response, making it very difficult to derive conclusions from just the check boxes.
- The box marked N/A does not easily allow for other responses, which meant that the context as to why certain questions were not answered was sometimes lost. However, in Scout utilized the box to often explain respondent's answers.
- The questions on universal access, gender, poverty, SRH, and psychosocial factors garnered valuable information, but these sections lacked an explanation or connection to GIPA and posed some confusion.

GIPA FINDINGS IN-COUNTRY: LESOTHO

11 respondents were interviewed; 6 females and 5 males. 9 PLHIV were interviewed from a number of national, regional and local community PLHIV networks, including care and support groups, organisations and one government ministry. UNAIDS and the National AIDS Commission were also interviewed.

When asked to indicate the greatest barriers preventing the greater involvement of PLHIV, PLHIV respondents in Lesotho address poverty, fears of actual discrimination and lack of confidence in PLHIV organizations and/or networks. Stigma and fears of discrimination were also addressed numerous times throughout responses. Many respondents illustrated a challenging landscape for PLHIV which lacks SRH services, mechanisms to deal with discrimination, unreliable treatment

access of which the generic supply can be of low quality, and a lack of other comprehensive support and health services. Second-line treatments are available, but a number of respondents identified worries about their quality and supply regularity.

There is slight improvement regarding the involvement of PLHIV as noted by respondents. At the same time respondents indicated that PLHIV have been regarded as beneficiaries more than implementers and when PLHIV make recommendations they are not adequately addressed.

There is no 'GIPA plan' at national level, but the application of the GIPA principle is somewhat incorporated within the programmes of the National HIV & AIDS Strategic Plan 2006-2011 (NSP). As such there is no specific budget allocated to the application of the GIPA principle. The National AIDS Commission (NAC) states that the Lesotho Network of People Living with HIV/AIDS (LENEPWHA) is fully funded by the Global Fund and NAC to address GIPA issues. Therefore the application of the GIPA principle is being taken care of (if the national network of PLHIV has funding). However, PLHIV networks say that there is not an adequate focus on the application of the GIPA principle in the NSP. It is addressed that there is a need for provision of adequate human capacity for the implementation of the plan, which currently does not exist.

Although respondents indicated that most national government ministries and private sector companies have HIV workplace policies, this is not the case at the local government level. Stigma and fear of discrimination can be so high that even when services are offered free from an employer, PLHIV workers will not access them. Fear of discrimination is not unfounded as a number of instances were indicated by respondents such as one health clinic known for giving women living with HIV a contraceptive without their knowledge or consent. Also many PLHIV in Lesotho do not know their status, due to high levels of stigma, even those who have access to services, do not access them.

A majority of PLHIV in Lesotho also feel that they are not adequately remunerated for their participation; one male respondent stating *"PLHIV are not adequately paid for their participation"*, while a female PLHIV respondent also said *"most PLHIV are paid 'tokens' or they are viewed as volunteers, not facilitators".*

Many respondents did not have much knowledge of GIPA and lacked an understanding of the principle. For a few, the GIPA Report Card interview was the first they had heard of the concept.

GIPA REPORT CARD: *KENYA*

GIPA REPORT CARD TOOL FINDINGS: KENYA

The GIPA Report Card in Kenya garnered valuable information and upon completion of project implementation, Joe Muriuki, the county consultant, reported that the tool was successfully able to evaluate GIPA implementation in the country. However, Muriuki identified that in order to ensure successful data collection, interviews needed to be supported by information and orientation on the GIPA principle to the interviewees

The following is a list of key issues that arose in regards to the GIPA tool in Kenya:

- Some of the respondents noted that the questionnaire was too long.
- Muriuki identified that it is important to appreciate that the application of the GIPA principle is practiced differently between PLHIV support groups where there are varying issues, including equality, equity, fairness and justice. This was important in regards to understanding definitions of the GIPA principle, which was lacking in the opening statement of the Report Card.
- The questions on universal access, gender, poverty, SRH, and psychosocial factors garnered valuable information, but these sections lacked an explanation or connection to GIPA and posed some confusion.
- The format of the card was a challenge in gathering qualitative data. If more info wasn't filled out there was no context to the checked off response, making it very difficult to derive conclusions from just the check boxes.
- If respondents were unaware of certain commitments or polices addressed in the questionnaire then they were not able to really input responses. There were no other ways to gather data, or to translate local experience into relevance on a larger scale. Also, there were no question on regional commitments and policy.
- Handwritten responses were very difficult to transcribe, and some information was lost due to illegibility.
- The country consultant addressed summarizing narrative sections of the questionnaire results to be a challenge.

GIPA REPORT CARD IMPLEMENTATION PROCESS FINDINGS: KENYA

In Kenya, interviews were done face-to-face in small groups, one-on-one, and also via email. Quite a few of the PLHIV respondents lacked knowledge about the application of the GIPA principle and knowledge about national HIV and AIDS policy in their countries; this meant that Muriuki had to orient interviewees to the GIPA principle and its rationale. For those who completed the questionnaire via email the file format posed a problem as it was available in a 'read-only' and 'PDF' formats, which meant inputting responses was not user-friendly.

Muriuki also noted that it was a challenge to summarize narrative parts of the GIPA Report Card and data synthesis for the final county report posed a challenge. Muriuki addressed that summarizing results was somewhat difficult and the initial country report lacked detail captured in the interviews, and was also lacking comprehensive data analysis. The final country report had to be written by both the country consultant and project manager and the final filled-in questionnaires were sent to the project manager to be synthesized and inputted into the final report along with Muriuki's report.

GIPA Report Card country consultant Joe Muriuki explains the implementation process:

"*The first task was to call for an expression of interest from PLHIV from all parts of the country through the PLHIV list serve. I got successes by receiving interest from Coast Province, Rift valley, Central Province Eastern Province and Nyanza Province and identified enough potential interviewees. One interviewee failed to turn up due to unforeseen commitment and wished the interviewee date would be postponed which was not possible and was replaced. Other challenges included being unable to follow application instructions such as using designated email and providing the required information.*

The next step was to organize for logistics including the timing for interviewees to come over to our place and arrange for their overnight stay for those from other provinces than Nairobi. The challenge here was some interviewees were reluctant to have their voices captured by the voice recorder, while others felt the questionnaire was too long. The voice recorder initially could not record as I had not known how to operate it and I got someone to take note alongside the voice recording and adopted this approach throughout the process.

Some of the successes were that even with time constraints there were overwhelming response to participate amongst PLHIV. But I had to have a meeting of some few PLHIV in Nyeri to clarify issues on the questionnaires as the one assigned to answer did not really understand what GIPA meant and thus could not contextualise."

GIPA IN-COUNTRY FINDINGS: KENYA

10 PLHIV were interviewed from a wide range of national and regional PLHIV networks, care and support organisations and one respondent in an employment position reserved for PLHIV in the Ministry of Health. Also interviewed, was a Program Officer from the National AIDS Control Council (NACC) and a representative from UNAIDS in Kenya for a total of 12 interviews.

Respondents identified that Kenya is beginning to have a well developed GIPA landscape in regards to national policy, but overall, in regards to policy development, a majority of respondents indicated that PLHIV are involved only at the implementation phase, not at the conception or development phase. Also, PLHIV respondents specifically indicated that representation is still tokenistic at many levels and PLHIV voices are not listened too even if they are involved.

Respondents also feel that GIPA has not been adequately addressed in the Kenyan National HIV and AIDS Strategic Plan (KNASP). It was identified that there is no GIPA focussed desk or officer and the KNASP has not yet been amended accordingly to reflect the newly developed National GIPA Guidelines.

It was indicated that PLHIV were not included in Universal Access target setting. Quality of ART and regularity of supply were addressed as concerns, as was access to second line ART.

A number of viable opportunities for meaningful involvement of PLHIV were identified as the newly developed GIPA Guidelines will be implemented soon, and it was indicated by respondents that there are employment positions available in the private sector and government based on the application of GIPA. However, one respondent employed by the government indicated that she is only there as an example for others and often asked to present her “story”.

Respondents listed poverty, lack of clarity about what GIPA is, and fear of stigma as the greatest barriers to meaningful involvement of PLHIV.

GIPA REPORT CARD:

TRINIDAD & TOBAGO

GIPA REPORT CARD TOOL FINDINGS: TRINIDAD & TOBAGO

Overall, the GIPA Report Card tool garnered a great deal of valuable and relevant data in Trinidad and Tobago and both consultants agreed that the tool was an effective method for evaluating GIPA in the country. The gathering of data in Trinidad and Tobago was relatively successful; however there were two issues that arose during implementation in regards to the GIPA tool:

- Many respondents were unaware of certain commitments or policies addressed in the questionnaire and they were not able to really input responses. There were no other ways to gather data, or to translate local experience into relevance on a larger scale. Also, there were no question on regional commitments and policy.
- Handwritten responses were very difficult to transcribe, and some information was lost due to illegibility.

GIPA REPORT CARD IMPLEMENTATION PROCESS FINDINGS: TRINIDAD & TOBAGO

Nicholas Granger and Sommer Williams were the two national consultants from Trinidad and Tobago selected with the support of UNAIDS to conduct the country interviews. The UNAIDS office and CRN+ provided a great deal of support to all project partners and consultants. The implementation of the GIPA Report Card in Trinidad and Tobago presented a number of challenges and ultimately took 4 months longer to complete then all the other pilot countries. Email communication was often the greatest challenge as a number of the contacts in Trinidad and Tobago do not use the internet frequently.

The 10 PLHIV interviewees were selected to participate as respondents in the GIPA Report Card interviews based on their membership and contribution to the PLHIV community, who either is working in an organization or networks or have previously worked on the application of the GIPA principle. The final 2 interviewees were from UNAIDS and National AIDS Programme. Interviews were conducted face-to-face, with each consultant conducting half of the interviews. Interview results were handwritten into the questionnaire which posed a challenge for legibility in some cases. Many of the respondents were also unaware of a number of the issues or policies presented in the questionnaire including UNGASS, the ILO Code of Practice, and the National Strategic Plan on HIV/AIDS. This presented somewhat of a difficulty in gathering relevant information through the report card interviews.

A majority of the respondents were familiar with the GIPA Principe. However, when asked how the Report Card could be improved both consultants suggested that more information about the GIPA principle be made available for the interviewees, as the interview process itself was regarded as a useful information exchange which could benefit the interviewee to do advocacy regarding GIPA afterwards.

Funds were delayed due to a communication issue, where the wrong bank information was provided to GNP+; this meant that respondents did not receive their $50 USD honorarium until sometime after their interview.

As there were two consultants this often posed a communication challenge with the project manager consultant. Ultimately this resulted in two separate reports being developed. The final country report was synthesised and written by both the country consultants and project manager, and the final filled-in questionnaires were sent to the project manager to be synthesized and inputted into the final report along with the consultant's reports.

GIPA IN-COUNTRY FINDINGS: TRINIDAD & TOBAGO

10 out of the 12 respondents interviewed were PLHIV working at CARe and CRN+. A UNAIDS representative and National AIDS Programme Director were also interviewed.

It was noted that there is no national 'GIPA Plan' in Trinidad and Tobago. Respondents said that the National Strategic Plan (NSP) has a budget that is operationalised through the National AIDS Coordinating Committee (NACC). Most respondents felt that there was a need for greater need for involvement of PLHIV in the implementation of the NSP.

Many of the respondents did not have much knowledge of UNGASS or other policies on SRH, employment or GIPA.

Respondents noted that while there is access to free ARVs and quality and supply are sufficient, that less than half of all PLHIV in the country are currently on ART.

In regards to provider stigma and discrimination, it was indicated that in some cases nurses and midwives still impose their views to pregnant HIV-positive mothers and children.

Respondents noted that a workplace policy on HIV was launched in April 2008 and legislative assessments are ongoing with the involvement of PLHIV towards amending the policy that aims to protect the rights of PLHIV. One respondent also noted that the ILO has embarked on a project in collaboration with the government of Trinidad and Tobago through the Ministry of Health in creating a HIV workplace policy.

When asked to identify barriers to involvement fear of stigma, fear of or actual discrimination, homophobia and other forms of prejudice, and low skill levels were most often identified by respondents.

Many respondents noted a number of opportunities including through policy level involvement in the NACC, working on access and ARVs issues, and opportunities to participate in public forums and ways to make your voice be heard as a PLHIV.

RECOMMENDATIONS

The following sections look at recommendations toward **how to improve** the GIPA Report Card tool so that is most effective, and on success factors toward **how best to implement** the GIPA Report Card in future phases. The following recommendations were gathered over the course of the pilot and are gathered from Report Card country respondents, country consultants who implemented the tool and the project manager. During the implementation anecdotal information was gathered evaluating the process to make recommendations for future Report Card roll out.

RECOMMENDATIONS FOR GIPA REPORT CARD TOOL

REVIEW OF REVISED TOOL BY RESEARCH PROFESSIONALS: To address the multiple challenges during pilot implementation and to ensure more effective and accurate data collection it is recommended that a research professional review the card to support more efficient and effective data collection.

INCREASE QUALITATIVE DATA COLLECTION: While quantitative research provides us with some data, qualitative research enables us to analyse responses in greater depth. For example, perhaps there was involvement of PLHIV in policy development, but *was* the involvement meaningful? The 'Comments' section was not used very often in many instances and with so many YES and NO questions this left out a lot of contextual information. Greater in-depth data collection and analysis could assist with providing more concrete results.

Also, in a number of cases respondents said 'NO' to something and they were incorrect. This could be an indicator of poor GIPA implementation, lack of knowledge, or poor communication/lack of engagement. This could also indicate that the interviewee was inappropriate, however either way this posed a challenge for summarizing results.

To better support gathering more data, a greater number of simple qualitative questions could be used, which would possibly provide more contextual data to better understand GIPA implementation.

DEVELOP 'GRADE' CALCULATION INDEX: It is currently not possible to measure one countries GIPA implementation against another based on how results are implemented. Also, it is not possible to calculate a "grade" for each country? Developing an index for the GIPA report card in order to do cross-country and regional comparisons could be useful. Designing the Report Card with the final product in mind and making it simple to implement results that are in turn easily understood could assist making the tool accessible and easy to implement. Also developing a simple index which can easily measure results to provide a way to measure against other countries would be beneficial.

SIMPLIFY LANGUAGE & QUESTIONNAIRE: Many respondents from all three countries stated that the wording was overly complicated; too long and sometimes had grammatical errors. A number of respondents had difficulty in understanding the intent of questions. Consultants had to pose questions various ways in person, but via email this was not possible.

AMEND CONTENT OF QUESTIONNAIRE:

- Include a question around communication, representation, accountability and transparency between/among the PLHIV groups and networks.
- Include questions to gauge knowledge of the GIPA principle, e.g. do you know the GIPA principle? If yes, how did you know about/ where did you get information regarding the GIPA principle? And then another question about how other PLHIV are informed of the GIPA principle?
- Include a question about barriers experienced by PLHIV staff in national AIDS coordinating bodies, international organisations and UN organisations.
- Find out whether written policies on employing HIV positive staff exist in national AIDS programmes, international NGOs and UN agencies, and if there is a specific organizational budget allocation for GIPA.

AMEND FORMAT OF QUESTIONNAIRE:

- Include a formalized section to gather contact details, such as email and postal addresses.
- Revise the 'N/A' box to allow for an elaboration in responses.

VARIOUS LEVELS (INSTITUTIONAL, ORGANISATIONAL, and INDIVIDUAL): The goal of the GIPA Report Card is to gather personal, organisational and institutional data. At the moment the report card questionnaire primarily looks only at the national level, however, it is also collecting a small amount of data regarding organizations and personal information. This posed some confusion and also presented a conflict for summarizing results as the overall report is primarily looking at the country as a whole, but organisational information was also collected (baseline data asks specific questions about organization structure etc., although this information was often useful for the final reports). Also, having one respondent from a particular organisation does not provide enough data to make assumptions or present results regarding that organizations specific GIPA implementation, so not all the baseline data was necessary all of the time.

The tool could be designed to monitor organisations, but in the pilot phase when looking at the overall country, collecting this data caused confusion in how to use it. It was also a challenge for all of the consultants to find PLHIV who had enough national experience to respond to all questions as more had state level experience. This had effects on the overall report, as the questionnaire may have missed out on how and if the GIPA principle is being implemented at the state level in countries. Had the questions been designed to cater for the various levels, more concrete information could have been collected.

CONNECT GIPA TO BROADER QUESTIONS: The questions on universal access, gender, poverty, SRH, and psychosocial factors lacked an explanation or connection to GIPA and posed some confusion.

IMPLEMENTATION RECOMMENDATIONS

WORKSHOP ON RESEARCH SKILLS FOR CONSULTANTS: Ensure that there is time to the research, interviewing and data collection skills of those implementing the Report Card. This could be done as an e-course or online workshop.

INTERVIEWS FACE-TO-FACE: Those who did interviews via email identified that it was not an effective way of implementing the card and more data would have been garnered had the pilot been designed in such a way that all interviews were conducted face-to-face. However due to time and budgetary constraints, this was not always possible, but this resulted in limited interaction between the interviewer and interviewee and a missed opportunity to gather more qualitative data.

TRANSLATION INTO LOCAL LANGUAGES: It is worth devoting an appropriate amount of resources to ensure that the tool is accurately translated. In Lesotho, our consultant translated the questionnaire verbally in-person during the face-to-face interviews when she realized that many of her interviewees did not understand the details of the questions in English. Some of the questions were difficult to translate into Sesotho and this proved a great challenge. This should be organised ahead of time to support the gathering of responses.

USER FRIENDLY FILE FORMAT AND LANGUAGE: Ensure that GIPA Report Card materials and questionnaire are in simple and widely used format to support the inputting of data. The use of PDF files caused a number of challenges for all pilot countries, as many respondents were not able to enter their responses into a read-only file. Converting to protected word file or an online questionnaire could make it easier to use and more effective to consolidate responses.

BUILD TECHNICAL KNOWLEDGE COMPONENT INTO REPORT CARD IMPLEMENTATION: In many cases interviewees lacked knowledge of the GIPA principle. This was especially the case when interviewing PLHIV, regardless of whether they were representing a PLHIV network. It was noted that some of them did not understand why they were being asked the questions and how the whole exercise would help improve their situation. Country consultants felt they could make better use of their time if they were able to do conduct a workshop on the GIPA principle following the interview and if this was regarded as a formal component of the process.

It was recommended that presenting contextual information and information sharing on the GIPA principle and its application could happen during the GIPA Report Card interview, so that PLHIV were better informed and had some technical capacity to advocate for the application of the GIPA principle after participating in the GIPA Report Card exercise.

REPORTING REVIEW PROCESS: Due to time constraints the final reports from country consultants did not go through a wide review process, and all of them had to be somewhat rewritten by the project manager. In future phases of the GIPA Report Card a wider review process could assist to build consensus and support the development of country consultants reporting skills.

UNAIDS COUNTRY OFFICES: Working closely with UNAIDS country offices worked well to support pilot implementation and is recommended to support with logistics for country implementation and knowledge of the Report Card in-country. Also, Report Card implementer consultants could connect with the UN System HIV Positive Staff Group (UN+) to access UN staff living with HIV in-country as interviewees for future GIPA Report Cards.

INTERVIEWEE SELECTION: The choice of interviewees were not in some cases appropriate during the pilot. Ensuring appropriate knowledge or relevant experience is not always easy, but devoting enough time to locate potential relevant interviewees will help. Loon Gangte highlighted "*we need to work on choosing the respondent as many people are often not involved in the national level but the question are mostly on the national level*". The same issue occurred in Lesotho, although respondent's lack of knowledge may be an indicator itself of lack of GIPA implementation, it was difficult under the time constraints to find those who are in fact involved in national processes.

GIPA REPORT CARD - Success Factors for Implementation:

- Autonomy of country consultants (to tailor to country needs and to remain independent of specific networks/organisations in country)
- Use of supporting documents on the pilot and the GIPA principle, e.g. information sheet
- Honorarium payment for interviewees
- Use of SKYPE for guidance during implementation management
- Consistent internet access
- Access to printing
- Digital recorders for recording interviews
- Electronically inputting response to ensure legibility

GIPA REPORT CARD
COUNTRY PILOT: *INDIA*

Prepared by: Loon Gangte & Alex McClelland

September 2008

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

LITERATURE REVIEW

India is demographically the second largest country in the world with a population of 1.13 billion. India has a federal structure and is divided into 35 States and Union Territories with 611 administrative districts. There are an estimated 2.47 million persons in India living with HIV, which corresponds to 0.36 percent of the total population. Approximately 50 percent of the PLHIV in India are under 24 years of age and 38 percent are women[2]. Currently 87.4 percent of infections are transmitted sexually, with other modes of transmission primarily being prenatal, through injection drugs and unsafe blood products. According to the National AIDS Control Organisation (NACO) the HIV epidemic in India is a heterogeneous concentrated epidemic, with HIV prevalence 6 to 8 times higher among people who inject drugs, MSM, and women engaged in sex work[3].

National AIDS Control Programme phase III, 2006-2011 (NACP-III) is the third phase of the national Indian plan. In alignment with the 'three-ones,' NACP-III is the one policy document guiding the national response to HIV and AIDS. The NACP-III also incorporates a national monitoring and evaluation framework and is implemented by the National AIDS Control Organisation (NACO). Phase III of India's national AIDS plan explicitly acknowledges the importance of PLHIV networks in the HIV response[4]. NACP-III also addresses that the new strategy will seek to engage PLHIV networks formally and to better support them financially.

PLHIV were involved in various aspects of the development of NACP-III, though a consultative process organised by NACO. PLHIV were also involved in various aspects of the preparatory process for NACP-III, and GIPA was the subject of one of the fourteen thematic working groups which submitted official recommendations towards the policy development. The Indian Network of People living with HIV/AIDS (INP+) was also consulted though the NACP-III development process[5]. Also, contributing toward the implementation of GIPA are the NACO GIPA Coordinators, which are employment positions in 21 states reserved for PLHIV as mandated by the NACP-III at the State AIDS Control Societies (SACS). Other initiatives of the NACP-III supporting GIPA are the establishment of PLHIV networks in most districts and all states by the year 2010; developing institutional structures within NACO, SACS and at district levels including all agencies, for planning, implementation and monitoring of the level of application of the GIPA principle; reviewing, adapt and develop advocacy, social mobilisation and communication strategies and tools to promote the GIPA principle and create an enabling environment for PLHIV and vulnerable communities; and to advocate with and build capacities of implementing agencies (government, private sector and civil society) to facilitate the application of the GIPA principle[6].

Based in Chennai, the Indian Network for People living with HIV/AIDS (INP+) is now 11 years old, and is the national level community-based organization representing PLHIV with 22 state level networks and 221 district level networks with a service membership of 114,000. INP+ has three core components –

[2] (National AIDS Control Organisation, 2008)
[3] (National AIDS Control Organisation, November 30, 2006)
[4] (National AIDS Control Organisation, November 30, 2006)
[5] (National AIDS Control Organisation, 2008)
[6] (National AIDS Control Organisation, November 30, 2006)

advocacy, network building and service delivery. The network also aims to provide technical assistance to the state and district networks in capacity building of its members in governance and leadership. INP+ participates in India's Country Coordinating Mechanism and has successfully advocated for ART and second line treatment to be made available. INP+ has also developed and implemented models of care and support services such as Drop-in-centres, Life Focus Centre, Family Counselling Centre, Positive Living Centre, and Treatment Counselling Centre. The Family Counselling Centre established in February 2004 is now providing services to approximately 900 people per month[7].

In 2005 INP+ developed the 'Greater Involvement of People Living with HIV/AIDS (GIPA) in National Response to HIV/AIDS in India Strategy Paper', which developed into the *National GIPA Strategy*[8]. This resulted in the jointly developed Implementation Plan for the NACO's National GIPA Strategy which addresses national, state, and district governmental actions towards the full implementation of GIPA over the course of NACP-III programme implementation and district implementation plans. The 'GIPA Implementation Plan' encourages the development of state and district 'GIPA Implementation Plans'[9].

For example, in 2007 the Uttar Pradesh Network of People living with HIV/AIDS (UPNP+) with the support of INP+ developed a GIPA Implementation Plan for the state in northern India, one of the country's largest with a population of 190 million people. The Uttar Pradesh GIPA implementation plan was developed with the goal of working in partnership with the Uttar Pradesh State AIDS Control Society (UPSACS) in the field of HIV prevention, treatment, care and support. The strategy for the 'GIPA Implementation Plan' to be implemented in Uttar Pradesh was developed covering following five broad areas, policy and advocacy, skills and capacity development, funding for PLHIV networks, treatment access, and documenting best practices in the application of the GIPA principle[10].

RESULTS OVERVIEW

10 PLHIV were interviewed representing national, and state PLHIV networks, as well as a number of care and support organizations and NGOs. The UNAIDS Country Coordinator and the Additional Secretary/ Director General of the National AIDS Control Organisation (NACO) were also interviewed, for a total of 12 interviews.

Respondents noted that India has quite a developed landscape in regards to the application of the GIPA principle in national policy. There is a National GIPA Strategy, National GIPA Implementation Plan and various state implementation plans, as well as mandated GIPA coordinators in a majority of states. India's national AIDS plan, the National AIDS Control Programme phase III, 2006-2011 (NACP-III) works to support the application of the GIPA principle in a number of ways including increasing the capacity of networks of PLHIV to be effective partners. However, most respondents do not feel that these policies, implementation plans and programs are effectively being communicated, as one respondent stated,

[7] (Indian Network of People Living with HIV/AIDS (INP+), March 2005)
[8] (Indian Network of People Living with HIV/AIDS (INP+), March 2005)
[9] (Indian Network of People Living with HIV (INP+) and National AIDS Control Programme (NACO), January 2007)
[10] (Uttar Pradesh Network of People living with HIV/AIDS (UPNP+), 2007)

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

"*GIPA guidelines are not clearly understood by many service providers or PLHIV or all the stakeholders".* It was also felt that India's strategy in regards to GIPA is top-down, therefore often alienating many PLHIV who are not involved at the national level. Respondents from state and regional PLHIV networks had less knowledge of the GIPA principle, and it was noted that the GIPA principle is not widely known or practiced on a state and district level.

In the NACP-III, while there is no explicit 'GIPA budget line', there are a number of expenditures that work towards the application of the GIPA principle, specifically the GIPA Coordinators within 21 states. While a number of respondents addressed the GIPA Coordinator's position, a few felt the GIPA principle was being interpreted solely as an employment provision and that more of a focused and planned capacity building process for meaningful involvement of PLHIV at all levels was needed. It was addressed that the state GIPA Coordinators' activities toward mobilizing community understanding of involvement of PLHIV may be limited. A number of respondents indicated that some of the GIPA Coordinator positions at State AIDS Control Society (SACS), which are reserved for PLHIV, were actually filled with HIV negative people.

Additionally, when there has been involvement; which is practiced at the national policy development level, as a majority of respondents indicated that PLHIV are involved from the development phase of policy development; PLHIV respondents noted that participation is still tokenistic, representation mechanisms were not always transparent, and recommendations from PLHIV are often not included or reflected accurately in final documents. PLHIV networks were also addressed as not practicing GIPA adequately, lacking transparent representation and identified as being elitist.

Multiple issues regarding networks of PLHIV were addressed in India and the networks themselves were highlighted as having a number of barriers; it is interesting to note that one informant said *"the definition of GIPA has to be changed to Greater Involvement of PLHIV Networks, not people living with HIV, so as to avoid favouritism and individualism".* However another informant said the *"PLHIV network doesn't practice GIPA",* while another informant provided more details about perceived barriers within PLHIV networks saying *"some individual in the network overburden work responsibility and burnout, but are still not willing to share their responsibility. The possible reason could be job security"* and another comment indicated *"PLHIV networks focus mostly on healthy PLHIV, often we don't address the issues of the people who are dying or sick of HIV related diseases."*

When asked to indicate the greatest barriers preventing the greater involvement of PLHIV, lack of confidence in PLHIV organizations and/or networks, lack of understanding and clarity on what GIPA means, and fear of or actual discrimination were identified as the main barriers to the meaningful participation of PLHIV in India.

<u>Interviewees living with HIV represented the following:</u>

- President, Indian Network for People living with HIV/AIDS (INP+), Chennai

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

- Vice-President, Indian Network for People living with HIV/AIDS (INP+), Uttar Pradesh
- President, Network of Indian People with Alternate Sexualities Living with HIV/AIDS (NIPASHA), Mumbai
- Projects Manager, UDAAN Trust, Mumbai
- Senior Physician and Researcher, YRG Care, Chennai
- President, Manipur Network of Positive People (MNP+), Manipur
- Coordinator, Delhi Network of Positive People (DNP+), Delhi
- Secretary, Network of Positive People (DNP+), Delhi
- President, South India Positive Network (SIP+), Chennai
- Individual PLHIV, working in an International Development Organisation

Interviewees not living with HIV represented the following:

- Country Coordinator, UNAIDS, Delhi
- Additional Secretary and Director General , National AIDS Control Organisation (NACO), Delhi

Demographic profile of respondents:

- 10 PLHIV, 2 non-PLHIV
- Age range 34 to 58 years old
- 2 Female, 1 Transgender, 8 Male
- 1 gay man
- 2 ex-injection drug users
- Representatives from 5 PLHIV networks
- UNAIDS Country Coordinator
- Additional Secretary and Director General , National AIDS Control Organisation (NACO)
- Wide range of urban and rural distribution in regards to where projects were being implemented from organisations.

People Living with HIV Staff and Volunteers:

9 respondents from 7 regional and national organisations indicated the number of PLHIV working in their organizations, including the NACO. UNAIDS was the only organization which indicated that it did not employ any PLHIV. Approximately 1600 PLHIV are employed in full-time and part-time positions across the interview sample. This includes the 21 NACO GIPA Coordinators, however some respondents from PLHIV networks addressed that there are a number of these position filled by persons not living with HIV. Also, there are an approximate 250 PLHIV volunteers working in various capacities across the organisations interviewed.

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

***Reading Report Card results**: the total responses from all of our respondents are included here. The following indicates the questions each interviewee were asked, and then how they indicated their response, either YES, NO, or in the N/A column (if another response was indicated it is also listed in the N/A column, if respondents answered N/A then this is counted solely as a number in that column). Open-ended questions and comments sections include synthesised results to highlight the major issues identified.*

National AIDS Plan	Yes	No	N/A
1. Is the GIPA Principle included in the National AIDS Plan?	***12***		
2. Were people living with HIV involved in developing the National AIDS Plan?	***11***		***1- don't know***
3. Has a baseline GIPA survey been undertaken disaggregating data by age and gender?	***1***	***10***	***1- don't know***
4. Is GIPA included in the national monitoring and evaluation framework?	***4***	***6***	***2-no response***

5. Are the National AIDS Plan and/or National GIPA Plan adequate i.e. has a budget, how have they been operationalized? How could they be improved?

Out of 12 respondents, 3 indicated the NACP-III has an adequate strategy and budget dedicated to GIPA. However, almost all the respondents indicated that they felt that there was no clear operational guideline for GIPA and no specific budget for GIPA indicated in the NACP-III or other implementation and policy documents. Most agreed that although there are policies in place that they are not adequately being implemented and translated into action. It was acknowledged numerous times that there could be improvement by involving more PLHIV throughout all processes using a bottom up approach.

In 2005 INP+ developed the *Greater Involvement of People Living with HIV/AIDS (GIPA) in National Response to HIV/AIDS in India Strategy Paper*, which has become the National GIPA Strategy. This then resulted in the jointly developed *Implementation Plan for the NACO's National GIPA Strategy* which addresses national, state, and district governmental actions towards the full implementation of GIPA over the course of NACP-III programme implementation and, highlights the role and involvement of PLHIV networks to patch up the lapse held during the implementation of NACP-II.

It was stated that in the NACO-III, while there is no explicit GIPA budget line, there are a number of expenditures that work towards GIPA, specifically the GIPA coordinator within 21 states. While a number of respondents addressed the GIPA Coordinator position, a few felt GIPA was being interpreted solely as an employment provision and that more of a focused and planned capacity

building process for meaningful involvement of PLHIV at all levels was needed. It was addressed that the state GIPA Coordinator's activities toward mobilizing community understanding of involvement of PLHIV may be limited. A number of respondents indicated that some of the GIPA Coordinator positions at State AIDS Control Society (SACS), which are reserved for PLHIV, were actually filled with HIV negative people.

Also, a number of respondents felt that understanding of GIPA is limited at many levels, one informant explained "*GIPA guidelines are not clearly understood by many service providers or PLHIV or all the stakeholders. To improve GIPA in India, first of all within the PLHIV community/Networks we must implement GIPA. Then the rest of the community and stakeholders will come*."

It is clear that there is no consensus on if the application of the GIPA principle is included in the NACP-III Monitoring & Evaluation component. However, results of the literature review find no specific mention of the GIPA principle in regards to monitoring and evaluation in the NACP-III. Although PLHIV networks are addressed as partners to engage in M&E in building networks and alliances to contextualize knowledge of local initiatives (section 15.12, pg. 168).

UNGASS	Yes	No	N/A
6. Will the government provide a report for 2008?	***7***	***1***	***2*** *-don't know* ***1****- no response* ***1****-govt. should respond*
7. Are organizations or networks of people living with HIV involved in drafting the report?	***5***	***3***	***1*** ***2*** *-don't know* ***1****-no response*
8. Will a civil society shadow report be developed for 2008?	***6***	***1***	***3*** ***1****-CS should develop this* ***1****-no response*

Comments

Most of the respondents felt the 2008 Indian UNGASS report was not adequate, mostly figured on prevention and was weak on qualitative issues. The UNGASS report highlights mostly on the progress and achievement but not gaps or challenges and lacks much information on treatment, care and support component. One informant addressed that the PLHIV community should make effort to be more involved in the report development, while another informant from what they called the grassroots level indicated they were alienated from this process.

Although there were a near equal number of responses of both YES and NO for question 7, there were no comments indicating the level of participation of PLHIV in the report development. It is indicated in the UNGASS report that civil society was consulted in the report development, but

there is no explicit mention of PLHIV. All of the NO replies to question 7 came from those respondents representing PLHIV networks.

Policy Development

9. At what point are people living with HIV generally first involved in national level policy development? Placed in order as indicated by how the majority of respondents answered:

Development/design	**7**
Conception/choice	**6**
Implementation	**6**
Monitoring or evaluation	**2**
All stages	**0**
Not sure	**0**

Comments

PLHIV are involved in various working groups of the NACP III, many respondents felt that the quantity and quality of involvement must be improved. Though PLHIV involvement is ensured at the national level it was seen by many respondents to be a "pick and choose approach" which doesn't allow for wider transparent participation. It was addressed that current processes exclude marginalised PLHIV like gay men and other men who have sex with men and people who inject drugs. Many respondents addressed that at state and district levels involvement of PLHIV is very low or minimal. However, the NACO says that PLHIV are involved at all levels.

10. How effective has the involvement of people living with HIV, including HIV-positive women's networks and organizations, been in policy development?

Most respondents did not comment on exactly "how effective" involvement has been, but addressed that although there have been opportunities for PLHIV involvement in policy development, recommendations from PLHIV are not included or reflected accurately in final documents and participation is often still tokenistic.

One informant provided an example of the policy impact of PLHIV, "*the Indian Network of Positive People (INP+) drafted a strategy plan to implement GIPA. Based on the strategy paper a National Policy on GIPA has been drafted, which is under finalization. Both INP+ & PWN+ participated and represented in all the related consultations held so far in lieu of formulation of the National GIPA policy*."

Also, one informant highlighted that there has been an impact in CCM proposal development, implementation and monitoring, but more training and capacity building is needed to support participation. Another informant said that the impact of PLHIV is demonstrated as the NACO is planning on opening more ART centres in rural areas so that people do not have to travel long distances and also planning for second-line treatment is beginning.

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

Universal Access	Yes	No	N/A
11. Has the government set universal access targets, including number of people to receive antiretroviral therapy by 2010?	***10***	***2***	
12. Were people living with HIV involved in the target setting process?	***8***	***3***	***1****-don't know*

Comments *(please include information on drug quality and regularity of supply)*:

Respondents commented that for many years the quality of ARVs and their access in India was not assured, but now it seems to be improving. However, the regularity of supply needs proper attention, as ART centers in smaller states continue to use expired medicine or lack funds and therefore run out of stock. A number of respondents commented that supply chain management system needs to be thoroughly looked into and involvement of PLHIV in this is a must.

Also, access to second-line ART continues to be a major issue, though the government has started pilot projects in centres in two states. One informant commented "*even though the ARV is supplied by Indian companies, there are many occasions that there is shortage of supply of ARVs in many state government run ART clinics... due to that many people develop resistance to their first line of treatment.*"

Although NACO did not comment on drug quality and regularity of supply they provided the targets of national ART programme under NACP-III which are as follows:

1. ***To provide free ART to 300,000 adult and 40,000 paediatric PLHIV by 2012 through 250 ART centres and 650 Link ART centres***
2. ***To involve inter-sectoral partners, NGOs, INP+. PWN+ and private partners, so as to have a comprehensive national framework of ART programme.***
3. ***To achieve and maintain a high level of drug adherence and minimise the number of patients lost to follow up, so that drugs are effective for longer period of time.***
4. ***To provide comprehensive care, support and treatment through establishment of 350 CCCs by 2012.***

Finally, INP+ identified that they regularly monitor and advise on preparing the country treatment update report for the ITPC "*Missing the Target*" report.

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

Psychological care	Yes	No	N/A
13. Has a national strategy been developed to provide psychological care to PLHIV, their families and communities?	*8*	*4*	
14. Were PLHIV involved in its development?	*9*		*3*

Comments

Beyond prevention, respondents indicated that care, treatment and support for PLHIV are one of the primary aims of the NACP-III. There is also a provision in NACP-III for funding for the PLHIV networks that in turn provide psychological care to PLHIV and families through their networks and also through the Community Care Centres. It was also indicated that through NACP-III there will be drop-in centers, which will be run in partnership with PLHIV networks, to be open in a number of states by 2010. However, it was indicated that PLHIV networks are not always involved in care delivery in all states and when this isn't in place the level of care is diminished.

Some respondents highlighted that when PLHIV are involved in psychological care that quality of care is increased and is more effective. A number of respondents indicated that although psychosocial care to PLHIV and their families is in national policy the quality of care and counselling on the ground is very poor, and most of the time PLHIV don't get the support they need, one said "*though we have the strategy our quality of counselling is still very poor*". A need for capacity strengthening and development was highlighted as was a need for the increased involvement of PLHIV in care delivery.

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

Research, and Sexual and Reproductive Health	Yes	No	N/A
15. Is the GIPA Principle applied in conducting medical research ***e.g. for drug trials and new prevention technologies?***	***7***	***4***	***1***
16. Does your country have a national sexual and reproductive health plan?	***9***	***1***	***1****-n/a* ***1****-no response*
17. Has a policy been introduced or incorporated into existing plans to address the sexual and reproductive health needs of women and men living with HIV?	***6***	***3***	***1****-n/a* ***1****-no response*
18. Was your organization involved in this?	***4***	***6***	***1****-n/a* ***1****-no response*

Comments

There were not many comments for this section, although a few respondents indicated the need to enhance the application of the GIPA principle in this political and policy area. UNAIDS indicated that it is advocating for a "*real policy on SRH of PLHIV*", but that it is still in the very early stages.

NACO provided the following comments: "*in partnership with the Indian network of People Living with HIV/AIDS (INP +) has undertaken significant programmes with women in high prevalence districts with the aim of:*

- ***creating networks***
- ***providing support to women and their families***
- ***creating sustainable opportunities for them***
- ***NACO and SACS have partnered with networks in mobilizing support and building advocacy for women positive networks in the country through consultations with government.***
- ***The national level training and consultation was organized by INP+ this year with support from the Ministry of WCD and NACO for organizing district level networks of positive women***"

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

Poverty Reduction Strategies	Yes	No	N/A
19. Does your country have a poverty reduction plan and/or strategy?	***10***	***1***	***1***
20. Was the poverty reduction plan and/or strategy developed with input from people living with HIV?	***1***	***8***	***2****-n/a* ***1****- don't know*
21. Has the poverty reduction plan and/or strategy been reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men?		***8***	***3****-n/a* ***1****-don't know*

Comments

One informant indicated that as a part of HIV mainstreaming, poverty reduction is talked about, but it is not addressed in the NACP-III. It was addressed by a number of respondents that there needs to be a greater understanding of the impact of HIV and people falling into poverty. One informant said "*even though there is a poverty reduction plan... it is not implemented properly in the grassroots level. There is no involvement of PLHIV network in poverty reduction plan strategy*"

The NACO provided the following response:
"To reiterate the Government's commitment to prevent the spread of HIV and to facilitate a strong multi-sectoral response to combat it effectively, National Council on AIDS has been constituted under the Chairmanship of Hon' ble Prime Minister of India. The council chaired by Hon 'ble Prime Minister consists of 31 Ministries, 7 State Chief Ministers, Indian Network of PLHIV representative and leading civil society representative. The functions of NCA are as follows:

1. ***To mainstream HIV and AIDS issues in all the Ministries & departments by considering it as a development challenge and not merely a public health problem.***
2. ***To lead the multi-sectoral response to contain the spread of HIV/AIDS in the country with special reference to youth and the workforce."***

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

Employment	Yes	No	N/A
22. Has the government enacted legislation in line with the ILO Code of Practice on HIV/AIDS and the World of Work[11]?	***2***	***8***	***1**-n/a* ***1**-don't know*
23. Were people living with HIV involved in its development?	***1***	***8***	***1**-n/a* ***1**-no response* ***1**-don't know*

Comments

A majority of respondents indicated that the Indian government has not enacted the ILO Code of Practice, but it was noted that an Indian lawyer's collective has drafted a bill related to HIV, discrimination and employment. However, this bill has been expected to be tabled for the past two years, but has yet to be discussed in parliament.

Respondents indicated that there are only few big companies in India that actually implement the ILO Code of Practice, but involvement of PLHIV is certainly limited or non-existent. However in many cases GIPA does not apply, e.g. how can GIPA be implemented in the informal labour, which is a huge sector in India?

[11] ILO (2001); International Labour Organization Code of Practice on HIV and the World of Work; http://www.ilo.org

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

GIPA Materials	Yes	No	N/A
24. Has your organization developed GIPA-related materials?	***7***	***4***	***1**-no response*
25. Are these being used by the government or other organizations?	***4***	***6***	***1**-n/a* ***1**-no response*
26. If your organization has developed or used GIPA-related materials, please describe these materials and provide a copy?			
Out of all of the key respondents, 6 organisations responded that they produce GIPA related material, most of which are policy documents. UNAIDS says anyone one can visit their website to access their GIPA materials, a state PLHIV network said that they have some workplace policies for PLHIV, while one organisation said they developed a poster related to stigma and discrimination for marginalised communities. **NACO says that *"based on the strategy paper a National Policy on GIPA has been drafted, which is under finalization and once finalized, it will be shared and made available on our website"* , and INP+ produces the following:** • **Training module on GIPA** • **GIPA Strategy Paper** • **GIPA Implementation Document** **Another organization highlighted that "we don't develop any GIPA related materials, but our organization is implementing GIPA 95% paid employee are PLHIV."**			

Financial Support	Yes	No	N/A
27. If people living with HIV participate in a government body, are their running costs such as travel, accommodation, child care and food reimbursed?	***8***	***3***	***1**-no response*
28. Are you adequately paid for your involvement?	***3***	***6***	***2**-no response* ***1**-can't comment*
Comments			
Respondents indicated that at the national level running cost are reimbursed, but this is not always the case at the state level. A number of respondents said that many of the State AIDS Control Societies (SACS) often deny running costs for participation in involvement also it was stated that "*most of the PLHIV who participate in such meetings or programmes are being underpaid without any assessing of their capabilities*". One informant said "*when govt. involves us they never pay us, but when NGO involve us we were paid for our time and resources*".			

GIPA REPORT CARD- COUNTRY PILOT: *INDIA*

Barriers to involvement

29. When asked to check off what are the three (3) greatest barriers to the greater involvement of people living with HIV, respondents indicated the following *(from top to bottom of how many respondents checked off each one*):

5 respondents	Lack of confidence in PLHIV organizations and/or networks	Fear of or actual discrimination	Lack of understanding and clarity on what GIPA is
	Low skill levels	Rejection by family, friends or the community	Funding constraints
2-5 respondents	Gender inequalities in access to education and services	Discrimination by health service providers	Poverty
	Lack of support services	Financial insecurity	Lack of access to ART and treatment for opportunistic infections
2 respondents	Homophobia and other forms of prejudice	Weak management	Fear of stigma
No respondents	Gender inequalities in domestic and childcare responsibilities	Gender inequalities in financial dependence on men	Involvement is not paid
	Discrimination in the workplace	Violence or fear of violence	Workplace policies
	No people living with HIV organization and/or network	Belong to minority or marginalized groups	

Comments and Additional Barriers

PLHIV and the networks themselves were highlighted as having a number of barriers; it is interesting to note that one informant said *"the definition of GIPA has to be changed to Greater Involvement of PLHIV Networks, not people living with HIV, so as to avoid favouritism and individualism".* However another informant said the *"PLHIV Network doesn't practice GIPA",* while another informant provided more details about perceived barriers within PLHIV networks saying *"some individual in the network overburden work responsibility and burnout, but are still not willing to share their responsibility. The possible reason could be job security"* and another comment indicated *"PLHIV Networks focus mostly on healthy PLHIV, often we don't address the issues of the people who are dying or sick of HIV related diseases."*

Also, another informant said *"PLHIV Network should follow the GIPA principle, since now we have many PLHIV who has skills/understand the issues and willingness to come out without fearing stigma. So our PLHIV individual /Network attitude should not reflect discriminatory behaviour within our community which acts further increase stigma which leads to lost to principle GIPA. It should never be "I" but "we" or "Us".*

The lack of mechanisms for accountability, inputting feedback and reporting to communities were also addressed and highlighted as barriers. The interviewer noted when summarizing discussions during interviews *"there's no communication or planning among the representatives and the community they represent, as a result it becomes tokenistic, and individualism and favouritism occurs. Because when PLHIV are involved in a national or state level body, they don't bother to take inputs or suggestion from the community they represent nor do they report back to the community."*

Opportunities for involvement

30. What are the three (3) current best opportunities for the greater involvement of people living with HIV? Respondents described the following:

Involvement in a policy making, design and implementation was named a number of times as a key opportunity for realising the greater involvement of PLHIV at all levels. Nationally, it was also stated that the labour law on non-discrimination is expected to be passed in 2008.

Engagement of PLHIV in monitoring and evaluation activities was addressed as a key opportunity.

Also, a number of PLHIV stated that the decentralization of access to ARV at community level and involvement supply chain management systems was an opportunity.

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GIPA REPORT CARD
COUNTRY PILOT: *LESOTHO*

Prepared by: Ellen Scout & Alex McClelland

September 2008

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

LITERATURE REVIEW

Lesotho has the third highest adult HIV prevalence in the world at 23.2%. It is considered a hyper-endemic country, with an estimated 270,273 people living with HIV in a country of only 1,795,000 people[12]. The country has one national AIDS plan, the five-year National HIV & AIDS Strategic Plan 2006-2011 (NSP), and one national M&E Plan. The NSP and M&E implementation are overseen through Lesotho's one coordinating body, the National AIDS Commission (NAC)[13]. The NSP itself addresses GIPA as a "Guiding Principle" throughout, and the Lesotho Network of People Living with HIV/AIDS (LENEPWHA) actively participated in the preparation of both the NSP and M&E plan[14]. The LENEPWHA states that they were "extensively consulted" throughout the strategy development[15].

Since the formation of LENEPWHA, the GIPA principle is starting to be addressed formally in Lesotho's response to HIV[16]. LENEPWHA was formed in 2005 as recognition of the vital role PLHIV play in ensuring a comprehensive HIV response and to strengthen the capacity and co-ordination of multisectoral implementers[17]. The NAC highlights the need for a strong civil society role in the implementation of the NSP, and indicates LENEPWHA as the primary partner in spearheading GIPA. The network is also tasked to take a leadership role in coordinating the needs of PLHIV in Lesotho[18].

LENEPWHA is an umbrella of network of 53 groups covering 10 districts and a membership of 1,940, of which 2/3 are female. The groups provide psychosocial support, address stigma and human rights for PLHIV and overall LENPWHA is increasingly being seen as a national hub of advocacy for the rights of PLHIV across Lesotho[19]. PLHIV in Lesotho are represented through LENEPWHA in a number of governance bodies like the CCM[20] and NAC HIV and AIDS Partnership Forum, among others. Representation of PLHIV is slowly increasing[21]however; LENEPWHA says that "representation of PLHIV on policy and decision-making bodies and associated events is inadequate, particularly in government"[22]. As part of their Five-Year Strategic Plan one of the strategic directions of LENEPWHA is the *Meaningful Involvement of PLHIV;* this strategic direction

[12] (National AIDS Commission, Government of Lesotho, 2007)
[13] (National AIDS Commission, Government of Lesotho, 2006)
[14] (National AIDS Commission, Government of Lesotho, 2007)
[15] (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006)
[16] (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006)
[17] With support from Action Aid International, UNAIDS and the Lesotho Government (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006)
[18] (National AIDS Commission, Government of Lesotho, 2007)
[19] (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006)
[20] The By-Laws for Lesotho's CCM indicate that 2 of the 25 membership seats are reserved for representation from PLHIV networks (Country Coordinating Mechanism (CCM), Lesotho, 2006).
[21] As indicated by the 2007 UNGASS Report and the LENEPWHA Five-Year Strategic Plan (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006) (National AIDS Commission, Government of Lesotho, 2007)
[22] (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006)

seeks to build capacity of PLHIV and support greater participation in government mechanisms; however this is the only part of the strategic plan of which there is no budget line[23].

There is no national strategy or policy on the application of the GIPA principle in Lesotho. In regards to the implementation of meaningful PLHIV involvement, beyond brief mentions in policy and as guiding principles, the NSP has a number of programmatic areas which address GIPA. One strategic direction of the NSP is "to reduce deterioration of socio-economic status of PLHIV", with the primary strategy being to support LENEPWHA in the development of effective governance to ensure the delivery of psychosocial support to PLHIV in their network[24]. The NSP also supports the integration of PLHIV in the provision of care, support and treatment activities. On the ground this translates into having PLHIV "expert patients" stationed at health facilities which support trained medical staff, as there is a severe shortage of trained medical professionals[25] and also sponsoring PLHIV to do door-to-door community gatherings to discuss "living positively with HIV" and stigma and discrimination.

The other area of the NSP which works towards the application of the GIPA principle is the "HIV and AIDS in the Workplace" indicators, which were to increase the number of employers, including government, which enacted HIV workplace polices to 80% by 2007[26]. However, LENEPWHA states that one of their challenges in reducing stigma and discrimination is that many government ministries have not enacted HIV workplace polices, and neither have many private sector companies[27].

[23] Other strategic directions in the LENEPWHA Strategic Plan include: Stigma & Discrimination, Care and Treatment, Psychosocial and Economic Support and Organisational Capacity and Institutional Development, among others. (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006).
[24] Annex 1 of the NSP, Impact Mitigation, People Living with HIV and AIDS, pg.72 (National AIDS Commission, Government of Lesotho, 2006)
[25] As part of the Guidelines for Implementation of Interventions in the Essential HIV and AIDS Services Package, and supported by the Clinton Foundation (National AIDS Commission, Government of Lesotho, 2006)
[26] Annex 1 of the NSP, HIV in the Workplace, pg.80 (National AIDS Commission, Government of Lesotho, 2006). No information was found during the literature review on if this target has been reached.
[27] (Lesotho Network of People Living With HIV/AIDS (LENEPWHA), 2006)

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

RESULTS OVERVIEW

11 respondents were interviewed; 6 females and 5 males. 9 PLHIV were interviewed from a number of national, regional and local community PLHIV networks, including care and support groups, organisations and one government ministry. UNAIDS and the National AIDS Commission were also interviewed.

When asked to indicate the greatest barriers preventing the greater involvement of PLHIV, PLHIV respondents in Lesotho address poverty, fears of actual discrimination and Lack of confidence in PLHIV organizations and/or networks as primary barriers to achieving meaningful PLHIV involvement. Stigma and fears of discrimination were also addressed numerous times throughout responses. Many respondents illustrated a challenging landscape for PLHIV which lacks sexual and reproductive health services, mechanisms to deal with discrimination, unreliable treatment access of which the generic supply can be of low quality, and a lack of other comprehensive support and health services. Second-line treatments are available, but a number of respondents identified worries about their quality and supply regularity.

There is slight improvement regarding the involvement of PLHIV. But respondents indicated that PLHIV have been regarded as beneficiaries more than implementers and when PLHIV make recommendations they are not adequately addressed.

There is no GIPA plan at national level, but GIPA is somewhat incorporated within the programmes of the National HIV & AIDS Strategic Plan 2006-2011 (NSP). As such there is no specific GIPA budget. The National AIDS Commission (NAC) states that the Lesotho Network of People Living with HIV/AIDS (LENEPWHA) is fully funded by the Global Fund and NAC to address GIPA issues. Therefore GIPA is being taken care of (if the national network of PLHIV has funding). However PLHIV networks say that there is not an adequate focus on GIPA in the NSP. It is addressed that there is a need for provision of adequate human capacity for the implementation of the plan, which currently doesn't exist.

Although respondents indicated that most national government ministries and private sector companies have HIV workplace policies, except at the local government level. Stigma and fear of discrimination can be so bad that even when services are offered free from an employer, PLHIV workers will not access them. Fear of discrimination is not unfounded as a number of instances were indicated by respondents such as one health clinic known for giving women living with HIV a contraceptive without their knowledge or consent. Also many PLHIV in Lesotho do not know their status, and stigma is so great that many wealthy PLHIV die before accessing services or getting tested.

A majority of PLHIV in Lesotho also feel that they are not adequately remunerated for their participation, one male respondent stating *"PLHIV are not adequately paid for their participation"*,

while a female PLHIV respondent also said *"most PLHIV are paid 'tokens' or they are viewed as volunteers, not facilitators".*

Many respondents did not have much knowledge of GIPA and lacked an understanding of the principle. For a few, the GIPA Report Card interview was the first they had heard of the concept.

Respondents living with HIV represented the following:

- Country Coordinating Mechanism member
- Lesotho Network of People Living with HIV/AIDS (LENEPWHA), President
- Senkatana Centre
- International Community of Women Living with HIV (ICW)
- St. Josephs Hospital
- Ministry of Finance and Development Planning
- Psycho-care
- Healthy Lifestyles Counselling and Testing Centre
- Positive Action

Respondents not living with HIV represented the following:

- UNAIDS, Partnership Advisor
- National AIDS Commission (NAC)

Demographic profile of respondents:

- 5 male, 6 female
- Age range 34 to 48
- 1 CCM member
- 3 PLHIV networks
- National AIDS Commission, Chief Executive
- Primarily country wide mandates for organisations represented, with a number of rural specific mandates.

People Living with HIV Staff and Volunteers:

8 organisations have paid employees of people living with HIV with total of 63 staff indicated. For those that indicated no PLHIV staff, 1 is a CCM member, 1 has volunteers only and 1 is UNAIDS and does not have them. The number of volunteers listed from 6 of the organisation was 478.

***Reading Report Card results**: the total responses from all of our respondents are included here. The following indicates the questions each interviewee were asked, and then how they indicated their response, either YES, NO, or in the N/A column (if another response was indicated it is also listed in the N/A column, if respondents answered N/A then this is counted solely as a number in that column). Open-ended questions and comments sections include synthesised results to highlight the major issues identified.*

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

National AIDS Plan	Yes	No	N/A
1. Is the GIPA Principle included in the National AIDS Plan?	***11***	***0***	***0***
2. Were people living with HIV involved in developing the National AIDS Plan?	***9***	***1***	***1-not sure***
3. Has a baseline GIPA survey been undertaken disaggregating data by age and gender?	***0***	***3***	***8-not sure***
4. Is GIPA included in the national monitoring and evaluation framework?	***9***	***0***	***1*** ***1-not sure***

5. Are the National AIDS Plan and/or National GIPA Plan adequate i.e. has a budget, how have they been operationalized? How could they be improved?

A number of respondents felt that there is slight improvement regarding the involvement of PLHIV, however overall respondents noted that there is a lack of GIPA policy in Lesotho. Many respondents addressed dissatisfaction with the lack policy seeking to operationalize GIPA and with appropriate budgetary allocation. Although GIPA is in the National HIV/AIDS Strategic Plan 2006-2011 (NSP), it is only as guiding principle. Also, it was noted that there is need for provision of adequate human capacity for the operationalisation the NSP, which 2 respondents felt currently didn't exist.

Summing up what a majority felt, one respondent from a PLHIV network indicated "*there is no GIPA plan at national level; however GIPA is incorporated within other programmes. As such there is no budget. So far the United Nations is the only body embracing the principle and ensuring that it is operationalised.*" Another respondent who is a PLHIV said "*PLHIV have been involved in discussions but their voices have not effected much change. Most are marginalized due to many factors including unemployment. We still do not have decision making power.*"

One respondent included that out of the NSP comes the Annual Implementation Plan which ensures that resources are allocated adequately and covers all implementing partners including PLHIV networks. The respondent from the National AIDS Commission also indicated that "LENEPWHA is fully funded by Global Fund and NAC to address the GIPA issues". However PLHIV networks say that there is not an adequate focus on GIPA in the NSP.

Local PLHIV network members indicated that at a community level there is a lack of information disseminated to organisations about what policies and opportunities exist, and overall financial support from the NSP is limited for PLHIV.

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

UNGASS	Yes	No	N/A
6. Will the government provide a report for 2008?	***8***	***0***	***3*** *-not sure*
7. Are organizations or networks of people living with HIV involved in drafting the report?	***1***	***5***	***5*** *-not sure*
8. Will a civil society shadow report be developed for 2008?	***2***	***4***	***5*** *-not sure*

Comments

UNAIDS and the NAC indicated that PLHIV were consulted during the development of the UNGASS report. But PLHIV respondents addressed often that they did not feel they were adequately represented or involved in UNGASS reporting. One respondent noting that "*concerns are not adequately addressed*" and the Lesotho Network of People Living with HIV/AIDS indicated that "*what exists is sheer tokenism; there is no part where LENEPWHA is involved... civil society does not come out clearly (in the UNGASS report).*"

NOTE: Many respondents (mainly PLHIV) lacked information on what UNGASS is and the interviewer had to provide background information, noting "*regarding UNGASS, especially question 7, respondents were consulted in order that they give inputs and were involved the validation of the report card.*"

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

Policy Development

9. At what point are people living with HIV generally first involved in national level policy development? Placed in order as indicated by how the majority of respondents answered:

All stages	**6**
Implementation	**3**
Not sure	**2**
Conception/choice	**0**
Development/design	**0**
Monitoring or evaluation	**0**

Comments

LENEPWHA says that PLHIV were consulted at all stages of the NSP development, NAC also says that PLHIV have been involved in all stages. A small number of PLHIV addressed that there was varied levels of participation, one respondent also noting "*there is a belief that PLHIV are not elite/educated, hence the lack of involvement in the conception stage*."

10. How effective has the involvement of people living with HIV, including HIV-positive women's networks and organizations, been in policy development?

PLHIV are still not involved in policy development, they have not been effectively involved,

ICW noted "*it has not been effective because it is not easy to meet. The women who usually meet are not representative of actual members*."

There were a number of comments highlighting the positive benefits of involving PLHIV, including reducing isolation, improving health and confidence of those involved, and the benefits to programmes.

LENEPWHA said that PLHIV have been effectively involved, while a number of other PLHIV said that PLHIV have not been effectively involved and have not had much impact.

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

Universal Access	Yes	No	N/A
11. Has the government set universal access targets, including number of people to receive antiretroviral therapy by 2010?	***10***	***0***	***1****-not sure*
12. Were people living with HIV involved in the target setting process?	***5***	***4***	***2****-not sure*

Comments *(please include information on drug quality and regularity of supply)*:

Respondents noted that services are available countrywide but since most people do not know their status services are not widely used. Also, it was highlighted that ART is free, but accessibility still remains a challenge due to the location of health facilities and some people still travel long distances to get to the nearest supply center to get their ART. One respondent saying "poverty *still affects our people – some people do not have means of traveling to health facilities*".

Another respondent said *"some health facilities can only see a limited number of patients per day. If a PLHIV is one but after the last they will not receive attention".* Also, It was also noted that attitudes and practices of health workers affect regular collection of ART and adherence, as stigma and discrimination affect PLHIV ability to freely access treatment. However, regarding treatment literacy 2 respondents noted that there has been some training on drug literacy and adherence for PLHIV support groups.

In regards to drug quality and regularity of supply respondent noted that replenishment of drug supply in some facilities is not regular and this can drastically affect service drastically, also, as said by one respondent *"AZT usually runs out, as it used for most people. However no problems have been encountered so far, the second and third lines are not easily available".* Another respondent noted *"the type of supply is generic; as such much cannot be said of the quality."*One respondent also noted *"our country depends on neighbouring South Africa for viral load checking. This is not appropriate and is indication that HIV and AIDS issues are not a priority".*

It was noted by LENEPWHA and a few other PLHIV that during the universal access targeting process PLHIV were not involved and that stigma still prevents many from being open and participating in policy processes.

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

Psychological care	Yes	No	N/A
13. Has a national strategy been developed to provide psychological care to PLHIV, their families and communities?	***8***	***3***	***0***
14. Were PLHIV involved in its development?	***5***	***2***	***4****-not sure*

Comments

It was noted by UNAIDS and NAC that psychological care is incorporated into the NSP strategic plan, specifically under the impact mitigation section. While one PLHIV said "*strategies exists but not at national level but at community and support group levels*".

It was noted by a respondent member of the PLHIV network that PLHIV have been treated and regarded as beneficiaries more than implementers in regards to care. While another PLHIV said that the NSP is there for PLHIV, but does not include family members.

One PLHIV said that PLHIV were not involved in the development of psychological care policy.

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

Research, and Sexual and Reproductive Health	Yes	No	N/A
15. Is the GIPA Principal applied in conducting medical research ***i.e. for drug trials and new prevention technologies?***	***3***	***6***	***2***
16. Does your country have a national sexual and reproductive health plan?	***11***	***0***	
17. Has a policy been introduced or incorporated into existing plans to address the sexual and reproductive health needs of women and men living with HIV?	***5***	***3***	***2****-not sure*
18. Was your organization involved in this?	***5***	***3***	***1*** ***2****-not sure*

Comments

It was indicated by a number of respondents that there is no research institution in Lesotho regarding ART and HIV, respondents noting that researchers are broad-based and also as said by one respondent "*the country's GDP is very low it cannot cope with reversing the impact of trials hence very sceptical to have trials in the country as possible reasons*".

In regards to the lack or appropriate sexual and reproductive health services respondents gave a number of indications, one PLHIV respondent said "*some PLHIV continue giving birth and there is no education regarding reproductive health for PLHIV*". While another noted "*traditional and Spiritual healers contribute by giving false hope to PLHIV. This has led to some PLHIV stopping medication on their own because they were prayed for*". Also, it was noted that in one centre PLHIV women were administered Depo-Provera as a contraceptive without their consent.

Also, one respondent noted that the Ministry of Health and Social Welfare is responsible for formulating the policy on sexual and reproductive health of PLHIV and other organizations only play an advisory role, and they also said "*PLHIV are usually only involved when time has run out and policies have to be presented to higher bodies for finalization*".

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

Poverty Reduction Strategies	Yes	No	N/A
19. Does your country have a poverty reduction plan and/or strategy?	***10***	***0***	***1****-not sure*
20. Was the poverty reduction plan and/or strategy developed with input from people living with HIV?	***5***	***4***	***2****-not sure*
21. Has the poverty reduction plan and/or strategy been reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men?	***2***	***6***	***3****-not sure*

Comments

Limited comments were collected for this section. Of the two comments collected on respondent stated that there is need for the poverty reduction document to be revisited to include the opinions of PLHIV, while the other stated that PLHIV were involved in the consultation process "*bearing in mind the fact that HIV and AIDS is the number one Millennium Development Goal in Lesotho*".

Poverty was however listed as the number one greatest barrier to the greater involvement of people living with HIV for question 29.

Employment	Yes	No	N/A
22. Has the government enacted legislation in line with the ILO Code of Practice on HIV/AIDS and the World of Work[28]?	***10***	***0***	***1****-not sure*
23. Were people living with HIV involved in its development?	***8***	***1***	***2****-not sure*

Comments

Although respondents indicated that most national government ministries and private sector companies have HIV workplace policies, except at the local government level. Management of some companies have agreed to assist their employees pay for medical costs but stigma and fear of discrimination can be so bad that even when services are offered free from an employer, PLHIV

[28] ILO (2001); International Labour Organization Code of Practice on HIV and the World of Work; http://www.ilo.org

workers will not access them because stigma is associated with the clinics.

It was also noted that fear of discrimination is not unfounded, as a number of instances were indicated by respondents, such as a known health clinic which has been giving women living with HIV a contraceptive without their knowledge or consent. One respondent said "*discrimination and stigma still remain in some workplaces. These include government departments, community and industry*".

GIPA Materials	Yes	No	N/A
24. Has your organization developed GIPA-related materials?	*8*	*2*	*1*
25. Are these being used by the government or other organizations?	*7*	*2*	*2*

26. If your organization has developed or used GIPA-related materials, please describe these materials and provide a copy?

Many respondents said they had developed pamphlets and posters, but none specifically on GIPA. Of those that replied with more information, UNAIDS said they have GIPA principle materials, ICW said they have a training manual, and Positive Action said they make red ribbon badges, beaded jewellery, grass baskets and a variety of other income generating items. LENEPWHA said they are working on developing GIPA materials. NAC listed that these questions were not applicable to them.

Financial Support	Yes	No	N/A
27. If people living with HIV participate in a government body, are their running costs such as travel, accommodation, child care and food reimbursed?	*6*	*3*	*2-not sure*
28. Are you adequately paid for your involvement?	*1*	*5*	*2* *3 -not sure*

Comments

Responses were limited for this section; however of the four short comments listed one respondent indicated that "*travel and accommodation are usually paid for*", another said "*PLHIV are expected speak in public but not given any remuneration*" and another said "*PLHIV are not paid adequately for their participation*", and finally one respondent said "*child care is not part of the reimbursement*".

GIPA REPORT CARD- COUNTRY PILOT: *LESOTHO*

Barriers to involvement

29. When asked to check off what are the three (3) greatest barriers to the greater involvement of people living with HIV, respondents indicated the following *(from top to bottom of how many respondents checked off each one*):

6-9 respondents	Poverty	Fear of or actual Discrimination	Lack of confidence in PLHIV organizations and/or networks
2-5 respondents	Funding constraints	Rejection by family, friends or the community	Low skill levels
	Weak management	Lack of understanding and clarity on what GIPA is	
1 respondent	Homophobia and other forms of prejudice	Lack of support services	Financial insecurity
No respondents	Gender inequalities in domestic and childcare responsibilities	Gender inequalities in financial dependence on men	Involvement is not paid
	Discrimination in the workplace	Violence or fear of violence	Workplace policies
	Gender inequalities in access to education and services	Fear of stigma	No people living with HIV organization and/or network
	Belong to minority or marginalized groups	Lack of access to ART and treatment for opportunistic infections	Discrimination by health service providers

Comments and Additional Barriers

Stigma was named as barrier to participation numerous times; it was indicated that most PLHIV do not know their status and others are afraid of knowing for fear or rejection and stigmatization. Also, most people who are open about their status are not highly educated and do not have adequate confidence. A number of respondents said that HIV is heavily related to class in Lesotho, and while many PLHIV do not know their status, stigma is so great that many wealthy PLHIV die before accessing services or getting tested. As indicated from one respondent "*high death rates among the elite due to HIV related complications as they were on denial and did not seek proper medical assistance*" was

listed as a barrier.

Other barriers we named such as poor attendance of government employees in activities organized by PLHIV.

One respondent listed PLHIV involvement formal decision making bodies as a barrier, listing that PLHIV are not included in the Parliament HIV and AIDS sub-committee, Cabinet sub-committee on HIV and AIDS, or on the National AIDS Board.

PLHIV organisations were also listed as having barriers to successful involvement of PLHIV, one respondent said "*...some groups are still not part of LENEPWHA. Some support groups are not made up of people living with HIV. These people are the ones who receive info and resources but do not ensure that PLHIV are benefiting*." It was also indicated that some PLHIV organizations do not have clear objectives and lack structure. Also, it was indicated by one respondent that PLHIV organisations lack support structures that can build confidence and resilience in people accepting themselves.

Opportunities for involvement

30. What are the three (3) current best opportunities for the greater involvement of people living with HIV? Respondents described the following:

Current momentum to reduce stigma in Lesotho was named as an opportunity in a number of ways, including the strengthening of campaigns such as the Integrated Know Your Status Campaign, and engagement of more PLHIV who are open about their status. Also, the existence of laws that protect the rights of PLHIV, and also that some religious bodies are taking steps in the fight against HIV/AIDS were named a progress forward to achieving greater involvement of PLHIV.

Support for and from PLHIV organisations were named a number of times as an opportunity, including the financial assistance that is channelled through LENEPWHA.

Involvement of PLHIV in care and support delivery as expert patients was addressed as a key opportunity. Also, the active participation of PLHIV in the NAC and other structures such as the CCM were indicated as important capacity building opportunities.

GIPA REPORT CARD
COUNTRY PILOT: *KENYA*

Prepared by: Joe Muriuki & Alex McClelland

GIPA REPORT CARD- COUNTRY PILOT: *KENYA*

LITERATURE REVIEW

Kenya is estimated to have one of the highest HIV prevalence in the Eastern Africa region and has a severe generalized HIV epidemic. Currently UNAIDS estimates that there are between 1.6 and 1.9 million people living with HIV among Kenya's overall population, which is approximately 37 million people. Prevalence for those between 15 to 49 years old is 7.1% to 8.3%. There are approximately 0.9 to 1.1 million women living with HIV in Kenya, while there are approximately 1.4 to 1.7 million children up to 14 year's old living with HIV[29]. In 2003, Kenya's President Kibaki declared the "Total War against AIDS" and mandated Kenya's one national HIV coordinating authority, National AIDS Control Council (NACC), to coordinate and manage the implementation of multisectoral approach to HIV and AIDS for a comprehensive national response to HIV and AIDS[30]. Since then there has been a trend in prevalence, improved access to testing and counselling, enhanced access to treatment, care and support and programmes aimed at mitigating the impact of HIV and AIDS on vulnerable populations[31].

The most recent Kenyan National Strategic Plan 2005/6-2009/10 (KNASP) was developed as a result of a Kenyan Joint HIV/AIDS Programme Review, which brought together many actors in the HIV response, including PLHIV network representatives. One of the core principles of the KNASP is the "Maximum engagement of PLHIV in the implementation of the strategy". Section 3.5 of the KNASP discusses the full implementation and operationalization of the GIPA principle into the KNASP, which will be achieved through the "*involvement of people living with HIV/AIDS at the highest levels in the development and coordination of the HIV/AID response; strengthening the capacity of PLHIV organisations to be involved effectively in prevention, treatment and care and mitigation of socio-economic impact; and supporting the creation of representative and effective PLHIV organisations at all levels*"[32].

Although there are no employment positions with a mandate to support the application of the GIPA principle at the NACC or indicated as part of the KNASP, the NACC has a GIPA Task Force and PLHIV networks are permanent secretaries on the NACC board[33]. The NACC aspires to full application of the GIPA principle, however there are only a number of clearly articulated directions which work towards achieving meaningful involvement of PLHIV in the policy. One of the KNASP Priority Areas is '*Improving quality of life of People Infected and Affected by HIV/AIDS*' [34] with the National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK) tasked as the

[29] http://www.unaids.org/en/CountryResponses/Countries/kenya.asp
[30] (National AIDS Control Council, Office of the President, Kenya, 2008)
[31] (National AIDS Control Council, Office of the President, Kenya, 2008)
[32] (National AIDS Control Council, 2005)
[33] Although the GYCA UNGASS Youth Shadow Report for 2008 indicates that young people living with HIV address that they are not represented at the NACC (Global Youth Coalition on HIV/AIDS, 2008).
[34] With indicators of at least 10 HIV/AIDS anti-stigmatisation advocacy groups established in each district; 50% of health workers in all health provider institutions sensitised on developing positive attitude towards PLWHA; and 75% of health workers in all health provider institutions sensitised on developing positive attitude towards PLWHA. The responsibility being tasked NEPHAK with support from NACC.

primary implementer. Though KNASP states GIPA is critical for effective prevention and mitigating the impact of HIV, neither NEPHAK nor other PLHIV groups are listed as partners in implementing either the Prevention or Mitigation of Socio-Economic Impact of HIV and AIDS policies[35].

The KNASP is also seeking to support the enactment of HIV workplace polices in the private sector and government ministries[36]; the policy also addresses the protection of human rights for PLHIV and vulnerable groups. Kenya has now enacted an anti-discrimination law and also the HIV Prevention and Control act[37]. It was recently noted in Kenya's 2008 UNGASS report that there are numerous violations of PLHIV rights happening in all sectors of society, and PLHIV human rights discussions are limited, if non-existent in public and political discourse.

The National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK) was established in 2003, which evolved as a grassroots movement and is now nationally recognized as the voice of PLHIV in Kenya. With representatives from all 9 regions of the country, all of which are elected. NEPHAK strives to promote the application of the GIPA principle with recent strategic objectives aiming to empower PLHIV to get meaningfully involved in HIV and AIDS programmes at regional and national levels. Also, the network is working to enhance its own capacity through initiatives to support capacity building, institutional strengthening to effectively monitor and evaluate programs, and to coordinate and facilitate member organizations to implement programs[38].

Beyond KNASP, in 2007 the Guidelines for Mainstreaming GIPA into the National HIV Response in Kenya were developed through the Constella Futures Group and funded by the UK Department for International Development (DFID). The aim of the guidelines is to provide information and build knowledge about the GIPA principles for different stakeholders involved in implementing various aspects of the current KNASP. The guidelines are intended to increase and improve the meaningful participation of PLHIV in different sectors throughout the broad national epidemic response in Kenya and are targeting all actors including government, PLHIV networks, CSOs and NGOs, and private sector stakeholders.

The guidelines look at a comprehensive view of GIPA which is supported by the UNAIDS GIPA definition and focuses on funding, training, employment, human rights, policies and programmes, and include specific guidelines for NACC with practical steps on how to achieve the meaningful involvement of PLHIV throughout the KNASP, as well as specific guidelines for all other sectors. The document also provides guidelines for GIPA monitoring and evaluation including the creation of

[35] (National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK), 2006)
[36] (National AIDS Control Council, Office of the President, Kenya, 2008)
[37] Has yet to be fully be operationalised (National AIDS Control Council, Office of the President, Kenya, 2008)
[38] (National Empowerment Network of People Living with HIV and AIDS in Kenya (NEPHAK), 2006)

specific indicators and looks to support technical capacity and skills training for PLHIV, so that PLHIV are effective and meaningful in their roles on governance[39].

[39] Organizations and stakeholders implementing HIV and AIDS programmes should develop appropriate indicators for GIPA mainstreaming.

- NACC to support the development of indicators for mainstreaming GIPA within the KNASP.
- NACC to ensure GIPA progress report are given within the JAPR for all priority areas and within the results framework.
- NACC to support documentation and dissemination of GIPA best practices to all stakeholders.
- All stakeholders, including NACC should review their M& E framework and indicators and develop tools to enhance GIPA tracking and reporting.
- Stakeholders implementing HIV and AIDS programmes to consistently carry out GIPA implementation assessment for all areas in the HIV and AIDS response.

GIPA REPORT CARD- COUNTRY PILOT: *KENYA*

RESULTS OVERVIEW

10 PLHIV were interviewed from a wide range of national and regional PLHIV networks, care and support organisations and one respondent in an employment position reserved for PLHIV in the Ministry of Health. Also interviewed, was a Program Officer from the National AIDS Control Council (NACC) and a representative from UNAIDS in Kenya, for a total of 12 interviews.

Respondents identified that Kenya is beginning to have a well developed landscape in regards to the application of the GIPA principle in national policy, but overall, in regards to policy development, a majority of respondents indicated that PLHIV are involved only at the implementation phase, not at the conception or development phase. Also, PLHIV respondents specifically indicated that representation is still tokenistic at many levels and PLHIV voices are not listened to even when they are involved.

Respondents also addressed the concerns that the GIPA principle has not been adequately addressed in the Kenyan National HIV and AIDS Strategic Plan (KNASP). It was identified that there is no desk or officer focussed on the application of the GIPA principle, and the KNASP has not yet been amended accordingly to reflect the newly developed National GIPA Guidelines.

Quality of ART and regularity of supply were addressed as concerns, as was access to second line ART. It was also indicated that PLHIV were not included in the development and setting of universal access targets.

Various opportunities were identified by respondents to support the meaningful involvement of PLHIV including the newly developed GIPA Guidelines, which will shortly be implemented. It was indicated by respondents that there are employment positions available in the private sector for PLHIV and government based on the application of the GIPA principle. However, one respondent employed in a government ministry indicated that she is only there as an example for others and often asked to present her “story” while her skills are not utilized.

Respondents listed poverty, lack of clarity about what GIPA is, and fear of stigma as the greatest barriers to meaningful involvement of PLHIV.

Respondents living with HIV represented the following:

- National AIDS/STI Control Program, Ministry of Health, Program Assistant
- Eastern Africa Treatment Access Movement
- USAID/Health Policy Initiative: Constella Futures Group
- PGH Hospital
- Coast Province People Living with HIV/AIDS (COPE), provincial network
- Goodwill Women Organization
- National Empowerment Network of People Living with HIV/AIDS in Kenya (NEPHAK)
- VIHDA, rural care and support organisation

GIPA REPORT CARD- COUNTRY PILOT: *KENYA*

- Nyeri Municipal Council and Nyeri People Living with HIV/AIDS (NYEPLWA)
- Maxfacta Youth Group, youth PLHIV network

Respondents not living with HIV:

- National AIDS Control Council, Program Officer
- UNAIDS

Demographic profile of respondents:

- Age range: 28-40 years
- 9 Female, 2 Male

People Living with HIV Staff and Volunteers:

- UNAIDS and NACC didn't provide answers
- Staff:25 from 7 organisations
- Volunteers:107 from 7 organisations (1 of which supports 6 national level PLHIV networks)

***Reading Report Card results**: the total responses from all of our respondents are included here. The following indicates the questions each interviewee were asked, and then how they indicated their response, either YES, NO, or in the N/A column (if another response was indicated it is also listed in the N/A column). Open-ended questions and comments sections include synthesised results to highlight the major issues identified.*

National AIDS Plan	Yes	No	N/A
1. Is the GIPA Principle included in the National AIDS Plan?	*6*	*5*	*1*
2. Were people living with HIV involved in developing the National AIDS Plan?	*7*	*5*	
3. Has a baseline GIPA survey been undertaken disaggregating data by age and gender?	*1*	*11*	
4. Is GIPA included in the national monitoring and evaluation framework?		*12*	
5. Are the National AIDS Plan and/or National GIPA Plan adequate i.e. has a budget, how have they been operationalized? How could they be improved?			
Of the respondents interviewed, 9 of the 11 felt that GIPA was not adequately addressed in the Kenyan National HIV and AIDS Strategic Plan 2005-2010(KNASP). Respondents stated that while there are mentions of GIPA in the KNASP, there was not a comprehensive focus on GIPA. It was noted that there is not a national GIPA plan or any resources allocated for staff or capacity development towards GIPA implementation. However, National GIPA Mainstreaming Guidelines were recently developed in 2007 and based on a country GIPA situational analysis. It was addressed that the National GIPA Guidelines are still in draft form but are undergoing review			

through the AIDS Control Council (NACC) communication structure which includes national, municipal, district and constituency representation. Also, one respondednt noted that the National GIPA Guidelines have also been costed to realize the required resourced need for full implementation, however UNAIDS said "*the GIPA guidelines have been completed, are being operationalized but there is an inadequate budget*".

Overall, among respondents there is general consensus that there is no budget allocated to the application of the GIPA principle within the KNASP 2005-2010 and a there is need for greater research to find out the extent of GIPA application in Kenya. Even NACC acknowledges there a lot more that needs to be done including operationalizing the GIPA, educating the public and putting appropriate structures in place. The NACC could state clearly if they have any HIV+ staff even on their questionnaire.

All respondents clearly stated that awareness on GIPA was low and where there is information, as in National AIDS and STD Control Programme (NASCOP), capacity is built towards countering occupational hazard occasioned by presence of HIV positive people. For example, "*at NASCOP GIPA is not a priority, its mainly headed and run by medical people who are concerned about giving drugs; and health worker capacities are built on how to provide various interventions to protect themselves from occupational exposure that may result in HIV infection*", as stated by one informant.

Also, 4 respondents stated clearly that PLHIV involvement was just tokenistic, and even then limited to a few select leaders who dominate meetings and seminars. *Others stated that GIPA* seen as solely as an employment provision. According to one informant, who says she is the only openly PLHIV staffer at a government AIDS programme, she stated that she is actually used as 'demonstration' to share her experiences for the benefit of others, despite her qualifications, and is also facing discrimination based on application of double standards for staff benefits even when funding is allocated by Center for Disease Control for her work.

UNGASS	Yes	No	N/A
6. Will the government provide a report for 2008?	*8*	*4*	
7. Are organizations or networks of people living with HIV involved in drafting the report?	*8*	*3*	*1*
8. Will a civil society shadow report be developed for 2008?	*4*	*4*	*4*

Comments

A majority of respondents stated that information on UNGASS is not widely communicated, and a few recommended the need for a greater number of civil society shadow reports. UNAIDS noted however that no decision has been made on a civil society shadow report. Although a number of respondents named the need for developing a shadow report, it was not clear if this was being developed.

Many respondents also stated that there a lack of effectiveness regarding PLHIV involved in reporting on the HIV response and report development, and a need for much greater involvement was often addressed. One respondent from the national PLHIV network noted "*individuals representing PLHIV do not give feedback, consultation is weak, and information does not get to the grassroots*". While another PLHIV respondent said that there is "*very little involvement of PLHIV, only leaders of the national network*", when addressing the UNGASS reporting process. However, the NACC response indicated a different understanding stating that PLHIV "*are involved in the country review and development of the country position paper. They also participate in UNGASS through representation of the network*".

Policy Development

9. At what point are people living with HIV generally first involved in national level policy development?

Conception/choice	***0***
Development/design	***1***
Implementation	***5***
Monitoring or evaluation	***6***
All stages	***1***

Comments

UNAIDS said PLHIV all stages of development, NACC says that PLHIV are involved at the highest policy level, they are also involved in the joint AIDS programme review.

PLHIV respondents specifically indicated that representation is still tokenistic at many levels and PLHIV voices are not listened too even if they are involved. Many respondents address that often those that are there are just there to represent are not empowered or actively involved, and they therefore feel their participation has been ineffective. One PLHIV network respondent said "*PLHIV have been involved in (policy) development but has not been wide consultation amongst PLHIV, representatives do not communicate widely, and we must improve communication and governance*". A number of respondents noted that when PLHIV are involved it is most often in implementation of care, specifically home-based care. However, it was indicated that the new GIPA guidelines have improved PLHIV participation in policy development and implementation, and will do so more widely upon further implementation of the guidelines.

10. How effective has the involvement of people living with HIV, including HIV-positive women's networks and organizations, been in policy development?

Respondents addressed that PLHIV are involved as a formality, and are often not listened to and involvement is not effective, and it was addressed the need for more involvement of women living with HIV, one PLHIV respondent stated "*there is representation, but not in policy development*", another PLHIV said "*women's networks are not very visible in policy development though they have representation in the NACC council and other policy making bodies*", and further described the situation by stating "*despite the fact that Kenya has a feminized epidemic a*

***majority of positive women are not engaged in policy and advocacy dialogues*".**

UNAIDS said "*PLHIV and women were involved the development of the HIV policy (KNASP)*". While the NACC said that although PLHIV are represented, but acknowledged that the situation could be improved.

One PLHIV respondent noted that there have been some successes with OVC organisations, who have been effectively involved in the national OVC policy development.

GIPA REPORT CARD
COUNTRY PILOT:
TRINIDAD & TOBAGO

Prepared by: Sommer Williams, Nicholas Granger & Alex McClelland

GIPA REPORT CARD- COUNTRY PILOT:

TRINIDAD & TOBAGO

LITERATURE REVIEW

Trinidad and Tobago is a small country with a population of 1.3 million people and HIV prevalence for those between the ages of 15 to 49 years at 1.5%. This means there up to 19,000 PLHIV in the country, more than half of which are women[40].

The HIV response in Trinidad and Tobago is coordinated by the National AIDS Coordinating Committee (NACC) and the HIV national response is guided by the National Strategic Plan (NSP) 2004-2008. The NACC is comprised of a wide range of stakeholders including representatives from public and private sector, civil society and PLHIV[41]. The NACC is divided in to 5 sub-committees who work on the key areas of the NSP Prevention; Treatment Care and Support; Advocacy and Human Rights; Surveillance and Research; Programme Management, Coordination and Evaluation. The key responsibilities of the NACC are coordination of the national response and policy advice. It is indicated by the NACC that PLHIV are involved in the NACC and sector levels[42].

A primary guiding principle of the NSP is inclusion of PLHIV and respect for the basic human rights of all PLHIV. The NSP looks to strengthen human rights for PLHIV and to strengthen support groups of PLHIV.

The NSP indicates that there is currently no legislation to protect the rights of PLHIV[43]. However, there is a Human Rights Desk, which was recently established and exists to document infractions against PLHIV. In the NSP under Advocacy and Human Rights sub-section, there is a focus on the creation of a legal framework that protects the rights of PLHIV, and also to promote openness and acceptance of PLHIV in the workplace and wider community. As a result, according to the 2008 UNGASS Report a report is currently underway assessing the human rights of PLHIV in Trinidad and Tobago as part of the development of the legal framework initiated through the NSP[44].

In other regards to the involvement and support of PLHIV in the NSP, there is a focus under the Treatment, Care, and Support sub-section of the NSP that seeks to provide appropriate economic and social support to PLHIV. The Programme Management, Coordination and Evaluation sub-section of the NSP addresses PLHIV, as this activity seeks to strengthen key constituencies that are part of the NACC, as well as strengthen and increase the number of support groups for PLHIV to better respond to the epidemic[45].

The NACC highlights the critical role of NGOs in implementing the NSP, among which it highlights PLHIV organisations and networks.

[40] http://www.unaids.org/en/CountryResponses/Countries/trinidad_and_tobago.asp
[41] (National AIDS Coordinating Committee, December 2007)
[42] (National AIDS Coordinating Committee, December 2007)
[43] (Office of the Prime Minister Republic of Trinidad and Tobago , December 2003)
[44] (National AIDS Coordinating Committee, December 2007)
[45] (Office of the Prime Minister Republic of Trinidad and Tobago , December 2003)

GIPA REPORT CARD- COUNTRY PILOT:

TRINIDAD & TOBAGO

A primary NGO in Trinidad and Tobago for PLHIV is Community Action Resource (CARe), a community-based PLHIV organisation which provides services such as individual and group counselling, support and care, home-care, a drop-in center, information and education, community outreach, and trainings. The organisation has many clients and is seen as key support for many PLHIV in a country where stigma and discrimination are intense daily pressures.

The Caribbean Regional Network of people living with HIV (CRN+) according to their mission statement "*is the authentic voice of Caribbean people living with HIV/AIDS, as a full and equal partner in the collaborative fight against HIV/AIDS, CRN+ is driven by PLHIV making a meaningful difference to their lives*"[46]. The network was established on September 28th 1996, with its Secretariat based in Trinidad and Tobago. CRN+ focuses on raising awareness of PLHIV through advocacy, lobbying and sensitisation activities. The network seeks to improve access to information exchange, advocacy, lobbying and to build capacity among PLHIV in the region.

In regards to UNGASS reporting, CSOs were consulted in the development of the UNGASS report, with key stakeholders, also related to universal access setting of indicators however PLHIV are not explicitly stated as being involved[47].

RESULTS OVERVIEW

10 PLHIV respondents interviewed were all primarily from CARe and CRN+, either members or staff of both organisations. A UNAIDS representative and National AIDS Programme Director were also interviewed.

It was noted that there is no national GIPA Plan in Trinidad and Tobago. Respondents said that the National Strategic Plan (NSP) has a budget that is operationalized through the National AIDS Coordinating Committee (NACC). Most respondents felt that there was a need for greater need for involvement of PLHIV in the implementation of the NSP.

Many of the respondents did not have much knowledge of UNGASS or other policies on SRH, employment or GIPA.

Respondents noted that while there is access to free ARVs and quality and supply are sufficient, that less than half of all PLHIV in the country are currently on ART.

In regards to provider stigma and discrimination, it was indicated that in some cases nurses and midwives still impose their views to pregnant HIV-positive mothers and children.

[46] http://www.crnplus.org
[47] National AIDS Coordinating Committee, December 2007

GIPA REPORT CARD- COUNTRY PILOT:

TRINIDAD & TOBAGO

Respondents noted that a workplace policy on HIV was launched in April 2008 and legislative assessments are ongoing with the involvement of PLHIV towards amending the policy that aims to protect the rights of PLHIV. One respondent noted that the ILO has embarked on a project in collaboration with the government of Trinidad and Tobago through the Ministry of Health in creating a HIV workplace policy.

When asked to identify barriers to involvement fear of stigma, Fear of or actual discrimination, homophobia and other forms of prejudice, and low skill levels were most often identified by respondents.

Many respondents noted a number of opportunities including through policy level involvement in the NACC, working on access and ARVs issues, and opportunities to participate in public forums and ways to make your voice be heard as a PLHIV.

Interviewees living with HIV represented the following:

- 4 respondents from Community Action Resource (CARe)
- 5 respondents from the Caribbean Regional Network of people living with HIV (CRN+)
- 1 respondent from Rapport

Interviewees not living with HIV represented the following:

- National AIDS Programme, HIV/AIDS Coordinating Unit, Ministry of Health, Programme Director
- UNAIDS Country Office, Trinidad & Tobago

Demographic profile of respondents:

- Age range: 31 – 63 years
- Sex: 6 Males/ 6 Females

***Reading Report Card results**: the total responses from all of our respondents are included here. The following indicates the questions each interviewee were asked, and then how they indicated their response, either YES, NO, or in the N/A column (if another response was indicated it is also listed in the N/A column). Open-ended questions and comments sections include synthesised results to highlight the major issues identified.*

GIPA REPORT CARD- COUNTRY PILOT:
TRINIDAD & TOBAGO

National AIDS Plan	Yes	No	N/A
1. Is the GIPA Principle included in the National AIDS Plan?	***10***	***1***	***1*** *n/a*
2. Were people living with HIV involved in developing the National AIDS Plan?	***12***		
3. Has a baseline GIPA survey been undertaken disaggregating data by age and gender?	***5***	***4***	***2*** *unsure* ***1*** *no response*
4. Is GIPA included in the national monitoring and evaluation framework?	***7***	***2***	***1*** *n/a* ***1*** *no response*

5. Are the National AIDS Plan and/or National GIPA Plan adequate i.e. has a budget, how have they been operationalized? How could they be improved?

It was noted that there is no national GIPA Plan in Trinidad and Tobago. Respondents said that the National Strategic Plan (NSP) has a budget that is operationalized through the National AIDS Coordinating Committee (NACC) under the Office of the Prime Minister. It was mentioned by 3 respondents that while the NSP is cost, government bureaucracy mitigates effective and timely expenditures for implementation.

Respondents noted that NGOs and CSOs must be part of the decision-making process at a government level to ensure adequate inclusion, and successful implementation of the NSP. Also, one PLHIV respondent said that the NSP does not adequately specify the needs of PLHIV, and 2 PLHIV respondents had concerns over their expressed lack of impact that the NSP has had on PLHIV. The Ministry of Health representative respondent mentioned that there is a PLHIV representative who assists with M&E activities regarding the NSP.

Despite a number of concerns, 5 respondents indicated that the NSP is adequate and has to be revised in 2009 identifying its five priorities: Prevention, Care Treatment & Support, Human Rights and Surveillance, Stigma & Discrimination and Monitoring & Evaluation.

3 of the respondent were unable to provide feedback, and a few of them noted that they have not seen or were part of the design phase of the NSP.

GIPA REPORT CARD- COUNTRY PILOT:
TRINIDAD & TOBAGO

UNGASS	Yes	No	N/A
6. Will the government provide a report for 2008?	***10***	***2***	
7. Are organizations or networks of people living with HIV involved in drafting the report?	***10***	***2***	
8. Will a civil society shadow report be developed for 2008?	***6***	***4***	***2*** *n/a*

Comments

Of the 7 respondents who commented noted that the government has provided a UNGASS report for 2008, however, a few felt that the development process was not transparent. One respondent indicated that a meeting was held, but that civil society members were not as active as they should be. Respondents identified access to antiretroviral treatment, and anti-discrimination legislation were some of the priority areas that the UNGASS report should cover.

Although 6 respondents indicated that a civil society shadow report would be development, most respondents who commented were unaware of the development of this report.

5 respondents were unable to provide feedback, having no knowledge of UNGASS or the purpose of the report.

GIPA REPORT CARD- COUNTRY PILOT:

TRINIDAD & TOBAGO

Policy Development

9. At what point are people living with HIV generally first involved in national level policy development?

Conception/choice	**8**
Development/design	**3**
Implementation	**4**
Monitoring or evaluation	**7**

Comments

The UNAIDS respondent noted "*HIV specific NGOs are represented on the NACC and its sub-committees where policy is derived, therefore, it involvement is usually from conception*". The Ministry of Health NAP representative respondent noted that PLHIV are invited to participate in all national HIV policy. Another respondent indicated that "*there are episodes of consultation before implementation but not always, usually after trial and error PLHIV are included in policy development*".

In regards to challenges for PLHIV participation in policy development, it was indicated by a majority of the respondents that stigma and discrimination are huge barriers to effective participation. One PLHIV respondent indicated "*people living with HIV are the last to know anything*". One respondent noted that after an initial consultation "*the rest is done and then people return to evaluate therefore, little information is available by the end of the process*".

A few respondents indicated that the only time PLHIV are consulted is when they become a member of a support group (as focus groups on certain policies are done at the support group level). One respondent noted that at the Human Rights Desk complaints by the PLHIV community have been utilized as an analyzing template to assess the needs of the PLHIV community.

10. How effective has the involvement of people living with HIV, including HIV-positive women's networks and organizations, been in policy development?

It was mentioned by one respondent that the NACC has been actively seeking to meet with PLHIV in regards to policy development around the rights and protection of PLHIV. One respondent noted "PLHIV are included in policies developed thus far and their inputs have been valued. Having been involved in decision-making and being on the board on the NACC, attention is paid in a meaningful and feedback emanates from the ground level of those mostly affected".

Respondents also noted that there are some major hindrances to PLHIV being involved in policy development such as stigma & discrimination, confidentiality and disclosure that impacts or influence the involvement.

GIPA REPORT CARD- COUNTRY PILOT:
TRINIDAD & TOBAGO

Universal Access	Yes	No	N/A
11. Has the government set universal access targets, including number of people to receive antiretroviral therapy by 2010?	*10*	*2*	
12. Were people living with HIV involved in the target setting process?	*6*	*6*	

Comments *(please include information on drug quality and regularity of supply)*:

Respondents noted that the introduction of ARTs began in Trinidad & Tobago in 2001 after negotiations between international pharmaceutical companies, the government and the Medical Research Foundation (MRF). A majority of respondents noted that ARVs are supplied free of charge at specified government institutions and supply is constant. However, respondents indicated that there remain many barriers to access such as physical, psychological, decentralization, financial constraints, job or house displacement as well as internal and external stigma and discrimination. One respondent noted that although quality of ARVs is good and supply is regular, that of all the PLHIV in Trinidad and Tobago only 4000 are on treatment.

Psychological care	Yes	No	N/A
13. Has a national strategy been developed to provide psychological care to PLHIV, their families and communities?	*8*	*4*	
14. Were PLHIV involved in its development?	*5*	*7*	

Comments

In regards to the need for greater psychological care one respondent noted "it's something that is necessary, reason being that a lot of social workers choose not to work in the HIV community, that is why CRN+ trained treatment advocates and peer counsellors" .

Respondents indicated that as part of the NSP, CRN+ has trained peer treatment counsellors, at testing sites pre and post counselling is available, and there is occasional support from a professional psychologist through CARe. Also, 2 respondents indicated that there are a small number of PLHIV who are directly involved with liaising with HIV-positive persons and their families to provide support.

6 respondents were unable to provide comment feedback, not having knowledge of this type of programming.

GIPA REPORT CARD- COUNTRY PILOT:

TRINIDAD & TOBAGO

Research, and Sexual and Reproductive Health	Yes	No	N/A
15. Is the GIPA Principal applied in conducting medical research *i.e. for drug trials and new prevention technologies?*	***5***	***5***	***1** n/a* ***1** unsure*
16. Does your country have a national sexual and reproductive health plan?	***10***	***2***	
17. Has a policy been introduced or incorporated into existing plans to address the sexual and reproductive health needs of women and men living with HIV?	***8***	***4***	
18. Was your organization involved in this?	***7***	***4***	***1** n/a*

Comments

It was noted by respondents that SRH is incorporated into the NSP and the UNAIDS respondent said that this "*speaks to the needs of women and men who are living with HIV*". One respondent noted that CARe played a role in the development of the SRH components in the NSP policy.

Also, a small number of respondents noted that multiple SRH programmes exist and are implemented through the Family Planning Association and supported by UNFPA.

In regards to provider stigma and discrimination, it was indicated that in some cases nurses and midwives still impose their views to pregnant HIV-positive mothers and children.

6 respondents were unable to provide feedback in the area of SRH.

Poverty Reduction Strategies	Yes	No	N/A
19. Does your country have a poverty reduction plan and/or strategy?	***10***	***1***	***1** unsure*
20. Was the poverty reduction plan and/or strategy developed with input from people living with HIV?	***4***	***6***	***2** unsure*
21. Has the poverty reduction plan and/or strategy been reassessed with the input of people living with HIV to reflect the differing impact of HIV on women and men?	***6***	***4***	***2** unsure*

GIPA REPORT CARD- COUNTRY PILOT:

TRINIDAD & TOBAGO

Comments

2 respondents indicated that a poverty reduction plan was developed for Trinidad & Tobago in the late 1990s and that the plan is presently being revised taking into consideration inputs from the PLHIV community. It was also noted that the former technical director of the NACC is now currently the Minister of Social Development who is very supportive in facilitating the needs of PLHIV into poverty reduction activities and policy.

Some respondent mentioned the availability of various programmes for PLHIV who are need of financially assistance such as the Unemployment Relief Program (URP).

7 respondents were unable to provide feedback.

GIPA REPORT CARD- COUNTRY PILOT:
TRINIDAD & TOBAGO

Employment	Yes	No	N/A
22. Has the government enacted legislation in line with the ILO Code of Practice on HIV/AIDS and the World of Work[48]?	*7*	*5*	
23. Were people living with HIV involved in its development?	*7*	*4*	*1 n/a*

Comments

Respondents noted that a workplace policy on HIV was launched in April 2008 and legislative assessments are ongoing with the involvement of PLHIV towards amending the policy that aims to protect the rights of PLHIV. Also, one respondent noted "the ILO has embarked on a project in collaboration with the government of Trinidad and Tobago through the Ministry of Health in creating a HIV workplace policy.

GIPA Materials	Yes	No	N/A
24. Has your organization developed GIPA-related materials?	*7*	*4*	*1 unsure*
25. Are these being used by the government or other organizations?	*4*	*5*	*2 unsure*

26. If your organization has developed or used GIPA-related materials, please describe these materials and provide a copy?

Respondents noted a number of materials such as:

- Adherence Guide, a booklet developed by CRN+
- National Strategic Plan
- CARe's brochures, educational workshops etc.

6 respondents were unable to provide answers for this question.

[48] ILO (2001); International Labour Organization Code of Practice on HIV and the World of Work; http://www.ilo.org

GIPA REPORT CARD- COUNTRY PILOT:
TRINIDAD & TOBAGO

Financial Support	Yes	No	N/A
27. If people living with HIV participate in a government body, are their running costs such as travel, accommodation, child care and food reimbursed?	*7*	*5*	
28. Are you adequately paid for your involvement?	*2*	*9*	*1 n/a*

Comments

Respondents noted that financial support and compensation is dependent on the agency and the agenda. 6 respondents indicated that stipends provided were insufficient to fulfill their needs. Often it was noted that stipends, when provided, are mainly to assist those in traveling, food reimbursement and accommodation. However, childcare costs are not regularly covered.

Respondents noted that the NACC stipends its members as well as pay for the professional work conducted on its behalf, such as sensitization by PLHIV.

Barriers to involvement

29. When asked to check off what are the three (3) greatest barriers to the greater involvement of people living with HIV, respondents indicated the following *(from top to bottom of how many respondents checked off each one*):

9 respondents	Fear of stigma		
3-6 respondents	Fear of or actual discrimination	Homophobia and other forms of prejudice	Low skill levels
	Discrimination in the workplace	Lack of support services	Poverty
	Rejection by family friends or the community		
2 respondents	Lack of confidence in people living with HIV organizations and /or networks	Financial insecurity	Weak management
	Discrimination by health care provider	Belong to minority or marginalized groups	Workplace Policies
1 respondent	Funding constraints	Gender inequalities in financial dependence on	Involvement is not paid

		men	
	Violence or fear of violence	Gender inequalities in domestic and childcare responsibilities	Lack of understanding and clarity on what GIPA is
0	No people living with HIV organization and /network		lack of access to antiretroviral therapy and treatment for opportunistic infections
	Gender inadequate in access to education and services		

Comments and Additional Barriers

Stigma and discrimination were overwhelming identified by a majority of respondents as key barriers to the effective participation of PLHIV in the HIV response. Respondents described a number is issues around stigma including how it creates barriers to participation in various activities when the fear of stigmatization through association by death is very strong, as is denial and self-stigma.

Poverty was also often identified; some respondents noted that some PLHIV are not physically or mentally strong to continue gainful employment and there is a greater need for training opportunities to support those who are not working.

Opportunities for involvement

30. What are the three (3) current best opportunities for the greater involvement of people living with HIV? Respondents described the following:

Many respondents noted a number of opportunities including through policy level involvement in the NACC, working on access and ARV issues, and opportunities to participate in public forums and ways to make your voice be heard as a PLHIV.

Many respondents identified becoming a role model /pioneer for the PLHIV community as champions for living positively with HIV as a key opportunity, but noted that this activity involves disclosure in an environment where stigma and discrimination exists and little support available.

A small number of respondents also noted that becoming a peer counsellor and providing support to other PLHIV was an important opportunity.

Also identified opportunities were education and trainings, and also acting as resource persons for organisations to assist with developing appropriate no stigmatizing materials for HIV awareness.

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Annexes

- I Interviewee Criteria
- II Consultant Tasks and responsibilities

ANNEX I: Interviewee Criteria

Consultants worked to ensure the below 3 (three) criteria were met where possible when selecting interviewees:

1) REPRESENTATION BASED ON COUNTRY EPIDEMIC

As much as possible interviewees were identified so as to be representative of how the epidemic is manifested in their country based on current prevalence data for each country.

2) REPRESENTATION IN COUNTRY RESPONSE

Interviewee pool should include representation from PLHIV who have participated in various aspects, organizations, and mechanisms related to the country response. The list below was a guide to support selection; however it was acknowledged that it was not always be possible to reach PLHIV in all these sectors and mechanisms, as there may not be any PLHIV who are involved:

- Country Coordinating Mechanisms
- UNAIDS secretariat and Co-sponsors
- Development agencies
- Civil Society Organizations
- National AIDS Councils
- Donor organizations

3) VARIOUS LEVELS OF INVOLVEMENT

Among the interviewee group consultants looked to achieve broad and diverse representation regarding how long people have been involved in the local response, including those who are newly involved and those who have been involved for many years.

ANNEX II: Project Manager and Country Consultant Responsibilities

Project Manager Responsibilities and Tasks:

Contact countries	• Help identify country consultants with GNP+ and country contacts. • Update contacts as to pilot progress and support needed.
Materials development	Develop the following documents to support guide and support the work of the GIPA Report Card Country Reports: • Interviewee Criteria • Community Member and Interviewee Information Sheet ((overview of project details and backgrounder) • Interview and Focus Group Methodology Guidelines- • Interviewee Consent Form • Country Report Template (used by each country to ensure consistency)
Country consultant support	• Brief each country consultant on project, including methodology, and action plan. • Introduce consultants via email. • Participate in regular Skype calls with project manager to update on progress. • Provide ongoing support as needed throughout implementation.
Literature review	• Work with country contacts and consultants to gather appropriate documents. • Conduct country-specific review including national and district strategic plans, organization by-laws, etc.
Evaluation tools development	• Develop tool(s) to evaluate pilot. • Plan feasibility review process. • Collect anecdotal data (not formal and based on conversations) on the *GIPA Report Card* interview tool from all interviewees.
Final report development	• Incorporate literature review, country reports and data, country case study in to draft final report. • Draft review process with reference group and GNP+ director of programs. • Write Final report.
Pilot evaluation and feasibility assessment	• Evaluate pilot process. • Produce feasibility assessment.

Country Consultant Responsibilities and Tasks:

Literature review	• Assist in collecting documents for literature review.
Country pilot management	• Participate in weekly Skype calls with project manager to update on progress. • Consult with project management consultant regarding proposed interviewees. • Manage budget for meeting expenses for the interview process, including honorariums for interviewees, as well as travel and per diem if applicable. • Consult with project manager on ongoing basis throughout pilot implementation.
PLHIV data collection (same task, activities, and timeline for each country)	• Identify 10 PLHIV based on interviewee criteria. • Contact 10 PLHIV to arrange availability and interview times. • Conduct focus group or individual interviews using *GIPA Report Card* interview tool according to *Interview and Focus Group Methodology Guidelines* (in person or via telephone) with 10 key PLHIV depending on needs and logistical constraints.
UCC and NAP Manager data collection (same activities, and timeline for each country)	• Contact UCC (or equivalent) and NAP manager to arrange availability and interview times. • Conduct individual interviews with UCC (or equivalent) and NAP manager using *GIPA Report Card* interview tool according to *Interview and Focus Group Methodology Guidelines.*
Country report development	• Synthesize all interview data and literature review info into report template. • Draft review process with consultant project manager. • Collect anecdotal data (not formal and based on conversations) on the *GIPA Report Card* interview tool from all interviewees. • Submit all rough interview data to project management consultant upon completion of draft report.