



Involving People Living with HIV: Support to PLWH Organisations in Cameroon

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The German HIV Practice Collection

Peer-reviewed

The German HIV Practice Collection is edited by the German HIV Peer Review Group (PRG), an initiative launched in September 2004 by AIDS experts working in German and international development cooperation. The aim of this group is to collaboratively manage knowledge about good practice and lessons learnt in German contributions to AIDS responses in developing countries.

Based on a set of jointly defined criteria for 'good practice' (see text box), PRG members assess different ways of responding to AIDS that have been submitted to them for peer review. Approaches that meet the majority of the criteria will be documented, published and widely disseminated as part of this Practice Collection. While some of the documented practices cannot fully meet, as yet, the criteria for 'good practice' (i.e. several external evaluations and multiple replications in different countries), all of them represent examples of 'promising practice' that may inform and inspire other actors in the complex and dynamic fields of HIV prevention, AIDS treatment, impact mitigation, support and care.

Selection Criteria

- Effectiveness
- Transferability
- Participatory and empowering approach
- Gender awareness
- Quality of monitoring and evaluation
- Innovation
- Comparative cost-effectiveness
- Sustainability

PRG members believe that collaborative knowledge management means 'getting the right people, at the right moment, to discuss the right thing'. Through the peer review, discussion and dissemination of innovative approaches, German development cooperation supports essential principles of capacity development:

- The process is organised as a transparent and mutual learning experience involving AIDS experts of German organisations, their partner institutions in developing countries and AIDS experts working for multilateral organisations.
- It provides planners and practitioners with a range of practical, evidence-based programming models.
- It focuses on the results of the reviewed approaches, looking at their achievements, challenges and lessons learnt.

PRG membership is open to AIDS experts and development cooperation planners and practitioners with an interest in German contributions to the AIDS response in developing countries. For more information, contact the Secretary of the Peer Review Group at aidsprg@gtz.de or go to <http://hiv.prg.googlepages.com/home>

Executive Summary

For too long, the important role of people living with HIV or AIDS (PLWH) in the fight against the epidemic has not been sufficiently recognized by policy makers and programme managers. And yet, involving PLWH is a crucial step towards addressing HIV/AIDS-related stigma and discrimination, two major hindering blocks for effective HIV/AIDS prevention and care. In the context of the international initiative for Greater Involvement of PLWH (GIPA), the GTZ-supported health programme in Cameroon has aimed to empower PLWH and to ensure their participation in HIV/ AIDS-related political processes and programmes. With this support, 73 PLWH organisations have been established in Cameroon, comprising more than 5000 members. They share the goal to fight stigma and discrimination, to improve the quality of life of PLWH and to prevent the further spread of HIV/AIDS by providing psychosocial support, voluntary counselling and testing (VCT), Home Based Care, support to treatment programmes and prevention campaigns.

In August 2000, these PLWH organisations established the Cameroon Network of PLWH organisations, RéCAP+ which coordinates the activities of its member organisations, aims at building their institutional capacities and at ensuring the representation of PLWH in political decision-making bodies at local and national level. With technical support by GTZ, a number of promising practices have been developed, including the representation of RéCAP+ in all principal HIV/ AIDS-related policy and programming bodies in Cameroon, public events addressing stigma and discriminations, workshops promoting the formation of PLWH organisations throughout the country, as well as training of PLWH organisations in management skills, in Home Based Care, counselling skills and treatment literacy.

Five years into its partnership with the GTZ health programme, a number of significant results have been achieved: RéCAP+ is playing an important role in the planning and implementation of the national HIV/AIDS programme, it has improved the services for PLWH and, thus, their quality of life, increased the public awareness of their rights and highlighted their potential and commitment to contribute to the fight against HIV/AIDS in Cameroon. Furthermore, the representation of PLWH in major HIV/AIDS-related decision-making bodies has contributed to improving the access to antiretroviral treatment for PLWHs, and the involvement of PLWH organisations in treatment programmes appears an effective way to enhance patients' compliance with their drug regimen. By working with young women in particular, the age and sex group most vulnerable to HIV-infection and its consequences, the network addresses the unequal position of men and women with regard to HIV/AIDS. Overall, the support to PLWH organisations promises to be an effective approach to fighting HIV/AIDS-related stigma and discrimination.

The Context

Cameroon, a country in Western Central Africa, is severely affected by the HIV/AIDS epidemic. According to current estimates, about 560.000 adults and children were living with the Human Deficiency Virus (HIV) the end of 2003. Almost seven percent of all adults (15-49) were infected and around 50.000 people died of AIDS in this year¹. In response to the epidemic and its social and economic consequences, the government established a National AIDS Control Committee (NACC) in 1985², headed by the Ministry of Public Health. A multi-sectoral National Strategic Plan against HIV/AIDS was launched in September 2000, aiming for the prevention of HIV-infections and the improvement of care and treatment for those infected.

Most people infected with HIV eventually experience periods of weakness or disease and suffer from different opportunistic infections. They have often lost family members, worry about their partners' and childrens' future and are threatened by poverty as they lose their capacity to work. The strenuous task to care for their AIDS patients at home puts an additional strain on affected families³. Because the health care system in Cameroon is in many parts of the country still ineffective and overburdened, and public social services are lacking, PLWHs often receive insufficient support.

At the same time, PLWH around the world have in the last years become active in the fight against HIV and AIDS. Given their growing number, the pressure to include PLWH in decision-making processes and HIV/AIDS programmes at local and at national level has steadily increased. Their political participation has, however, often been hindered by stigma and discrimination and by the lack of democratic structures for civil society involvement.

Against this background, the GTZ-supported health programme in Cameroon has since 1997 focussed on empowering PLWH by ensuring their involvement both in HIV/AIDS-related political processes and service delivery. Chapters 2-5 describe the GTZ approach to strengthening the role and building the capacity of PLWH organisations in Cameroon. The remainder of this first chapter outlines the stigma and marginalisation faced by PLWH in countries like Cameroon and presents the global initiative to their greater involvement in the fight against HIV/AIDS.

Stigma and Discrimination against PLWH

As HIV/AIDS is strongly associated with "immoral" sexual behaviour and death, people living with HIV or AIDS are often confronted with extreme stigma and discrimination. In Cameroon, like in many other countries, PLWH are often rejected by their families and friends or blamed for getting infected. Women are especially affected by discrimination, because they are often accused of spreading the virus⁴. Studies have shown that stigma is higher in medium-prevalence countries like Cameroon than in high-prevalence regions, because less people are openly HIV-positive⁵. In the beginning of the epidemic, some prevention campaigns unwillingly fostered the stigmatisation of HIV-positive people, because they equated an HIV-infection with death. People's fear of death and disease led to the rejection of PLWH. Stigma and discrimination take place not only at individual and community level, but also at institutional level⁶. PLWH are for example denied visa for travelling or discriminated against at the workplace, because employers fear costs related to illness or death.

As a consequence of stigmatisation, many PLWH feel ashamed, withdraw from their environment and go into hiding. Often, they do not disclose their HIV-status to their family and friends out of fear of moral condemnation and social exclusion.

1 UNAIDS 2004: Epidemic Fact Sheet Cameroon. 2004 Update.

2 Tsala Tsala, Jacques-Philippe 2004: L'ascenseur et l'escalier – la lutte contre le SIDA au Cameroun: Journal des Aspects Sociaux du VIH/SIDA.1 (3). p. 144

3 cf. Dilger 2005: Leben mit AIDS. Krankheit, Tod und soziale Beziehungen in Afrika. Frankfurt a. M./New York.

4 Dilger 2005: Leben mit AIDS.

5 De Loenzien, M. 1996: Knowledge, Opinions and Attitudes towards AIDS in rural Africa (Senegal, Cameroon, Burundi). Current Research. Societes Afriques et SIDA 13: 11-13.

6 Parker, Richard and Peter Aggleton 2002: HIV/AIDS-related stigma and discrimination. A conceptual framework and an agenda for action. Horizons Program. The Population Council.



Stigma and discrimination are now the major limiting factors for effective HIV/AIDS prevention and care⁷. They prevent people from seeking voluntary counselling and testing as well as treatment and care and thereby increase the suffering of people living with HIV or AIDS⁸.

Besides leading to violations of human rights to e.g. employment, free movement and health care, stigma and discrimination against PLWH seriously hamper the fight against HIV and AIDS for all.

- Discrimination and stigma have a negative effect on prevention efforts. People are discouraged from seeking voluntary counselling and testing (VCT) and will, thus, not be inclined to change their behaviour. When AIDS is perceived as an immoral disease, open communication about the disease and the ways of transmission becomes more difficult. As long as PLWH have to hide their sero-status to avoid moral condemnation, HIV/AIDS will not be seen as something “real”, and people will be less likely to protect themselves.
- Furthermore, stigma and discrimination serve as a barrier to proper care, support and treatment for PLWH. People will be afraid to know their sero-status, or, should they be positive, to disclose it to others. Fear of stigmatisation may keep them from seeking and receiving adequate treatment. Also, discrimination by health personnel against PLWH can lead to lack of appropriate health care for them. Especially women, who are often blamed for spreading the virus, often lack adequate support. Overall, stigma and discrimination lead to psychological distress, which will further undermine the state of health and general well-being of a person living with HIV or AIDS.

Greater Involvement of PLWH in the Fight against AIDS

In the first decade of the epidemic, the prevention of new HIV infections was at the core of most national AIDS programmes in Sub-Saharan Africa. Care and support for those already infected with HIV or suffering from AIDS constituted only a secondary goal. PLWH were usually not involved in decision-making processes at local, national or international level. Their needs and interests, but also their potentials have, thus, for a long time not been sufficiently considered. When policies or programmes addressed PLWH, infected persons tended to be treated as passive victims in need of care and support rather than as crucial stakeholders and experts on their own needs, hopes and visions.

In the 1990ies, public awareness for the important role of PLWH for effective HIV/AIDS programmes grew steadily. At an international level, the greater involvement of PLWH was agreed upon in Paris in 1994. Representatives of 42 states agreed that the knowledge and expertise of PLWH should contribute to decision-making at all levels and in all relevant institutions, and that their needs and insights should be reflected in policy and programme development. Part of the initiative for 'Greater Involvement of People living with AIDS' (GIPA) was the goal to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community-based organisations and, thus, increase civil society involvement in the fight against the epidemic⁹.

In recent years, advocacy activities of national and international PLWH networks have contributed to improving access to antiretroviral treatment at low cost in many African countries. For instance, the Global Network of People Living with HIV/AIDS (GNP+) as well as the Treatment Action Campaign (TAC) in South Africa have fought for equal access to ARV in Africa, pushing pharmaceutical companies to give up patent rights for ART in order to save lives¹⁰.

"To be able to face the epidemic, I am now completely committed to the fight against AIDS. I had to make myself useful. Since then, my look at the world has changed. While before I had been a victim and doomed, I started to become an actor in the fight against this terrible illness through my active participation in prevention campaigns. It is my most cherished wish that some day soon a vaccine will be discovered that will save humankind."

Testimony by Efficace, a PLWH in Cameroon

Even though the GIPA initiative was launched over ten years ago, appropriate mechanisms for the involvement of PLWH in the development of HIV/AIDS-related policies and programmes are not yet firmly established in many Sub-Saharan countries. For one, discrimination against PLWH has for a long time hindered this process. Secondly, many PLWH lack the knowledge and skills and the economic resources to actively participate in political processes¹¹. National and international networks of PLWH, e.g. the Global Network of People living with HIV/AIDS (GNP+), have begun to tackle these problems and have come a long way in ensuring their participation in decision-making bodies. The creation and empowerment of PLWH organisations have been a central component of the GTZ health programme in Cameroon. Its approach and lessons learned in the process will be outlined in the following chapters.

9 GNP+/NGEN+ *The Dawn of New Positive Leadership. Conference Report of the 11th International Conference for People Living with HIV/AIDS*, October 26-30, 2003.

10 Holzemer, W.L.; Uys, L.R. 2004: *Managing AIDS Stigma. Journal of Social Aspects of HIV/AIDS* 1 (3): 165-174.

11 UNAIDS 2000, *ibid.*: p. 4.

Getting started: The Development of PLWH Organisations in Cameroon

Like in many other countries of Sub-Saharan Africa, people living with HIV or AIDS in Cameroon founded self-help groups in the 1990ies in order to provide each other with mutual support and to work against stigma and discrimination. The first of these associations in Cameroon was AFSU (Association des Frères et Soeurs Unis), established in 1994 by PLWH in Yaoundé. This group has provided care and support for people living with HIV and AIDS and their partners or family members.

The fight against HIV/AIDS has been one of the key components of the GTZ health programme in Cameroon since 1987. The promotion of community participation, including the involvement of PLWH, has been regarded as crucial for the programme from the start. In 1997, the programme started supporting AFSU by providing training in management and administration skills to its members and by covering travel expenses for their participation at regional and international meetings. Through technical and financial support of GTZ, AFSU members gained experience and hope and became more active and confident.

Following an initiative of the French Cooperation, seven “antenna” organisations of AFSU were established throughout the country between 1997 and 1998, in order to reach more people living with HIV or AIDS. In 1999, it became clear that this rapid expansion had not worked as planned: Firstly, AFSU did not distribute funds evenly between the centre and the smaller, often rural antenna groups, causing mistrust and anger on the side of the latter. For related reasons, GTZ disapproved the AFSU Action Plan 1998-99 because it focussed on the renovation of the AFSU centre, whilst its antenna associations across the country did not have sufficient resources for basic care and support for families affected by HIV/AIDS.

Secondly, the “antenna” groups were mostly headed by medical personnel and not by PLWH. In some cases, doctors acted as representatives for PLWH without their consent. Against this background the GTZ health programme decided to support the creation of new associations of PLWH, independent of both the AFSU network and the

medical establishment. Individuals infected with or affected by HIV/AIDS were encouraged to form autonomous associations, to identify and defend their own interests and to manage their associations by themselves. In 2000, two new PLWH organisations were thus established: The “Association des Femmes Actives et Solidaires” (AFASO, association of active and solidary women) in Yaoundé and “SunAIDS” in Douala.

Since these beginnings, the demand for PLWH organisations has continued to grow. In the past years, the health and HIV/AIDS component of GTZ has encouraged many people living with HIV or AIDS in different provinces to create their own associations. To date, 73 PLWH organisations have been established in Cameroon.



“Many organisations started to get organised because the people realised that it wasn’t a solution to just stay at home and keep one’s hands folded – no, one had to get up and become part of an organisation in order to become a useful member of the community. Following the workshops that GTZ organised for the training of PLWHs, the people were better informed about the virus and about «living positively». So I think that this has been very helpful, to many young people in particular”.
Gisèle, a PLWH in Cameroon

Living Positively: Aims and Activities of PLWH Organisations in Cameroon

GTZ-supported PLWH organisations in Cameroon vary in size and in the scope of their activities. Some only count five active members, others over one hundred. All of them have the common goal to improve the quality of life for PLWH by providing mutual support and care and by fighting against stigma and discrimination. In addition, PLWH organisations want to change the public image of people living with HIV/AIDS as passive victims, or deviants, or both. They present themselves as "living positively" (see box), a concept developed in the United States and transferred to Africa by the Ugandan AIDS support organisation TASO. By joining a PLWH organisation, individuals can participate actively in the fight against the epidemic and build "resistance identities"¹², avoiding self-stigmatisation and helping them to fight stigma and discrimination in their environment.

Living positively means:

- accepting your status
- understanding the facts about HIV/AIDS
- protecting others from infection
- taking care of one's health
- having access to emotional support
- participating in social life
- eating well
- avoiding, or learning to cope with stressful situations.¹³

Membership Composition

Eligible for membership in PLWH organisations are people living with HIV or AIDS and people affected by it, such as partners and family members of PLWH. Members are mostly young adults between 20 and 25 years of age. This is also the age group at greatest risk of HIV-infection as the combined effects of the economic crisis and the contradictory values and expectations facing youths in societies in transition have led to an increase in transactional sex at a young age¹⁴.

The large majority of members of PLWH organisations in Cameroon are female, with women constituting 90% of all members. This can in part be explained by the fact that in Cameroon, like elsewhere in Sub-Saharan Africa, women are at greater risk of HIV infection due to biological, social and economic factors. Young women often depend on financial support by older men in exchange for sex and are therefore particularly vulnerable¹⁵. Another reason for the larger proportion of women amongst members appears to be that women infected with HIV have less access to other support systems. Many of them are young widows without financial and social support after their husbands' death¹⁶. While mutual support systems between women still exist in rural areas, community based organisations, including PLWH organisations, often substitute these in urban settings¹⁷.

Some of Cameroon's PLWH organisations focus on particular target groups. AFASO (Association des Femmes Actives et Solidaires) based in Yaoundé is an organisation for women only. The association CEJES (Cercle des Jeunes Engagés dans la lutte contre le SIDA), based in Yaoundé, is an organisation for young people and consists mostly of students.

¹² Farmer, Aggleton 2002, *ibid*: p. 10.

¹³ cf. Kaleeba, Noerine and Sunanda Ray 1991: *We miss you all. AIDS in the Family*. Harare: p. 79.

¹⁴ Mburano Rwenge 2000: *Sexual Risk Behavior Among Young People in Bamenda, Cameroon*. *International Family Planning Perspectives* 26 (3).

¹⁵ Mburano Rwenge 2000, *ibid*.

¹⁶ Memfih, Ntangsi Max 2005: *Assessing the Socio-Economic Effects of HIV/AIDS at the Level of Households in Cameroon*. Paper Submitted for Presentation at the IAEN Conference on the AIDS-Development Nexus, Cape Town, South Africa, April 4 – 7, 2005.

¹⁷ Lachenmann, Gudrun 1992: *Die Gefährdung sozialer Sicherung in der Krise und Perspektiven neuer Strategien der Selbstorganisation: Fall Kamerun*: p. 12.

Aims and Activities

With financial and technical assistance by GTZ, PLWH organisations have developed a range of interventions, reaching from psychosocial support, voluntary counselling and testing to Home Based Care and prevention campaigns. They supplement family support systems when these are overburdened with care for orphans and for sick family members, or where families have fallen apart due to labour migration or death. Overall, their fields of intervention can be classified as follows:

- **Mutual support and information through regular group meetings**

Usually members meet once a week to support each other and to share information on and discuss relevant topics such as treatment possibilities, legal and financial issues, the experience of stigma and discrimination, advantages and disadvantages of disclosing one's status in the family and questions regarding sexuality or members' wish for a pregnancy. Within PLWH organisations, members are expected to disclose their HIV-status. Whilst most members are prepared to be open on their serostatus within the PLWH organisations, many have not disclosed their HIV-status to their families¹⁸. A study carried out by GTZ Cameroon among HIV-positive women in 2003 showed that only 8% of them had disclosed their status to a family member.

In this sense, for many members these meetings represent the only occasion at which they can talk about their fears and problems and seek information regarding effective coping strategies.

“At the hospital, I met with a counsellor who received me with a big smile. But I started crying. She calmly watched me for a few minutes and then she said: “Madam, I am seropositive, too.” I couldn't believe it because she looked so well, was nicely dressed, wore jewellery and must have weighed around 100 kilos. We held a dialogue and she gave me a lot of useful advice on nutrition and healthy living, and she promised to take me along to a meeting with other seropositive people. And so she did. And, to my big surprise, I found a room full of people who were smiling, fat, in good health – everything you would not have expected after the images that they usually show on television. After a few meetings with them, I also started to smile again. And I joined this organisation, and go there regularly now while I continue to work in my profession.”

Testimony by Rigoureuse, a PLWH in Cameroon

- **Support to treatment programmes**

Since the introduction of antiretroviral treatment (ART) in Cameroon, PLWH organisations increasingly also function as treatment support groups. By educating members on ART, supporting their access to treatment, and by ensuring that enrolled patients adhere to their drug regimen, PLWH organisations play a key role in the rollout of ART¹⁹.

- **Awareness raising and prevention campaigns**

Members of PLWH organisations often participate in HIV/AIDS prevention campaigns. Some organisations carry out prevention campaigns for specific target groups like truck drivers or military personnel (e.g. the Jolly Friends Association in Tiko). Young PLWH are particularly effective in the dialogue with their peers because they acknowledge the difficulties of adhering to “ABC” (abstain, be faithful, condomize) while at the same time describing, from their own personal experience, the suffering when not doing so. The so-called “testimonies” are a particularly effective way of fighting stigma and raising public aware-

¹⁸ cf. Dilger, Hansjörg 2005, *ibid.*

¹⁹ Centre for Health Policy, School of Public Health University of Witwatersrand 2004: *Non-governmental organisations providing support groups for people living with HIV/AIDS in Gauteng Province.*



ness: At group meetings and during public events, PLWH talk about how they got infected and how, today, they are living positively. By sharing their own experience, they encourage their audience to protect themselves and others, to get tested and to disclose their status to their family and friends. Testimonies of organised PLWH are important to raise awareness for their situation and to break the silence around HIV/AIDS. Speaking out about their status can also be a rewarding experience for PLWH, because it allows them to break out of secrecy and shame.

- **Home Based Care**

Hospital capacities in Cameroon are insufficient when it comes to providing care for the increasing number of AIDS patients. In addition, PLWH frequently experience discrimination by hospital staff. This is why PLWH organisations offer Home Based Care to sick members, washing the patient, cleaning the house and providing essential goods (soap, salt, sugar etc.). Home Based Care visits are often combined with counselling of the patient and his or her family. Some PLWH organisations also offer medical care for opportunistic infections.

- **Voluntary Counselling and Testing**

18 PLWH organisations in Cameroon offer pre and post-test counselling in cooperation with hospitals and health centres. Many more provide peer-counselling to individuals who have just tested positively. Learning about one's positive HIV-test result is a stressful and disturbing experience

and can lead to depression or even suicide. Peer-counselling by someone who has gone through the same experience constitutes an effective intervention as it shows that living positively is possible and that support is available.

- **Legal support**

Some PLWH organisations also offer legal support to their members. They fight human rights violations and discrimination at the workplace and help members with will-writing and other property issues. In the past years, legal issues around antiretroviral medication have become a major issue for PLWH organisations. Legal advice is also needed when it comes to research ethics, because some pharmaceutical companies have violated these when testing new drugs.

- **Orphan Care**

Some PLWH organisations offer special support to orphans whose parents died of AIDS. In Cameroon, an estimated number of 240.000 children are orphaned by AIDS²⁰. In addition to existential economic hardship, AIDS-orphans are often confronted with stigma and discrimination and suffer from trauma after their parents' death. This is why some PLWH organisations support AIDS-orphans by paying for their food or their school fees (e.g. APICAM, Bafoussam).

Together we'll succeed: Building a National Network of PLWH Organisations

"Together, we will succeed." – Motto of RéCAP+²¹

Reasons for the Creation of National Networks

Once there are a number of PLWH organisations in a country, the creation of a national network is the next important step towards the greater involvement of PLWH in political processes and HIV/AIDS programming. In contrast to local PLWH organisations, national networks can

- facilitate exchange of information and experiences between different PLWH organisations in a country, and between PLWH networks in different countries;
- establish a common code of conduct and thus assure cohesion and transparency in the organisations' aims and actions

- introduce shared quality standards and assure these through an agreed M&E system
- raise funds and technical support for local organisations at national level so that these have the resources to provide Home Based Care or voluntary counselling and testing.
- prevent doubling of services and the parallel utilisation of different NGOs ("NGO-hopping"²²)
- support capacity development measures for representatives of member organisations, e.g. regarding project management skills or counselling skills.
- ensure the continuity of democratic political representation of PLWH in crucial national committees, such as the NACC and the Country Coordination Mechanism (CCM).

RéCAP+: Objectives and Organisational Set-up

When the RéCAP+ network (Réseau Camerounais des Association de Personnes Vivant avec le VIH/SIDA) was established during a workshop conducted by the Network of African People living with HIV/AIDS (NAP+) in August 2000, such networks had already existed for some time in the high-prevalence regions of Southern and Eastern Africa. In medium-prevalence countries like Cameroon, they were just beginning to emerge. At the beginning, RéCAP+ brought together only three associations, AFSU, AFASO and SunAIDS. Since then, the network has continued to grow as new groups of PLWH emerged and affiliated with RéCAP+.

From the start, the RéCAP+ network has defined the political representation of PLWH at all levels of policy-making as its overall objective. This includes their representation in relevant national committees as much as the strengthening of democratic participation at the community level.



The specific objectives of RéCAP+ are

- to encourage and support the creation of new PLWH organisations and, where necessary, to denounce fictive associations.
- to strengthen the effectiveness of member PLWH organisations through capacity building workshops and the exchange of information and experience.
- to organise joint activities of member PLWH organisations.
- to collect, process and distribute useful information for member associations.
- to promote the rights of PLWH.
- to advocate and lobby for PLWH in different decision-making bodies in order to find just and equitable solutions for their problems.
- to inform the national and international public about the existence of PLWH organisations.
- to mobilize funds in order to assure the formation of network members and the financing of programmes.

RéCAP+ represents 73 member PLWH organisations from all provinces of Cameroon, comprising more than 5000 PLWH. Every two years, representatives of all member associations of RéCAP+ meet at the General Assembly, which takes place in different parts of Cameroon. During this meeting, the Executive Board of RéCAP+ is elected for two years by the associations' representatives. It consists of the president, the general secretary, the treasurer and two accountants. All members of the Executive Board come from different PLWH organisations to ensure the representation of interests from various groups and provinces. The Executive Board nominates the Executive Secretariat that is responsible for carrying out the decisions by the Executive Board, for communicating with the member PLWH organisations and for raising funds for the activities of the network. The Executive Secretariat of RéCAP+ is located in Yaoundé.

In each province, a Provincial Focal Point is elected from one of the PLWH organisations. He or she serves as the interface between the Executive Secretariat and the associations in the province, transmits information in both directions and organises provincial meetings of PLWH organisations. The Provincial Focal Points support the establishment of new PLWH groups in the region and supervise the existing ones. The RéCAP+ Focal Points also participate as PLWH-representatives in the Provincial Technical Group of the National AIDS Control Committee.

To be admitted to RéCAP+, an organisation must have statutes and internal regulations that are respected by its members. It has to submit regular activity reports to RéCAP+ and show that its actions are in accordance with the RéCAP+ objectives.

Every member organisation of RéCAP+ has to pay 10.000 Central African Francs (ca. 15,25 Euro) to join the network and an annual fee of the same amount²³. By this payment, they acquire the right to vote at the General Assembly and access to the advantages of being a network member, including information, training and the facilitation of donor support.



Developing the Capacities of PLWH Organisations and their Networks:

The GTZ health programme has provided substantial financial and technical support to RéCAP+ from its inception. While other donors have also supported RéCAP+ and its member associations financially, GTZ, as a technical agency, has concentrated on capacity building and organisational development. In the following, a number of promising practices for the strengthening of PLWH organisations and their networks are presented.

Ensuring political representation

“The time has come for people living with AIDS to move from just giving the epidemic a human face and voice to truly participating in the development and implementation of multisectoral strategies needed to fight AIDS.”

Salvator Niyonzima, GIPA Adviser for UNAIDS, 2001

Cameroon’s National Strategic Plan to Fight HIV/AIDS includes the goal to integrate and empower people living with HIV/AIDS and the GTZ health programme has supported the representation of RéCAP+ in the major HIV/AIDS-related policy- and programming bodies in Cameroon. Today, representatives of RéCAP+ are permanent members of the two main decision-making structures in the Cameroonian fight against HIV/AIDS:

1. The President and the Executive Secretary of RéCAP+ are members of the National AIDS Control Committee (NACC).
2. The President of RéCAP+ participates in the Country Coordinating Mechanism of the Global Fund to Fight AIDS, Tuberculosis and Malaria (CCM)²⁴.

In addition, representatives of the PLWH network are actively involved in various other national initiatives like the committee discussing the National Action Plan to Fight HIV/AIDS in Cameroon. At the provincial and local level, representatives of the Provincial Focal Points of RéCAP+ are participating in the Local AIDS Control Committees and the Provincial Technical Group of the NACC/Ministry of Health where they lobby for the rights and needs of PLWH in their region.

In these policy-making bodies, RéCAP+ raises awareness for the rights and interests of PLWH in Cameroon. In November 2002, the network organised a workshop on stigma and discrimination against PLWH in the National Assembly of Cameroon. Members of parliament, traditional and religious authorities and representatives of multi- and bilateral donors were sensitized on the discrimination of PLWH and the need to protect their human rights through legal measures.

GTZ has been supporting RéCAP+ in its demands that consultant missions organised by the NACC and the CCM should always include PLWH representatives. By lobbying for the employment of PLWH by different AIDS-programmes in Cameroon, RéCAP+ also fights against their discrimination at the workplace.

RéCAP+’s efforts in the fields of representation and advocacy have increased the visibility of PLWH in the public and have improved their legal standing and their access to medical services. At a more general level, the advocacy of PLWH organisations like RéCAP+ has begun to transform Cameroon’s political landscape as it has strengthened civil society participation in political decision-making processes.

Access to ARV treatment

More recently, access to ARV treatment has been one of the major issues for which RéCAP+ has lobbied the government and opinion leaders. The “3 by 5” initiative of the WHO, which pursues the goal to give at least three million HIV/AIDS patients access to ART by the end of 2005, explicitly states that PLWH have to be part of the ART distribution process. In the past years in Cameroon, RéCAP+ representatives advocated for the reduction of the price of ARV treatment and the improvement of access to treatment for all PLWH who need it. Ultimately, RéCAP+ envisions free ARV treatment throughout the country. In many regions of Cameroon, the PLWH organisations also function as “watchdogs” in the clinics and health centres to prevent corruptive distribution behaviour from doctors, pharmacists and nurses.

Building partnerships

GTZ health programme assisted RéCAP+ in building partnerships with many national and international organisations. Through partnerships with the World Health Organisation and Medecins sans Frontières (MSF), RéCAP+ for instance closely participates in the decentralisation process of ARV treatment, which is pushed forward by these two organisations.

Development of a legal framework

GTZ assisted RéCAP+ in establishing a partnership with the network on Law, Ethics and HIV/AIDS, REDS (Réseau sur l’Ethique, le Droit et le SIDA). REDS actively participated in the establishment of the network by providing a legal framework for the network and its members²⁵ (See Toolkit for a model for statutes and internal regulations).

Supporting the creation of new PLWH organisations

Since 2002, GTZ has supported numerous workshops for PLWH who are not yet organised in groups in different parts of the country. The aim of these workshops is to encourage PLWH to start “living positively” and to form their own PLWH organisation. The workshops address the HIV/AIDS epidemic in Cameroon, the role of PLWH in the fight against HIV/AIDS, how to live positively with HIV/AIDS and how to get adequate treatment and care. In addition, the workshops explain how to establish a PLWH organisation and impart basic leadership and management principles to the participants. (see toolkit for content of these workshops).

The recruitment of participants for these workshops is not easy, because PLWH who have not yet shared their sero-status with others fear to be found out and then stigmatized. However, the GTZ team and RéCAP+ have developed a range of channels (through health workers, social workers, traditional authorities etc.) to spread information on these workshops. In addition, PLWH of member associations travel to different parts of the region to encourage people to participate in the workshops. In all cases, GTZ assures complete discretion towards the participants.

25 Santos Filho, Ezio Távora dos 2004:ibid.: pp. 7-8.



“In 2002, I was in Buea town and, by coincidence, a friend of mine, who is also a doctor, informed me that GTZ was organising a workshop in town. It was a workshop for the training and information of PLWH. Honestly, for me this was a moment of transformation because when I got there, I realised that, even though I used to be optimist and keen to live, despite all, at that meeting I met people who became role models for me, and I thought ok, if people like that can live with HIV and still smile and be full of courage and ready to start up new initiatives without any apparent problems, then why not me?”

James, a PLWH in Cameroon

Skills building for RéCAP+ member organisations regarding management, communication and Home Based Care

Once PLWH have formed an organisation and joined the RéCAP+ network, GTZ, in cooperation with RéCAP+, provides training in administrative, management and communication skills. Participants practise how to write their organisational statutes, to plan activities, apply for funding and how to monitor and evaluate their activities. Furthermore there are workshops on leadership qualities, on mobilising techniques and on the giving of testimonies.

GTZ and RéCAP+ also offer training on the provision of Home Based Care, as most hospitals in Cameroon are overcrowded and an unfit environment for chronically ill AIDS patients. When they return home, families often need help with the strenuous task of providing appropriate care for them. Participants learn how to physically care for AIDS patients, what they need to know about the most common opportunistic infections and their treatment, on ARV treatment guidelines and the management of its side effects. The training is not just theoretical but comprises practical training sessions at a local hospital (see toolkit for content of the workshop).

But AIDS patients need more than just physical care. Participants are also taught how to provide counselling to PLWH and their family members after a positive test result. They learn about the importance of confidentiality, about giving hope in times of despair and how to cope with the emotional strain that being an HIV/AIDS counsellor may at times cause them.

Facilitating South-South cooperation between national networks of PLWH organisations

In order to strengthen the exchange and skills development between networks of PLWH organisations in different countries and parts of the world, in 2004, GTZ invited the president of a Brazilian PLWH network, who is also an internationally renowned HIV/AIDS activist, to conduct an evaluation of RéCAP+ and some of its member organisations. On the basis of lessons learnt by PLWH organisations in Brasil, the consultant formulated a range of recommendations and has since stayed in close contact with RéCAP+. He has also initiated contacts between RéCAP+ and other international PLWH networks and is currently working towards ensuring that RéCAP+ get funding by the European Union.



In 2005, GTZ has supported RéCAP+ in providing technical advice to more recently created PLWH+ networks in countries such as Guinea. Four PLWH organisations in Guinea have established a network based on the experience of RéCAP+ in Cameroon²⁶.

Support to advocacy and campaigning

With the support of the GTZ health programme, the RéCAP+ network has played a key role in the organisation of all commemorative events on HIV/AIDS in Cameroon. Every year, World AIDS Day on December 1st and the Cameroon Week of the Fight against HIV/AIDS are important occasions at which RéCAP+ members heighten the visibility of PLWH and raise awareness for their needs and interests. Also, GTZ supported RéCAP+ in organising the visit of the Director General of the World Health Organisation, an event accompanied by considerable publicity for the national network.

Testimonies: a powerful tool in the fight against HIV/AIDS

The courageous decision of PLWH to talk publicly about their sero-status and living positively is an effective advocacy tool for several reasons: In Cameroon, many people still deny the existence of HIV/AIDS²⁷. The more Cameroonians witness when PLWH testify their sero-status and its meaning for their lives, the more difficult it becomes for them to question the existence of HIV/AIDS. Testimonies have been done by PLWH organisations throughout the world in order to “give a human face to the epidemic”. In addition to raising public awareness, they also strengthen the solidarity between PLWH and their self-confidence because they can make a personally meaningful contribution to the fight against AIDS. This is why the GTZ health programme has supported trainings for PLWH organisations on how to testify publicly. When families don’t want their relatives to testify out of fear of stigma and discrimination, meetings are organised to negotiate between PLWH and their family members. In Cameroon today, RéCAP+ members testify on the radio and on TV, in workshops, in schools, companies and at funerals. Each of these testimonies contributes to raising awareness, compassion and solidarity for PLWH.

The GTZ health programme has encouraged RéCAP+ to employ different strategies to focus public attention on their campaign for the rights of PLWH: During the 2002 Week of the Fight against HIV/AIDS, they organised a soccer game with the topic “Fight Stigma and Discrimination associated with HIV/AIDS”. HIV-positive members of RéCAP+ associations played against journalists and members of the National AIDS Control Committee (NACC). The game succeeded in showing that HIV+ people can still be active and that close contact with them during sports does not entail the risk of infection. As soccer is a very popular game in Cameroon, this event increased RéCAP+’s publicity and popularity substantially.

²⁶ Ndonko, Keita 2005: Organisation des PVIH à Mamou.; Ndonko, Keita 2005: Guinée. Organisation des personnes vivant avec le VIH/SIDA à Mamou, République de Guinée.

²⁷ Schwab Zimmer, Monika: "Seven Plus One": Meinungen über Aids im anglophonen Kamerun: p.3.

The Results

Five years into its partnership with the GTZ health programme, a number of significant results have been achieved: RéCAP+ is playing an important role in the planning and implementation of the national HIV/AIDS programme, it has improved access to services for PLWH, increased the public awareness of the rights of PLWH and highlighted their crucial role in, and commitment to, contributing to the fight against HIV/AIDS in Cameroon.

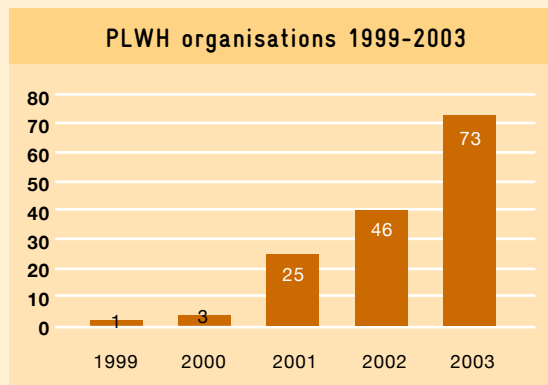
Commissioned by the GTZ supra-regional project “AIDS Control in Developing Countries” and the GTZ health programme in Cameroon, the network and some of its member organisations were evaluated by the president of a network of PLWH in Brasil in 2004²⁸. RéCAP+ itself has also conducted some monitoring and evaluation of its member organisations. On this basis, the following results were identified:

PLWH organisations exist throughout Cameroon, and PLWH benefit from their care and support

The campaign for the creation of local PLWH organisations has resulted in an exponential increase in their number, from the three founding associations in the year 2000, all based in the main cities Yaoundé and Douala, to 73 associations in 2004, representing more than 5000 PLWH. The organisations are active in all ten provinces of the country. Over 60 of these groups have received funding for workshops, conferences and other activities by the Ministry of Health and other partners through the help of the network²⁹. Over the past years, 3.500 meetings of PLWH took place.

Through social and psychological support and medical care, PLWH organised in these associations enjoy a higher quality of life than those not associated. The increase in Voluntary Counselling and Testing by members of the PLWH organisations has the effect that PLWH suffer less after a positive test result and the number of suicides after a positive test result has significantly declined³⁰.

PLWH organised in an association are proven



to be more compliant with treatment of opportunistic infections and antiretroviral treatment. They therefore have a higher life expectancy and are less likely to cause drug resistance. While of those PLWH not organised in associations, many stop their ARV-treatment, members of PLWH-associations show much higher adherence and compliance. This significantly improves their health, prevents opportunistic infections (pneumonia, tuberculosis, meningitis) as well as the development of resistant viral strains³².

Greater involvement of PLWH in Cameroon

The participation of PLWH in the major committees in the fight against AIDS has an impact in political decision-making in Cameroon. Certainly, this involvement in high-level decision-making has increased public awareness for the situation of PLWH. Moreover, the needs, activities and interests of PLWH are now more often taken into consideration in the fight against the epidemic. Through the establishment of the network of PLWH organisations, PLWH can more effectively advocate for their problems³³.

In addition to these government structures, RéCAP+ has succeeded in involving PLWH in multi- and bilateral and non-governmental organisations involved in the fight against HIV/AIDS. More than 200 PLWH have been recruited as consultants, e.g. for the NACC, UNAIDS, GTZ, World Bank, UNDP and different NGOs³⁴. In some HIV/AIDS programmes, RéCAP+ has succeeded to

28 Santos Filho, Ezio Távora dos 2004, *ibid.*: p. 15.

29 Kayo JC, Mounton P: *The Cameroon network of associations of PLWH (RéCAP+) Networking associations of PLWH in Cameroon. Int Conf AIDS 2004 Jul 11-16.*

30 AGEK/Koppenleitner, Reinhard 2005, *ibid.*: p. 39.

31 Laurent, C; Mello, H.; Guiard-Schmid, J.B. et al.: *Antiretroviral therapy in public and private routine health care clinics in Cameroon: lessons from the Douala antiretroviral (DARVIR) initiative.*

32 AGEK/Koppenleitner, Reinhard 2005, *ibid.*: p. 39.

33 Kayo JC, Mounton P. 2004, *ibid.*

34 Kayo JC, Mounton P. 2004, *ibid.*

introduce “positive discrimination” of PLWH (meaning that HIV+-candidates are given preference when there are two candidates with the same qualifications). The network’s capacity building activities have also contributed to this integration. More than 350 PLWH have in the past years been trained in management skills, psychosocial counselling and Home Based Care by the network.

At a more general level, the participatory approach of the RéCAP+ network facilitates the interaction of the different levels of policy-making (community, provincial, national and international) at which PLWH now play a role, thus increasing their sense of ownership for new policies and their implementation. This is especially important in the case of access to ART treatment, because adherence and, thus, sustainability is improved when PLWH are part of the decision-making process.

Better access to antiretroviral treatment in Cameroon
 GTZ-support to RéCAP+ has enabled the network to achieve important goals in their fight for affordable access to ART. Between 2000 and 2004, the price for ART has come down from 75.000 CFA (115 Euro) to 14.000 CFA (max. 21 Euro) per year in 2004³⁵. The cost for laboratory tests and drugs for the main opportunistic infections of HIV/AIDS has also decreased³⁶. While in 2000 only a few PLWH had access to the treatment they needed, 12.000 were receiving ART in September 2004. With support from GFATM, ART costs between 3.000 - 7.000 FCFA (5 - 11 Euros) per month per person since 2005.

Treatment Map Cameroon³⁷

Number of people in need of ART (Sept. 2004) 86,000
 Number of people on ART (Sep. 2004). 12,000
 Number of people expected to be on ART (End 2005) 36,000

“Finally I understood that a positive sero-status does not mean death. I follow my treatment schedule and I live my life from day to day. Which makes people around me wonder whether I am truly sick. Because I am well and I keep up my occupation. I continue to lead my life like in the past, but with more reserve and more prudence. Today, my morals are high thanks to my cousin and to the other members of SunAids with whom I have found a group of buddies who have given me advice. I am no longer alone. Today, I have accepted my seropositivity and I live with it, in spite of some problems.”
 Testimony by Luz, a PLWH in Cameroon

Prevention of new HIV-infections and of re-infections

The increase in PLWH support groups, to which the GTZ health programme contributed, also has a measurable preventive impact. For one, prevention campaigns for the general public in which PLWH participate are known to be very effective³⁸. Secondly, members of PLWH organisations are more careful to protect themselves and others from (re-) infection. According to a study in Cameroon, 50% of PLWH organised in an association report condom use in comparison to 0% of those who are not member of an association. In theory, this prevents 12.500 new infections per year³⁹.

Greater public awareness for the rights of PLWH

PLWH from member associations have held more than 4.000 open testimonies in Cameroon in the past five years. Some of these were broadcast on radio and television⁴⁰ Through public campaigns and advocacy activities there is greater awareness of, and more solidarity and empathy with PLWH and their problems, needs and potentials among the Cameroonian public. As many PLWHs report in their testimonies, stigma and discrimination have decreased and people are more inclined to get tested and to disclose their status - which again would have a positive preventive effect.

³⁵ Santos Filho, Ezio Távora dos 2004, *ibid.*: p. 15.

³⁶ Kayo JC, Mounton P. 2004, *ibid.*

³⁷ UNAIDS: Treatment map Cameroon. www.unaids.org

³⁸ GNP+/NGEN 2003: *ibid.*, pp. 20.

³⁹ GTZ/PGCSS 2004: Der Beitrag der GTZ zur Umsetzung der Millenniumserklärung. Beispiel: Der Beitrag des Sektorprogramms Gesundheit zur Erreichung des Millenniumsentwicklungsziel 7 (Bekämpfung von HIV/AIDS) in Kamerun.

⁴⁰ Kayo JC, Mounton P. 2004, *ibid.*

Lessons Learnt and Perspectives

As important as the positive results of this cooperation are the lessons that the GTZ health programme and RéCAP+ learnt in the course of it.

As networks of PLWH organisations grow, communication with and support to the more remote member organisations must remain a priority

Many member organisations lack the necessary infrastructure to conveniently communicate with each other or the RéCAP+ Executive Secretariat. Email and landlines are not available for most groups so that information has to be transmitted by mobile phone. Important written information is often not transferred to groups without email connection or to those in remote regions, causing frustration because they then feel undervalued and excluded. Also, most information material of the network is only produced in French, excluding associations in the English-speaking part of the country from full participation⁴¹.

Because of the higher stigma and lesser awareness of the rights of PLWH in rural areas, rural organisations have more difficulties recruiting members. In addition, representation and advocacy are less successful at the provincial and local level. While PLWH are actively participating in the decision-making processes at national level, PLWH in the Provincial Technical Groups of the NACC are at times only invited to give testimonies yet not fully included in decisions regarding provincial HIV/AIDS programmes⁴².

These factors lead to a hierarchy between groups that increases when some groups receive more funding and have better access to training and communication. The resulting competition undermines the cooperation and coordination between PLWH organisations and yet these are essential for the effective functioning of the network⁴³.

To address such dynamics, GTZ-support to PLWH networks can promote decentralisation, communication and integration of weaker, rural organisations, also by providing training in administrative and management skills to these latter ones in particular.

More systematic monitoring and evaluation procedures must be developed

Up to now, RéCAP+ does not have a standardized monitoring and evaluation system⁴⁴ for monitoring the performance of its members or itself. To better understand the impact of their interventions, the change of attitudes towards PLWH in the regions where PLWH organisations are active or the way in which policy- and decision-making bodies are influenced by the integration of PLWH needs more systematic evaluations. In addition, a standardized monitoring and evaluation system may help identify the organisations' needs in terms of training and technical and financial support.

Uncoordinated funding may lead to corruption

The amount of financial and material support received by the network has immensely increased in the past years, e.g. through a new World Bank programme. Because PLWH organisations are now supported by various multilateral and bilateral donor organisations, coordination between the donors needs to be improved in order to avoid an unequal distribution of funds.

With the increase of funding, the network's Executive Board and Secretariat are in a powerful position towards the member associations in spite of the bottom-up structure of RéCAP+. Thus, paradoxically, more funds in recent years have led to less outcome⁴⁵. It appears that, in order to prevent abuse of funds, better control mechanisms need to be established. The strategy of GTZ so far has been to concentrate on capacity development rather than on financial support.

41 Santos Filho, Ezio Távora dos 2004, *ibid.*: p. 13.

42 Santos Filho, Ezio Távora dos 2004, *ibid.*: p. 13.

43 Ndonko, F.T.2004: *Cadre conceptuel de collaboration avec les Associations des PVVS. Powerpoint Presentation. Bamenda: SRJA/PGCSS (GTZ).*

44 AGEK/Koppenleitner, Reinhard 2005: *KV-Sektorprogramm Gesundheit/AIDS Kamerun (PN 2000.2082.6). GTZ Kamerun. Projektfortschrittskontrolle (PFK): p. 48.*

45 AGEK/Koppenleitner, Reinhard 2005, *ibid.*: p. 59.



WHO Director General visiting RéCAP+, November 2005

A promising perspective: PLWH organisations can make ARV programmes more equitable and effective Access to ARV treatment and the reduction of its price is an important goal for PLWH. In Cameroon, the decentralisation of ARV-treatment is planned for the year 2006: PLWH support groups play a key role in this process and RéCAP+ needs to consider the challenges accompanying it.

Firstly, the associations can serve as treatment support groups. As different studies have shown, adherence and compliance are much better when PLWH are organised in a support groups. In addition, training on dosage, adherence, side effects etc. (“treatment literacy”) can be carried out through the existing PLWH organisations to avoid misuse, interruption of treatment and the development of drug resistance. This is why GTZ collaborates with the network ESTHER (Ensemble pour une Solidarité Thérapeutique en Réseau), to develop a training curriculum for PLWH to support compliance to ARV treatment.

Secondly, advocacy issues play a big role when it comes to equity and equal access to ARV programmes, and to ethical issues surrounding drug tests, patient rights etc. PLWH representatives can potentially play an important role in assuring programmes’ ethical soundness and equitable access to ARV treatment in Cameroon and elsewhere.

Following a request by the RECAP+, the German Development Service (DED) will be providing three Technical Assistants to the network in 2006 (one at RECAP+ headquarter and 2 at regional level) to help them with new challenges in institutional organisation, management and treatment compliance.

Conclusion: Why are these Practices Promising?

According to the German HIV Peer Review, supporting PLWH organisations and their networks, as practised in exemplary fashion in Cameroon, is a promising approach to fighting the HIV/AIDS epidemic with the active participation of those most directly affected, according to the following criteria:

- 1. Effectiveness:** The support to the creation and capacity development of PLWH organisations and to PLWHs' political representation in Cameroon has resulted in the existence of a nationwide network of PLWH organisations, providing mutual support, facilitating access to care and ensuring the active participation of PLWH in all committees defining the national response to the epidemic.
- 2. Transferability:** The GTZ-support has enabled RéCAP+ to provide technical assistance to its member organisations and, more recently, to other, less experienced national networks of PLWH organisations. The exponential increase of PLWH organisations in Cameroon in response to the GTZ-RéCAP+-workshops in different regions, and the interest in their expertise by similar networks in neighbouring countries, indicate that the developed practices can effectively be adapted to different regional contexts.
- 3. Empowerment:** Many documented testimonies by PLWH in Cameroon confirm that they feel empowered by their membership in a PLWH organisation, by the concept of "living positively" and by the public recognition PLWH representatives of RéCAP+ have been receiving over recent years. PLWH organisations are powerful agents in the fight against stigma and discrimination because they allow PLWH to be open about their status, to find out about their rights and to jointly aim for their realisation.
- 4. Gender Awareness:** In Subsaharan Africa, young women are the group most vulnerable to and affected by HIV/AIDS. They are also the group most represented in PLWH organisations, a fact which indicates their need for the social support offered by these groups and for the benefits they draw from them. HIV/AIDS and gender inequality are closely linked: PLWH organisations that empower their female members are an effective means to address this double challenge. Women, who are more affected by the epidemic and its social and economic consequences, are strongly represented at all levels of the network, including in leadership positions of the Executive Secretariat and the Executive Board⁴⁶. RéCAP+ thus provides a viable alternative to the usual male dominance in leadership positions of civil society organisations in Cameroon. It empowers women by highlighting not just their special problems in relation to HIV/AIDS but also their unrecognized potential as community leaders.
- 5. Sustainability:** This GTZ-approach has focussed on technical assistance oriented towards enabling PLWH organisations and their networks to raise public awareness for their needs and rights, to become involved in HIV/AIDS-related policy debates, to raise funding for their activities, and to distribute and use these according to good governance principles. Today, RéCAP+ and its member organisations receive funding from many different sources and are firmly established members of HIV/AIDS committees at all levels.
- 6. Ethical Soundness:** Because of the ongoing stigma and discrimination, the assurance of ethical standards is of special importance when working with PLWH. The activities of the network are ethically sound because they ensure their members' anonymity, excluding any members who might disregard the right to anonymity; because they closely monitor the ethical aspects of any medical research involving PLWH; and because they fight against discrimination of PLWH at the workplace and in the public sphere.

Bibliography

AFASO 2004: Statutes, Règlement Intérieur et Code Electoral. Yaoundé.

AGEG/Koppenleitner, Reinhard 2005: KV-Sektorprogramm Gesundheit/AIDS Kamerun (PN 2000.2082.6). GTZ Kamerun. Projektfortschrittskontrolle (PFK).

De Loenzien, M. 1996: Knowledge, Opinions and Attitudes towards AIDS in rural Africa (Senegal, Cameroon, Burundi). Current Research. Societes Afriques et SIDA 13: 11-13.

Dilger, Hansjörg 2005: Leben mit AIDS. Krankheit, Tod und soziale Beziehungen in Afrika. Frankfurt a. M./New York.

GNP+: A Multi-Country Study of the Involvement of People Living with HIV/AIDS (PLWH) in the Country Coordinating Mechanisms (CCM). GNP+/NGEN+ The Dawn of New Positive Leadership. Conference Report of the 11th International Conference for People Living with HIV/AIDS, October 26-30, 2003.

Goldin, C.S. 1994: Stigmatization and AIDS: Critical Issues in Public Health. Social Science and Medicine 39 (9): 1359-66.

GTZ/PGCSS 2003: AIDS-Bekämpfung in Kamerun. Ein Erfahrungsbericht der Zusammenarbeit mit HIV-infizierten Menschen.

GTZ/PGCSS 2004: Der Beitrag der GTZ zur Umsetzung der Millenniumserklärung. Beispiel: Der Beitrag des Sektorprogramms Gesundheit zur Erreichung des Millenniumsentwicklungsziel 7 (Bekämpfung von HIV/AIDS) in Kamerun. Holzemer, W.L.; Uys, L.R. 2004: Managing AIDS Stigma. Journal of Social Aspects of HIV/AIDS 1 (3): 165-174.

Jean-Robert, R.M. 2003: The woman's status and condom use in Cameroon. African Journal of Reproductive Health 7 (2): 74-88 Kaleeba, Noerine and Sunanda Ray 1991: We miss you all. AIDS in the Family. Harare.

Kayo JC, Mouton P: The Cameroon network of associations of PLWH (RéCAP+). Networking associations of PLWH in Cameroon. Lecture at the International AIDS Conference July 11-16, 2004.

Laurent, C; Meilo, H.; Guiard-Schmid, J.B. et al.: Antiretroviral therapy in public and private routine health care clinics in Cameroon: lessons from the Douala antiretroviral (DARVIR) initiative. Social Science and Medicine 39 (9): 1359-66.

Memfih, Ntangi Max 2005: Assessing the Socio-Economic Effects of HIV/AIDS at the Level of Households in Cameroon. Paper Submitted for Presentation at the IAEN Conference on the AIDS-Development Nexus, Cape Town, South Africa, April 4 - 7, 2005.

NDONKO, F.T. 2004: Cadre conceptuel de collaboration avec les Associations des PVVS. Powerpoint presentation. Bamenda.

NDONKO, F.T. 2002: Evolution du nombre des Associations des PVV au Cameroun (1994-2002) Power Point Presentation. Yaoundé.

NDONKO, F.T. 2003: Rôle des PVVS dans la lutte contre le VIH/SIDA. Power Point Presentation. Yaoundé.

NDONKO, F.T.; FOUNDJE, R. 2002: Contribution de la GTZ dans l'encadrement des PVVS au Cameroun. Power Point Presentation. Yaoundé.

NDONKO, F.T. 2003: People Living with HIV in the Fight Against AIDS in Cameroon. Power Point Presentation. Yaoundé.

Parker, Richard and Peter Aggleton 2002: HIV/AIDS-related stigma and discrimination. A conceptual framework and an agenda for action. Horizons Program. The Population Council.

Paxton, S. 2002: The paradox of public HIV disclosure. *AIDS Care* 14 (4): 559-567.
RÉCAP+ 2002: Règlement Interieur du Réseau Camerounais des Associations de Personnes Vivant Avec le VIH/SIDA. Yaoundé.

RÉCAP+ 2004: Statutes du Réseau Camerounais des Associations de Personnes Vivant Avec le VIH/SIDA. Yaoundé.

RÉCAP+ 2002: Rapport Final. Atelier d'information, de formation et d'échange d'expériences entre les associations de personnes vivant avec le VIH/SIDA. Yaoundé.

Mburano, Rwenge 2000: Sexual Risk Behavior Among Young People in Bamenda, Cameroon. *International Family Planning Perspectives* 26 (3): 118-123.

Santos Filho, Ezio Távora dos 2004: Consulting Report on Mission to Cameroon. Evaluation on RéCAP+ support by PGCSS (by GTZ in Cameroon).

Schwab Zimmer, Monika: "Seven Plus One": Meinungen über Aids im anglophonen Kamerun. SUNAIDS 2005: Rapport d'Activités Annuel 2004. Douala.

UNAIDS 2000: Enhancing the Greater Involvement of People Living with or affected by HIV/AIDS (GIPA) in sub-Saharan Africa. A UN response: how far have we gone? (UNAIDS Best Practice Collection).

UNAIDS 2004: Cameroon Epidemiological Fact Sheet. Update 2004. Geneva.

Abbreviations

ABC	Abstain, be faithful, condomize	HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
AFASO	Association des femmes actives et solidaires (Association of active and solidary women/Yaoundé)	MSF	Médecins sans Frontières
AFSU	Association des frères et soeurs unis (Yaoundé)	NAAC	National AIDS Control Committee
ARV	Antiretroviral	NAP+	Network of African People living with HIV/AIDS
ART	Antiretroviral Treatment	NGO	Non-governmental Organisation
CCM	Country Coordinating Mechanism	PRG	HIV Peer Review Group
CEJES	Cercle des jeunes engagés dans la lutte contre le SIDA (Yaoundé)	PLWH	People living with HIV
DED	Deutscher Entwicklungsdienst (German Development Service)	RéCAP+	Réseau camerounais des associations de PVVIH (Cameroon Network of PLWH organisations)
ESTHER	Ensemble pour une Solidarité Thérapeutique en Réseau (Network for Therapeutic Solidarity in Hospitals)	REDS	Réseau sur l'éthique, le droit et le SIDA (Network on Law, Ethics and HIV/AIDS)
GFATM	The Global Fund to fight AIDS, Tuberculosis and Malaria	TAC	Treatment Action Campaign
GIPA	Greater Involvement of People Living with HIV	TASO	The AIDS Support Organization
GNP+	The Global Network of People living with HIV/AIDS	UNAIDS	The Joint United Nations Programme on HIV/AIDS.
GTZ	Gesellschaft für technische Zusammenarbeit (German Technical Cooperation)	VCT	Voluntary counselling and testing
		WHO	World Health Organisation

Tools

The following tools and materials were developed in the course of this project and can be downloaded at

<http://hiv.prg.googlepages.com/toolbox-involvingpeoplelivingwithhiv>

- Training modules for PLWH organisations on “Living positively”, treatment literacy, Home Based Care (french)
- Statutes and Internal Regulations of RéCAP+ (french)
- Statutes and Internal Regulations of one association (as an example) (french)

Contacts and credits

Expert responsible for the approach

Dr. Flavien Ndonko Tiokou
E flaviennndonko@yahoo.fr

Published by:

The German HIV Peer Review Group
Project 'Strengthening the German contribution
to the global AIDS response'
Responsible: Dr. Thomas Kirsch-Woik
Deutsche Gesellschaft für
Technische Zusammenarbeit (GTZ) GmbH
Dag-Hammerskjöld-Weg 1-5
65760 Eschborn / Germany
E aidsprg@gtz.de
I <http://hiv.prg.googlepages.com/home>

Contact at GTZ

Health, Education and Social Protection Division
Project "Strengthening the German
contribution to the global AIDS response"
E aids.ms@gtz.de
I www.gtz.de/aids

Contact Person in the Federal Ministry for Economic Cooperation and Development (BMZ)

Dr. Jochen Böhmer, Section 311
E jochen.boehmer@bmz.bund.de

Writers: Johanna Offe, Anna von Roenne

Photos: Flavien Ndonko Tiokou,
WHO Multimedia Centre

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