

a world to involve

Report of the Exploratory Study on the GIPA Principle

For STOP AIDS NOW! Partners and Development Projects

Tanne de Goei
Verona Groverman
May 2009



STOP AIDS NOW!
is a partnership
between Aids Fonds,
Cordaid, Hivos, ICCO
and Oxfam Novib

20091877

Executive Summary

STOP AIDS NOW! contracted two consultants to conduct an exploratory study on the opportunities to improve the incorporation of the GIPA principle in STOP AIDS NOW! partner programs and STOP AIDS NOW! Development Projects.

GIPA is a principle that aims to realize the rights and responsibilities of people living with HIV (PLHIV), including their right to self-determination and participation in decision making processes that affect their lives. PLHIV involvement in program development and implementation, and policy making will improve the relevance, acceptability and effectiveness of programs. Experiences have shown that when communities are proactively involved in ensuring their own well-being, programs are likely to be more successful. The engagement of PLHIV is all the more urgent as countries scale up their national responses to achieve the goal of universal access to prevention, treatment, care and support services. Organisations and networks of PLHIV are central to the achievement of GIPA and the enhancement of the AIDS response at large as these organisations and networks represent the interests of PLHIV and give them a voice.

The study focused on the capacities of PLHIV organisations and the relationships between PLHIV organisations and STOP AIDS NOW! partners and cooperating organisations. The study was divided in three parts:

1. Information collection from STOP AIDS NOW! partners/development projects;
2. Information collection from PLHIV organisations and networks;
3. In-depth information collection from PLHIV organisations and networks in selected countries (case studies).

This exploratory study tried to answer four key questions - which are based on the activities and expected products described in the Terms of Reference - to come up with recommendations for the STOP AIDS NOW! partners/development projects:

1. What are the capacities of PLHIV organisations and networks a) to make the voices of PLHIV heard in order to address their practical needs and strategic interests and/or b) to empower PLHIV to make their own voices heard?
2. What factors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works, at different levels?
3. What actors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works at different levels?
4. To what extent do STOP AIDS NOW! Partners/development projects include the GIPA principle in their programs?

The study has an exploratory character. Since it is not possible to generalise findings and draw hard conclusions based on a limited number of PLHIV organisations and networks operating all over the world in different contexts the report is about common issues and trends and points at items of relevance related to the GIPA principle. It is left to each STOP AIDS NOW! partner and STOP AIDS NOW! as a whole to pick and choose the issues that need attention in view of existing policies and opportunities.

In the first part of the study interviews took place with all policy advisors/program coordinators in charge of HIV/AIDS at the different partners of STOP AIDS NOW! as well as the project managers of the STOP AIDS NOW! Development projects. The outcomes of these interviews have been discussed in a workshop in which they participated.

- The study found out that the STOP AIDS NOW! Partners totally support 31 PLHIV organisations and networks spread over the continents.
- All Partners give attention to GIPA within their HIV/AIDS policy although not all regard it as a priority issue (yet). Aids Fonds has a specific policy on GIPA being one of its focus areas for partner support. Oxfam Novib planned to set out a policy to invest in PLHIV networks at the end of 2008. ICCO has set a target for counterparts to include

GIPA in their policy in 2010. Other STOP AIDS NOW! partners apply general principles to guide their work as donors which implicitly include PLHIV.

- STOP AIDS NOW! partners/development projects have their limitations in influencing counterparts to respond to HIV and AIDS or to purposely involve PLHIV in needs assessment and other phases of a program. However, all STOP AIDS NOW! Partners have a high ambition in addressing HIV in workplaces.
- In the view of the STOP AIDS NOW! partners/development projects there exists a number of opportunities and challenges to jointly with PLHIV organisations/networks promote GIPA. Many relate to the strengths (as opportunities) and weaknesses (as challenges) of the PLHIV organisations and networks as perceived by the STOP AIDS NOW! partners. Later parts of the study showed that their perceptions of the strengths and limitations to a large extent overlap with the information collected from the PLHIV organisations and networks themselves, which indicates that the policy advisors/program officers in charge have good knowledge of the counterparts supported by their organisation.

The second and third part of the study focused on the views of the PLHIV organisations and networks supported by STOP AIDS NOW! partners/development projects. In the second part information was collected through questionnaires and interviews. 19 of the 31 supported organisations and networks filled out the questionnaire, among which six of the organisations included in the in-depth studies. In the in-depth studies four local consultants gathered information of eight PLHIV organisations and one network in five countries (Costa Rica, Indonesia, Kenya, Nicaragua and Zambia). Both the questionnaire and in-depth studies included PLHIV being staff of the organisations or networks. Since it was not possible to ask about a person's status no differentiation could be made between responses of PLHIV and non-PLHIV. Furthermore, PLHIV at the beneficiaries level or members of PLHIV networks have not been interviewed in the in-depth studies because this was beyond the scope of the exploratory study.

- In regard to the capacities of PLHIV organisations and networks the studies found that the strengths of the PLHIV organisations/network studied in-depth are clear and focused visions and missions; staff's and volunteers' dedication and total commitment to the cause of PLHIV; registered and accepted organisations/networks, trusted by government, civil society and the communities; groups served are clearly defined and they focus on activities that they feel they can handle and if not, they refer clients to other specialised organisations with which they have sought partnership; and systems, mechanisms and procedures are put in place to adequately run the organisation and their programs. Another strength is the intensity of relationships and partnerships they have developed over the years at the local, national and international level, with AIDS service providers, governmental organisations and with other local, national, and international NGOs, including other PLHIV organisations and networks.
- As regards the common weaknesses of the nine organisations/network studied in-depth they generally concern organisational issues rather than programmatic issues: insufficient staff to fully implement all the activities and programs; overloaded and overworked staff; heavy dependence on volunteers; and recruitment of PLHIV staff. Other weaknesses are lack of staff knowledge and skills in some essential areas to run the organisation and to meet challenges of the growing demands of PLHIV for services and support; lack of monitoring and evaluation systems; and limited financial resources. A few in-depth studies looked into decision making and assessed it a weaker point due to its top-down nature and dependency on the director. None of the organisations/network studied in-depth had developed a HIV workplace policy.
- The identified strengths and limitations of the nine organisations/network are to a large extent in line with the outcomes of the questionnaire (usually filled out by one person at higher management level) with some interesting differences, concerning monitoring and evaluation, budgets, the dependency on the director, and decision-making. Table 6 in chapter 3 gives an overview of organisational capacities.
- The PLHIV organisations and network studied in-depth follow different ways of building the capacity of their staff, volunteers and, where applicable, their members.

Several organisations mentioned problems in building capacities, more especially lack of funding. Most organisations responding to the questionnaire preferred a PLHIV capacity building organisation over a general capacity building organisation. The consultants who conducted the in-depth studies suggested a proper training needs assessment to identify specific needs. The question has to be posed if volunteers also need to be included in capacity building efforts and how volunteers who are trained can be maintained in the organisation.

In regard to factors that influence the participation and meaningful involvement of PLHIV, the study found that the main barriers identified by PLHIV organisations/networks are (the fear of) stigma and discrimination. Other important hindrances are funding constraints, low skill levels of PLHIV, belonging to a minority or marginalised group, poverty, lack of understanding and clarity on what GIPA is, gender inequalities in access to education and services and lack of workplace policies. 'Lack of access to ARV therapy and treatment for opportunistic infections' is only mentioned by a third of the respondents which could be due to improved availability of ARVs in Africa, Latin America and parts of Asia.

- The level of understanding of the GIPA principle is much higher at the staff of PLHIV organisations and networks at national level than at those at local level. According to the respondents of the questionnaire the PLHIV organisations/networks generally involve PLHIV in the implementation of activities and programs, and although to a lesser extent, in decision making processes. They also feel that their programs and activities are based on the needs and views of PLHIV. They do not perceive the issue of representation of diverse constituencies as a great barrier to the meaningful involvement of PLHIV.
- In the in-depth studies we see quite some variation in the level of involvement of PLHIV and in the extent to which needs and views are taken seriously. The needs and interests of PLHIV that come out the in-depth studies are related to health and social issues but also to poverty, education and employment. However, most PLHIV organisations/network studied in-depth have a rather narrow focus of activities: their health activities relate to HIV and do not seem to address wider, general health issues or include TB, HCV or malaria; they work on stigma reduction and empowerment through support/self-help groups; and hardly attend to poverty and food security issues; they are not very effective in income generation support. Their lobby/advocacy towards government and other organisations is mainly focused on access to health services and, to a much lesser extent on rights issues. None of the studies provided information about specific needs of the different vulnerable groups they serve or different concerns brought forward by PLHIV or differentiated between male and female PLHIV.
- Concerning the incorporation and application of the GIPA principle in national policies the questionnaires show that in less than 30% of the countries covered by the questionnaire the GIPA principle is sufficiently included in the National AIDS plans. Less than 50% feels that PLHIV have been sufficiently involved in the development of the National AIDS Plan but such inclusion of PLHIV does not imply that GIPA is taken seriously. Various respondents of the questionnaire pointed at tokenism. About the involvement of PLHIV at national policy level the respondents of the questionnaire are not very positive, more in particular where it concerns development issues that impact their lives, such as poverty reduction. One of the obstacles towards meaningful involvement of PLHIV is the lack of understanding at different government levels apart from lack of implementation in general and lack of resources for implementation. Moreover, the in-depth studies speak of competition between PLHIV organisations as a hindering factor to make PLHIV voices effectively heard.
- From the limited information available it seems that local development NGOs, CBOs and ASOs recognise GIPA as an useful principle for involving PLHIV, but its application leaves to be desired. This has to do with misunderstanding about the Principle, lack of proper information about the Principle and how to apply it, and lack of knowledge about national policies and strategies. At the same time, it is remarked that PLHIV do not make sufficient efforts to demand a meaningful participation in development programs.

The outcomes presented above give rise to a number of critical issues which we feel should be given more consideration, leaving it to the individual partner to pursue or not.

- A first issue, which directly relates to the topic of the study, is the insufficient level of skills and education of staff and volunteers to effectively run the organisation and its programs as observed in many PLHIV organisations/networks. It is even more problematic because capacity building of staff only takes place in an ad-hoc manner due to lack of staff's time, training opportunities and of funds.
- A second issue is the observed lack of attention – or even consciousness - among the PLHIV organisations/networks to the diversity among people living with HIV. It may lead to exclusion of certain groups and disregard of their concerns. Of special concern is the poor attention to gender inequalities and women's issues. Even the in-depth studies were rather gender blind.
- Third, the PLHIV organisations/networks in our sample focus on HIV-related issues in its narrow sense and hardly take up broader issues affecting PLHIV as reflected in their activities and the relationships with development institutions and organisations. In turn, the in-depth studies taught us that development organisations do not establish sufficient or effective contacts with the PLHIV organisations/networks and government institutions do not adequately consult them in policy-making processes. Thus, opportunities are missed out to effectively improve the situation of PLHIV.
- Four, a general observation at government institutions and all kinds of development organisations are the low level of understanding of GIPA. Good knowledge about the Principle is a basic requirement for its application.
- Fifth, it is unclear to what extent PLHIV benefit from activities of the PLHIV organisations/networks mainly due to poor monitoring and reporting. The STOP AIDS NOW! Partners/development projects, therefore, are not well informed about outcomes and impact, which hinders them making the right strategic choices. We should keep in mind though that it is difficult to demonstrate impact while funding continues to be only project-based.
- A sixth issue important to the running of an organisation/network and to a proper application of GIPA is the top-down nature of decision making and the dependency on the director in various organisations and networks.
- Last but certainly not least, PLHIV organisations/networks have not developed a workplace policy, which is important in view of the emphasis of STOP AIDS NOW! partners/development projects on the issue.

At the end of the report a few recommendations have been added for STOP AIDS NOW! partners/development projects in line with the outcomes and critical issues mentioned above. They focus on the three key items of the exploratory study: 1. the capacities of the PLHIV organisations and networks supported the Partners/development projects, 2. how to build these capacities, 3. in order to ensure GIPA.

Abbreviations:

ARV(s)	Anti-RetroViral(s)
ART	Anti-Retroviral Therapy
ASO(s)	AIDS Service Organisation(s)
CBO(s)	Community Based Organisation(s)
CCM	Country Coordinating Mechanism (for GFATM)
CSW(s)	Commercial Sex Worker(s)
DFID	Department for International Development, UK
FBO(s)	Faith Based Organisation(s)
GBV	Gender Based Violence
GFATM	Global Fund to fight AIDS, Tuberculosis and Malaria
GIPA	Greater (or: Meaningful) involvement of People living with HIV/AIDS
GLBT(s)	Gay(s), Lesbian(s), Bisexual(s), Transsexual(s)
HBC	Home-Based Care
HCV	Hepatitis C Virus
IDU(s)	Injecting Drug User(s)
IDP	Internally Displaced Persons
IEC	Information, Education and Communication
JICA	Japanese International Cooperation Agency
MSM	Men having Sex with Men
NAC	National AIDS Commission
NGO(s)	Non-Governmental Organisation(s)
OVC	Orphans and Vulnerable Children
PLHIV	People living with HIV
SG(s)	Support Group(s)
SRHR	Sexual and Reproductive Health & Rights
TB	Tuberculosis
TOR	Terms of Reference
WPP	Work place policy

Contents

Executive Summary	2
Abbreviations:	6
Contents	7
1 Introduction	9
1.1 The need for an exploratory study	9
1.2 Focus and nature of the exploratory study	10
1.3 Methods applied in the exploratory study	11
1.4 The process of the research	15
2 The views of the STOP AIDS NOW! partners/development projects on GIPA and the work of PLHIV organisations and networks	17
2.1 Introduction	17
2.2 STOP AIDS NOW! partners/development projects' GIPA policy and HIV/AIDS policy	17
2.3 Involvement of PLHIV in programs supported by STOP AIDS NOW! partners/development projects	20
2.4 STOP AIDS NOW! partners/development projects' assessment of the capacities of the supported PLHIV organisations and networks	21
2.5 STOP AIDS NOW! partners/development projects' views on challenges and opportunities to jointly with PLHIV organisations and networks promote the GIPA principle	21
2.6 Cooperating as STOP AIDS NOW! partners/development projects in the application of the GIPA principle	23
2.7 Summary	23
3 Capacities of PLHIV organisations and networks supported by STOP AIDS NOW! Partners/development projects	25
3.1 Introduction	25
3.2 Common strengths of PLHIV organisations and networks	26
3.3 Common weaknesses of PLHIV organisations and networks	29
3.4 Capacity building of the PLHIV organisations and networks	32
3.5 Summary	33
4 The GIPA principle and involvement of male and female PLHIV	35
4.1 Introduction	35
4.2 PLHIV Organisations and Networks	35
4.3 People living with HIV and the GIPA principle	40
4.4 Governmental institutions and policy makers	40
4.5 Other NGOs and civil society organisations	43
4.6 Summary	44
5 Outcomes of the exploratory study and Recommendations	46
5.1 Introduction	46
5.2 Outcomes of the exploratory study	46

5.3	Critical issues for consideration	51
5.4	Recommendations to STOP AIDS NOW! partners/development projects	53

1 Introduction

1.1 The need for an exploratory study

GIPA is not a project or program. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. GIPA also aims to enhance the quality and effectiveness of the AIDS response.¹

Promoting greater [or meaningful] involvement of people living with HIV and AIDS (GIPA) is a critical condition for enhancing the quality and effectiveness of the AIDS response. Involving people living with HIV (PLHIV) in program development and implementation and in policy making will improve the relevance, acceptability and effectiveness of programs and policies. GIPA, however, is much more than that: it is a right in itself. People living with HIV have rights and responsibilities of a life in dignity like any other person who is not infected with HIV. PLHIV have the right to self-determination and participation in decision-making processes that affect their lives. Organisations and networks of PLHIV are central to the achievement of GIPA and the enhancement of the AIDS response at large as these organisations and networks represent the interests of PLHIV and give them a voice.

"If we are to tackle the AIDS epidemic, we have to make sure the voice of those living with HIV and AIDS is heard. Networks of people living with HIV and AIDS are in a unique position to represent the interests of those who are HIV positive and giving them a voice where policies and decisions are being made that affect their lives."²

In spite of its codification in the declaration of the AIDS Summit 15 years ago in Paris there is still a long way to go before the GIPA principle is fully put into practice.

The frustration is that [...] after so many years we're still trying to make a reality today of what was agreed quite a long time ago. Although there has been some progress toward achieving GIPA [...] I am not convinced it has been very effective. The general response has been tokenism, not real support. If there had been better progress, I think the AIDS response would have been more advanced. It is really one of the missing links.³

The different parties cooperating in STOP AIDS NOW! (SAN!) want to focus more on people with HIV in order to contribute to the realisation of GIPA and to improve their response to the HIV epidemic. Several evaluations have shown the need for a stronger focus. The MBN evaluation⁴ states that the GIPA principle is not often applied within STOP AIDS NOW! partners and their counterparts, including HIV organisations. It is recommended to collect the accumulated experiences within STOP AIDS NOW! partners and to identify what is needed to improve the appliance of the GIPA principle. The STOP AIDS NOW! Mid Term Review⁵

¹ Policy Brief GIPA, UNAIDS 2007

² Gareth Thomas, UK International Development Minister, August 2006, on the occasion of new funding for PLHIV Networks.

³ Peter Piot, UNAIDS Executive Director at 1st Donor Consortium Conference, Noordwijk, March 2006

⁴ MBN HIV/AIDS Evaluation, Final Report, ACE Europe, February 2006

⁵ STOP AIDS NOW! TMF-supported program 2005 – 2008, Mid-term review, EOS Consult, USBO, Chigudi & Associates, September 2007

mentions that the relevance of STOP AIDS NOW! development projects⁶ will be enhanced by involving PLHIV as active actors⁷.

Support to and cooperation with PLHIV organisations and networks is a strategic choice as these organisations are central to the achievement of GIPA. Scattered experiences, however, show that many organisations and networks of PLHIV face a number of challenges. Some relate to their internal affairs: weak management, poor planning of activities, lack of evaluation of successes and failures, internal disputes over power, and so on. Furthermore, challenges concern their relationships with other organisations and institutions, such as competition for funding, lack of recognition, inadequate support and cooperation, high demands to involvement in consultation processes, and the like.⁸

Considering the above, STOP AIDS NOW! partners/development projects felt the need to better understand the opportunities, constraints and challenges of PLHIV organisations and networks with the aim to improve their strategic choices. They hired two independent consultants to carry out an exploratory study, Tanne de Goei and Verona Groverman. Their Terms of Reference are attached in Annex I. The study focused on the capacities of PLHIV organisations and the relationships between PLHIV organisations and STOP AIDS NOW! partners and development projects. The study did not focus on non-PLHIV counterparts and their efforts to involve PLHIV in their programs and organisation as this was not indicated in the scope of work in the TOR. The study was divided in three parts:

1. Information collection from STOP AIDS NOW! partners/development projects (from April – July 2008)
2. Information collection from PLHIV organisations and networks (from April – July 2008)
3. In-depth information collection from PLHIV organisations and networks in selected countries - case studies (September 2008 - February 2009)

This report presents the outcomes of the three parts and includes conclusions and recommendations. The draft version is discussed with the reference group set up to support the study and the comments made are incorporated in this report where relevant and possible. We have tried to find a proper balance between the at times contradictory comments and suggestions from the members of the reference group.

1.2 Focus and nature of the exploratory study

The study focused on the PLHIV organisations and networks supported by STOP AIDS NOW! Partners/development projects and examined their capacities and contribution to the GIPA principle. It explored their strengths, limitations, opportunities and challenges in order to help STOP AIDS NOW! and each of its partners identify issues of concern and steps to better apply the GIPA principle. The study had an exploratory character and was not a (in-depth) research. It also did not look into the effects of the interventions of the PLHIV organisations (see the TOR).

The study attempted to answer four key questions to come up with recommendations:

1. To what extent do STOP AIDS NOW! partners/development projects include the GIPA principle in their programs by a) supporting PLHIV organisations and networks and b) considering the situation of PLHIV in the design, planning, implementation and monitoring and evaluation of their programs, the benefits and impact of their programs on PLHIV?

⁶ STOP AIDS NOW! Development projects are: the projects that are initiated and organized by the STOP AIDS NOW! Secretariat: Gender, Workplace policies, Youth & Prevention and Orphans & Vulnerable Children.

⁷ “The relevance of development projects will be enhanced by stipulating explicitly that pilot activities target people living with or affected by aids as active agents and experts on their own life and context. Such a condition would help to stay close to the mission of STOP AIDS NOW! It necessitates a sound participatory context analysis at grassroots level before choices are made about potential interventions.” [Mid-term review, p 47]

⁸ POLICY, GNP+ and GTZ (2004). Challenging, Changing and Mobilizing: A Guide to PLHIV Involvement in Country Coordinating Mechanisms. See also: Think Tank Meeting (2005). Revitalizing the Global Movement of People Living with HIV. Nairobi, Kenya, 28–30 November 2005.

2. What are the capacities of PLHIV organisations and networks a) to make the voices of PLHIV heard in order to address their practical needs (e.g. service delivery) and strategic interests (e.g. through advocacy) and/or b) to empower PLHIV to make their own voices heard (i.e. empowerment of PLHIV)?
3. What factors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works, at different levels (such as stigma, access to treatment, national policy, etc.)?
4. What actors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works at different levels? Apart from the PLHIV organisation or network they include support organisations at community, district or national level, capacity building organisations, donors, and so on.

As mentioned, the exploratory study was meant to give recommendations to STOP AIDS NOW! Partners/development projects. Evidently, it is not possible to generalise findings and draw hard conclusions based on a limited number of PLHIV organisations and networks operating all over the world in different contexts. Therefore, the report describes common issues and trends and points at items of relevance related to the GIPA principle. It is left to each STOP AIDS NOW! partner/development project and STOP AIDS NOW! as a whole to pick and choose the issues that need attention in view of existing policies and opportunities. In box 1 we have given working definitions of a few key concepts of the study.

Box 1: Definitions of key concepts in the study

PLHIV organisations and networks: Organisations and networks set up by people living with HIV that work for people living with HIV and with people living with HIV.

Organisational capacities: The financial, technical, material, and human resources which affect whether an organisation and its staff can implement activities and achieve their objectives.

Capacity building of organisations/networks: Developing capacities of an organisation/network to function and participate more effectively in the changing context in which it operates.

Advocacy: An organised political process that involves the coordinated efforts of people to change policies, practices, ideas, and values that perpetuate inequality, prejudice, and exclusion. Getting to the decision making table with a new set of interests and changing the decision making processes to accommodate a new set of actors – in our case PLHIV. It implies challenging imbalances of power and ways of thinking.⁹ Lobby is a strategy or technique of advocacy.

1.3 Methods applied in the exploratory study

We used a variety of methods to collect information. The study started with document review and collecting information at STOP AIDS NOW! partners/development projects on the number and type of the PLHIV organisations and networks they supported (TOR activity 1).

- Background reading on GIPA and related issues. Most documents are to be found in the GIPA resource centre at the library of GNP+ (www.gnpplus.net). It included the evaluation reports 'MBN HIV/AIDS Evaluation, Final Report, ACE Europe, February 2006', the 'Mid Term Review STOP AIDS NOW! TMF program 2005-2008, Lida Zuidberg, September 2007' and - while writing the report - the 'GIPA Report Card – Pilot Phase Report, GNP+/Alec McClelland, December 2008'. Review of information on STOP AIDS NOW! counterparts: short descriptions of the PLHIV organisations and networks and their projects supported by the STOP AIDS NOW! Partner.

The result of this last activity, which is shown in table 1 below, was the starting point of further data collection.

⁹ Veneklasen, Lisa & Valerie Miller (2002) A New Weave of Power, People and Politics. The Action Guide for Advocacy and Citizen Participation. World Neighbors and The Asia Foundation. Paragon Press, Inc., Oklahoma City.

The next step was getting more information about the capacities of the PLHIV organisations and the support provided by STOP AIDS NOW! partners/development projects. In this step we involved the STOP AIDS NOW! partners/development projects and the PLHIV organisations supported.

- Interviews with the STOP AIDS NOW! partners/development projects. All policy advisors or program coordinators in charge of HIV/AIDS at the different partners of STOP AIDS NOW! as well as the project managers of the STOP AIDS NOW! Development projects have been interviewed. In one situation two more staff members took part in the interview. They were also asked to provide a list of PLHIV organisations, their profiles, and contact data and a list of relevant capacity building organisations. Annex II gives the semi-structured interview guide and annex III the names of the interviewees.
- Workshop with the STOP AIDS NOW! partners/development projects with the aim to get feedback of the reference group on the results of part 1 of the study and to get their views on further steps of the study. Eight people participated in the workshop that took place on 7 July 2008. Annex IV gives the report of this workshop.
- Questionnaire. All the 31 PLHIV organisations supported received a questionnaire by email with an invitation letter from STOP AIDS NOW! to contribute to the study. Both had been translated in English, Spanish and Portuguese. Annex V and VI give the questionnaire and invitation letter.
- Workshop at the XVII International AIDS Conference, August 6, 2008, Mexico City where Alex McClelland of GNP+ gave an up-date on the GIPA Report Card pilot and Tanne de Goei an up-date on this study, followed by a discussion on the obstacles and challenges of both studies. About 10 persons participated in this workshop including a representative of the Dutch Ministry of Foreign Affairs.
- Interviews with 7 PLHIV organisations to go more in-depth. Three PLHIV organisations have been interviewed face-to-face, two during a visit to Malawi and another organisation at their international secretariat in Amsterdam. Additionally, four have been interviewed by telephone after they had returned the questionnaire.

Table 1: Overview PLHIV organisations and their involvement in the study

Organisation	Country	Kind of organisation/ network	Question naire returned	Additional interview	Donor
AELWHA	Ethiopia		no		Cordaid / STOP AIDS NOW! -wpp
All Ukrainian Network +	Ukraine	National network	yes	Yes	Oxfam Novib
ANARELA+	Africa		no		ICCO
Asociacion Atlacatl (AIDES)	El Salvador		no		Hivos
ASONAPPVSIDAH	Honduras		no		Hivos
ASONVIHSIDA	Nicaragua	National organisation	yes		Hivos
ASOVIHSIDA	Costa Rica		no		Hivos
ASPALSIDA	Angola		no		Oxfam Novib
Collaborative Fund	Global	International organisation	yes		Aids Fonds
COWLHA	Malawi		no	Yes	Cordaid
ECUO	Eastern Europe	Regional organisation	yes	Yes	Oxfam Novib
GNP+	Global	International	yes	Yes	Hivos / AIDS

		network			Fonds
ICW	Global	International network	yes	Yes	Oxfam Novib
INP+	India	National network	yes	Yes	Hivos / STOP AIDS NOW! - wpp
KENWA	Kenya	National organisation	yes	Yes	STOP AIDS NOW! – gender/Hivos
KINDLIMUKA	Mozambique		no		Hivos
MANET +	Malawi	National network	yes	Yes	Hivos
MEDAN PLUS	Indonesia	Local organisation	yes		Hivos
METTA	Birma		No		Oxfam Novib
NAFOPHANU	Uganda	National organisation	yes		STOP AIDS NOW! -wpp
NIVENYEE	Mozambique		no		Hivos
NZP+	Zambia	National network	yes		Cordaid/Oxfam Novib
PROSA	Peru	National organisation	yes		Hivos
RBP+	Burundi	National network	yes		Oxfam Novib
Redvihda	Bolivia	National network	yes		Hivos
Stigma Foundation	Indonesia	Local organisation	yes		Hivos
TAC	South Africa		no		Hivos
TAPWAK	Kenya		no		STOP AIDS NOW! – gender/Hivos
Vencer	Paraguay	National organisation	yes		ICCO
WOFAK	Kenya	National organisation	yes		STOP AIDS NOW! – gender/ Aids Fonds
Yayasan Pita	Indonesia	Local organisation	yes		STOP AIDS NOW! – gender/Hivos

Using questionnaires teach us about the reality on the ground, but the method has its limitations. It may only reflect the views of the person who filled out the questionnaire and there could be misinterpretations of questions or answers. We therefore included a third step in the information collection to get a better insight in the issues at stake:

- Case studies in selected countries. We contracted four local consultants to interview the PLHIV organisations and networks in three countries and one region (two countries) who worked according to detailed TOR prepared by us (see annex VII) We used the following criteria to select countries for the case studies:
 1. Coverage of all continents;
 2. Representation of organisations/networks supported by the different STOP AIDS NOW! partners/development projects;
 3. Representation of different types of organisations (organisations and networks, operating at national and local level).

The case studies concerned the nine organisations/network in five countries given in table 2 below which shows their main characteristics.

Table 2: Characteristics of organisation/network¹⁰

Country	Name organisation	Type of organisation/network	Number of staff/volunteers
Indonesia	Yayasan Pita Founded: 2004 (Registered: 2005)	Organisation operating at local level	4 staff : 75% female, 22% PLHIV 4 active volunteers of the 15 (3 males, 12 females, 0% PLHIV)
	Stigma Foundation Founded: 1994	Organisation operating at local level	21 staff: 50% female, 19% PLHIV no volunteers
	Medan Plus Founded: 2003 (NGO: 2005)	Organisation operating at local level	27 staff: 37% female, 63% PLHIV
Nicaragua	ASONVIHSIDA Founded: 1997	Organisation operating at national level 350 Members, 50% women	6 staff: 50% female 0% PLHIV 70 volunteers: 100 % PLHIV
Costa Rica	ASOVIHSIDA Founded: 1997	Organisation operating at national level 350 members	8 staff, at least 1 female 3 professional volunteers
Zambia	NZP+ Founded: 1996	Network operating at national level Over 3500 members (i.e. self-help groups of 10 people average, majority women)	10 staff (4 posts unfilled), % PLHIV unknown Many volunteers at the community level, all PLHIV
Kenya	KENWA Founded:	Organisation operating at national level - 100% women	30% PLHIV
	WOFAK Founded : 1995	Organisation operating at national level - 100% women	30% PLHIV
	TAPWAK Founded: 1990	Organisation operating at national level	30% PLHIV

The last steps in the study included the following:

- Analysis of the information collected and drawing of conclusions and recommendations towards the key questions and expected products of the assignment.
- Feedback meeting with the STOP AIDS NOW! partners/development projects (23 March 2009)

Concluding, the study is primarily qualitative in nature being based on perceptions of people within STOP AIDS NOW! partners/development projects, PLHIV organisations/networks as well as the consultants involved in the case studies in the selected countries. Evidently, both the questionnaire and in-depth studies included PLHIV being staff or volunteers of the

¹⁰ Based on the reports of the in-depth studies. They did not include all the requested data.

organisations or networks. Since we could not ask about a person's status we can not differentiate between responses of PLHIV and non-PLHIV. Furthermore, PLHIV at the beneficiaries level or members of PLHIV networks have not been interviewed in the in-depth studies because this was beyond the scope of the exploratory study.

1.4 The process of the research

During the three parts of the study we encountered different challenges and opportunities. We summarised them in order to draw lessons for future research of this nature.

In part 1, one of the greatest challenges was the collection of the names and contact details of PLHIV organisations. In chronological order:

- Glimpsing through more than 100 pages with the profiles of all HIV and AIDS organisations supported by one STOP AIDS NOW! Partner to identify PLHIV organisations and networks;
- It was necessary to contact other program officers than the policy advisors (our first contact) within the STOP AIDS NOW! partners or their regional offices to get profiles and contact details because they were the ones who dealt with a PLHIV organisation/network. It then appeared that more organisations were being supported than the ones on our original list. Moreover, some organisations were phasing/phased out so they had to be removed from our list.
- Organisations/networks in Latin America and Angola/Mozambique did not master English so we had to arrange for translations of both the covering letter and questionnaire. There was (only) one francophone organisation of which the coordinator managed to fill out the form in English.

The challenges in part 2 were the following:

- The rate of return of the questionnaires was slow. Some organisations did not open the message (no return receipt). The persons who we had contacted (directors, coordinators) appeared to be very busy people. We sent at least two times reminders and additionally, used personal contacts to urge the organisations to fill out the form.
- We asked a few people if they could be interviewed after responding to the questionnaire to better understand the answers. Due to the late or lack of reply we could interview less persons than planned. We postponed interviews with organisations in Central America to the case studies.

In part 3, the case studies, there were challenges as well:

- It took considerable time to find local consultants with the required knowledge on HIV/AIDS-related issues and skills in doing research in the four selected countries/region. We started the search in September and the last consultant began the work early December.
- It appeared that most local consultants did not have the easy access to internet/Skype as they had stated. Therefore, it was difficult to guide them during the case studies (Costa Rica encountered power cuts among others due to heavy storms, two consultants had to frequent busy internet café's or did not have headphones). As a result their draft reports had to be returned several times to fulfil the TOR.
- Two studies were undertaken during the Christmas holiday (a suitable period for one of the consultants) which meant that the local consultants encountered problems in making appointments. Adding to that, one consultant fell ill and had to postpone the study a few weeks.
- Due to the varying quality of the reports of the case studies (between very good and moderate) we had to spend much more time on drafting the final report than foreseen.

To end with the positive lessons, we encountered a number of opportunities. The most important ones have been the help we received from different corners and the commitment of people closely involved in the study.

The opportunities in part 1 were:

- The time which the policy advisors and program coordinators made available for the interview and its correction.

- Most policy advisors and program coordinators who we interviewed, very fast provided us the information of the PLHIV organisations/ networks.
- A number of other program officers within the STOP AIDS NOW! partners (including local offices) have been very helpful and quick in responding to our request to check our list of organisations and to send additional information.

For part 2 we saw the following opportunities:

- Some of our personal contacts took time to contact PLHIV organisations/networks to speed up the return of the questionnaire.
- The fast translations provided by STOP AIDS NOW! Secretariat.
- The interest of some PLHIV organisations and networks in the study as reflected in the time made available for the interview.

The opportunities in part 3 were as follows:

- The commitment of all the four local consultants towards the tasks was good.
- The excellent quality of the Indonesian report.
- The STOP AIDS NOW! partners/development projects made their commitment and interest in the exploratory study tangible by extending the time set for the study and providing more funding to finalise it.

Having explained the process of the study, we now turn to the content of this report. In the next chapter (2) the outcomes of part 1 are presented: the information collection at the STOP AIDS NOW! partners/development projects about the GIPA principle and how it is put into practice. Chapter 3 and 4 focus on the outcomes of the data collection at the PLHIV organisations and networks. In chapter 3 we describe the capacities of the organisations and networks while chapter 4 is about the GIPA principle and if and how it is put into practice. The following chapter (5) gives the conclusions and recommendations. The four reports of the case studies are attached in annex XI.

2 The views of the STOP AIDS NOW! partners/development projects on GIPA and the work of PLHIV organisations and networks

2.1 Introduction

The first part of the exploratory study involved information collection of STOP AIDS NOW! partners/development projects, which took place in May/June 2008. The purpose was to get an impression of how STOP AIDS NOW! partners/development projects apply the GIPA principle and the constraints and opportunities they face. It concerned the following issues (see TOR).

- To map organisations of PLHIV (including national and regional networks) that have been or are being currently supported by STOP AIDS NOW! Development projects and STOP AIDS NOW! partners – table 1 in chapter 1 reflects the result of this effort.
- To map the extent to which PLHIV are identified as beneficiaries and are involved in project making and decision making within STOP AIDS NOW! partners programs and STOP AIDS NOW! Development projects.
- To identify the current situation (on organisational & institutional capacity, including networking and advocacy, funding donors) of organisations of people living with HIV (including national and regional networks) within the spectrum of this research.
- To identify the opportunities, challenges and possible improvements while working with organisations of PLHIV (including national and regional networks), from the perspective of STOP AIDS NOW! partners/development projects.
- To identify strong organisations or networks of people living with HIV which can play a role as peer mentors for other organisations in need of organisational and institutional development.

As mentioned in chapter 1 we conducted interviews with mainly the policy advisors of STOP AIDS NOW! partners/development projects followed by a workshop for the interviewees to discuss the outcomes of the interviews. Below we present the results of the interviews and workshop. In order to understand STOP AIDS NOW! partners/development projects' support to PLHIV organisations and networks we start with their policies on GIPA and HIV/AIDS and look at the involvement of PLHIV in programs supported by them. Next, we summarise STOP AIDS NOW! partners/ development projects' views on the capacities of the organisations they support. The following sections focus on their views on how to promote the GIPA principle.

We have chosen not to mention the views of individuals for reasons of confidentiality. Where interesting for learning purposes we have added the names of the STOP AIDS NOW! partners/ development projects. Lastly, we like to add that the interviews took 1½ to 2 hours.

2.2 STOP AIDS NOW! partners/development projects' GIPA policy and HIV/AIDS policy

The interviewees interpreted GIPA first and foremost as involving people living with HIV in decision-making processes from design to evaluation of programs and policies. Thus, policies and programs are not designed for PLHIV but with the involvement of PLHIV. To them, GIPA also refers to support to PLHIV in their own right in order to realize their access to resources, medicines and facilities and to empower them to fight for their rights. Some added that GIPA is not only about people infected with HIV but also about those affected by HIV.

As shown in table 3 all partners give attention to GIPA within their HIV/AIDS policy although not all regard it as a priority issue (yet). Only Aids Fonds has a specific policy on GIPA being one of its focus areas for partner support. Oxfam Novib planned to set out a policy to invest in PLHIV networks at the end of 2008. And ICCO has set a target for counterparts to include GIPA in their policy in 2010. Other STOP AIDS NOW! partners apply general principles to guide their work as donors, which implicitly include PLHIV. For example, the principle 'participation of target groups' which implies that everybody irrespective his/her HIV status is involved in programs and projects. Or the principle 'vulnerability', which includes HIV positive children and adults as specific categories. It was commented though that the implementation of such guidelines could vary among individual program officers (PO), or, as one policy officers stated: "HIV is integral part of strategic plans of all bureaus, but it depends on the bureau and the PO how much attention is given to the issue."

Table 3: GIPA Policies and Involvement of PLHIV by STOP AIDS NOW! Partners and development projects (situation May/June 2008)

STOP AIDS NOW! Development projects	GIPA Policy	Involvement PLHIV organisations in the STOP AIDS NOW! Development projects	Challenges to involve PLHIV
OVC	Discussion on infected children as target group started in early 2008 – no policy yet. Meaningful participation of children in all phases, but not specifically infected children.	Only in Pakistan PLHIV organisation involved, though program in Pakistan not yet started.	If you single out HIV-positive children you make them extra vulnerable for stigma and discrimination.
Gender	Has a GIPA policy.	In Kenya PLHIV organisations involved (KENWA, TAPWAK.) and one as coalition coordinator (WOFAK). In Indonesia training by PLHIV organisation (Spiritia) and involvement of Yayasan Pita (PLHIV organisation) and Yakita (IDU organisation with many PLHIV).	To involve PLHIV in the Indonesian province of Papua: trying to involve PLHIV support group.
Workplace policy	In all stages of the Workplace Policy Development Project PLHIV are involved, but no involvement of PLHIV Networks yet. Signed NGO Code of Good Practice.	PLHIV organisations are consulted for the country programs and the Steering Committee of the country programs should include at least one PLHIV organisation.	Capacities PLHIV organisations important, representation only is not good enough. How to involve PLHIV in the implementation? PLHIV should be involved in training but beyond giving testimonies.

STOP AIDS NOW! Partners	GIPA Policy	Support to PLHIV organisations	Attention for HIV in other programmes
Aids Fonds	Support to PLHIV is one of 3 priorities for the funding policy. GIPA internal Policy in discussion. Supervisory board must have one PLHIV member.	PLHIV organisations target group ICCS (International Civil Society Support) program. Support GNP+ and Collaborative Fund.	Aids Fonds has only HIV/AIDS programs
Hivos	Within HIV/AIDS policy much attention for GIPA. PLHIV partner organisations involved in development HIV/AIDS policy. TAC & GNP+ strategic partners. Target groups HIV/AIDS policy: PLHIV, MSM, LGBT, CSW, youth and poor women.	Support AIDES, ASONAPPVSI DAH, ASONVIH SIDA, ASOVIH SIDA, GNP+, INP+, KENWA, Kindlimuka, MANET+, MANASO, MEDAN+, Nivenyee, Prosa, Redvihda, Stigma Foundation, TAC (and in Serbia, Montenegro & Albania)	Mainstreaming HIV/AIDS (but not specifically GIPA). In Gender/Women program HIV gets much attention. No specific HIV targets in human rights program, though LGBT & CSW are target groups of this program.
ICCO	GIPA policy within HIV/AIDS policy: from program development to M&E, in 2010 60% counterparts should have GIPA in policy. Strategic partners: ACCESS & Vencer. Target groups: women and youth (girls).	Support ANARELA+, Vencer & ASOs	Mainstreaming HIV in health care (SRHR, human resources) & education & food security (in high prevalence countries) & GBV (in DRC). In micro-financing some partners. Workplace policies.
Cordaid	No GIPA policy, voice of PLHIV important (participation principle). Strategic plan mentions enhancing access to care for PLHIV and improving its quality.	AELWHA, COWLHA, NZP+ & 15 HBC organisations	Mainstreaming HIV in workplace policies; Ad hoc attention in general.
Oxfam Novib	No GIPA policy yet – expected later in 2008. STOP AIDS NOW! funding criteria for PLHIV networks applied. Mainstreaming HIV/AIDS in organisations & programs (workplace policy); linking HIV and Gender.	All Ukrainian Network of PLHIV, ASPALSIDA, ECUO, ICW, METTA, RBP+, NZP+	HIV is integral part of strategic plans of bureaus, but it depends on the bureau and the PO how much attention is given to the issue. HIV is one of the innovative funds (together with education and gender). In humanitarian programs there is not much attention for it yet

The HIV/AIDS policies of the STOP AIDS NOW! partners each have a different focus and priorities but generally encompass issues such as awareness, prevention, care, treatment,

access to medicines, VCT, stigma reduction, empowerment, capacity building, internal and external mainstreaming, and policy influencing. A few Partners (Hivos, Oxfam Novib, Aids Fonds) focus on specific target groups such as MSM, GLBT, PLHIV, youth, poor women, OVC, sex workers. ICCO and Cordaid include religious leaders and faith-based organisations to their target group of HIV programs. Generally, gender gets specific attention as well as sexual and reproductive health.

2.3 Involvement of PLHIV in programs supported by STOP AIDS NOW! partners/development projects

STOP AIDS NOW! Partners/development projects support 31 organisations/networks of PLHIV (see table 1). Three of these are international networks, two are regional networks and 26 are national or local organisations/networks in 20 countries.

STOP AIDS NOW! partners/development projects have their limitations in influencing counterparts to respond to HIV and AIDS or to purposely involve PLHIV in needs assessment and other phases of a program. The reason is that rarely STOP AIDS NOW! partners/development projects implement programs themselves, they support counterparts to do so. It could be both HIV-specific programs and non-HIV programs, in line with the Partners' policy regarding HIV and AIDS mainstreaming. The extent to which HIV is getting attention in non-HIV programs depends on the program officer and/or the counterpart, or, as one policy officer stated: *"Ideally beneficiaries should participate in the steps in every programme of a counterpart but it does not happen everywhere that PLHIV are included."*

As regards the counterpart itself, all STOP AIDS NOW! Partners have high ambition in taking up HIV in workplaces and promote the development of a HIV workplace policy. As one policy officer stated: *"The responsible policy officers have organised trainings, lunch sessions, etc. for all staff to build their expertise. GIPA is always mentioned and part of the content"*. Cordaid, ICCO and Oxfam Novib have made efforts to put HIV pro-actively on the agenda of some counterparts. This has helped increase support to staff living with or affected by HIV, clarifying rights of PLHIV and improve their access to treatment and support. In the STOP AIDS NOW! Gender Development Project, PLHIV organisations and networks have been purposely involved: in Kenya one PLHIV organisation is the coalition coordinator and two PLHIV organisations are included in the Project, in Indonesia one PLHIV organisation has been taken in for training and one PLHIV and one IDU organisation are part of the Project. In the STOP AIDS NOW! Workplace Policy Development Project PLHIV organisations are consulted for the country programs and the Steering Committee of the country programs should include at least one PLHIV organisation. In all stages of the Workplace Policy Development Project PLHIV are involved.

In case people living with HIV participate in programs of counterparts supported by STOP AIDS NOW! Partners/development projects what can the interviewees tell us about possible benefits of PLHIV? The Partners/development projects depend on the reports provided by their counterparts, which, however, do not include concrete data about outputs and even less on impact and also lack good indicators. Still, they feel that PLHIV do benefit. It concerns immediate needs of PLHIV, such as material needs, more income, more/nutritious food, access to treatment, and the like. Other benefits relate to psychosocial needs, for instance, more use of VCT, peer education, or stigma reduction at community level. Programs that focus on interests and rights of PLHIV (such as property rights, SRHR, and those related to gender-based violence) and legal support on property rights and gender-based violence are said to contribute to their empowerment and to more recognition in the community or society as a whole.

Naturally, the reports of PLHIV organisations and networks provide better information about specific benefits for PLHIV. The interviewees give examples of benefits such as improved access to treatment and more provision of home-based care. Perhaps the most important impact of the work of PLHIV organisations and networks is that the situation of PLHIV has been made known and put on the agenda. There is greater attention for living a positive life

when infected with HIV. Moreover, the role of grandparents, children of parents infected with HIV, and women as carers of ill people have been put on the agenda of local and higher levels of decisions making. Some networks report on specific impact on political and policy level.

2.4 STOP AIDS NOW! partners/development projects' assessment of the capacities of the supported PLHIV organisations and networks

With regard to capacities of supported PLHIV organisations and networks STOP AIDS NOW! partners/development projects recognise a number of strengths and weaknesses. They are generalised and summarised in annex VIII. In short, outstanding strengths are the staff commitment, staff's knowledge and insight in HIV, AIDS and PLHIV issues in both PLHIV organisations and networks. Other strengths of PLHIV networks have to do with their networking and advocacy capacity. It is felt that networks attend to the diversity of PLHIV in their constituency (IDUs, MSM, women, men, and so on). At the same time, the interviewees are aware that not all networks active at national level have an effective relation with the PLHIV at the local level. They believe that PLHIV organisations can effectively provide services and support to PLHIV and form a bridge between the national AIDS responses and the local level.

In terms of weaknesses the STOP AIDS NOW! partners/development projects observe that staff of PLHIV organisations and networks put a high workload on their shoulders. This and the number of requests and invitations from outside result in scattered agendas and ineffectiveness of the work. Moreover, PLHIV organisations, especially young ones, often lack a clear focus and a well-developed internal structure with systems, which is partly due to limited management knowledge and skills. In some networks a tension is noticed between staff living with HIV and those who are not infected. Both networks and organisations can be narrow-minded due to their specific focus on PLHIV. They lack attention to general poverty issues and do not establish contact with broader-oriented development actors. The STOP AIDS NOW! partners also noted that sometimes conflicts arise in the network/organisation either because of lack of funds or lack of absorption capacity of funds supplied.

STOP AIDS NOW! partners generally assist their counterparts in building their capacities, but it is usually done in an ad-hoc, rarely structural way. Cordaid has a capacity development trajectory for PLHIV support groups in two countries. Although capacity strengthening could be done by PLHIV organisations in the country or region, it was generally felt that this was not automatically the most effective way: non-PLHIV organisations could certainly play a role in capacity building.

2.5 STOP AIDS NOW! partners/development projects' views on challenges and opportunities to jointly with PLHIV organisations and networks promote the GIPA principle

Most STOP AIDS NOW! partners work together with PLHIV networks on GIPA, mainly national networks, but also regional and international networks. Sometimes it concerns strategic partnerships, e.g. Hivos with TAC and GNP+, Aids Fonds with Collaborative Fund and GNP+, and ICCO with Vencer. In other cases the Partners cooperate with one counterpart on specific topics and coordinate certain programs. The Partners also involve counterparts in promoting HIV or AIDS mainstreaming in development organisations.

STOP AIDS NOW! partners/development projects believe that a number of opportunities and challenges exists to jointly promote GIPA. Many opportunities perceived build on the strengths of the PLHIV organisations and networks identified by the STOP AIDS NOW! partners/development projects,

- PLHIV networks have access to national or regional consultations as members or parties.

- PLHIV organisations and networks can play an important role in mainstreaming issues specific to the situation of people living with HIV in non-PLHIV organisations and supporting PLHIV in that process.
- Quite a few PLHIV organisations and networks have a good understanding of and experiences with the specific situation of female PLHIV and bring their issues to the fore.
- PLHIV organisations and networks can also play an important role in putting HIV on the agenda of other sectors.
- PLHIV networks have a lot of knowledge on HIV issues and much expertise in advocacy which non-PLHIV organisations can exploit.
- PLHIV organisations and networks implement effective projects.

Additionally, the problematic situation of PLHIV is seen as a strong incentive to address more seriously HIV and AIDS issues. People living with HIV become visible and audible which in turn strengthens the GIPA principle. If STOP AIDS NOW! wants to promote the GIPA Principle, involvement of PLHIV organisations and networks is necessary to create ownership.

STOP AIDS NOW! partners/development projects also recognise challenges. Here we observe a relation with identified weaknesses of PLHIV organisations and networks,

- PLHIV are often not visible in many sectors – how to change it and exploit their expertise? At the same time PLHIV networks are very active: how to seek a balance between their carrying capacity and the multitude of momentums and agendas in which the voices of PLHIV should be heard? How can broader-oriented organisations be involved to bring those to the fore?
- How can PLHIV organisations broaden their horizon beyond a focus on needs and interests of PLHIV and include poverty reduction issues and other development issues.
- How to deal with weak management capacities?
- How to bridge the gap between the national level where discussions take place about rights and the position of PLHIV and the local level where concrete needs and constraints of PLHIV are major issues?
- What could be the role of local PLHIV organisations to satisfy needs and constraints of PLHIV versus the role that service providing organisations play?

Apart from these challenges related to weaknesses in PLHIV networks and organisations STOP AIDS NOW! partners/development projects pointed out a few specific challenges,

- People living with HIV are very diverse and have many different voices. On one hand, the challenge is how all these different voices can be made heard. On the other hand, to what extent should and can needs and constraints of PLHIV be given priority over those of people with other problems or life-threatening illnesses? How to prevent a gap between HIV-positive people and those who are affected by HIV and AIDS? There are moral as well as financial limitations in this respect.
- How to address needs and constraints of certain HIV-positive groups? For instance, should specific programs be set up for infected children or should attention to infected children be mainstreamed in programs for youth? How can meaningful participation of children be given shape? Or, to give another example, how to give more voice to HIV-positive women in male dominated PLHIV organisations/networks?
- Stigma and discrimination are still widespread and form a major hindrance to start programs, e.g. for HIV-positive children.
- A different challenge concerns the ethical question around disclosing one's status. Generally, highly educated people are less often coming out than poorer people, which reinforces the 'image' round HIV as an infection of poorer and less powerful people.
- Last, but not least, how to deal with tokenism is a challenge. Often PLHIV are being invited at different events and platforms but not given recognition, influence and power. It can even lead to taking an HIV infected person in without considering whose voice he or she is representing.

2.6 Cooperating as STOP AIDS NOW! partners/development projects in the application of the GIPA principle

How do STOP AIDS NOW! partners/development projects look into the issue of applying GIPA within the STOP AIDS NOW! setting? The Partners/development projects see clear opportunities of doing so. The mere fact that STOP AIDS NOW! exists is considered an asset. It was felt that discussing and focusing on similar issues contribute much to the learning of each Partner. The STOP AIDS NOW! partners/development projects also pointed to the challenge of adequate and timely communication and coordination between the Partners. Some issues are well shared– for instance, about HIV workplace policies - but on other issues it leaves to be desired, such as efforts how to promote GIPA. It was further recognised that it is not always easy to implement the GIPA in the STOP AIDS NOW! partner organisation – and even the STOP AIDS NOW! Secretariat. Much depends on the commitment at the management as well as the program staff level. Moreover, how to ask staff's attention for an important principle amidst the bulk of priorities of each organisation?!

Finally, the participants in the feedback workshop on part I of the exploratory study came up with four suggestions on how to put the GIPA principle into practice as STOP AIDS NOW!,

- The STOP AIDS NOW! Secretariat could play a more steering role by drawing the attention of the STOP AIDS NOW! partners more often to the GIPA principle.
- In accordance with the GIPA principle the Secretariat should make PLHIV visible within the Secretariat itself, which should also be done at the STOP AIDS NOW! partner organisations.
- STOP AIDS NOW! partners could support each other in the development of a GIPA policy for the own organisation.
- Improve the tuning of who does what and where between the STOP AIDS NOW! partners in order to strengthen the efforts on GIPA amidst the variety of donors and organisations that wish to jointly work with PLHIV networks.

2.7 Summary

1. The purpose of this chapter was to get an impression of how STOP AIDS NOW! partners and development projects apply the GIPA principle and the constraints and opportunities they face. Organisations and networks of PLHIV which have been or are being currently supported by STOP AIDS NOW! Development projects and partners have been mapped as well as the extent to which PLHIV are identified as beneficiaries and are involved in project making and decision making within STOP AIDS NOW! partners programs and Development projects.
2. STOP AIDS NOW! Partners/development projects support 31 organisations/networks of PLHIV. Three of these are international networks, two are regional networks and 26 are national or local organisations/networks in 20 countries. Hivos and ICCO have strategic partnerships with some of these organisations/networks.
3. All Partners give attention to GIPA within their HIV/AIDS policy although not all regard it as a priority issue (yet). Aids Fonds has a specific policy on GIPA being one of its focus areas for partner support. Oxfam Novib planned to set out a policy to invest in PLHIV networks at the end of 2008. ICCO has set a target for counterparts to include GIPA in their policy in 2010. Other STOP AIDS NOW! partners apply general principles to guide their work as donors, which implicitly include PLHIV.
4. Program officers of the STOP AIDS NOW! Partners put the involvement of PLHIV on the agenda of their dialogue with counterparts, though it is up to the counterparts to put GIPA into practice. STOP AIDS NOW! Partners support organisations on many issues important for PLHIV such as awareness, prevention, care, treatment, access to medicines, VCT, stigma reduction, empowerment, capacity building, internal and external mainstreaming, and policy influencing. A few Partners focus on specific target groups. In general gender and sexual and reproductive health gets specific attention.
5. STOP AIDS NOW! partners/development projects have their limitations in influencing counterparts to respond to HIV and AIDS or to purposely involve PLHIV in needs assessment and other phases of a program. However, all STOP AIDS NOW! Partners have a high ambition in addressing HIV in workplaces.

6. In regard to benefits for PLHIV the STOP AIDS NOW! Partners and development projects depend on the reports provided by their counterparts, which do not include concrete data about outputs and even less on impact and also lack good indicators. The reports of PLHIV organisations and networks provide better information about specific benefits for PLHIV.
7. Identified strengths of the PLHIV organisations/networks are staff commitment and knowledge; insight in HIV, AIDS and PLHIV issues; good networking and advocacy capacity; attending to the diversity of PLHIV in their constituency; effective provision of services and support to PLHIV and bridging between the national AIDS responses and the local level.
8. Identified weaknesses of the PLHIV organisations/networks are high workload of staff; scattered agendas and lack of clear focus; limited management knowledge and skills; less effective relations with PLHIV at the local level; lack of attention to general poverty issues and insufficient networking with broader-oriented development actors.
9. STOP AIDS NOW! partners/development projects believe that a number of opportunities and challenges exists to jointly promote GIPA. Many opportunities perceived build on the strengths of the PLHIV organisations and networks identified by the STOP AIDS NOW! partners/development projects. The problematic situation of PLHIV is seen as a strong incentive to address more seriously HIV and AIDS issues. PLHIV become visible and audible which in turn strengthens the GIPA principle. If STOP AIDS NOW! wants to promote the GIPA principle, involvement of PLHIV organisations and networks is regarded as necessary to create ownership.
10. The Partners/development projects see clear opportunities to apply the GIPA principle. The mere fact that STOP AIDS NOW! exists is considered an asset. It was felt that discussing and focusing on similar issues contribute much to the learning of each partner. They also pointed to the challenge of adequate and timely communication and coordination between the Partners. Some issues are well shared– for instance, about HIV workplace policies - but on other issues it leaves to be desired, such as efforts how to promote GIPA.

3 Capacities of PLHIV organisations and networks supported by STOP AIDS NOW! Partners/development projects

3.1 Introduction

As we set out in chapter 1 the exploratory study was primarily meant to learn more about the capacities of PLHIV organisations and networks since they are considered central for the application of the GIPA principle and the enhancement of the AIDS response at large. Our study deals only with those organisations and networks supported by the STOP AIDS NOW! partners/development projects in order to help them strengthen their counterparts and, thus, provide an impetus to the GIPA principle. As mentioned earlier we do not address the issue of effectiveness of efforts of the organisation/network to make the voices of the PLHIV heard or to empower PLHIV. This would require an evaluation of programs/interventions.

Focus of the chapter

This chapter deals with the topic of the second key question of the exploratory study: the capacities of PLHIV organisations and networks a) to make the voices of PLHIV heard in order to address their practical needs (eg. service delivery) and strategic interests (i.e. through advocacy) and/or b) to empower PLHIV to make their own voices heard (i.e. empowerment of PLHIV).¹¹ We focused our study on organisational capacities, related to the running of the organisation or network and to the operation of programs. To assess those capacities we made use of a framework developed by World Neighbors¹² (see last section of annex VII). This instrument helps assessing strengths and weaknesses of organisations or networks, i.e. it considers internal capacities to continue operating and to grow and capacities related to building and maintaining relations with other institutions and organisations. It categorises capacities into four areas: what the organisation is and who it represents (“to be”); what the organisation does at organisational level and at community/target group level (“to do”); how the organisation operates (“to manage”); and, with whom/which organisations/institutions the organisation relates (“to relate”). Some of the issues are also dealt with in chapter 4.

Sources of information

The findings we present here are based on information collected through questionnaires and interviews (the second part of the exploratory study) and the in-depth or case studies (part 3 of the exploratory study). As mentioned in the first chapter, 19 organisations and networks filled out the questionnaire, among which six of the organisations included in the in-depth studies. In these studies, local consultants gathered information of eight PLHIV organisations and one network in five countries. Since the PLHIV organisations and networks are located in different parts of the world and operate in different settings we choose to describe overall similarities and differences and to leave out details. We use examples from the questionnaires and case studies to illustrate the observations made. For details we refer to the country reports in annex XI.

¹¹ This question is in line with two issues of the TOR of the exploratory study:

- To identify the current situation (on organisational & institutional capacity, including networking and advocacy, funding donors) of organisations of people living with HIV (including national and regional networks) within the spectrum of this research;
- To identify strong organisations or networks of people living with HIV which can play a role as peer mentors for other organisations in need of organisational and institutional development.

¹² Based on Peter Gubbels & Catheryn Koss (2000) From the Roots Up. Strengthening Organisational Capacity through Guided Self-Assessment. Field Guide 2 Capacity Building. World Neighbors.

Limitations in the information collection and analysis

Evidently, we had to rely on the perceptions of the informants and the data reported by the local consultants. As the reader will notice there are some gaps in information. First, the in-depth reports were rather descriptive and less analytical than we had expected. In spite of their common TOR some consultants went more in-depth than others, thus complicating a consistent comparison of information. There was one critical issue that did not come out clearly enough: the specific situation of female PLHIV and gender-related constraints and opportunities.

A difficulty in the analysis was to clearly distinguish between the capacities of PLHIV organisations operating at local level and those at national or higher levels. Most of the counterparts of the STOP AIDS NOW! partners/development projects run activities at national level as can be seen table 1 in chapter 1. Of the four counterparts that work at local level we included three in the in-depth studies. We did not, however, observe significant differences between the capacities of these organisations and the higher level ones. Moreover, five organisations studied in-depth are membership organisations operating at national level which did not differ much from the national network included in the studies. We refer to the illustrations in the boxes for details.

In the next sections, we first describe common strengths followed by weaknesses among the organisations and networks studied. Thereafter, we pay attention to how organisations and networks build their capacities. Both sections help identify on what issues and in what ways STOP AIDS NOW! partners/development projects could improve their support to their counterparts – which is the focus of the last chapter.

3.2 Common strengths of PLHIV organisations and networks

The findings of the various in-depth studies show similarities in strengths and weaknesses of the eight PLHIV organisations and the one PLHIV network. We start summarizing their common strengths. We have added the findings of the questionnaires/interviews where applicable.

1. All organisations/network of the in-depth studies (although we do not have details from two Indonesian and the Costa Rican organisations) have developed **a clear and focused vision and mission**. The network has a clear mandate.
2. In all organisations/network studied in-depth both the paid staff and, where applicable, the volunteers show **dedication and total commitment to their cause**, i.e. generally, uplifting the situation and status of PLHIV, and the pursuit of their organisation's vision and mission.
3. All organisations/network studied in-depth are **registered and accepted and trusted by government, civil society and the communities**.
4. It can be considered a strength that all the organisations/network studied in-depth have **clearly defined the groups they serve**. In the two African countries and Nicaragua it concerns the general group of people living with AIDS, both men and women (adults and adolescents). Two Kenyan organisations focus on women only because of specific gender-related problems of rejection and poverty. The three organisations in Kenya also pay attention to orphans and vulnerable children (OVC) and the elderly who take care of OVC. The organisations in Indonesia have selected particular groups based on the trends of the HIV epidemic and the fact that these groups are more susceptible to HIV infection due to social, cultural, biological, behavioural or political factors. They support IDUs and their partners, young people, transgenders, sex workers, prisoners and MSM/homosexual men.

These data appear to reflect the groups served by the PLHIV organisations/networks that filled out the questionnaire – see table 4.

Table 4: Type(s) of PLHIV population(s) that the organisation/network serves in percentage (N=19)

5. Without exception all 19 organisations and networks are involved in services provision, empowerment and advocacy activities although to different degrees of intensity and with varying focus areas – see table 5. It can be considered a strength that the nine organisations/network studied in-depth **focus on activities that they feel they can handle and if not, they refer clients** to other specialised organisations with which they have sought partnership. For example, the three Kenyan organisations deal with the VCT services, relief, and nutritional services and they refer their members to other organisations dealing with PLHIV for services that they can not offer. In Indonesia, the three organisations responded to the ever worsening epidemic and changing needs of the community in a way typically of PLHIV organisations in that country. They moved from simply offering an environment where people affected by HIV and AIDS could draw support and strength from one another, to working in a range of areas, from service delivery to empowerment and advocacy. The two Central America organisations support PLHIV through the peer system: a person who already knows for some time that he/she is HIV-positive establishes a support relation with a recently diagnosed person to give advice, information, help based on his/her experience.

Table 5: Focus areas of activities by PLHIV organisations and networks (N=19)

Services	Empowerment	Lobby/Advocacy
74% Awareness raising (prevention)	88% Training & education	88% Access to prevention, treatment, care and support
68% Special groups	88% Human rights	65% Human rights
68% Adherence support	82% Support & self-help groups	59% Criminalisation
63% Counselling	82% Awareness raising (stigma & discrimination)	59% Gender Based Violence
53% Treatment preparedness	76% Information	47% Access to resources, input, extension, credits, etc.
53% Psycho-social support	65% Awareness Gender Based Violence	
53% Food and nutritional assistance		
53% Income generating projects		
47% Home based care		
47% Legal assistance		
37% VCT		
32% Buddy care		
26% Harm reduction programs		
21% Shelter		

6. The organisations/network studied in-depth have **put in place systems, mechanism and procedures** – for planning, financial administration information sharing, recruitment, administrative matters, facilities, and so on - **to adequately run the organisation and their programs**. It confirms the general picture of 19 organisations/networks – see table 6 below.

7. Another strength of the organisations/network studied in-depth is the **intensity of relationships and partnerships** they have developed over the years at the local, national and international level, with AIDS service providers, governmental organisations as well as other local, national, and international NGOs, including other PLHIV organisations and networks.

In all countries covered by the in-depth studies a variety of organisations – NGOs/CBOs, FBOs, and governmental institutions - are active in the various fields which relate to HIV and AIDS – among them PLHIV organisations and networks. Numerous NGOs and CBOs work on HIV/AIDS issues. They play a key role in implementing HIV prevention and intervention programs through conducting outreach, training, mentoring for PLHIV, giving support, counselling and the needed care and support for treatment. They also play a crucial role in motivating PLHIV to establish self-help groups for mutual support and facilitating PLHIV to become more involved in HIV programs. In countries like Indonesia where the stigma around PLHIV is high, they are critical in reaching hidden populations that are often not easily accessible by the government, most notably vulnerable and most at risk youth, sex workers, IDUs, and PLHIV. Unfortunately, in all cases the cooperation between NGOs often leaves to be desired because they often consider each other as competitors for funds and attention.

The organisations/network studied in-depth cooperate with other organisations and institutions to promote effectiveness of their activities. In view of their limitations in terms of human and financial resources, as well as knowledge and expertise, the development of the organisations/network and their capability to respond effectively to the epidemic depends to a large extent on their ability to create and utilize these relationships effectively. They have working relations with NGOs, CBOs, FBOs and government institutions, including the policy level. Generally speaking they use the contacts for referral for further services, in addition to empowerment, advocacy and capacity building, which is in line with the type of services the organisations/networks focus on and which they feel are the needs of the PLHIV they serve. They also build relationships for funding purposes, mostly with international donors. Relationships with policy makers are felt very important to promote support, commitment and implementation of policies on HIV/AIDS. The governments of all countries in the in-depth studies, except for Nicaragua, have national policies and strategies to combat HIV (we elaborate on this in the next chapter on GIPA principle).

The organisations/network studied in-depth also interact with religious leaders – who are important actors because of their influence and authority. In Zambia, for example, these leaders play a role in providing Home-Based Care and other support services to PLHIV. In Kenya, there are debates among the PLHIV organisations on how to approach churches because many religious leaders are against prevention measures such as use of condoms among the youths, and interfere in treatment and adherence through promoting spiritual healing. In Nicaragua on the contrary, the organisation studied cooperates well with the different churches (Lutheran, Catholic, Evangelical) on issues of prevention and perception of risks, in spite of the strongly negative attitude of the Catholic Church. In Costa Rica the church stands too strongly against sex education, etc. to cooperate with. In box 2 some examples of relationships are given.

Box 2: Examples of external relationships of the PLHIV organisations/network (source: *in-depth studies reports*)

In *Indonesia*, the PLHIV organisations recognized that in order to create maximum impact, it is crucial for them to network for advocacy purposes with governmental institutions, since government and policy makers are the key players. However, for issues such as capacity building, fighting stigma and discrimination, information and education campaigns, empowerment of staff and target group, referrals, etc. they are aware of the importance of forging partnerships with other NGOs, including other PLHIV organisations, community groups, and health service providers and others.

In *Zambia*, the Network is supported by various organisations, among which the National AIDS Council (NAC), providing technical and financial support, the Zambia AIDS Law Research and Advocacy Network (ZARAN) providing training skills to the Network members on basic human rights, and the AIDS Alliance, which conducts Treatment Literacy Training sessions that cover adherence to treatment.

The three *Kenyan* organisations work with organisations dealing with PLHIV at local level, national and international level. The – satisfactory- relations at the local level, for instance, concern resource mobilization, information sharing, and advocacy on issues affecting PLHIV. The relations at the international level focus on inputs needed to provide services to PLHIV, advocacy for better treatment and access to basic human rights, ART and medical treatment. They include USAID affiliated organisations such as PEPFAR and Future groups, DFID and JICA.

The *Costa Rican* organisation refers people they cannot support to other organisations and institutions, for example, on gay issues, specific child problems, transgender issues, legal issues, and medical help. Many organisations and institutions though are not HIV-sensitive or even PLHIV-friendly. Discrimination and stigmatisation, mostly rooted in ignorance, even among professional health workers, are great problems. Dentists, for instance, often refuse HIV-positive clients. PLHIV are denied jobs and they are even sacked due to their status. The most important player in this battle is the National Health Service. They supply medication like ART and attend to PLHIV to their best interest, often though hampered by too little knowledge and financial resources. The PLHIV organisation also works with the Ministry of Health in planning and discussing how to change laws and policies on HIV/AIDS related issues.

3.3 Common weaknesses of PLHIV organisations and networks

The nine organisations/network studied in-depth show a number of common weaknesses, which we present below. They generally concern organisational issues rather than programmatic issues although the first have definitely an impact on the latter. We have added some comments on critical issues or challenges faced.

1. All organisations/network studied in depth stated the problem of obtaining and maintaining qualified and sufficient staff. All except one felt that they have **insufficient staff** to fully implement all the activities and programs that they would like to. They believe that they achieve as much as they can with the staff they have available, but often work remains undone or done with severe strain. This means that it is not an uncommon problem for staff to be overloaded and overworked, which in turn can affect the quality of their performance at work or result in high staff (and volunteer) turnover as one organisation reported. For the Network this inadequate staffing concerns both the national and the lower level offices. Most of the organisations/ network are therefore heavily depending on volunteers who are mostly poorly remunerated, ill prepared and working more on ad hoc basis. A few organisations feel it is primarily a question of funding – if more funds are available more staff can be hired. In the *Costa Rican* organisation, for instance, it is not possible to offer a competitive salary to a lawyer or a psychologist or other higher educated professionals.

Comment: PLHIV and/or non-PLHIV staff?

A challenge felt by all the organisations/network studied in-depth is the recruitment of PLHIV staff. Some organisations have HIV-positive staff or even purposely recruit staff of the PLHIV groups they serve, but in most cases the majority of the staff is not HIV-positive. The Costa Rican organisation, for instance, recruits only PLHIV. PLHIV staff can act as role model and are an encouragement and inspiration to the members of the organisations. Several organisations, however, expressed that hiring PLHIV staff may comprise the quality required for the job. The Indonesian study explains the dilemma as follows: *“Among the commonly encountered problems are low skill and educational levels, frequent absence due to illness, and unreliability due to common instances of relapse. The poor quality of health services also results in many PLHIV being forced to spend much of their time and energy pursuing adequate medical care such as ART. Even if training is invested into PLHIV staff, the nature of HIV means that it is nearly impossible to achieve longevity because as the virus takes its course, capable and experienced PLHIV staff are lost due to illness or death.”* The three Indonesian organisations use various ways to deal with the issues, such as ongoing skill building and mentoring to ensure the sustainability of programs and leadership; and, non-PLHIV staff taking over the work of the PLHIV that has fallen sick. The question is if this also applies to countries where the availability of ARVs is improved drastically.

As regards the volunteers, on whom particularly the African and Central American organisations to a large extent rely in the field, their HIV-status varies per organisation. In some organisations all are PLHIV, while others work with non-PLHIV volunteers as well. Many volunteers are women. The tasks of volunteers vary from advice on pre/post testing, counselling, adherence and antiretroviral treatment, support to groups, community mobilisation to advocacy, promotion and awareness raising to the general public on HIV and AIDS and human rights issues. They usually receive some kind of training to prepare them for the work. Generally, it is not difficult to find volunteers, however, to get PLHIV with the right skills is said to be difficult mostly because of their low level of education and skills.

2. The concerns related to the work of PLHIV in the organisation touch on the issue of a **workplace policy**. None of the organisations/network studied in-depth had developed a HIV workplace policy. Three organisations do not have any policy concerning human resource management. One organisation has special health policies in place for PLHIV staff, another solves AIDS-related problems of its staff on ad-hoc basis. Additionally, two organisations did not feel the need for a HIV workplace policy yet, but indicated that they plan to develop one in the near future.
3. The organisations/network involved in the in-depth studies felt that many of the staff **lack knowledge and skills** in some essential areas to run the organisation and to meet challenges of the growing demands of PLHIV for services and support. The consultants of the in-depth studies observed weaknesses in the areas of financial management, data and general management, database and documentation, communication skills, writing skills and program development, GIPA principle and its indicators, and, lobbying. Management shows weaker points as well. In some organisations it concerns communication and coordination between activities carried out at different levels. Again others do not manage their external networking well. A third category of weaknesses, observed in three organisations only, was the lack of a system and procedures for the handling of funds in terms of accountability, transparency and security.
4. All organisations/network studied in-depth appear to **lack monitoring and evaluation systems**. It ranges from data collection and management of information to analysis and taking follow-up action. Such has severe consequences since the organisations/network do not have proper insight in the implementation of projects and activities and lack information relevant for management and planning.
5. Another weakness generally felt by the nine organisations/network studied in-depth is **limited financial resources**. It regards both organisational issues such as communication costs (transport, telephone) and activities to meet the needs of the increasing numbers of

PLHIV seeking support. The situation of the Central American organisations is very critical in this respect.

6. The in-depth studies of six organisations pays attention to **decision making – and**, apart from the Nicaraguan organisation, **assesses it as a weaker point**. In three organisations in Kenya planning and decision-making is a top-bottom process: the director takes key decisions while other staff and members are not much involved. This situation is disquieting because these organisations do not have deputy directors and the interviewees expected to face major challenges in case the executive director would leave – they did not have contingency plans. Also for Indonesia it is stated that for PLHIV organisations in general, the strength of their management depends only on one or two individuals, in other words these organisations are vulnerable in terms of management. The Indonesian and Central American studies are the only two mentioning that the three organisations studied provide equal opportunities for women in recruitment and sharing equal rights and responsibilities in decision-making. They feel strongly in greater involvement of women and addressing women’s needs.

Comparing the findings of the in-depth studies and the questionnaires

The identified strengths and limitations of the nine organisations/network are to a large extent in line with the answers to the questionnaire. Interesting are some differences, such as in the area of monitoring and evaluation, budgets, the dependency on the director, and decision making – see table 6 below.

Table 6: Assessment of organisational capacities (N=19)

	Very much/ very good	Sufficient	Not good, not bad	Insuf- ficient	Not at all
1. Our organisation has a vision	79%	21%			
2. We have planning procedures for our activities/ programs	68%	29%	5%		
3. We manage our time and avoid overloading of staff	47%	21%	21%	5%	
4. We have budgets for most of our activities/ programs	32%	47%	10%	10%	
5. We have problems handling the many funds we receive			21%	16%	53%
6. We monitor our activities/ programs and learn from successes and failures	47%	47%	5%		
7. We plan, record and monitor our financial activities	63%	37%			
8. We have built in flexibility to ensure that our organisation continues functioning	42%	37%	18%	5%	
9. We have a functioning board	37%	47%	10%		
10. We have put in place procedures which ensure that the right steps are	47%	32%	5%	5%	

	followed, for example, concerning administrative matters, project proposals, budget allocation, recruitment of staff, use of facilities, etc.					
11.	We take decisions and we follow them up	42%	42%	16%		
12.	We are able to manage internal conflicts	21%	53%	21%		
13.	Our staff/ volunteers know their tasks and responsibilities	47%	42%	10%		
14.	We have sufficient and capable staff to run our organisation and activities	10%	26%	37%	26%	
15.	When our director/ leader/ management will leave the organisation we expect to have problems to continue working		16%	16%	5%	58%
16.	Before we start any activity/ program we analyse the situation	37%	53%	5%	5%	
17.	We have established relationships with other organisations and groups to better achieve our goals	68%	26%			

3.4 Capacity building of the PLHIV organisations and networks

The PLHIV organisations and network studied in-depth follow different ways of building the capacity of their staff, volunteers and, where applicable, their members. Some take advantage of invitations to attend trainings, workshops, seminars and the like, made by organisations in their networks. The Network uses other strategies, such as senior staff passing on knowledge and skills to junior staff; allowing multi tasking among the network staff and members; training (on project development and management) to lower units (called districts) which become resource centres to support other districts; and, on demand organising various capacity building trainings.

Several organisations mentioned problems in building capacities. Lack of funding presents the principal obstacle to carrying out such activities for their own staff and, also, for their target groups. It seems that most organisations do not have a special budget to cover for capacity building and integrate costs for training staff into project budgets. The difficulty in finding trainers with sufficient knowledge on HIV/AIDS and co-related issues was another challenge mentioned.

When it comes to the question how best capacities could be built the questionnaire shows that 79% (n=19) of the organisations that responded feel that the capacities of PLHIV organisations and networks can best be strengthened by a PLHIV capacity building organisation while 16% disagree and 1 is neutral. The organisations involved in the in-depth studies have proposed the names of capacity building organisations but interestingly only the Indonesian list includes PLHIV capacity building organisations (In annex VIII the capacity building organisations are listed).

As mentioned the consultants of the in-depth studies observed a number of weaknesses in staff capacities. They felt that capacity building requirements might vary from organisation to organisation but also among the different levels at which the organisation operates – and a proper training needs assessment therefore has to be carried out to identify specific needs.

The question has to be posed if volunteers also need to be included in capacity building efforts and how volunteers who are trained can be maintained.

Apart from the own staff and volunteers the membership organisations and network studied in-depth have their ways of building capacities of their members, i.e. the male and female PLHIV organised in support or self-help groups. The Network organises special training for facilitators (of the Support Groups - SG) and for representatives of the SG. The participants are expected to train their fellow members but this in-depth study revealed that they do not share the information as effectively as they received it. The Network's Secretariat feels therefore that attention should be focussed on building capacity of the SG rather than the Secretariat. The Secretariat also organises awareness sessions on human rights (including gender and sexual violence) and discussion forums for the members and it distributes information, education and communication (IEC) print materials. Each SG has an IEC person. In Nicaragua volunteers educate members (mostly people between 15 -24). These volunteers have been trained in a wide area such as advocacy, promotion and public defence, human rights and non-discrimination, leadership and working in groups, self-esteem and sexual responsibility, adherence and antiretroviral treatment, advice on pre/post testing, and advice on antiretroviral treatment.

3.5 Summary

1. This chapter dealt with the strengths and weaknesses concerning the organisational capacities of PLHIV organisations and networks. It looked at capacities into four areas following the assessment framework of World Neighbours: what the organisation is and who it represents ("to be"); what the organisation does at organisational level and at community/target group level ("to do"); how the organisation operates ("to manage"); and, with whom/which organisations/institutions the organisation relates ("to relate"). The findings were based on information collected through questionnaires, interviews, and the in-depth or case studies in five countries (nine organisations/network).
2. Strengths of the PLHIV organisations/network studied in-depth in the area 'to be' are a clear and focused vision and mission; staff's and volunteers' dedication and total commitment to the cause of PLHIV; registered and accepted organisations/networks, trusted by government, civil society and the communities. In the area of 'to do' common strengths are clearly defined groups served by the organisations/networks and a focus on activities that they feel they can handle and if not, they refer clients to other specialised organisations with which they have sought partnership. In terms of operating the organisation/network ('to manage') a clear strength is that systems, mechanisms and procedures are put in place to adequately run the organisation and their programs. In the area 'to relate' a common strength is the intensity of relationships and partnerships they have developed over the years at the local, national and international level, with AIDS service providers, governmental organisations and with other local, national, and international NGOs, including other PLHIV organisations and networks.
3. As regards the common weaknesses of the nine organisations/network studied in-depth they generally concern organisational issues – the area 'to manage' - rather than programmatic issues. A first set of weaknesses is insufficient staff to fully implement all the activities and programs that the organisations/network would like to; overloaded and overworked staff; heavy dependence on volunteers; and a challenge felt by all the organisations/network studied is the recruitment of PLHIV staff. A second weakness is lack of staff knowledge and skills in some essential areas to run the organisation and to meet challenges of the growing demands of PLHIV for services and support. A third weakness is lack of monitoring and evaluation systems. Number four is limited financial resources. A few in-depth studies looked into decision making and assessed it a weaker point due to its top-down nature and dependency on the director. None of the organisations/network studied in-depth had developed a HIV workplace policy.
4. The identified strengths and limitations of the nine organisations/network are to a large extent in line with the outcomes of the questionnaire (usually filled out by one person at higher management level) with some interesting differences, concerning monitoring and evaluation, budgets, the dependency on the director, and decision-making. Table 6 above gives an overview of organisational capacities.

5. The PLHIV organisations and network studied in-depth follow different ways of building the capacity of their staff, volunteers and, where applicable, their members. Several organisations mentioned problems in building capacities, more especially lack of funding. Most organisations responding to the questionnaire preferred a PLHIV capacity building organisation over a general capacity building organisation. Annex VIII gives capacity building organisations mentioned by the organisations/network involved in the in-depth studies. The consultants who conducted the in-depth studies observed a number of weaknesses in organisational capacities but felt that capacity building requirements vary from organisation to organisation and between the different levels at which the organisation operates. They suggested a proper training needs assessment to identify specific needs. The question has to be posed if volunteers also need to be included in capacity building efforts and how volunteers who are trained can be maintained in the organisation.

4 The GIPA principle and involvement of male and female PLHIV

4.1 Introduction

In the previous chapter we looked into the organisational capacities of PLHIV organisations and networks. Strong organisations are more likely to address PLHIV's practical needs and strategic interests – provided they are well informed about these needs and concerns. In this chapter we look deeper into the extent to which PLHIV organisations and networks involve the PLHIV they intend to serve in planning, implementation and decision-making. Do they consider PLHIV as beneficiaries of services or as actors in processes of change or something in between? Adequate involvement is in line with the GIPA principle – what is the understanding of these organisations of the Principle? Evidently, the efforts of PLHIV organisations/networks to bring the cause of PLHIV to the fore is helped or hindered by other actors: government institutions and policy makers and other NGOs and civil society organisations. What is their understanding of the GIPA principle and how do they apply it? We also pay attention to the PLHIV themselves as one of the key actors influencing the space to make their own voices heard and how they understand the GIPA principle. Our source of information are the PLHIV as staff or members of the PLHIV organisations/network in the in-depth studies.

In this chapter we present the different views collected through the in-depth studies and the questionnaire on the GIPA principle and its application. It describes information to later on answer the key question 3 and 4 of the exploratory study¹³:

3. What factors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works, at different levels (such as stigma, access to treatment, national policy, etc.)?
4. What actors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works at different levels? Apart from the PLHIV organisation or network they include support organisations at community, district or national level, capacity building organisations, donors, and so on.

As stated in the first chapter GIPA is not a project or program, but it is a principle that aims to realize the rights and responsibilities of people living with HIV. At times we speak of the term implementation of the GIPA principle because this expression has been used in the various in-depth studies. However, as GIPA is a principle it is not possible to implement or mainstream it. A principle is applied or put into practice, which has to do with creating an enabling environment for a meaningful involvement of PLHIV.

4.2 PLHIV Organisations and Networks

In this section we look into PLHIV organisations'/networks' understanding of the GIPA principle and what they are doing to promote the principle; how they involve PLHIV in their organisations and networks and if all groups of PLHIV are included; and how they address PLHIV's practical needs and strategic interests and/or empower PLHIV.

Understanding of the GIPA principle

The in-depth studies did teach us more about how PLHIV organisations and networks understand the GIPA principle. Although most people who are active in the

¹³ These questions relate to two items we have been asked to address in the TOR.

- To map within STOP AIDS NOW! Partners programs and STOP AIDS NOW! Development projects to what extent PLHIV are identified as beneficiaries and to what extent they are involved in project making and decision making.
- To identify the opportunities, challenges, and possible improvements while working with STOP AIDS NOW! Partners, from the perspective of the organisations of people living with HIV (including national and regional networks).

organisations/network at national level do understand the GIPA principle, the majority of their members are unaware of the Principle or do not understand what it is or how it could be applied. Two examples are shown in box 3 below.

Box 3: Examples of understanding of the GIPA principle within a PLHIV network and organisations (source: in-depth studies reports)

The levels of understanding of the GIPA principle varied from the national secretariat to the support group in the case of the *Zambian* Network. The secretariat and district chapter staff understood that GIPA is a principle that seeks to promote a meaningful involvement of the PLHIV in realising their rights and responsibilities in order to improve their quality of life. The support group members interviewed, however, did not fully grasp what the Principle is and what it is all about.

In *Indonesia*, the study identified a discrepancy in the comprehension of the GIPA principle between different members of staff in the PLHIV organisations due to the fact that some newer members have not yet been trained about GIPA. Those staff that have been trained do not always have the time to pass the knowledge they have gained to other members of their organisation.

The understanding of the GIPA principle is also reflected in the extent to which PLHIV organisations and networks 1) involve the groups they serve in planning, implementation and decision making on activities and programs; 2) their efforts to empower PLHIV and 3) their activities to bring their concerns of PLHIV to the fore through advocacy and lobby. These issues are dealt with below.

Involvement of PLHIV in planning, implementation and decision-making

The questionnaires and the in-depth studies tell us about how the PLHIV organisations and networks assessed the level of involvement of the PLHIV they serve in their activities. By and large the answers to the questionnaire give a positive picture. As shown in table 7, the PLHIV organisations/networks generally involve PLHIV in the implementation of activities and programs, and although to a lesser extent, in decision making processes. The organisations/networks also feel that their programs and activities are based on the needs and views of PLHIV. A few organisations only stated that the needs of PLHIV were not well taken care of, because few openly known PLHIV (1 out of the 9 members) were sitting in its board or because the board's decision-making was said to be too slow for effective advocacy. Box 4 gives some examples on how PLHIV are being involved.

Table 7: Involvement of PLHIV in activities and decision making (N=19)

Issue	Very much/ very good	Sufficient	Not good, not bad
(Pt 17). Our activities/ programs are based on the needs and views of our target groups	53%	42%	
(Pt 18). We involve the target group in the implementation of activities/ programs	68%	32%	
(Pt 19). We involve the target group in decision making about activities/ programs	42%	37%	21%

Box 4: Examples of involvement of PLHIV in PLHIV organisations and networks

(source: questionnaire and in-depth studies reports)

The All-Ukrainian Network of PLHIV stated that PLHIV are being fully involved in the Network's activities. Their Executive director, deputy executives and other staff members express the problems and needs of PLHIV on behalf of the PLHIV community.

The PITA Foundation in *Indonesia* asks and assesses the needs of PLHIV e.g. by planning a focus group discussion before setting up a training for PLHIV.

The in-depth studies give a mixed picture of the involvement of PLHIV in planning, implementation and decision-making. The three organisations in *Indonesia* very much include their target groups in the implementation of their activities and their programs and at least sufficiently in decision making about their activities and programs. In *Kenya* the three membership organisations though lack effective members' involvement in planning and decision-making. One reason is the irregularity of General Assembly meetings. Other factors - which are faced by more organisations/network studied in-depth - are lack of interest and the varying literacy levels of PLHIV and, in some cases language barriers which hinder effective involvement of PLHIV. To the contrary, the Network in *Zambia* has bottom-up combined with up-down systems for information sharing and decision making in place. Moreover, this Network holds a General Assembly meeting every two years. Interestingly, its secretariat felt this bottom-up type of information flow very effective in ensuring that members' views are considered but the members interviewed held another view. Representatives of the support groups (SGs) said that they mostly met the district level staff during workshops and according to them the information is usually not adequately disseminated to the rest of the SG members. Box 5 gives an example about the involvement of PLHIV in the case of the *Zambian* Network.

Box 5: Involvement of PLHIV in plans of action – an example from *Zambia*

(source: in-depth studies reports)

The *Zambian* Network involves its members through the formation of support groups (SGs) composed of women, men or both men and women. The support groups are categorised in three types: workplace based support groups, community based SGs and Faith-Based SGs. Within their respective groups the members of the SG identify specific issues and challenges they want to address. These are communicated to the district chapters (i.e. the units of the Network at district level) where they are incorporated in the plans of action. These issues are taken to the NAC through the NZP+ Board Chairperson (member of the NAC steering Committee). According to the study it was not apparent that a national plan of action incorporated all the desired action points from all the districts.

Furthermore, the Network organised a strategic planning process with broad participation of its SG members (female participants outnumbering male) and prior to designing the advocacy/lobbying strategy it conducted a research to determine advocacy needs for the PLHIV among the PLHIV.

Addressing practical needs and strategic interests

The extent to which PLHIV organisations and networks seriously take the needs and concerns of PLHIV into account is furthermore reflected in the activities they undertake: the services and support they provide or issues they take up for advocacy or lobby. Common problems mentioned by people living with HIV in the five countries of the in-depth studies are high poverty level; inadequate food within their households; unemployment; low level of education; relevant skills to handle their situation; and knowledge. Widespread are stigma and discrimination from the community and at the workplace. The latter is having a serious impact on employed PLHIV, making them hesitant to take their medicines at prescribed times out of fear that their status will be discovered. Another common problem among PLHIV concerns the distance to centres where medicines have to be collected – which is a burden for those PLHIV who are not feeling well. Moreover, in case health facilities have specific ART clinic days, there is much congestion which results in long waiting hours before they can access their medicines. Looking at the activities of the PLHIV organisations/network included in the in-depth studies it appears that their main focus areas relate to the health and social status of the PLHIV they serve. They work on improving PLHIV's access to health services, fighting against stigma and discrimination, and empowerment through self-support or self organisation (support groups). The Zambian Network, for instance, encourages the formation of peer support groups in workplaces as an approach to reduce stigma. Concerning health, most of the organisations/network appear to focus on activities related to HIV and do not seem to address wider, general health issues or include TB, HCV or malaria. Only one in-depth study mentioned that relationships had been built with organisations dealing with TB and malaria. Furthermore, as came out the Kenya studies, services for HIV-positive expectant and new mothers to avoid HIV transmission to their new born such as healthy and hygienic feeding practices, were far from sufficient. Some consultants felt that the PLHIV organisations concerned miss out on opportunities for collaboration with organisations which have expertise in areas that do affect PLHIV although they do not work in the field of HIV/AIDS itself.

What can be said about the efforts of the PLHIV organisations/network studied in-depth concerning strategic interests of PLHIV - for example, specific PLHIV issues that should be addressed in development interventions or greater involvement in decision-making processes, more especially at policy level. Remarkable is that these nine PLHIV organisations/network hardly attend to poverty and food security issues. Income generating activities are not widespread and appeared not very effective. Those organisations that do address the issues are often restricted by funding constraints and lack adequate (commercial) skills to support PLHIV. Only three organisations do partner with government, private sector or Global Fund to provide food supplements of packages for the very poor PLHIV. Experiences in Nicaragua though are not very positive since the package (containing basic food like rice, beans, oil, sugar, etc.) lasts for a few days and does not stimulate people to find work or produce food. Furthermore, the lobby/advocacy of the organisations/network studied in-depth towards government and other organisations is mainly focused on access to health services and, to a much lesser extent on rights issues - see Box 6 for some examples.

Box 6: Examples of advocacy/lobbying activities (source: in-depth studies reports)

In *Indonesia*, two PLHIV organisations recognised that in order to create maximum impact, it is crucial for them to network for advocacy purposes to governmental organisations, since government and policy makers are the key players. For example, in order to change policies that treat drug users as criminals rather than ill people, PLHIV organisations concentrate their advocacy efforts towards the National Drugs Agency, the Police Department, and the Department of Law & Human Rights. Some of their members have been involved in working groups established by NAC, such as the Harm Reduction and Media Working Group. Involvement in NAC is also reflected through provincial/district AIDS commissions.

The *Zambian Network* conducted prior to designing the advocacy/lobbying strategy a research to determine advocacy needs for the PLHIV. Two major issues came out: the need for information and the need for treatment. Two officers in the secretariat are engaged in advocacy/lobbying activities through policy dialogue, which has been found effective when evidence-based information is shared. The Network gathers evidence from the community in support of the issue to be lobbied for, translates it in focussed presentations - whether in the form of drama sketches, poems or life testimonies - and finally presents it to a wider stakeholders audience often targeting influential policy makers. Its challenge is how to get senior policy makers involved since they usually request their junior, less influential staff to represent them. The Network has taken up advocacy issues such as criminalisation of HIV transmission, gender-based violence and access to resources, more especially the funds from the Zambia National AIDS Network.

Another way to find out if organisations and networks are active in addressing the GIPA principle is the response to the question in the questionnaire about the development of GIPA-related materials. 63% of the organisations/ networks did develop or are developing GIPA materials themselves, while 26% did not. Only one organisation provides funds to do so. There was one organisation that did not understand what GIPA-related materials are. Some organisations use materials developed by other organisations in their country or from international institutions, like UNAIDS. From the developed materials 82% are used by the government and/or by other organisations. In annex X the titles of the GIPA-related materials are listed.

The diversity of PLHIV

We have spoken about people living with HIV in general terms. In reality they are a very diverse group and they have many different voices. The challenge is how all these different voices can be made heard, more especially when organisations/networks serve PLHIV in general. To the PLHIV organisations that responded to the questionnaire, the issue of representation of diverse constituencies is not perceived as a great barrier. Most feel that they know the needs and constraints and based on those they design and implement activities and actions. Only 16% feel it is a barrier. On another related issue, that of empowerment of diverse constituencies within PLHIV (male, female, transgender, IDU, sexual minorities, etc.) to stand for their rights 21% feel that lack of empowerment is a barrier.

The in-depth studies do not help us to better understand how PLHIV organisations and networks deal with the issue of diversity of concerns and voices. We mentioned in 3.3 under strength 4 that all organisations/network have clearly defined the groups they serve. However, none of the studies provided information about specific needs of the different vulnerable groups they serve or different concerns brought forward by PLHIV. They also did not differentiate between male and female PLHIV, so we do not have a good picture of possible differences in involvement of male and female PLHIV or relevant gender-related concerns to be addressed through lobbying or advocacy.

Moreover, groups such as transgenders, sex workers, prisoners and homosexuals and even women are not easy to reach due to severe stigmatisation and discrimination by society. The organisations/network in Africa do not make efforts to reach these 'unaccepted and unrecognised' groups. At the same time the interviewees in the in-depth studies stated that for the men or women with these identities or way of life it is risky to come out openly to access services or resources. The three Indonesian organisations use the tactic to employ some

transgenders, female PLHIV or female drug users as staff. They remarked that it is necessary to address stigmatisation of transgenders by fellow staff. The Nicaraguan organisation uses the support of one of its partners, the ICW-LAC to find strategies to address women's and gender issues. One staff member also tries to meet homosexuals in their work and social environment to learn about their needs. The different strategies applied in Indonesia and Nicaragua help individuals of the groups directly gain income, knowledge or skills and it adds to their empowerment. In addition, it gives the PLHIV organisation concerned an entrance to a specific community. Even in Africa where many women are HIV-positive but also in Indonesia, it appears more difficult to reach female PLHIV than male PLHIV mainly due to cultural factors. In spite of this, the four African organisations/network have been able to reach many women – the majority of their members are female PLHIV.

To continue on diversity, these African organisations pointed at the issues of socio-economic class and urban-rural division. It is much easier to reach PLHIV of low-income groups and PLHIV in rural areas than the urban wealthy who can pay for services and medicines and without becoming openly HIV-positive. The HIV-positive people from the middle class are said to be easily reachable in Zambia, which contradicts with the study in Kenya.

Lastly, none of the organisations/network studied seem to pay attention to refugees, IDP and migrant people – which is remarkable because of the situation in countries like Kenya and Indonesia.

4.3 People living with HIV and the GIPA principle

In this section we pay attention to PLHIV' understanding of the GIPA principle and their willingness to take action to improving their situation.

To start with, our information about the PLHIV's understanding of the GIPA and active involvement in its implementation is limited for a number of reasons. Evidently, both the questionnaire and in-depth studies included PLHIV being staff of the organisations or networks. Since we could not ask about a person's status we cannot differentiate between responses of PLHIV and non-PLHIV. Furthermore, PLHIV at the beneficiaries level or members of PLHIV networks have not been interviewed in the in-depth studies because this was beyond the scope of the exploratory study.

Indirectly the in-depth studies tell us something about how PLHIV understand and apply the GIPA principle. The three Indonesian organisations mentioned that they face barriers to applying the GIPA principle externally because some PLHIV choose not to participate in empowerment activities, feeling that it is enough for them to be involved merely as beneficiaries. The latter also appears to apply to members of the three Kenyan organisations, especially to the poor members. The general characteristics of the PLHIV served by all the 19 organisations and networks show other barriers in this respect, such as poverty, illiteracy, and low level of education.

The Kenyan in-depth study points at the importance of readiness of PLHIV to take action: *“While the national response seeks to address the personalised needs of those living positively with HIV, it is a paradox that PLHIV remain marginalised, particularly HIV-positive women. There is clearly a disconnect between policy and practice creating a major gap. Without a motivated PLHIV community, sustaining GIPA mainstreaming over the long run may become increasingly difficult as few PLHIV will be ready to participate.”* In the next section we focus on the efforts made at the side of governments to seriously and actively involve PLHIV.

4.4 Governmental institutions and policy makers

In this section we focus on governmental institutions and policy makers. Has the GIPA principle been incorporated in national policies and brought into practice? How do PLHIV organisations and networks evaluate the involvement of PLHIV at national policy level and the understanding of the GIPA principle by governmental institutions and policy makers?

In most countries governments nowadays have developed or are in the process of developing a national AIDS plan and/or strategies, including the instalment of a National AIDS Commission. Nicaragua is an exception in this respect, although there exists a National Commission for Aids and a national coordinating mechanism, which are important supporters

to the Nicaraguan PLHIV. In the in-depth studies we attempted to find out more about the inclusion of the GIPA principle in such plans. Indonesia is a good example of a National AIDS Strategy in which GIPA is explicitly addressed – see box 7.

Box 7: GIPA principle in National AIDS Strategy (source: in-depth studies reports)
Indonesia: The National AIDS Strategy [also] recognizes the challenge in ending stigma and discrimination. It calls for increased peer involvement. Aiming to reduce suffering caused by HIV/AIDS, to prevent further spread and improving the quality of lives of people living with HIV, it calls for programs that provide support for PLHIV, empower PLHIV, and allow them to live full lives in line with GIPA principles. PLHIV active participation in HIV/AIDS prevention is encouraged. Support, accurate and comprehensive information as well as skills, knowledge, medication, care, education and employment are part of the planned programming.
Costa Rica: The government developed a multi-sectoral strategy to combat AIDS, with specific HIV budget provided to the following sectors: health, labour, justice, women, and young people. The government supplies budgets to institutions upon submitting their operative plans. The strategy includes crosscutting issues: human rights protection; HIV, AIDS and poverty, gender empowerment and equality; stigma and discrimination; *involvement of people living with HIV*; specific vulnerable subpopulations; youth; workplace; orphans and other vulnerable children.

Only 43% of the respondents (covering less than 30% of the countries covered in this study) to the questionnaire indicated that the GIPA principle is sufficiently included in the National AIDS plans, as can be read in table 8.

Table 8: Involvement of PLHIV in national decision making processes

Issue	N =	Very much	Sufficient	Not good, not bad	Insufficient	Not at all
1. The GIPA principle is included in the National AIDS Plan	14	7%	36%	43%	14%	
2. PLHIV have been involved in developing the National AIDS Plan	16	6%	44%	32%	19%	
3. PLHIV have been generally involved in national level policy development	16	6%	25%	50%	19%	
4. ARVs are accessible and affordable	15	20%	20%	40%	13%	7%
5. The poverty reduction plan and/or strategy has been developed/ reassessed with input from PLHIV	14		7%	28%	50%	14%
5. Involvement of PLHIV has been effective	15	7%	46%	7%	33%	7%

PLHIV have been involved in the development of the National AIDS Plan – 44% feels it has been sufficiently – but such inclusion does not imply that GIPA is taken seriously. Various respondents of the questionnaire pointed at tokenism. Box 8 gives a few comments of different respondents and statements from the questionnaire and in-depth reports.

Box 8: Comments regarding involvement of PLHIV at national level

(source: questionnaire and in-depth studies)

- While in *Malawi* the GIPA principle is recognised in the HIV/AIDS National Action Framework, there is little emphasis on ensuring that it is translated into practice. The Network regards the acknowledgement of GIPA in this manner as simple tokenism.
- In *Ukraine*, the involvement of PLHIV is sometimes very visible and active. For example, the Head of Coordination Council of the Network is Deputy Head of Country Coordination Mechanism on HIV/AIDS (CCM). However, due to the rapid change of governments and highly corrupted bureaucratic system the CCM exists only on paper. It does not function properly and actually, is not a mechanism of regulation of HIV/AIDS issues.
- In *Indonesia*, GIPA is already mentioned a lot, but in fact the PLHIV do not have enough control and power to be effective participants or to monitor processes or goals of policy making. There is no minimum standard of PLHIV involvement at national or local level and less understanding among stakeholders about the GIPA principle. This is because mostly the involvement of PLHIV happens at HIV programs only and not at decision making about or designing programs.
- From the *Indonesian* in-depth study: “Many PLHIV are still regarded more as tokens in policy levels, hindering their meaningful participation in decision making, formulation and implementation of public services. Some who do, are involved and are hired by health clinics as field workers but their involvement is often limited to implementation of such services.”
- From the *Kenyan* in-depth study: “However while [the National AIDS Plan] intended and did indeed involve community [...], its intention to have active participation of PLHIV was not met as the actual involvement of PLHIV turned out to be tokenistic”.

The responses to the questionnaire, moreover, show that PLHIV have not been sufficiently involved in national level policy development (table 8: 69%). Where it concerns HIV/AIDS issues the respondents are more positive about the involvement of PLHIV (50%). Looking at involvement of PLHIV in policy making on other development issues that impact their lives, such as poverty reduction they are even less involved. In general, half of the respondents regard the involvement of the PLHIV in policy making sufficiently effective. The figures presented in table 8 speak for themselves.

We can learn about obstacles towards meaningful involvement of PLHIV from the in-depth studies. They mention lack of implementation in general, lack of resources for implementation and lack of understanding at different levels. The Kenyan report states that “*There has been no development of an appropriate implementation framework or a communication strategy. The community lacks operational manuals as well as implementation guidelines and even clear understanding of GIPA issues to be addressed. There are no resources set aside for GIPA.*” In Indonesia, there is a “*Lack of understanding among stakeholders in national and provincial levels regarding GIPA principle and its standards, causing PLHIV to be involved only in the basic level of program as recipients and in implementation, and not having any meaningful involvement in designing and decision making process in programs that are supposed to meet their needs.*”

Another hindering factor that comes out the studies of Kenya and Indonesia concerns the relationships between PLHIV organisations. It is generally felt that cooperation and networking would add to more effective advocacy and lobby. However, in both countries competition between the PLHIV organisations was mentioned as an obstacle – see box 9 for examples.

Box 9: Cooperation between PLHIV organisations in Kenya and Indonesia

(source: *in-depth studies reports*)

Two *Kenyan* membership organisations network with other PLHIV organisations and networks at different levels. They both rated the relationships good where is concerns sharing/learning of best practices, referrals, training and advocacy. One of the major challenges of networking and cooperation is competition among the PLHIV organisations themselves. The PLHIV organisations do not look at each other as partners in fighting against HIV/AIDS but often regard each other as rivals. [...] Advocacy, however, requires concerted effort, joint planning and pooling of efforts, resources, skills and time which should be harnessed to make progress.

The PLHIV organisations in *Indonesia* do get involved in advocacy networks, however, these networks are yet to be utilized fully. All three organisations share the belief that they are in a better position than non-PLHIV organisations to represent the needs of PLHIV due to their personal, firsthand experience of living with HIV. However, even if individual organisations are strong, they would have greater impact advocating the needs of PLHIV as one voice, as opposed to several single voices. When advocating policy makers, they will be heard more if they work together, especially as PLHIV organisations generally share the same goals. A strong partnership among PLHIV organisations and other NGOs working in related areas is far more likely to induce a change in policy than several organisations approaching policy makers alone.

Last but not least, the *Kenyan* study points at another important issue that goes together with effective implementation of HIV/AIDS/GIPA policy: how to translate the GIPA concept into activities that can be monitored and can change the present scenario where PLHIV are mere passive observers.

4.5 Other NGOs and civil society organisations

This section is about how PLHIV organisations and networks evaluate the understanding of the GIPA principle by other NGOs and civil society organisations and if these organisations involve PLHIV in their programs and planning and to what extent has the GIPA principle been incorporated in their policies and put into practice.

In most of the countries covered by the in-depth studies there are numerous NGOs and CBOs that undertake activities related to HIV and AIDS. In section 3.2 we paid attention to the relationships between the PLHIV organisations/network and those non-PLHIV NGOs and CBOs (strength 7). The relationships are felt important for services and empowerment purposes but also, and to a much lesser extent for advocacy and lobby to the policy making level.

Although neither the in-depth studies nor the questionnaire provided much information about local development NGOs, CBOs and AIDS Service Organisations, we understand that they recognise GIPA as an useful tool of involving PLHIV. However, here also this conviction is not put into practice. The lack of application has to do with misunderstanding about the Principle, lack of proper information about the Principle and how to apply it, and lack of knowledge about national policies and strategies. At the same time, PLHIV do not make sufficient efforts to demand a meaningful participation in development programs. In box 10 several illustrations are given.

Box 10: GIPA application by non-PLHIV NGOs and CBOs

(source: in-depth studies reports)

Kenya: “This [recognition of GIPA] has not been translated into meaningful involvement with measurable targets. There are no GIPA targeted activities incorporated in their programs. Most interpret GIPA (or misinterpret) GIPA to mean participation of PLHIV in their meetings and occasionally select PLHIV representatives to their Board meetings. In this regard, networks and support groups are not consulted and there is no mechanism to connect PLHIV issues with their representatives. No training on empowerment or on stigma reduction skills exist and few or no materials or information on GIPA principle are available while PLHIV mobilization is mainly left to support groups as indicated by the bulk of referrals for counselling directed to the existing PLHIV organisations. The PLHIV networking itself is also weak and lacks one effective centralized voice.”

Indonesia: “In many cases, few members of civil society are familiar with UNGASS-related the Declaration of Commitment on HIV/AIDS and are not aware of the requirements and opportunities available to them to participate in related processes. Other than that, many PLHIV do not have the skills needed to make a meaningful contribution towards developing country reports. In addition, often government agencies perceive that they have sufficient data systems to provide a picture of HIV and AIDS situation in the country, hindering the involvement of civil society in compiling country reports. PLHIV networks would need to learn to give constructive inputs to have meaningful involvement at all levels.” [...] “Despite the inclusion of the GIPA principle in the National AIDS Strategy, it is yet to be fully implemented, or even fully understood by PLHIV themselves. Most local PLHIV networks still operate as support groups and are yet to fully grasp the implication of these policies and how they could take advantage of this opportunity to improve their lives through becoming more active in skill building programs, decision making, and advocacy.”

4.6 Summary

1. This chapter dealt with the extent to which different organisations involved PLHIV with their different backgrounds in planning, implementation and decision-making – in other words, are PLHIV meaningful involved in line with the GIPA principle. We looked into the organisation’s understanding of this Principle and how they applied it using the information collected through the questionnaires and in-depth studies.
2. The level of understanding of the GIPA principle is much higher at the staff of PLHIV organisations and networks at national level than at those at lower level. According to the respondents of the questionnaire the PLHIV organisations/networks generally involve PLHIV in the implementation of activities and programs, and although to a lesser extent, in decision making processes. They also feel that their programs and activities are based on the needs and views of PLHIV. They do not perceive the issue of representation of diverse constituencies as a great barrier to the meaningful involvement of PLHIV.
3. The organisations/network included in the in-depth studies show more nuance. There is quite some variation in the level of involvement of PLHIV and in the extent to which needs and views are taken seriously. The needs and interests of PLHIV that come out the in-depth studies are related to health and social issues but also about poverty, education and employment. Most PLHIV organisations/network studied in-depth have a rather narrow focus of activities: their health activities relate to HIV and do not seem to address wider, general health issues or include TB, HCV or malaria; they work on stigma reduction and empowerment through support/self-help groups; and hardly attend to poverty and food security issues; they are not very effective in income generation support. Their lobby/advocacy towards government and other organisations is mainly focused on access to health services and, to a much lesser extent on rights issues.
4. None of the studies provided information about specific needs of the different vulnerable groups they serve or different concerns brought forward by PLHIV or differentiated between male and female PLHIV. Therefore, it is difficult to understand how they deal with the diversity of PLHIV, more especially in advocacy work.
5. Concerning the incorporation and application of the GIPA principle in national policies the questionnaires show that in less than 30% of the countries covered by the questionnaire

the GIPA principle is sufficiently included in the National AIDS plans. Less than 50% feels that PLHIV have been sufficiently involved in the development of the National AIDS Plan but such inclusion of PLHIV does not imply that GIPA is taken seriously. Various respondents of the questionnaire pointed at tokenism. About the involvement of PLHIV at national policy level the respondents of the questionnaire are not very positive, more in particular where it concerns development issues that impact their lives, such as poverty reduction. One of the obstacles towards meaningful involvement of PLHIV is the lack of understanding at different government levels apart from lack of implementation in general and lack of resources for implementation. Moreover, the in-depth studies speak of competition between PLHIV organisations as a hindering factor to make PLHIV voices effectively heard.

6. From the limited information available it seems that local development NGOs, CBOs and AIDS Service Organisations, recognise GIPA as an useful tool of involving PLHIV, but again its application leaves to be desired. This has to do with misunderstanding about the Principle, lack of proper information about the Principle and how to apply it, and lack of knowledge about national policies and strategies. At the same time, it is remarked that PLHIV do not make sufficient efforts to demand a meaningful participation in development programs.

5 Outcomes of the exploratory study and Recommendations

5.1 Introduction

You have now come to the last chapter of the report of the exploratory study. The study focused on the capacities of PLHIV organisations and networks supported by STOP AIDS NOW! partners and their contribution to the GIPA principle. More insight into the strengths, limitations, opportunities and challenges of PLHIV organisations and networks would help STOP AIDS NOW! and each of its partners to identify issues of concern and steps to better apply the GIPA principle. In chapter 3 we presented the findings concerning the organisational capacities of the PLHIV organisations and networks studied. The chapters 2 and 4 set more light on how STOP AIDS NOW! partners/development projects, PLHIV organisations/networks and other key actors such as government institutions and local NGOs and CBOs understand the GIPA principle and how they apply it or, to what extent PLHIV are meaningful involved in program and policy making. In this chapter we give the outcomes or conclusions of the study by answering the four key questions of the exploratory study. From these outcomes we can draw some lessons learnt or critical issues for consideration. In the last section we present recommendations for the STOP AIDS NOW! partners.

5.2 Outcomes of the exploratory study

The first question of the exploratory study is the following:

1. **To what extent do STOP AIDS NOW! Partners/development projects include the GIPA principle in their programs by a) supporting PLHIV organisations and networks and b) considering the situation of PLHIV in the design, planning, implementation and monitoring and evaluation of their programs, the benefits and impact of their programs on PLHIV?**

Conclusion 1: The exploratory study learnt that the STOP AIDS NOW! partners/development projects totally support 31 PLHIV organisations and networks spread over the continents. Based on the experience that the search for these data was quite cumbersome we conclude that most policy advisors/program coordinators in charge of HIV/AIDS at the different partners of STOP AIDS NOW! lack a good overview of the PLHIV counterparts. This could be due to the fact that program officers are primarily responsible for support to/contact with counterparts and to the autonomous status of the country offices of some STOP AIDS NOW! partners.

Conclusion 2: All Partners give attention to GIPA within their HIV/AIDS policy although not all regard it as a priority issue (yet).

Conclusion 3: It is difficult to conclude about the extent to which STOP AIDS NOW! partners/development projects consider the situation of PLHIV in the design, planning, implementation and monitoring and evaluation of their programs. One reason is that the programs/projects are implemented by the counterparts and STOP AIDS NOW! partners/development projects have their limitations in influencing them to respond to HIV and AIDS or to purposely involve PLHIV in needs assessment and other phases of a program.

Conclusion 4: Hard conclusions about the programs/projects' benefits and impact on PLHIV can not be drawn because the counterparts' reports usually do not include concrete data about outputs and even less on impact. They also lack good indicators. The interviewees of STOP AIDS NOW! partners/development projects, however, feel that PLHIV do benefit, mostly in terms of immediate needs, but also psychosocial needs. Programs that focus on strategic interests and rights of PLHIV are said to contribute to their empowerment and more recognition in the community or society as a whole. The reports of the PLHIV organisations and networks supported contain more about specific benefits for PLHIV, such as immediate needs. According to the STOP AIDS NOW! partners the most important impact of the work of

the PLHIV organisations/networks is that the situation of PLHIV is much better known and their concerns are put on the agenda.

The second key question reads as follows:

2. What are the capacities of PLHIV organisations and networks a) to make the voices of PLHIV heard in order to address their practical needs (e.g. service delivery) and strategic interests (e.g. through advocacy) and/or b) to empower PLHIV to make their own voices heard (i.e. empowerment of PLHIV)?

Conclusion 5: Looking at the characteristics of the PLHIV organisations and networks in our sample we can conclude that they all support people who are in need and/or live in poverty. They show a high level of solidarity in a situation with great urgency to help/service new PLHIV. In view of these increasing numbers of PLHIV many lack the funds to provide sufficient services. Many organisations/networks heavily draw on volunteers who have few skills and a low level of education. Due to the high workload staff have hardly time to reflect on what is being done or the context in which they work.

Conclusion 6: The findings of the in-depth studies and questionnaire presented in chapter 3 pointed at similarities in organisational strengths and weaknesses among the PLHIV organisations and networks. In table 9 below we summarised the strengths and weaknesses using the organisational assessment framework of World Neighbors applied in the in-depth studies. It categorises the capacities of an organisation into four areas: to be, to do, to manage, and to relate. We generalised the information collected although we are aware that organisations have specific organisational characteristics and cultures, and operate in different contexts. Due to the small number of organisations/networks in our sample and the qualitative nature of the information (mostly perceptions of people) it is not possible to further differentiate and draw conclusions on certain categories of organisations.

Conclusion 7: We did not find any organisation or network that scored strong on all the items considered.

Table 9: Summary of strengths and weaknesses of PLHIV organisations and networks

Capacity areas	Strength of the PLHIV organisations/networks	Weakness of the PLHIV organisations/networks
TO BE (what the organisation is and who they represent)	All organisations/networks know where they stand for and why they work that hard to make change.	Although the organisations/networks state that they represent the diversity of PLHIV voices the outcomes of the in-depth studies show that most organisations/network do not differentiate between different groups of PLHIV. They usually do not make a distinction between the diverse needs and opportunities, more particularly, a gender perspective is lacking.
TO DO (what the organisation does at organisational level and at community/target group level)	All focus on areas which, in their view, they can handle.	- Insufficient staff - Lack of knowledge and skills in critical areas, such as management of programs and of the organisation, thematic programmatic areas.
	Involvement of the target groups in the implementation of activities and programs.	

	Involvement of target groups in decision-making processes - by PLHIV organisations operating at the local level and that focus on specific marginalised groups.	Lack of effective members' involvement in planning and decision-making - by PLHIV organisations/ networks operating at national level.
	Needs and views of PLHIV are reflected in programs and activities of PLHIV organisations/networks.	Apparently little attention to specific needs and concerns of different vulnerable groups and male and female PLHIV - except for the local organisations with a focused target group. None of the target groups in the in-depth studies include refugees, IDP and migrant people.
	Activities/programs focus on certain main concerns of PLHIV: their health and social status and empowerment through self-support or self-organisation.	<ul style="list-style-type: none"> - The activities/ programs related to HIV do not address wider, general health issues nor include TB, HCV nor malaria. - Generally, the attention to poverty and food security issues and enhancing income is poor.
		Lack of appropriate systems to monitor and evaluation activities and programs with adequate attention to diversity/gender.
TO MANAGE (how the organisation operates)	Adequate systems, mechanism and procedures for planning, administration (general and financial), information sharing within the organisation, facilities, human resource management, and so on, in order to run the organisation and the programs.	Some organisations/networks lack accountable and transparent system/ procedures for the handling of funds.
		Mobilisation of sufficient financial resources for the organisation and programs.
		Staff capacity is built ad-hoc, among others, due to lack of funds (a budget line is lacking). Additionally, trainers with sufficient knowledge on HIV/ AIDS issues are difficult to find.
	Decisions are taken and follow-up is made.	High dependency on the director. Decision-making is usually in the hands of a few people; more often it is a top-down system rather than a bottom-up system.
		Poor time management leading to overworked/overburdened staff.
		Some organisations poorly manage their external networking.
TO RELATE (with whom/ which organisations/ institutions the organisation)	Effective functional relationships (referral systems) with NGOs and CBOs that undertake activities related to HIV and AIDS, that help carry out their objectives concerning service delivery and empowerment.	The relationships with NGOs, CBOs, government institutions do rarely include food security issues, income generation, credit/micro finance, poverty in general, and other health issues (TB, malaria).

relates)	To a much lesser extent, relationships are built for advocacy and lobby to the policy making level.	
	Purposeful relations with governmental organisations exist (advocacy, especially for health-related issues) because government and policy makers are the key players.	
		High dependency on donor funding and competition for funding between PLHIV organisations/networks.

The third key question of the exploratory study is the following:

3. What factors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works, at different levels (such as stigma, access to treatment, national policy, etc.)?

Conclusion 8: In order to effectively apply GIPA an enabling environment is needed consisting of political, social and financial support and capacity building for PLHIV active in the organisations and networks. The study helped us better understand what factors are hindering meaningful involvement of PLHIV. In table 10 below we combined the different factors that form barriers, based on the responses to the questionnaire and insights gained through the in-depth studies. Fear of stigma and discrimination and actual discrimination are considered the most important barriers. Related to these is the ethical issue around disclosing one's status. It plays a role in a PLHIV organisation itself in which infected and not-infected staff work together, and in the groups which a PLHIV organisation or network wants to serve. It appears much easier to reach PLHIV of low-income groups and PLHIV in rural areas than the urban wealthy who can pay for services and medicines without being open about their status. This situation confirms the 'image' round HIV as an infection of a people who are poorer and less powerful.

Conclusion 9: Other important hindrances are funding constraints, low skill levels of PLHIV, belonging to a minority or marginalised group, poverty, lack of understanding and clarity on what GIPA is, gender inequalities in access to education and services and lack of workplace policies.

Conclusion 10: Lack of access to ARV therapy and treatment for opportunistic infections is mentioned by 37% of the respondents, which could be due to improved availability of ARVs in Africa, Latin America and parts of Asia. It could imply that the focus of many PLHIV organisations and networks on health issues related to HIV is becoming less urgent in these regions.

Conclusion 11: Meaningful involvement of PLHIV leaves to be desired due to the tokenistic way key actors (government institutions, policy makers, NGOs, CBOs, ASOs, FBOs, etc.) involve PLHIV. People living with HIV are mostly involved at implementation level of programs and services only or in prevention programs and not in designing an adequate response to the HIV epidemic nor in monitoring and evaluation. At one hand the actors lack understanding of the GIPA principle, at the other hand PLHIV also do not have proper understanding and even awareness and lack skills to make effective use of the Principle.

Table 10: The greatest barriers which hinder the meaningful involvement of PLHIV (GIPA principle) (N=19) (Source: questionnaire and in-depth studies)

68%	Fear of or actual discrimination
63%	Fear of stigma
58%	Funding constraints. <i>The in-depth studies pointed to the “Competition for funding between PLHIV organisations and networks”</i>
47%	Low skill levels
	Discrimination by health service providers
	Belonging to minority or marginalised groups. <i>The in-depth studies learnt that various legal, social and cultural factors are at stake here.</i>
	Poverty - <i>Poverty appeared an important barrier for PLHIV to becoming actively involved in making change in their situation. Other barriers in this respect are lack of interest, varying literacy and education levels, language as a general barrier.</i>
	Gender inequalities in access to education and services
	Lack of understanding and clarity on what GIPA is
42%	Workplace policies
	Rejection by family, friends or the community
	Discrimination in the workplace
37%	Gender inequalities in domestic and childcare responsibilities
	Lack of access to antiretroviral therapy and treatment for opportunistic infections
32%	Gender inequalities in financial dependence on men
	Homophobia and other forms of prejudice
28%	Financial insecurity
	Involvement is not paid
	Violence or fear of violence
21%	Weak management
	Lack of support services
	Finding a balance between the diverse needs within the group of PLHIV (male, female, transgender, IDU, CSW, sexual minorities, ethnicity, etc.)
	Empowerment of diverse constituencies within PLHIV (male, female, transgender, IDU, CSW, sexual minorities, ethnicity, etc.) to stand for their rights
	Lack of confidence in PLHIV organisations and/or networks
16%	Representing the diverse constituencies within PLHIV at different fora and levels
10%	No PLHIV organisation and/or network.

The fourth key question the study attempted to answer was:

4. What actors influence the space of PLHIV to make their voices heard in the context in which the PLHIV organisation or network works at different levels? Apart from the PLHIV organisation or network they include support organisations at community, district or national level, capacity building organisations, donors, and so on.

Conclusion 12: Government, especially the policy level is most important in providing space to PLHIV. In most countries government and NGOs, among which PLHIV organisations and

networks are partners in fighting against HIV and AIDS. In few countries government has limited the space for NGOs to operate. Although in all countries included in the exploratory study, HIV and AIDS policies have been developed, with national strategies and other mechanism for implementation, in few cases attention is paid to GIPA. Moreover, very rarely the Principle is put into practice due to lack of resources and skills, and often due to lack of understanding at different levels of what the Principle is about.

Conclusion 13: Other important actors influencing the case of PLHIV organisations and networks are the religious institutions because of their influence and authority. Depending on the country and nature of the religion PLHIV organisations and networks find partners in religious organisations. For instance, PLHIV get services from AIDS Service organisations (ASOs) of whom many are related to a religious institution. However, religious institutions and leaders can also have a negative influence, e.g. prevention (against condom use and sexual education, specifically regarding youth), and treatment and adherence to treatment (promoting spiritual healing).

Conclusion 14: Most local development NGOs, CBOs and ASOs recognise GIPA as an useful tool of involving PLHIV. However, these organisations also rarely apply the GIPA principle due to misunderstanding about the Principle, lack of proper information about the Principle and how to put it into practice, and lack of knowledge about national policies and strategies on HIV/AIDS.

Conclusion 15: STOP AIDS NOW! Partners/development projects influence the space of PLHIV organisations/networks in a positive way. The supported organisations and networks consider the relationship with the Partners/projects positive, important and critical to sustainability. Funding and support are appreciated very much, though unpredictability of funding and a lack of a long-term policy are regarded as constraints.

5.3 Critical issues for consideration

The exploratory study is meant to give insight into the capacities of PLHIV organisations and networks as important vehicles for GIPA. The study should help STOP AIDS NOW! and each of its partners identify issues of concern and steps to better apply the GIPA principle in view of existing policies and opportunities. The outcomes presented above give rise to a number of critical issues which we feel should give more consideration, leaving it to the individual partner to pursue or not.

- A first issue, which directly relates to the topic of the study, is the insufficient level of skills and education of staff and volunteers to effectively run the organisation and its programs as observed in many PLHIV organisations/networks. It is even more problematic because capacity building of staff only takes place in an ad-hoc manner due to lack of staff's time, training opportunities and of funds.
- A second issue is the observed lack of attention – or even consciousness - among the PLHIV organisations/networks to the diversity among people living with HIV. It may lead to exclusion of certain groups and disregard of their concerns. Of special concern is the poor attention to gender inequalities and women's issues. Even the in-depth studies were rather gender blind.
- Third, the PLHIV organisations/networks in our sample focus on HIV-related issues in its narrow sense and hardly take up broader issues affecting PLHIV as reflected in their activities and the relationships with development institutions and organisations. In turn, the in-depth studies taught us that development organisations do not establish sufficient or effective contacts with the PLHIV organisations/networks and government institutions do not adequately consult them in policy-making processes. Thus, opportunities are missed out to effectively improve the situation of PLHIV.

- Four, a general observation at government institutions and all kinds of development organisations is the low level of understanding of GIPA. Good knowledge about the Principle is a basic requirement for its application .
- Fifth, it is unclear to what extent PLHIV benefit from activities of the PLHIV organisations/networks mainly due to poor monitoring and reporting. The STOP AIDS NOW! Partners/development projects, therefore, are not well informed about outcomes and impact, which hinders them making the right strategic choices. We should keep in mind though that it is difficult to demonstrate impact while funding continues to be only project-based.
- A sixth issue important to the running of an organisation/network and to a proper application of GIPA is the top-down nature of decision making and the dependency on the director in various organisations and networks.
- Last but certainly not least, PLHIV organisations/networks have not developed a workplace policy, which is important in view of the emphasis of STOP AIDS NOW! partners/development projects on the issue.

The exploratory study makes clear that it is not easy for all parties concerned how to apply the GIPA principle. Therefore, we like to end this section with an example of how it can be applied. It is taken from the study “Beyond the ‘Hello my name is ... and I am HIV –positive’ speech - Application possibilities of the GIPA principle”,¹⁴ (to be found in the GIPA resource centre at www.gnpplus.net), assigned by the Dutch Ministry of Foreign Affairs. The study focused on the possibilities for application of the GIPA principle within the work of the RNEs in middle and low-income countries. Box 11 gives a model of participation of PLHIV which can help understand to what extent PLHIV are being involved and how to increase its meaningfulness.

Box 11: Model of Participation of PLHIV

Level of Participation	Openings	Opportunities	Obligations
1. Initiated and directed by PLHIV	Are RNEs willing to support the ideas and activities of PLHIV?	Do RNEs have the resources (financial, human, social) to support the ideas and activities?	Is it a policy requirement that the ideas and activities of PLHIV are supported?
2. Initiated by PLHIV, shared decision-making	Are RNEs willing to follow an initiative of PLHIV and share decision-making power with them?	Is there a procedure that enables RNEs to share power and responsibilities for decisions with PLHIV?	Is it a policy requirement that PLHIV have an equal share of power and responsibility for decisions?
3. Initiated by others, shared decision-making	Are RNEs willing to share decision-making power with PLHIV?	Is there a procedure that enables RNEs to share power and responsibilities for decisions with PLHIV?	Is it a policy requirement that PLHIV have an equal share of power and responsibility for decisions?
4. Representative of PLHIV networks involved	Are RNEs willing to involve representatives of PLHIV networks in relevant activities?	Is there a procedure that enables RNEs to involve PLHIV in relevant activities?	Is it a policy requirement that PLHIV are involved in various activities?

¹⁴ Dieneke ter Huurne for the Dutch Ministry of Foreign Affairs

5. PLHIV consulted and informed	Are RNEs willing to take PLHIV's views into account?	Is there a procedure that enables RNEs to take the views of HIV+ people into account?	Is it a policy requirement that the views of PLHIV must be given due weight in decision-making?
6. Assigned but informed	Are RNEs willing to assign PLHIV certain roles in relevant activities, while keeping them informed?	Is there a procedure that enables RNEs to assign and inform PLHIV?	Is it a policy requirement that PLHIV should be assigned a role in and informed about the activities of RNEs?

Note of the author: What makes it interesting to work with this model when it concerns the Greater Involvement of People living with HIV/AIDS, is that the GIPA principle is already an obligation. Although the Ministry of Foreign Affairs never sent out an official instruction to the RNEs on the involvement of PLHIV the Netherlands did sign several international declarations, committing itself to the GIPA principle.

5.4 Recommendations to STOP AIDS NOW! partners/development projects

In this last section we suggest a few recommendations for STOP AIDS NOW! partners/development projects in line with the outcomes and critical issues mentioned above. We focus on the three key items of the exploratory study: 1. the capacities of the PLHIV organisations and networks supported the Partners/development projects, 2. how to build these capacities, 3. in order to ensure GIPA.

- ***A first set of recommendations focuses on how to address critical weaknesses of the PLHIV organisations and networks***
 - STOP AIDS NOW! partners/development projects should stimulate and support networking and/or network organisations at national level to set up a combined advocacy of PLHIV organisations and networks nationally in order to avoid competition and to ensure effectiveness and efficiency.
 - STOP AIDS NOW! partners/development projects should encourage PLHIV organisations and networks to broaden their relation network and cooperate with development organisations to more effectively alleviate poverty and other constraints of PLHIV. Such closer relations will also positively impact on the work and vision of general development organisations.
 - STOP AIDS NOW! partners/development projects should support PLHIV organisations and networks in developing policies regarding gender and vulnerable/marginalised groups in order to ensure that their specific needs, constraints and opportunities are overtly on the agenda.
 - In line with its focus STOP AIDS NOW! partners/development projects should stimulate and support PLHIV organisations and networks (including financial support) to set up a workplace policy regarding HIV/AIDS (and other health-related issues) in order to ensure and maintain the sustainability of programs and of the organisation itself. Such a policy should not exclusively address the health situation but also ensure an organisation in which there is space for all diversities, male and female.
- ***Secondly, we suggest a recommendation on how to facilitate Capacity Building of PLHIV organisations and networks***
 - STOP AIDS NOW! partners/development projects should develop and implement a policy for capacity building, which should stress needs assessment and, based on its outcome a focused and tailor-made approach in order to strengthen the PLHIV organisations and networks. In view of the gaps identified in the study such capacity building should include monitoring and evaluation.

- ***A third set of recommendations concerns the GIPA principle and how to promote its application***
 - In order to put the GIPA principle into practice skills building on how to promote meaningful and inclusive involvement of PLHIV at all stakeholders is necessary. STOP AIDS NOW! partners/development projects should address the GIPA principle at and offer skills building specifically to their counterparts. The Partners should also support each other to enhance understanding of the among colleagues in the own organisation.
 - STOP AIDS NOW! partners/development projects should revisit their HIV policy to ensure that the GIPA principle is explicitly attended to in programs and workplace.
 - STOP AIDS NOW! partners/development projects should promote that non-PLHIV counterparts address and mainstream issues specific to the situation of people living with HIV (male and female) and they should support the involvement of PLHIV in that process. Of special importance are income generation and food security.
 - STOP AIDS NOW! partners/development projects should more consciously work towards strategic partnerships with PLHIV (and non-PLHIV where relevant) organisations and networks to strengthen advocacy and lobby on specific issues to enhance GIPA and the situation of male and female PLHIV.