Nothing for us, without us

A 40-year community mobilization against **AIDS**

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COALITION
INTERNATIONALE SIDA

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Editorial

For the past 14 years, Coalition PLUS has been advocating for a community-based approach to the fight against AIDS and hepatitis, based on its members' decades of experience in this field. Nevertheless, despite these years of experience, this approach remains difficult to define, sometimes even within the organisation.

From Gandhi's "nothing about us without us" to "we are not victims, so do not do anything for us without us!" conveyed by the first people living with HIV in 1983 in the Denver Principles, the community-based approach has developed over time and through the experience of the most disadvantaged and discriminated against.

The AIDS epidemic was a huge catalyst for this approach, as it brought together the elements integral to its development. People living with AIDS, instead of seeing themselves as victims, which society deprived them of because their behaviour and lifestyle choices were contrary to what was deemed "morally appropriate" and because their deaths created fear and denial, quickly transformed the anger they felt as a result of this discrimination, into collective action and a force for social transformation.

They developed the necessary skills to engage with and support social change by mobilising themselves and their immediate medical and social circles. Rather than seeking to change the world for themselves, as they were aware that this process would take time and that their experiences were now part of history, they sought to ensure that people living with AIDS in the future would not have to live through what they had experienced.

Resolutely facing a future they no longer had, and with their own mortality as a constant reminder, they quickly realised that ending the epidemic would only be possible if the most affected communities mobilised before the number of people living with

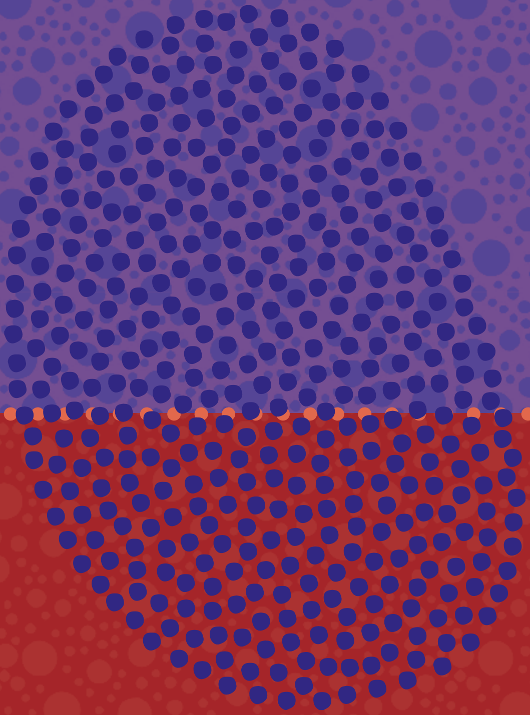
AIDS increased. Therefore, access to healthcare for everyone was a driving force for advocacy, not only for personal reasons but also for the collective purpose of achieving an epidemiological impact.

Time was, therefore, a crucial element in creating the community-based approach. Every step standardised past achievements, and every victory paved the way for other battles in such quick succession that the process itself has often been forgotten.

This book is intended to be analytical. We are once again at a defining moment because the world has changed. Fighting this epidemic is an ongoing battle that has not yet been won. We need to learn from the impact of the community-based approach on the fight against HIV in other areas of society and access to healthcare worldwide with respect for human rights.

For today, as yesterday, and undoubtedly for tomorrow, do nothing about us without us!

Vincent Pelletier
Former CEO of Coalition PLUS



An overview of Coalition PLUS

Coalition PLUS is an international network of community-based NGOs fighting against AIDS and viral hepatitis. Founded in 2008, Coalition PLUS works with around 100 civil society organizations in 52 countries.

Our member and partner associations involve the communities most vulnerable to HIV/AIDS and hepatitis in developing and implementing prevention, care, and advocacy programs.

They promote innovative approaches that are tailor-made for people at the greatest risk of discrimination regarding access to healthcare.

Our values: solidarity, respect for diversity, non-judgemental and innovation.

16 member organizations
52 countries
100+ partner associations

Network
All the listed countries

Offices

- Brussels (Belgium)
- Dakar (Senegal)
- Geneva (Switzerland)
- Pantin (France)

Members

- 100% LIFE, Ukraine
- AIDES, France
- ALCS, Morocco
- ANCS, Senegal
- ANSS, Burundi
- ARAS, Romania
- ARCAD Santé PLUS, Mali
- COCQ-SIDA, Canada (Quebec)

- Fundación Huésped, Argentina
- GAT, Portugal
- Groupe santé Genève, Switzerland
- IDH, Bolivia
- Kimirina, Ecuador
- Malaysian AIDS Council, Malaysia
- PILS, Mauritius
- REVS PLUS, Burkina Faso

Our geographical, topic-specific and linguistic networks

- Americas-Caribbean Platform: Bolivia, Canada (Quebec), Colombia, Ecuador, France (French Guiana, Martinique, Guadeloupe, Saint-Martin), Guatemala
- Central and Eastern Africa Platform: Burundi, Cameroon, Central African Republic, Chad, Congo-Brazzaville, Democratic Republic of Congo, Rwanda
- Europe Platform: Belgium, France, Portugal, Romania, Switzerland (Geneva), Ukraine
- Indian Ocean Platform: Comoros, France (Mayotte, Reunion), Madagascar, Republic of Mauritius (Mauritius island, Rodrigues island), Seychelles
- MENA Platform: Algeria, Lebanon, Mauritania, Morocco, Tunisia
- West Africa Platform: Benin, Burkina Faso, Côte d'Ivoire, Guinea-Conakry, Mali, Niger, Senegal, Togo
- AGCS PLUS: Algeria, Benin, Burkina Faso, Burundi, Cameroon, Côte d'Ivoire, Guinea-Conakry, Mali, Morocco, Senegal, Togo, Tunisia
- Hepatitis C: Brazil, Colombia, India, Malaysia, Morocco, South-East Asia
- Portuguese-speaking network: Angola, Brazil, Cape Verde, Guinea-Bissau, Mozambique, Portugal, Sao Tome and Principe, East Timor
- RIGHT PLUS: Bolivia, Brazil, Chile, Guatemala, Mexico, Peru, Portugal, Spain

Foreword

This book is the fruit of 40 years of studying and analyzing the global fight against AIDS.

We are all more or less aware of the major successes in the fight against AIDS in the 1990s and 2000s, which helped save millions of people living with AIDS worldwide and which continue today to keep people in treatment in often difficult circumstances. However, we know far less about the community-mobilization approach that has led to this success. Neither its contribution nor the conditions necessary for its implementation, nor the people involved have piqued global interest. We want to clarify these aspects for the voluntary sector, and for decision-makers in the public health system.

We have not tried to provide an exhaustive document on this subject. Instead one of the main objectives of this book is to encourage people to have necessary conversations, suggest research topics, and, above all, appreciate the work of all those involved. Some of those people have since passed away, while others are focused on continuing this community work but often with little recognition. With this book, we want to pay them a modest tribute.

This is an important issue at a time when the fight against AIDS is no longer a top priority for policy-makers or the public health system. It is a fight that needs to be recognized for its exceptional contribution to community health. The fight against AIDS does not claim to have invented community health. However, there are success stories from around the world that are due, first and foremost, to activists and other people working to put an end to HIV—people who often live with HIV themselves. Thanks to the tightly-woven network between human rights and access to health for stigmatized populations, they could carry out this work. Another objective is to consider the fight against AIDS in conjunction with the main community health declarations drawn up since the 1980s and to assess whether this fight met the community health criteria set out in the international declarations to support global health.

In addition, we have tried to highlight the major lessons learnt from the community mobilization against AIDS, which should benefit other pandemics, other health conditions, and other groups with poor access to healthcare. As you will see, there is much more to community health than access to healthcare, as it also focuses on the social determinants of health. Therefore, it is no surprise that the fight against AIDS improved community health by proving that respect for human rights is the most important social and societal factor by empowering ostracized populations to enjoy better health and well-being.

This book is for all those involved in the fight against AIDS or in community health, whether implementers or policy-makers in public health. It seeks to bridge the gap by providing a greater understanding of diverse concerns and finding collective solutions. We cannot reiterate enough how fundamental community health is to the global public health approach. Therefore, it is necessary to identify the places and, above all, the people to allow this engagement in the public health system. Without such a strong focus, it is unrealistic to talk about global health.

The seven chapters of this book are relatively independent of each other and can be read in any order that best suits the individual reader's needs. Even though reading it in order will provide greater clarity, it is not essential.

Last but not least, this book is based on the combined experiences of Coalition PLUS members and some other organizations. We have used experiences in the field to illustrate the points made in parts of the book that may sometimes seem theoretical.

The purpose of this book is also to be adapted, critiqued and improved upon in order to be re-appropriated. As a result, the concept of community health will become clearer and can be implemented as the main approach to healthcare access and to prevention for the most marginalized in our communities. This is what Coalition PLUS stands for.

We hope you find it interesting.

D^r Hélène Rossert
For Coalition PLUS

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Concepts and definitions: what are we talking about?

From Alma-Ata to the concept of global health

“The overall guiding principle for the world, nations, regions and communities alike is the need to encourage reciprocal maintenance - to take care of each other, our communities and our natural environment.” (World Health Organization, 1986, Section on Health Promotion Action)[1]

Introduction

The concepts of community health, primary health care and community involvement in care predate the HIV/AIDS epidemic. They need to be redefined in the broader context of international public health (see the definition below) to see how the community approach specific to the fight against AIDS (FAA) was created. There is a need to understand more precisely 1) the elements on which it relied on to move forward, and 2) those which were strengthened by it. The FAA has done more than borrow the concept of community health. It has reinvented and expanded community involvement in health decisions. In fact, two parallel worlds have been created which have a lot in common but are separated by differences which have yet to be discussed in detail.

There are several definitions of public health.

A definition of public health by Éditions Le Coudrier[2]:
“Public health is a discipline that addresses health collectively and in all its dimensions, and the purpose of which is to improve the state of health of the population. It calls upon a range of sciences: epidemiology, demography, sociology, health economics, etc.”

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[1] World Health Organization. (1986). Health promotion. Ottawa Charter. **https://www.euro.who.int/__data/assets/pdf_file/0004/129532/Ottawa_Charter.pdf**

[2] Published by Éditions Le Coudrier. (2018). Qu’est-ce que la santé publique ? Qu’entend-on par santé publique ? (paragraphe 2) *[What is public health? What is meant by public health? (paragraph 2)]*. **https://www.edition-lecoudrier.fr/store/page/28/qu-est-ce-que-la-sante-publique**

According to the World Health Organization (2002)[3], public health is an organized effort by society, primarily through its public institutions, to improve, promote, protect, and restore the population's health through collective action. The French Public Health Code specifies in Article L1411-1 the scope of public health policy. It includes:

- **monitoring and observing the health status of the population and its determinants;**
- **the fight against epidemics;**
- **the prevention of disease, trauma and disability;**
- **improving the health status of the population and the quality of life of people who are sick, have disabilities or use drugs;**
- **informing and educating the population about health and organizing public debates on health issues and health risks;**
- **identifying and reducing any possible health risks related to factors in the environment, working conditions, transport, food or consumption of products and services that may affect health;**
- **reducing health inequalities by promoting health, developing access to healthcare and diagnosis throughout the country;**
- **the quality and safety of healthcare and health products;**
- **the organization of the health system and its ability to respond to prevention and support needs for illnesses and disabilities;**
- **and the demographics of healthcare professions.**

Understanding these different approaches before analyzing their interaction or lack of interaction is vital to obtaining a perspective that drives progress in public health.

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[3] Regional Committee for the Western Pacific, 053. (2003). Essential public health functions: the role of ministries of Health. WHO Regional Office for the Western Pacific. **http://apps.who.int/iris/bitstream/handle/10665/138383/WPR_RC053_10_MOH_Roles_2002_en.pdf?sequence=1&isAllowed=y**

Primary health care and health promotion

In the Alma-Ata Declaration of 1978, **primary health care** (PHC) is defined as “essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the **community through their full participation** and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination.”(World Health Organization, 1978, Section VI)[4]

PHC was a key tool, at the time, for achieving the objective of the World Health Organization (WHO) to reach “Health for all by 2000” by renewing public health in the world on a basis centered more on prevention and with greater access to services for communities.

The Alma-Ata Declaration clearly stated that “people have the right and duty to participate individually and collectively in the planning and implementation of their health care.” (World Health Organization, 1978, Section IV). This was a pioneering perspective of individual and collective involvement in health care.

“Primary health care includes at least [...]:

- education concerning prevailing health problems and the methods of preventing and controlling them;
- promotion of food supply and proper nutrition;
- an adequate supply of safe water and basic sanitation;
- maternal and child healthcare, including family planning
- immunization against the major infectious diseases;
- prevention and control of locally endemic diseases;
- appropriate treatment of common diseases and injuries;

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[4] World Health Organization. (1978). Declaration of Alma-Ata. https://www.euro.who.int/__data/assets/pdf_file/0009/113877/E93944.pdf

- and provision of essential drugs[5]." (World Health Organization, 1978, Section VII)

In a progressive way, the Alma-Ata Declaration mentions the need for egalitarian teamwork between health professionals and community workers and, above all, teamwork to meet the communities' needs. The word "community" does not yet appear in the context of this teamwork.

After the Alma-Ata Declaration, the Bamako Initiative (BI) was introduced in 1987. This arose from devastating findings regarding 1) poor access to healthcare by populations in sub-Saharan African countries, particularly rural populations, and 2) the lack of transparency and fairness in health care systems. It was introduced when structural adjustment policies imposed by the International Monetary Fund (IMF) and the World Bank forced governments to control public spending by the over-indebted African States.

The BI thus relied on the Alma-Ata Declaration to promote PHC concerning greater access for communities:

- by decentralizing health services for greater access for communities;
- by providing transparency in the management of health centers by involving local communities in center management;
- by defining a minimum package of care which is all PHC, including essential medicines in generic form, thereby helping to make them affordable;
- however, the BI brought user-paid healthcare to communities to establish what is known as cost recovery.

The implementation of PHC aimed to provide access to healthcare for everyone by 2000, especially in countries with limited resources. We all know what happened next... the HIV/AIDS pandemic took

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[5] WHO definition: "Essential medicines are the medicines that satisfy the priority health needs of the population. They are selected according to public health relevance, evidence on efficacy and safety and comparative cost–effectiveness. Essential medicines are intended to be available within the context of functioning health systems at all times, in adequate amounts, in the appropriate dosage forms, with assured quality, and adequate information, and at prices the individual and the community can afford." (World Health Organization).
Essential medicines and pharmaceutical policies
http://www.emro.who.int/essential-medicines/strategy-policy/

place in the 1980s and 90s on and wreaked havoc, particularly in low-income countries. In addition, the chronic under-funding of healthcare and the fact that care had to be paid for by individuals put a stop to hopes for “Health for everyone in 2000” in a matter of years.

Between 1978 and 2018, other factors appeared in primary health care, demonstrated by the Ottawa **Charter** in 1986 **on health promotion** and by the Astana Declaration in 2018, 40 years after the Alma-Ata Declaration.

We should remember that the Ottawa Charter, however progressive it may be, is focused on health promotion. This concept covers all the means given to individuals and communities to improve control over their health and create favorable conditions beyond the health sector to encourage good health.. The Ottawa Charter was set in 1986 aiming at achieving “Health for all by 2000” by renewing public health globally.. Its vision is broad regarding means but restrictive concerning objectives relative to the healthcare system. As a matter of fact, it does not directly address the curative aspects of healthcare, nor secondary prevention (screening for illnesses) or tertiary prevention (limitation of after-effects of conditions). However, this interpretation is debatable, and inclusion in curative care and screening for conditions can be regarded as managing one’s own health or that of the community.

In the Ottawa Charter on health promotion, several concepts arise which are interesting for our analysis:

- “The strengthening of community action…through concrete and effective community action… in setting priorities, making decisions, planning strategies and implementing them to achieve better health” (World Health Organization, 1986, p. 4). In this Charter, there is an interpretation regarding the maturity and responsibility of communities. The Charter also states that “community development draws on existing human and material resources from the community […] to develop flexible systems for strengthening public participation and direction of health matters”;

- The development of personal skills—or **the strengthening of abilities and skills**. For health promotion to take place on an individual and collective level, the Charter recognizes the need for access to information, health education and enhancing life skills. This learning must be facilitated in all settings, including through community, professional and voluntary bodies, and within the institutions themselves;
- **The need for coordinated action** by all potential players in health promotion, such as governments, the health and social sector, economic actors, non-governmental organizations (NGOs) and voluntary organizations, the media, the private sector and local authorities. These elements form an intersectoral approach, even though the term was not yet used at this point;
- The development of health policies. Here too, the Charter promotes a cross-cutting approach and mentions a new concept that was subsequently to evolve: identifying **obstacles to adopting health policies in non-health sectors**[6] and the means to overcome these obstacles. Did this mark the beginning of th idea of human rights and access to healthcare?

In a pioneering move, the 38 countries that signed the Ottawa Charter committed themselves, among other things, to:

- “accept the community as the essential voice in matters of its health, living conditions and wellbeing” (p. 5);
- make health services “share power with other sectors, other disciplines and most importantly with people themselves”.

How do things look 30 years on? An article published in 2016 in the *Public Health*[7] Journal is a harsh reading of what health promotion, as envisaged by the Ottawa Charter, has become. Nevertheless,

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[6] The non-health sector includes all other sectors outside of health that contribute to the health status of populations: for example, the workplace, the school environment, the legal framework, social welfare, housing, etc. Thus, intersectorality refers to encouraging all or some of these sectors to enter into discussions with the health sector to improve the health status of a population.

[7] Breton, E. (2016). The Ottawa Charter: 30 years without an action plan Public Health, 28(6), 721-727. **https://www.cairn-int.info/article.php?ID_ARTICLE=E_SPUB_166_0721**

the author identifies aspects of the Charter circulated in societies, notably the now undisputed interest in the living conditions of clients as a factor influencing their state of health. We will see later how the FAA can, surprisingly, say that, in its community form, it is completely in line with the principles of the Ottawa Charter.

In **the recent Astana Declaration**[8], other concepts have emerged since Alma-Ata, such as universal health coverage[9] tailored to different contexts and the use of technology. However, some concepts have regressed, such as community involvement, overseen here by health professionals. The concept of human resources for health only mentions professionals. It completely omits community health workers, volunteers and even family members, who are still the greatest source of human resources for health worldwide. Equally surprising is that no mention is made of what has happened in the world of health over the past 40 years. There is nothing about AIDS, Ebola or other types of bird flu. This signs the big comeback of governments and health professionals. Human rights are barely mentioned alongside national sovereignty, and there is clearly a conflict between these two concepts: human rights are, in essence, universal and national sovereignty is... national.

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8 World Health Organization. (2018, 25-26 October). Astana Declaration: International Conference on Primary Health Care. **https://www.who.int/docs/default-source/primary-health/declaration/gcphc-declaration.pdf**

9 According to the WHO, universal (health) coverage means that the whole community has access to the preventive, curative, palliative, rehabilitative and health-promoting services they need, and that these services are of sufficient quality to be effective, without their cost causing financial hardship to users.

Community involvement in health and the development approach

In the 1970s, the development approach decided solely by external decision-makers and based on a few people's physical, or material improvement was called into question. The involvement of local urban and rural communities in development strongly resurfaces in Latin America with Paolo Freire[10] and Augusto Boal[11]. By encouraging the use of education and theater, these two figures also made it easier for oppressed populations who were largely poor and illiterate to learn and express themselves. This was primarily a citizen's initiative to give the disenfranchised communities access to the vote, which happened in Ecuador in 1979.

Since the early 1990s, the major development sponsors (the World Bank and the Organization for Economic Co-operation and Development (OECD) have adopted a participatory approach. The Alma-Ata conference in 1978 drew attention to the health professionals' unchecked takeover of healthcare due to the technification of medicine. The conference raised the risk of distancing the health system from the populations it was meant to serve if community involvement was not allowed (Khassay & Oakley, 1999[12]). Furthermore, the conference stipulated that communities should be involved in PHC with regard to support the running of health services, the definition of health priorities and allocation of resources at the local level. For the first time, services were rejected based on needs perceived by health professionals in favor of services defined by and for the community. The Bamako Initiative drew inspiration from this with regard to community involvement in the management of health centers and the local definition of the minimum care package for each community.

At the time of Alma-Ata and the Ottawa Charter, the community had a geographical meaning as it had initially had in the approach

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[10] Freire, P. (1974). The Pedagogy of the Oppressed. Maspero Edition. (originally published in Portuguese in 1969)

[11] Boal, A. (2003). The Theatre of the Oppressed. La Découverte. (originally published in Portuguese in 1979)

[12] Kahssay, H. M. & Oakley, P. (1999). Community involvement in health development: A review of the concept and practice. World Health Organization.

to Africa in the 1940s. A geographical community meant acting as a village or neighborhood.

The fight against AIDS broadened the concept of community to groups with a common interest or those with a difficult situation in common, such as groups who were marginalized by difficulties in accessing care and sometimes criminalized. These communities are on the margins of society because of who they are, such as men who have sex with men or transgender people, or sometimes because they live with HIV, or because of what they do, including people who use drugs, sex workers, etc. However, who these populations, *referred as key-populations,* are or what they do is not enough to make them a community if they do not regard who they are or what they do *as part of their identity,* or if they do not have *a common interest or do not feel connected by a common problem* through collective action. This is an identity-based community or a community of belonging or fate.

Community involvement is, however, a concept subject to interpretation. There can be various forms of involvement (Kahssay & Oakley, 1999, p.5). A distinction is drawn between:

- involvement as collaboration, probably still the most used form where the local population or the identity-based community group is involved in implementing a program. It often acts as labor but has no direct involvement in developing the program, its management and its oversight. In its most insidious form, it can be regarded as the instrumentalization of the community;
- involvement targeted at the beneficiaries of health projects or programs. This approach includes marginalized or excluded populations with particular vulnerabilities in health projects. In a report from 1987, the World Bank[13] defines community involvement as "an active process whereby beneficiaries influence the direction and execution

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[13] Paul, S. & World Bank. (1987). Community Participation in Development Projects: The World Bank Experience. World Bank.

of development projects rather than merely receive a share of project profits”. We will see later that, in the FAA, this model came to dominate;

- involvement as *empowerment*/capacitation[14]. This is an active mode of involvement in which, by their action, communities excluded from healthcare increase their access to and control of services. It is an opportunity to initiate, undertake and decide on actions deemed essential for a community by the community. In this definition, the word *empowerment* clearly implies taking power. It is usually used today with a weaker meaning. Although preferable, this model is rarer though found in FAA action and geographical community action.

This classification is naturally a simplification, and we often see a combination of levels of involvement, but **two levels** can generally be identified (Kahssay & Oakley, 1999, p.7):

- community involvement as a means of collaboration and cooperation by beneficiaries with often external programs (development aid). In “classic” large development aid programs in the 1990s and 2000s, the usual situation was this mode of collaboration with a program usually designed outside the country and implemented in part by its beneficiaries. The Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund or GF), GAVI (the vaccine alliance) and Unitaid (the fast tracker of Global Health innovations) re-drew the lines. Or perhaps they just moved them a bit? A country’s public administration in the form of the “classic” health system had now become the “external” financial backer of communities and of the community health system . It does so with a top-down approach to beneficiary involvement in order to comply with the demands of the aforementioned international backers and above all, to have cheap operational labor. It is, however, essential to note that, since the creation of the Global Fund, people living with the diseases and so-called key populations have to be represented within the decision-making bodies of major international

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[14] From this point on, we will use the term empowerment, which is widely used in the field of development.

organizations and in their representation in countries *(see Chapter 6 on community expertise);*

- community involvement as an objective. In this approach, the *empowerment* of excluded populations becomes one of the major objectives of the projects or programs implemented. For example, *empowerment* in the fight against poverty and exclusion is now seen as an essential condition for the sustainability of projects and programs.

What are the necessary conditions for community involvement
(Kahssay & Oakley, 1999, p.8)?
Two concepts will be developed further in this book.

Community involvement depends on a long-term factor that is rooted in a rich network of **protagonists and stakeholders**. It entails a network that is open to fields beyond that of health, reaching out to economy, culture, education, justice, political decision-makers, to name but a few, and, **above all, to peers**. This involvement in networks allows communities to establish sustainable roots in the landscape of a country while securing their resources in the long term.

It also depends on a short-term factor: **the strengthening of skills of individuals and the capabilities of community-based organizations** allow credible community involvement. It thus promotes access to the network of development stakeholders.

The concept of community involvement is so important that it is sometimes wrongly understood as the only condition for community health.

Community health

Historical context and principles

Community health is an old concept dating back to the 1950s in China and Thailand[15,16] to address the shortcomings of health systems in providing healthcare to the poorest people. Thus, in these countries, two bodies of healthcare providers for remote and poor populations were created: “the barefoot doctors” in China and the “village health volunteers” in Thailand.

This concept is rooted in countries with limited resources. Community health emerged in developing countries to deal with the shortage of health professionals and its use was later extended to poor or marginalized populations in rich countries. The Alma-Ata Declaration and the Ottawa Charter will put it back on the agenda for rich and poorer countries. Furthermore, valuing community involvement in health promotion can encourage changes in so-called “harmful” behaviors and question the “all-medical” approach to improving health.

As valued as community health seems to be by international organizations working on health, it is still confined to a vague and peripheral field of health systems. The WHO does not use this term and prefers terms such as “community healthcare”, “community management”, etc., but it does use the term “community health workers”.

France, for instance, does not have a clear legislative framework governing community health. Canada, and particularly Quebec, pioneers in community health in the 1970s and 1980s. However this country nowadays has taken a step backwards by abandoning the autonomy of local community management by local community service centers (CLSCs). These health centers, originally run by the

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[15] Lehmann, U. & Sanders, D. (2007). Community health workers: What do we know about them? The state of the evidence on programmes, activities, costs and impact on health outcomes of using health workers. World Health Organization. **https://chwcentral.org/wp-content/uploads/2013/07/Community-Health-Workers-What-do-we-know-about-them.pdf**

[16] De Wet., K. (2010). The three ages of community health in South Africa. Social Sciences and Health, 28(3), p. 85-107.

community, in this case a neighborhood or municipality, have been transferred to the state and have now become service providers. Health priorities are no longer discussed locally.

In Africa, in particular, community health is well established and probably stronger than before, thanks to funding from the Global Fund[17], an international funding body established in 2002. Moreover, it appears to be a viable instrument for achieving universal health coverage and the 2030 Sustainable Development Goal on health. However, this instrumentalized reading of community health is often a search for cheap operators without any real direct community involvement.

In fact, community health is so multifaceted that there is no agreed definition. On the other hand, the strategies covered seem quite clear and specific[18]:

- It is about a community (this means an action that is local or has a limited group of beneficiaries);
- It favors an approach of co-development by all players;
- It is based on shared knowledge and power;
- It promotes and pools community resources.

Methodologically, it requires a planning process through a shared, scalable and ongoing evaluation of the programs implemented for the benefit of the community (European Secretariat for Community Health Practices, 2009).

Like public health, community health places greater emphasis on health promotion and disease prevention. Like public health, it is also concerned with disease control and rehabilitation.

Like public health, community health stands at the intersection of the health and social fields. However, it is more concerned with the social rather than the health determinants of health, i.e., the factors that determine an individual or community's state of

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[17] https://www.theglobalfund.org/en/

[18] European Secretariat for Community Health Practices. (2009). Community action in health: international observatory of practices. SEPSAC.

health[19]. The determinants approach allows behavioral changes to be supported by environmental conditions in the broad sense of the term. It opens up an upstream approach to prevention by looking at the causes of practices or behaviors that increase health risks.

The Public Health Agency of Canada has identified 12 determinants of health. Some are directly health-related (9 and 10), some purely social (1, 2, 4 and 5), some cultural, some workplace-related, and some mixed:

1. Income and social status (being rich or poor);
2. Social support networks (having family, friends, work colleagues, volunteering, access to support services);
3. Education and literacy;
4. Employment and working conditions;
5. Social environments (stigma or not);
6. Physical environments (rural, urban, pollution, etc.);
7. Personal health practices and coping skills;
8. Healthy child development (infant support, nursery schools, maternal and child welfare services);
9. Biology and genetic endowment (individual factors);
10. Health services (access to services);
11. Gender (individual factor)[20];
12. Culture.

The more positive ‘determinants’ a person has, the better his or her chances of being healthy.

The constituent elements of the community health field are analyzed by Jourdan et al. (2012)[21] as a **multidisciplinary and multi-sectoral** field of initiatives and research that draws on:

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[19] World Health Organization. (2004). Social Determinants of Health: The Facts. **https://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf**

[20] Gender and sexual orientation are not mentioned at this time.

[21] Jourdan D. et al. (2012). Quarante ans après, où en est la santé communautaire ? *[Forty years on, where does community health stand?]* Santé publique, 24(2), p. 165-178. **https://bdsp-ehesp.inist.fr/vibad/controllers/getNoticePDF.php?path=Sfsp/SantePublique/2012/2/165_178.pdf**

- **individual or organizational players**, whether a citizen living in a given geographical area, a person belonging to a particular social group, associations, health, social and educational professionals, etc., in a position where they are **facilitators**, policymakers, researchers;
- **key values**: social justice, political commitment, *empowerment*;
- **concepts and theories:** social determinants of health, social change, participation;
- **target populations and areas for action:** key populations, local living environment, access to care;
- **objectives:** improvement of health and well-being, social development, prevention;
- **methods:** involvement of everyone, partnership approach, from needs assessment to evaluation.

The huge diversity of community health action becomes evident by varying these elements. It is also apparent that many of these parameters belong to health promotion and, more broadly, modern public health. This is the case with the multidisciplinary and multi-sectoral aspects, improvement in health and well-being, the transformation of health determinants, etc. They are also components of community health. However, it is worth summarizing the essential elements for an action to qualify as community health:

- involvement in a decision-making position held by the beneficiaries of the action (with or without a facilitator);
- involvement of beneficiaries at all stages of the action, but more so at the time of needs' assessment to improve health (initial phase) and evaluation of the action (final phase);
- a commitment to activism that seeks to empower the beneficiaries, aiming to achieve social justice and a transformation of the determinants of health, especially social determinants of health, through the indispensable contribution of community expertise.

In community health, community involvement is important, but above all, the positioning of the community in action as a decision-maker/expert with the objective of acting on the determinants of health. Community expertise is driven by profound knowledge of lifestyles, the social and physical environment, personal experience of the community's obstacles and assets, and the will to transform an individual story into a collective success. We will look at this in detail in Chapter 3 on community expertise.

This is an idealistic view of community health, of course. Through the analysis of the mutual influence of the FAA and community health, we will see how the methods for implementing community health action have evolved. The pragmatism and the interface role with the health system are provided by 1) the facilitator and 2) by the multidisciplinary nature of the community health protagonists (beneficiaries and facilitators, networks and partners).

Community health facilitation

The community facilitator is often called a 'community health worker' in African countries. These are people, both within and outside the community, whose role is to act as an intermediary between the community and the health system and support the community in all aspects of the implementation of the action. The facilitators are not normally decision-makers unless the community wants them to be and gives them collective decision-making power. These facilitators provide the community with useful expertise in implementing the action or mediating with the health system.

The mutual influence of community health and the fight against HIV/AIDS

It is risky to talk about the influence of community health on the FAA, especially in the 1980s and in the Northern countries where the FAA was first organized. Nevertheless, if we cannot talk about influence, we can at least look for the community health components, which can be found in the community organization of the FAA in North America and Western Europe. For Africa and Latin America, it is more complex because the concept of community health is more prevalent there, more recognized, and more accepted by the health system.

Let us start with community and community mobilization in the FAA. It takes different forms at its creation, depending on the factor that initiates the mobilization. Here are some examples which are not classifications but rather broad trends:

- In the early 1980s, community mobilization in the FAA clearly encompassed urban MSM communities in major US cities (New York/Greenwich Village, San Francisco/Castro, Los Angeles/West Hollywood, etc.), affecting the first people living with HIV and their partners, their social networks and their neighborhoods. This initial mobilization contained a geographical dimension, which is the basis of the mobilization and the action of proximity support. The feedback on needs in terms of care did not require any facilitators or studies. People affected knew what they needed: access to care, decent hospital conditions, end-of-life support, psychological counseling, legal advice, recognition for their partner(s) to allow them to keep the shared home, access to inheritance or funds for funeral costs, HIV screening resources and research into treatments. This community was also sufficiently organized, educated and connected to the health system to express its needs and influence the responses clearly. The community provided the healthcare system with a level of expertise on its life and daily constraints. It could drive the FAA forward whenever progress was made. It could adapt to the changing needs of its members and provide support in the areas it needed: hospital and research environment, social services, legal services, business world, etc. In addition, it was to create its services by solidarity relying on voluntary services[22]. Strengthening the skills of volunteers soon followed and provided information and services acceptable to the community members and credible for health professionals. The community's claim to belong to the MSM population makes it an identity-based

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[22] Volunteering in the FAA does not have a single definition. However, volunteer, which was first used by English speakers, has a more proactive concept in its mission of social transformation than volunteer. In the FAA, volunteers are necessarily trained, supervised and are subject to a specific ethical framework. These are the people who, more often than not, make up the associative general assemblies from which the associative leaders meet as a board of directors.

community approach. Community health, the likes of which has never existed before, but who does not know that this mobilization is community health in the purest sense. We see here a mobilization and community action which sets priorities which rely on community resources. And we find members of the community who acquired the skills they needed for the action, and who negotiated/coordinated with health and social services. They identified, probably long ago, the obstacles to the adoption of health policies in the non-health sector. Through its new organizations, such as the Gay Men Health Crisis (GMHC), the most famous of which was established in 1982. These organizations set the tone and occupied a role of knowledge and power. They are the product of a particular environment, that of the ghetto and of identity affirmation. Faced with the unprecedented crisis for the MSM population that AIDS represented in the 1980s, they had no other option, no other way. These organizations, such as the GMHC and the Terrence Higgins Trust (THT) in England, have set the tone for the FAA worldwide in a resolutely community-based way. However, it is unlikely that at this time any of the members had any particular interest in the Alma-Ata Declaration and the Ottawa Charter. They had many other things to do;

- Shortly after, in 1984 in France, AIDES was created differently, this time rooted in political activism, an example of a shift in social movements. Indeed, most of the initial AIDES activists came from the prison information group created by Michel Foucault. AIDES was created in connection with the unacceptable conditions of his death from AIDS-related complications. Daniel Defert, the founder of AIDES, visited the GMHC and THT but wanted a different model, a more political and more open model, as there was no question of an MSM neighborhood in France as there was in the United States. With AIDES, the relationship with the medical institution will be more strained to meet the needs of people living with AIDS and their families. The pooled expertise of various people such as doctors, lawyers, sociologists and sex workers and people who use drugs created high-quality community expertise that would defy the healthcare system and help

> improve it and stimulate research. AIDES also expressed, at this time, the community approach of geographical proximity by favoring the creation of autonomous AIDES associations in many towns and cities in France to respect the approach of local sociocultural diversity. The concept of community in AIDES was more open than in the GMHC: it aimed to bring together everyone affected by AIDS and those who wanted to work with them, without any stated hierarchy. The task was to transform the dominant system of health and society and have social justice prevail for people living with HIV or people at risk of acquiring HIV, which is almost everyone. Although never mentioned in AIDES, the determinants of health are omnipresent in all its work. Indeed, there is a huge similarity with the Ottawa Charter in which, in 90% of cases, "health promotion" is replaced by "fight against AIDS".

AIDES was the only "major NGO" in the North, created at the start of the FAA, to initiate and drive a multipronged international program, including an African one called "Africa 2000" *(see box "From the Africa 2000 Network to Coalition PLUS" on p. 37)* and a European program. The latter prompted a high-quality discussion between the NGOs in the FAA in Western and Southern Europe to join forces to influence the policies of the European Commission, in particular harm reduction associated with drug use. This international program was based on the same community engagement values as in France. AIDES has now put an end to this international program in order to participate in a new international organization, Coalition PLUS, with the majority of Africa 2000 partners or those with a long history of connection with AIDES. Coalition PLUS's working principles are more egalitarian *(see box "From the Africa 2000 Network to Coalition PLUS" on p. 37)* and rooted in a community approach by partner organizations. AIDES maintains international programs with its neighboring countries, in Guyana and the Caribbean, while driving the European platform of Coalition PLUS.

- PLHIV associations such as ANSS, REVS PLUS, PILS. These associations were set up due to a response led by their founder(s) who were people living with HIV. Stigmatization, rejection, and injustice prompted them to speak out publicly to spread the word that HIV is no longer a terminal condition and can affect everyone, and that empathy is needed. These associations were pioneers in the FAA because they humanized it. They were concerned with raising awareness, HIV testing, people publicly sharing their HIV status and support for other people living with HIV and their families. They then, more or less quickly, added medical expertise to set up the medical care and monitoring of people living with HIV/AIDS;

- Associations started by health professionals such as ALCS in Morocco and ARCAD Santé PLUS in Mali. These associations, created by doctors facing the first cases of AIDS in their countries, had to deal with the lack of treatment, end-of-life support and the distress of people living with AIDS whom hospitals refused care. These founding doctors understood that the response had to come from freer, less stigmatizing structures than those of the public sector. These health professionals have therefore surrounded themselves with people living with HIV and those close to them. They offered a solution that meets the needs for support in the day-to-day life of people living with HIV and their relatives. They adapted or supplemented medical services within hospitals or other health centers;
- Associations created in a context of the fight for human rights and health: ARAS in Romania, Kimirina in Ecuador, IDH in Bolivia. These associations were set up in difficult legislative environments: during the fall of the Iron Curtain and the discovery of the tragic HIV infection of a large number of children in Romania, or because of low mobilization on HIV issues in Latin America where the issue of human rights and access to health had yet to be developed. These associations first developed information and education campaigns about HIV in their own context. They then campaigned for the right to antiretroviral therapy (ARV), the right to social integration, and the right to compensation. These associations promoted first and foremost the rights of people exposed to or living with HIV/AIDS, as they were aware that disease prevention could only be achieved if human rights were respected. They have therefore developed by integrating both specialists and service users.

From the Africa 2000 Network to Coalition PLUS

At the end of the 1980s, AIDES established the first contacts with African associations. First, in Morocco, developing a response to AIDS that was not only medical. Then other associations of people living with HIV in Burundi and Burkina Faso, where there was no response to care, called on AIDES for access to care. The role of people affected by HIV/AIDS was central to this mobilization, in the same way as it had been in France with AIDES, for example.

Towards the end of the 1990s, international networks of associations were gradually set up to support and roll out advocacy and warning campaigns for States and international institutions to mitigate the difference in access to care in various parts of the world. The mobilization mantra was: “patients in the South and medicines in the North”.

The development of campaigns by “Africa 2000 Network”, a network of AIDES partner associations created in 1997, made it possible to prove the feasibility of quality care and access to antiretroviral medicines. We should not forget that at that time, only HIV prevention was considered and financed for African countries by international donors, including the World Bank, the European Union and rich countries in the North, except for France with its International Therapeutic Solidarity Fund initiative launched in 1997 in Abidjan by President Chirac.Care responses were provided by reinforcing the skills of players in the community and the capacities of their organizations. A system of exchanges between peers achieved this strengthening to contribute jointly to the FAA. The same principles as those which defined AIDES’ action applied in the network: involvement of the people concerned, joint action and action via the network and cooperation with the health authorities. In the mid-2000s, the heads of the African partner associations joined the AIDES Board of Directors. However, this model was called into question as it was not judged to be egalitarian with regard to the African organizations. A system of shared governance between the various network members was put in place instead leading to the creation of Coalition PLUS. In 2008, Coalition PLUS was launched with four founding

members (ALCS in Morocco, ARCAD Santé PLUS in Mali, COCQ-SIDA in Quebec/Canada and AIDES in France). Today, 16 member associations sit on the Coalition PLUS's Board and have equal voting rights, and Coalition PLUS works in 52 countries with over 100 associations.

Common factors among the approaches of community-based AIDS NGOs

- The close proximity to people living with HIV/AIDS (PLWHA) and their families translates immediately into action to respond to the most urgent needs of PLHIV.
- An activist approach to empowering people living with HIV transforms their respective countries' health system and society.
- All those community structures are associations specifically focused on HIV, having sometimes added the fight against hepatitis to their association's purpose.
- Even in PLHIV associations and identity associations (MSM associations or associations for people who use drugs), there is greater proximity with clinical medicine and medical research than with public health players.
- They are all sources of inspiration or matrices for other associations or other groups vulnerable to HIV.
- All have strong approaches to strengthen their capabilities, which consolidate their credibility.
- They all have difficulties balancing community activism with a service approach to the health system.
- These associations quickly became integrated into national and even international multidisciplinary and multi-sectoral networks.
- When these associations started, the methodological approach to planning and evaluation was almost non-existent and way down the list of preoccupations of activists or players in community associations. The Anglo-Saxon organizations were the first to rationalize needs' assessment in the late 1980s and thus allowed the move to an approach of methodical public health action.

Differences between community-based AIDS NGOs

- All the organizations mentioned above are different in terms of creating their non-governmental organization for the FAA. This is partly because the governmental FAA also differs depending on the society and the health system in place.
- Some are confined to the city where they were born, particularly in the United States, while others have spread throughout the country (AIDES, Deutsche Aids Hilfe, ARCAD Santé PLUS, ALCS).
- Depending on how the associations were set up, they will use community facilitators sooner or later. The associations created by doctors will need them rapidly to remain in touch with community expertise as opposed to identity associations and associations of people living with HIV, which will need them later to expand their scope of work.
- In contrast to wealthy countries, FAA associations in low-income countries rely on a smaller pool of educated activists who belong to influential networks, rendering them more dependent on public fundings for their survival.
- From the time antiretroviral therapy became available, FAA associations in low-income countries became the leading promoters and dispensers of antiretroviral therapy as the public health system was initially confined to the distribution of preventive means. In wealthy countries, due to the robust nature of healthcare systems, the inverse phenomenon occurred, and associations were extremely important in terms of access to prevention. They even invented the concept of harm reduction and safer practices in relation to drug use and sexual activity.
- The quality of associative governance allowing beneficiaries to participate in decisions is very diverse and, regrettably, sometimes weak in some associative structures.

Approximation[23] of the differences between community-based AIDS NGOs and "classic" community-based structures[24]

Types of NGOs involved in community health Criteria	Community NGOs in the FAA	Generalist community NGOs in low-income countries contributing to primary healthcare	Community-based NGOs in Northern countries contributing to a social approach to health
Community membership	Generalist community NGOs in low-income countries contributing to primary healthcare	Geographical and mainly women	Geographical and mainly migrants or others, marginalized populations
Demographic importance	+/-	++++	+
Empowerment of beneficiaries	++	+/-	+
Ability for action in national and international networks	+++	-	+/-
Strength of advocacy	+++	+/-	+
Access to health system decision-makers	+++	+/-	+

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[23] This table is subjective and there is not really any literature on the subject. It is based on the experience of those at Coalition PLUS.

[24] The term "classic" refers to generalist community NGOs where the community is geographically defined: a village or neighborhood involved in PHC in low-income countries for example.

Training for facilitators	++	?	+++ (health and social professionals)
Recognition of facilitators	+/-	+/—	++ (health and social professionals)
Positioning of actions in the health system	Vertical	Horizontal related to primary healthcare	In relation to the social aspects of health
Importance of funding	+++	+/-	+/-
Ability to innovate	+++	++	++
Ability to disseminate innovations	+	-	+/-

This necessarily subjective comparison of classical community health (CH) with the FAA nevertheless raises several points:

- there are, of course, intermediate models, in particular community approaches to tuberculosis and malaria, but also those described in the community health picture in Northern countries;
- the community approach to FAA has sometimes lost its advocacy component in favour of working for the public health system;
- the FAA is more dynamic and more technical, more adaptable, suited to community needs and better funded, but it covers a small number of people;
- generalist community health represents many more communities and needs to be covered.

This table shows that bringing the FAA and the “classic” community health focused on primary healthcare together would provide an acceptable solution for everyone. Access to healthcare could be developed further, even in HIV epidemics concentrated in marginalized populations, depending on two conditions. The first would be to make the FAA horizontal *(see Chapter 5 on* *integration)* to ensure sustainable access to healthcare for marginalized populations. The second would make the involvement of communities in primary healthcare more technical.

In the context of global health, consistency needs to be established between the diversity of community health concepts and measures put in place. In order to consider a **cross-functional integration of the FAA**, which means switching from a vertical approach to a horizontal approach to FAA measures *(see Chapter 5)*, it would be necessary to analyze what brings together rather than what differentiates the different generalist or specific community health approaches. This would make it possible to envisage a future of mutual enrichment of "classic" community health with the FAA to benefit the health of the world's populations. Community expertise *(see Chapter 3)* provided by the two approaches must be identified to be able to envisage common courses of action.

Beyond the technical aspects, there are also different aspects in approaches associated with associative and financial governance. They must also be explored to envisage approaches to cross-functional integration of the community FAA and possible financing options which benefit everyone.

Conclusion

There is a tendency among committed FAA players to think of community health as "public health done right". Reference to the definitions of public health quotes in the early part of this chapter shows that it is by collective action that public health acts technically with its own disciplines: epidemiology, hygiene, health economics, prevention and education for health, organization of the healthcare system, etc.

Until the advent of AIDS, specialist technicians used these disciplines. However, these previously relatively watertight specialityspecialty boundaries have been made permeable by the introduction of the expertise of living with the disease of people living with HIV, and by their activism to influence the healthcare system:

- through a good level of information on diseases managed by the clients themselves (i.e., publications managed by FAA associations such as *Remaides*[25]);
- through prevention reinvented, organized and promoted by key population groups at higher risk of HIV exposure with their peers (harm reduction activities);
- through the provision of services previously only available to health professionals, such as community-based testing or access to preventive drugs pre-and post-exposure to HIV, by trained peer educators;
- by contributing to epidemiological knowledge through peer mapping of key populations at higher risk of HIV exposure;
- and by carrying out a high level of community health research, which is nothing more than public health research with the involvement of the groups affected by the research, who are no longer pawns but participants in the research.

It is clear that the FAA has transformed the technical and compartmentalized approach to public health and has used community health to implement its social justice objective. However, will these contributions stand the test of time?

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[25] Periodic publication of information about HIV/AIDS by the AIDES association.

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The creation of associations and their different origins:

the Coalition PLUS experience and beyond

Michaël Pollak[1] said in 1988: "One day when historians write the social history of AIDS, the mobilization in the associations formed beyond the medical field will undoubtedly be the most striking fact."

Introduction

Eight associations fighting AIDS (FAA), including seven members of Coalition PLUS (AIDES in France, ARAS in Romania, ALCS in Morocco, ARCAD Santé PLUS in Mali, ANSS in Burundi, Kimirina in Ecuador, and REVS PLUS in Burkina Faso), and Kénédougou Solidarité in Mali all have different stories to tell. Grouping them into broad categories is certainly reductive, but exploring their current diversity and shared vision is potentially enlightening.

By analyzing the story behind how these FAA associations were created, it helps us establish a link between the circumstances in which they were created, when, why and above all, by whom, and their future in terms of opening up to others, their governance and services offered, while considering the very different contexts in which these associations have evolved. These developments are also linked to national and international agendas such as political changes, international commitments made by countries, and funding availability. In addition, there are, of course, significant differences between the organizations in the North and those in the South. Daniel Defert, the founding President of AIDES, always stresses how important it is to know how and with whom an association was created in order to understand its choices, even a long time after its creation.

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[1] Pollak, M. (1988). Les homosexuels et le sida : sociologie d'une épidémie *[Gay men and AIDS: Sociology of an epidemic].* Éditions Métailié.

The main characteristics of AIDS organizations in the South and in the North

In low-income countries, organizations in the FAA rely on a smaller pool of "educated" activists and committed professionals with networks of influence compared to organizations in richer countries. In addition, the persistent stigma surrounding HIV/AIDS further depletes the pool of people involved.

When triple combination antiretroviral therapy became available in the late 1990s, associations in low-income countries were the first to promote and provide this treatment, thanks to direct international funding. In this sense, they were pioneers and ahead of the public health system, which was at the time limited to the distribution of prevention tools. Nowadays, however, financial flows have changed the situation. International funding for the FAA is most often channel ed through national healthcare systems, which makes associations in the South dependent on international and national funding for survival. Inevitably, this dependence has impacted how these associations see their future.

In rich countries, the strength of civil society and a legal system which protects the right of association allowed associations to mobilize sooner, often during the 1980s, in reaction to discrimination against people living with HIV/AIDS (PLHIV) and a doctor-dominated healthcare system with an unbalanced doctor/patient relationship. Due to à larger pool and the diversity of the highly educated people involved in the associations, they have influenced decision-making at all levels of society, including research in both the medical and social sciences.

With experience leading a social movement, whether prison-related, men who have sex with men or feminists embracing sex workers' cause, those involved immediately included people from key populations. Referred to at the time as "groups at risk", these included primarily men who have sex with men in the North and sex workers in low-income countries, particularly Africa[2]. Later, they

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[2] Delaunay, K. (1999). From risk groups to the vulnerability of African populations, a discourse on a pandemic. Other. 12(11), 37-51.

included people who use drugs and migrants, except for Haitians in the United States, who were part of an initial wave of stigmatization (Delaunay, 1999) etc. These key populations may not have had an educational background, but they had life experiences that were recognized and valued.

Finally, due to the strength of curative care systems in rich countries, we initially witnessed a phenomenon opposite to that seen in resource-limited countries. The associations have been instrumental in providing access to prevention tools, and information for reducing risks (harm reduction) associated with drug use and then sexual risks, pushing for early availability of drugs to treat people living with HIV. They also stimulated and provided critical interpretations of research on all aspects of a HIV diagnosis.

Today, community players claim to provide care for “their people” because of the discrimination experienced by communities in the healthcare system. This situation is temporary but may last for a generation or two while caregivers are trained, and attitudes change.

An attempt to classify associations according to their creation

1. The associations created by people living with HIV/AIDS and their relatives would be at the center;
2. The second circle would be of associations created by health professionals;
3. The third one made of associations involved in political or social activism and human rights.

This type of analysis classifies associations according to their creation, particularly in relation to who created them.

We chose to look at the creation of eight FAA associations that are members of or are close to Coalition PLUS for this analysis in order to limit its scope in a very complex field with barely any scientific literature. We made our choice by trying to create diversity in the first protagonists mobilized and geographical diversity.

We have not analyzed identity associations[3], where the AIDS fight is not central but has often allowed access to useful funding for identity claims associated with the rights of sexual minorities or people who use drugs.

Associations created by people living with HIV/AIDS and their relatives: ANSS and REVS PLUS

Created in 1993 by and for people living with HIV (PLHIV), **the National Association for people who are HIV-positive and living with AIDS (ANSS)** is the first PLHIV association in Burundi. Its initial objectives were to defend the rights of people living with HIV and to promote voluntary and anonymous testing. However, it very quickly had to deal with the lack of access to testing. It responded by setting up an anonymous and voluntary community testing center in 1995. The second step was to offer outpatient medical care, including the first antiretroviral therapy (ARVs) to PLHIV that public health bodies no longer wanted to help. The ANSS has thus become a pioneer in access to ARVs, leading the way for public hospitals to do so. To achieve this, it has, from the outset, sought and obtained the support of health authorities, in particular, the national AIDS program to gain support for the necessary political and health worker mobilization. Over time, the ANSS has opened up to working with people who were not living with HIV who have since contributed their technical expertise to the organization by becoming employees or volunteers.

Established in 1997 in Burkina Faso, **REVS PLUS** started out as a self-support group for mainly women living with HIV. Due to the situation in the country, which offered few services for PLHIV, **REVS PLUS** responses were initially limited to face-to-face consultations. These quickly diversified to include responses focused on prevention, testing, counseling, social support, medical care, advocacy, human

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[3] By identity-based, we mean men who have sex with men, women who have sex with women or transgender associations, associations for people who use or used drugs, or sex workers.

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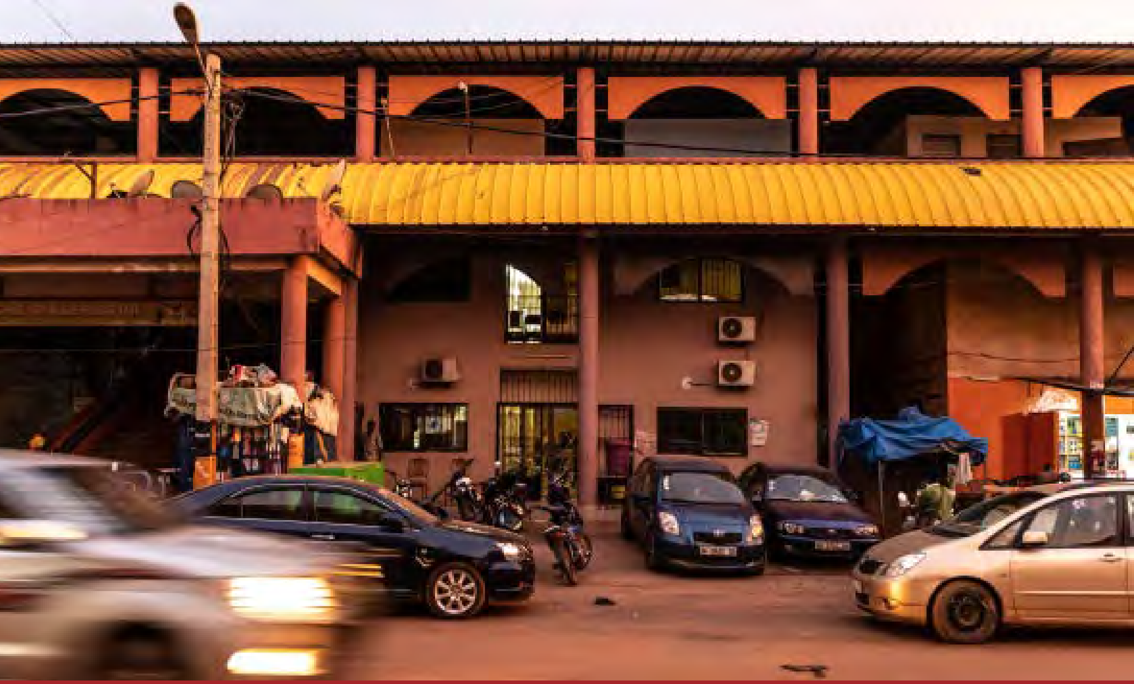
Created in 1993 by and for people living with HIV in Burundi, the National Association of Support for People Living with HIV and AIDS (ANSS) has become a pioneer in access to antiretroviral therapy.



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The ARCAD Santé PLUS's Halles clinic is located in a market in Bamako, Mali, and it is hidden from view.

rights (including those of key populations) and community-based research. To this end, it very quickly opened its doors to people who were not living with HIV who worked as volunteers and employees to help define its structure, become more professional, and gain the trust of public bodies and partners.

These associations, which were initially made up of people living with HIV and people in close proximity to HIV, then welcomed professionals in healthcare, social action, human rights and specialists in finance and organizational management. The y aim to improve their structure, gain credibility, improve the quality of their responses and obtain funding. However, people living with HIV/AIDS and most often the original activists/founders themselves continue to govern these associations and remain in executive management positions. The original activists/founders often find it difficult to pass on the baton, to the new people involved, and even less so to people who are not living with HIV, who are often confined to technical positions.

Associations created by health professionals: ALCS, ARCAD Santé PLUS and Kénédougou Solidarité

ALCS (Association de Lutte Contre le Sida) was officially created in 1988 by the head of the infectious diseases department in Casablanca, Morocco. Initially, she headed up this association with her departmental colleagues and then with infectious disease physicians from other hospitals in major Moroccan cities. This movement evolved from their inability to offer care to people living with HIV in their hospitals. In unfavorable political, social, religious and legal circumstances, and in the absence of the health authorities having a pragmatic strategy for prevention and access to treatment, the creation of a freer, more flexible and more reactive structure, both in its discourse and in its action, became a necessity. ALCS uses legal expertise to defend the right to dignified AIDS treatment for marginalized populations, advocate for access to generic ARVs, defend human rights and set up prevention programs for people involved in sex work and people who use drugs. ALCS quickly integrated PLHIV and people from key populations as volunteers and staff, making doctors a minority. Nevertheless, its national board is still largely composed of doctors who head up the local sections.

ARCAD-SIDA[4] is an FAA association created in 1994 by doctors practicing in Bamako's community health centers (CSCOM) in Mali, including the one in Sébénikoro. They cared for people living with HIV/AIDS who had come to die of AIDS-related complications in their home village. Sociologists working for the Institute for Research and Development (IRD) on HIV and nutrition research were also mobilized. At the time, it was necessary to "keep AIDS quiet". It was customary to talk about "B83" in hospitals. This was the diagnostic code for people living with HIV. ARCAD-SIDA decided to have an inclusive and participatory approach that has always put people that benefit from its work at the heart of what it does. In 1996, it opened the Center for Counseling, Support and Advice (CESAC) in Bamako, Mali's first free care site for people living with and affected by AIDS. This Center offered HIV testing and advice on test results, medical care, counseling and social support. From then on, people living with HIV/AIDS played a decisive role in the care and support they received from the medical team. ARCAD had to open new care centers in many cities in Mali after 2002. However in 2021, ARCAD left the decentralized Care and Support Units it had been managing to the Ministry of Health and since then has been managing only five community centers. Thanks to ongoing advocacy with associations for people living with HIV, whose creation ARCAD supported, and with the support of sociologists, it succeeded in setting up the Malian ARV Access Initiative in 2001. This sustained activism helped influence policies in 2004 that made ARV therapy free. By 2019, it provided 51% of Malians living with HIV, or 24,846 people, with access to ARVs, and has expanded its focus to include access to prevention and care for key populations such as sex workers, men who have sex with men, and people who inject drugs. One of ARCAD-SIDA's strengths is that it has had a multidisciplinary team (doctors, socio-anthropologists and psychologists) at its disposal since its creation. It has also welcomed people affected themselves, whom it has also helped to organize into associations whose structure it has supported. ARCAD Santé PLUS is now the primary recipient of funds from the Global Fund for civil society in Mali.

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[4] Now ARCAD Santé PLUS.

Kénédougou Solidarité. Kénédougou Solidarity. Creating the Kénédougou Solidarité association came from a group of non-medical “FAA professionals” (socio-anthropologists and health project managers) from CESAC in Bamako. The aim was to bridge the gap in care for PLHIV in the Sikasso region of Mali. At the time, there was no question of ARCAD having regional branches. People living with HIV often arrived in the terminal phase after spending a very long time seeing traditional therapists, attending private clinics and relying on public health bodies. Being a little more aware of the AIDS problem, public health bodies could only test them when the reagents were available and suggest to those who could afford it to go to Bamako, hoping that they would be able to access treatment. Since its creation, Kénédougou Solidarité has integrated people affected (living with and affected by AIDS), both as volunteers and employees. Through the CERKES (Kénédougou Solidarité referral center) in Sikasso, the first community site offering free care for people living with and affected by AIDS outside the Malian capital, the association has offered many services. These include voluntary advice and testing with test results, medical care, including ARVs, counseling and social support. It subsequently extended its scope to include key populations. The majority of the people (board members and employees) present when Kénédougou Solidarité was created have passed the baton to the new generation. However, the decrease in funding sources and the difficulties that the association faces for its survival have pushed the current team to call upon the “old-timers”, most of whom are still activists. As a consequence, the presidency is still held by one of the founders.

These associations, originally made up of health and social sector professionals, have opened up and welcomed PLHIV, people affected by HIV and, often, human rights activists into their ranks. This has enabled them to better adapt their actions to the recipients’ needs, offer them quality services, and gain the trust of technical and financial partners. They are still governed or managed by health professionals and, again, often by the same early activists. They also find it difficult to pass on the baton, rarely passing it on to people affected by HIV or PLHIV who usually occupy lower-ranking positions, both in the governance bodies and salaried positions.

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The sexual health center Le SPOT Beaumarchais in Paris, France, welcomes key populations—including men who have sex with men, bisexual men and people living with HIV—for counseling, support groups, and prevention and information activities.

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The volunteers at AIDES Paris have all the necessary equipment for distribution during community activities.

Associations created by people involved in political, social and human rights activism: AIDES, ARAS, and KIMIRINA

AIDES was created in 1984 in France on a model rooted in political activism. It is a classic example of a social movement shift, as many of the original AIDES activists came from the prison information group. The latter was created by Michel Foucault, among others, whose AIDS-related death in unacceptable conditions is closely linked to the creation of AIDES. The founders of the association, as indicated in the first chapter on concepts and definitions, wanted, from the outset, to make it an organization with a political and open dimension, as opposed to the identity-based organizations created at the time, which were all composed of men who have sex with men, claiming to be such. Within this dimension, the relationship with the medical institution has l initially been strained to meet the needs of people living with AIDS and their relatives. AIDES has had two guiding principles since its creation[5]: the person living with AIDS is an expert on his/her illness because he/she knows what it is like to live with AIDS (on a personal level), and expressing oneself publicly on his/her illness must transform society (collective/ community level).

The paradox is that at the beginning, AIDES was composed of many volunteer doctors. However, these doctors were either living with AIDS or men who have sex with men or both, were on the fringe of the medical mainstream, or were female doctors, many of them from the feminist abortion rights movement.

This important medical presence enabled AIDES to make technical and credible claims for AIDS prevention from the outset. The pooled expertise of professionals and lay people (doctors, lawyers, sociologists, sex workers, unemployed people, etc.) created high-quality community expertise. It challenged the healthcare system and contributed to its improvement, stimulated research, and promoted testing or new treatments, while retaining a critical approach to the side effects of drugs.

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[5] Maguet, O. & Caldéron, C. (2007). Aides, Une réponse communautaire à l'épidémie de sida *[AIDES, a community response to the AIDS epidemic]*. AIDES.

AIDES has made it possible to bring together everyone affected by AIDS and those who want to act with them, without any established hierarchy, to transform the dominant system in both health and society and to achieve social justice for people living with or at risk of HIV (i.e., everyone).

From the outset, AIDES wanted people's autonomy to be central to its approach, betting on the grouping of people affected by a "community of destiny" to structure their reinforcement and collectively fight more effectively against AIDS.

Thanks to being close to the people concerned, the association has the content to develop analysis s and arguments essential for raising public awareness and advocating for a better place for people living with AIDS in society.

It is a social movement that has embraced the fight against hepatitis B and C. It has made a decisive contribution to the emergence of health democracy in France for everyone who uses the healthcare system.

There is also a history of strong activism at AIDES, with a turnover within its board of directors and regular changes in its presidency. PLHIV regularly, but not systematically, occupy the most important positions in the association.

The **ARAS** association was launched in Romania by volunteers with different specializations (public health doctors, epidemiologists, psychologists, architects, lawyers, medical assistants, students etc.). It has emerged as a response and stimulus to the sluggishness and lack of an appropriate response from the Red Cross and government policies of the day to HIV/AIDS, particularly among marginalized people. There followed a long period of diverse responses in defense of human rights, both individual and collective, without which health rights cannot be guaranteed. The key role that ARAS has played in developing harm reduction in Romania must be emphasized. ARAS encouraged people who inject drugs to ask the Minister of Health for access to appropriate services and to demonstrate in front of this institution when there were no resources for substitution treatment or needle exchange programs. In the absence of specialized medical and social services for people who inject drugs provided by the State, ARAS took the initiative to develop them. Even though this program was not nationwide and hardly sustainable, it saved lives, gave many people their dignity, and set an example. ARAS encouraged the establishment and empowerment of several non-governmental organizations (NGOs) formed by people living with HIV/AIDS or people who used to inject drugs, but also by men who have sex with men and women who have sex with women to better advocate for their interests.

In 1999**, Kimirina** was created in Ecuador by doctors and community development specialists in a particular context. The Ministry of Public Health had established a national HIV program that did not have the resources to focus on prevention or to articulate actions with civil society. The association was thus set up to enable HIV education programs to be rolled out on an urban level, where the HIV epidemic was most concentrated, and to combat discrimination. Kimirina, through the commitment of its activists to a health project, provided a safe place for impoverished PLHIV and sex workers. From the beginning, the association quickly understood that the response to HIV was multi-dimensional, and it set up a multidisciplinary team made up of high-profile people working in health, academia, human rights promotion, and community development, in particular, concerning populations that were vulnerable due to their precarious socio-economic conditions. Since its creation, Kimirina has contributed to strengthening the social fabric of Ecuadorian society and has helped many partners involved in the fight against HIV to develop and strengthen their individual and collective capacities. This has enabled the country to build a stronger civil society.

Kimirina has always assumed its role as an advocate for the rights of people exposed to or living with HIV.

Kimirina also advocates for the development and strengthening of community-based organizations for populations at risk of being diagnosed with HIV in order to contribute to improving their quality of life in an inclusive and healthy manner and to create a social fabric to support the struggle of these populations.

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In Guayaquil, Ecuador, a community health worker from Kimirina distributes condoms to a transgender woman.

For example, Kimirina promoted the creation of the Ecuadorian Coalition of People Living with HIV (CEPVVS) and the creation of the Ecuadorian Network of Female Sex Workers (REDTRABSEX). It also strengthened transgender organizations (SILUETA X, Alfil, Futpen) for their greater involvement in Ecuadorian society.

These associations were initially created by activists from many different backgrounds, including PLHIV, key populations and health and social care professionals, and were soon integrated. Except for AIDES, the founders still have a strong presence when it comes to decision-making positions today, without any real handover.

What do these associations have in common?

Although the reasons for creating these FAA associations often vary, they all have **the indignation, the defense of people's rights**, the fierce will to act in the face of injustice and human suffering linked to the causes and consequences of AIDS in common.

If, due to the circumstances and context of their creation, these associations had very different objectives, targets, modes of governance and structures at the time of their creation, these, over time, have converged with strong similarities, guaranteeing their survival and the sustainability of their work. The most noticeable similarities are how they are governed (boards of directors, statutory texts and separation of political and technical powers), how rigorously they are financially managed, and a repertoire of similar services offered.

Wherever these associations originated from, they all diversified their **human resources** from both a professional and voluntary point of view. Therefore, there are now PLHIV, people from key populations of HIV or HCV[6], and professionals from the health and social care, communication, human rights, management, and financial sectors in all these associations.

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6 Hepatitis C virus.

Thus, the women living with HIV who created REVS PLUS decided to set up an open support group where people could discuss their experiences with some basic structure in place in order to deal with the lack of information on HIV/AIDS, stigmatization, discrimination and the virtual non-existence of care. Thanks to the support of several technical and financial partners, the open-mindedness and commitment of REVS PLUS members have enabled it to welcome professionals from various fields, including health, social action, advocacy and the defense of human rights, to become an association initially and then a credible NGO, with a similar structure to those in the North. It has gradually, alongside its structure, broadened its field of responses to include prevention measures, testing, counselling, social support, medical care, advocacy and defense of human rights, including the human rights of key populations and community research. It now offers an array of health responses similar to ALCS and ARCAD Santé PLUS, created by health professionals.

Driven by their commitment, the implementation of actions, quality, and sustainability, the associations have all **aimed to open up, decompartmentalize, get out of the ghetto, and achieve accountability and professionalization** in their work. This commitment has also prompted associations of health professionals to open up to people living with or affected by HIV. This same commitment allows political, social and human rights activists to work with the first two categories.

The founders of all these associations also have knowledge networks capable of **influencing policymakers**. Thus, these associations use both advocacy for change and influence in more political decision-making circles to achieve significant changes for the benefit of PLHIV and those around them.

More surprising is the **low** turnover **of their decision-makers**, with the founders often in place for a long time, either as chair of the board, or as directors for decades. There are several possible explanations for this.

- In regard to the associations founded by PLHIV this can be explained by the low number of **PLHIV/ people concerned with the required**

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At the reception desk of the Kimirina community medical center in Quito, Ecuador, a user of PrEP, medication that can prevent HIV, collects his treatment.

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A beauty salon in Quito, Ecuador, frequented by key populations, becomes a point of care for Kimirina's "brigadistas".

skills, availability, motivation and willingness to take on these high-profile positions that may expose them;

- The **changing international landscape** has also played a role, as decision-makers in associations have wanted to defend a model they believe in over the long term. With the arrival of massive international funding, we have seen the arrival of many opportunistic local associations created from scratch in the early 2000s, sometimes by public decision-makers, who were more interested in access to funding than a real motivation for social justice;
- In the category of associations founded by health professionals, international non-governmental organizations have also been competing for international funding and national responsibilities, forcing the founders of national FAA associations with their legitimacy and expertise to retain full control over the operation of associations to maintain a community and national approach.
- In countries with limited resources, there is a lack of confidence in the contemporary culture of associations, which is often justified. It requires an approach that shows committed and tenacious human resources committed to the defense of associations;
- In her internship report, Barbara Perelman[7] suggests that a potential loss of control and focus is the reason for retaining full control over the association's operation. Honors, prestige, professional career and other benefits[8] (travel to international conferences and high-level meetings, additional income etc.) could play a role in the low turnover of decision-makers in these associations. There is no point in denying that these abuses exist, but in the case of Coalition PLUS associations, this explanation is unsatisfactory or inadequate;
- It should also be noted that FAA associations have a particular internal culture, which is made up of questioning the established

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[7] Perelman, B. (2003). Les associations de lutte contre le sida à Ouagadougou : contexte d'émergence, profils, pratiques *[AIDS associations in Ouagadougou: context of emergence, profiles, practices]*. IRD. **https://horizon.documentation.ird.fr/exl-doc/pleins_textes/divers13-07/010039901.pdf**

[8] Barbara Perelman explains: "In the case of AIDS associations, the stakes and interests are such that we are increasingly witnessing tensions between the various actors, linked to the many personal interests and benefits generated by the association's activities (travel to international conferences, among others)". (Perelman, 2003, p. 36)

> order, promoting innovations and spaces for the free expression of otherwise repressed behaviors. In addition, they face significant financial instability that triggers a permanent struggle for survival in competition with established humanitarian or international non-governmental organizations. The intensity of community life in FAA community associations is as tiring and wearing as it is necessary. This particular culture, which exists in both the North and the South, may explain why founders and decision-makers are so attached to it since they have almost no chance of finding it in another professional or activism-based environment.

However, the FAA community associations should, and in some cases already do, think about finding and training the next generation and pragmatically supporting them in the handover that will inevitably occur one day.

Conclusion

An important question that needs to be addressed is how the emergence of these structures has influenced how associations are governed and the "community" nature of Coalition PLUS bodies or non-members. It is important to mention that none of them referred to "community" when they were created, except perhaps the Malians, who referred to territorial community in the classic sense as in the Bamako Initiative. The same is true for the people of Quebec to a certain extent, with the creation of an autonomous community action movement[9], particularly in terms of its decision-making power which relied on the involvement of citizens from the 1960s onwards, culminating in a government policy recognizing community action in 2001[10]. In this book, we use "community" to refer to the people at the heart of the action or the people who represent them who are present and involved in all the associations' decision-making bodies and make a real contribution to the development of associations' policies. This

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[9] For more information: **https://rq-aca.org/aca/**

[10] Drouin Busque, G. (2001). L'action communautaire : une contribution essentielle à l'exercice de la citoyenneté et au développement social du Québec. *[Community action: an essential contribution to the exercise of citizenship and social development in Quebec]*. **https://bel.uqtr.ca/id/eprint/1262/1/6-19-709-20060207-1.pdf**

question is theoretically irrelevant in PLHIV organizations, which should be community-based by their very nature. However, is this always true in practice?

After more than 20 years, we no longer distinguish between these associations by how they were created but rather by whether they are based in countries with limited resources or rich countries. This is certainly for reasons of resources but, more than anything, due to the positioning of the civil society sector in relation to the public sector, state governance and opening up society to key populations' ways of life. In 20 years, however, attitudes have changed everywhere, and the community sector has played an important role in influencing the acceptance of other lifestyles. This is evidenced by the network of sexual and gender minority identity associations in North, West and Central Africa, the Global Alliance of Communities for Health and Rights, a topic-oriented network of Coalition PLUS.

The Global Alliance of Communities for Health and Rights (AGCS PLUS), previously known as Africagay, is a network of about twenty identity-based and generalist associations fighting against HIV. It caters for sexual and gender minorities (men who have sex with men, transgender people and sex workers). This network, created in 2007 with the support of AIDES, covers 10 French-speaking African countries and became a topic-oriented network of Coalition PLUS in late 2018.

AGCS PLUS supports its members in advocating for the rights of sexual and gender minorities in Africa to address the stigma and discrimination that fuel the HIV epidemic and increase the vulnerability of key populations, specifically men who have sex with men and transgender people.

AGCS PLUS members: Besyp-Benin, APCS-Algeria, AAS, ALAVI and REVS PLUS Burkina Faso, ANSS-Burundi, Affirmative Action, Alternatives-Cameroun, Colibri-Cameroon, Espace Confiance, Ruban Rouge and RSB-Côte d'Ivoire, ARCAD Santé PLUS-Mali, AIDES Senegal, Yeewu Yeete and Prudence-Senegal, ATL MST SIDA – Tunisia and EVT-Togo.

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After a talk on self-esteem, clients who have sex with men and bisexual clients stay at the ALCS sexual and reproductive health center in Agadir in Morocco, where they are welcomed without being judged or discriminated against.

3

Community expertise– When will this specific knowledge receive the recognition it deserves?

“Scientific rationality without social rationality remains empty, social rationality without scientific rationality remains blind.” (Beck, 2001, p. 55)[1]

Introduction: What is it about?

The concept of community expertise in the fight against AIDS (FAA) emerged from the community approach taken by the first activists in the fight against AIDS, i.e., in the early 1980s. In France, acquiring knowledge through the experiences of those living with a chronic condition emerged in the 1970s with people with diabetes under the supervision of nursing staff. As we saw in Chapter 1 on concepts and definitions, it was thanks to health promotion and the Ottawa Charter that user involvement in the healthcare system really developed in the 1980s.

However, this idea of using knowledge gained from the experiences of those living with a health condition is several decades behind that of the experience of poverty as knowledge of dignity, as stated by Father Wresinski of ATD Fourth World in the 1950s. In fact, in the 1970s, using the momentum of ATD Fourth World, the universities of poverty were created with a significant convergence between associations and the academic world, as Yves Lochard writes[2], the beginnings of what was to be enshrined in France by the 2002 law on the Validation of Prior Learning (VAE).

The idea of valuing knowledge gained from the real-life experience of living with a condition is the subject of many articles. However, it is worth noting the common-sense approach of Jeannette

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[1] Beck, U. (2001). *The risk society*. Aubier.

[2] Lochard, Y. (2007). L’avènement des “savoirs expérientiels” *[The advent of ‘experiential knowledge’]*. *The Ires Review*, *55*(3), 79-95. **http://www.ires.fr/index.php/publications-de-l-ires/item/2606-l-avenement-des-savoirs-experimentiels**

Pols[3] , who compares the change that Denise Jodelet[4] calls the "hybridization of knowledge" between medical practice and biomedical research data. Knowledge is further hybridized from the doctor to the person receiving care. The knowledge of persons receiving care is primarily practical. It considers the social context, the values of the persons receiving treatment, their priorities, and their life plan. For Pols (2013), all these forms of knowledge are just different forms of medical knowledge.

We will not use the terms "lay" expertise or "lay" knowledge as they would suggest this expertise is inferior to the hegemony of scientific expertise.

We will define community expertise as the sum of the experiential knowledge of people receiving care shaped by a broader collective ownership.

Community expertise is where the two worlds converge.

- An individual approach with the "patient-expert" based on singular experiential knowledge[5]. Involving and informing the person receiving care is necessary to promote compliance and informed consent in clinical trials. This individual knowledge of experience will then become collective through listening and self-support[6]. Denise Jodelet (2017)[7] explains this emergence

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[3] Pols, J. (2013). Knowing Patients: Turning patient knowledge into science. *Science, Technology and Human Values, 39*(1), 73-97. **https://doi.org/10.1177/0162243913504306**

[4] Jodelet, D. (2014) About games and knowledge issues in Therapeutic Patient Education. In E. Jouet, O. Las Vergnas & E. Noël-Hureaux (Eds.), *New reflexive cooperations in healthcare: From patients' and professionals' experiences to partnerships in care, training and research* (pp. 9-20). Contemporary archives edition.

[5] Grimaldi, A. (2010). The different habits of the lay expert. *Health Forums*, *27*(2), 91-100.

[6] It should be noted that doctors living with HIV from the early days of the epidemic played a founding role in this self-organization by contributing their technical expertise and their activism.

[7] Jodelet, D. (2017). Patients' experiential knowledge, its epistemological and social status. In A. Oliveira Silva & B. Vizeu Camargo (Eds.). *Representações sociais do envelhecimento e da saúde* (pp. 270-294). Edufrn - Editora da UFRN.

of experiential knowledge from the people receiving care by the shortcomings of the biomedical model, which had to be compensated by listening and accompanying techniques. The self-help model among people with addiction, such as Alcoholics Anonymous, is a relatively old model that empowers people outside the traditional medical or social field. However, the figurehead of the patient-expert remains the person living with HIV.

- A collective approach with the arrival of what Didier Tabuteau[8] calls the “citizen expert”. This citizen expert is part of the association movement that questions the operating methods and the balance of power established in public health and between public health and political power. Thanks to this collective strength, the availability of treatment has increased, health and social organization methods have been reviewed, and people living with AIDS and their relatives are participating in the political debate on the epidemic. In 1989, Daniel Defert[9], the founder of AIDES, called this “the sick as social reformer”. Until now, no condition or epidemic has created such a powerful and technical citizen investment as the FAA. In addition, the initiation and subsequent involvement of members in patient collectives and FAA organizations have also generated what has been referred to in France as “health democracy”. This has allowed healthcare system reform, including other conditions and representatives of people living with conditions and their relatives since the early 2000s. This mobilization also made “marriage for all” possible in France in the 2010s. Thanks to this collective mobilization on several fronts, the FAA associations have been a powerful tool for social change inFrance and elsewhere.

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[8] Tabuteau, Didier. L’expert et la décision en santé publique *[The expert and the decision in public health]* Les Tribunes de la santé, vol. 27(2), 33-48.

[9] Defert, D. (1989). *A New Social Reformer: The Patient* [Speech]. Fifth International AIDS Conference. Montreal, Canada.

The different aspects of community expertise in the fight against AIDS

The origin of community expertise in the FAA is undoubtedly based on the process of listening and self-support, as well as on the ability to mobilize. These then allow for the collectivization of experiences and the creation of expertise.

While in many chronic diseases, “therapeutic patient education (TPE) should enable patients to acquire and maintain abilities that allow them to optimally manage their lives with their disease” (WHO, 1998)[10], it is most often done under the guise of the strong involvement of healthcare staff. In the FAA, *counseling and empowerment,* the latter being determined by the level of influence a person can exert on the events of his or her life (Jouet, 2009)[11], have most often been implemented by FAA associations themselves. These were very quickly training professionals in TPE, but also in primary prevention (promotion of condoms and creation of the concept of “harm reduction”, for example) and care (publication of the *Remaides* newspaper, for example, published by AIDES and also intended for professionals). Regarding HIV testing, people living with HIV also quickly proved to be the best supporters of healthcare professionals in counselling, especially those recently living with HIV. In addition, the FAA invented concepts such as “Summer Schools for People in Treatment” and “Summer Schools for Young Researchers”, where health professionals and people in treatment participate and train on an equal footing.

They have gone from expert patients to patient-trainer to patient-helper and then become a *peer educator* (Jouet, Flora &

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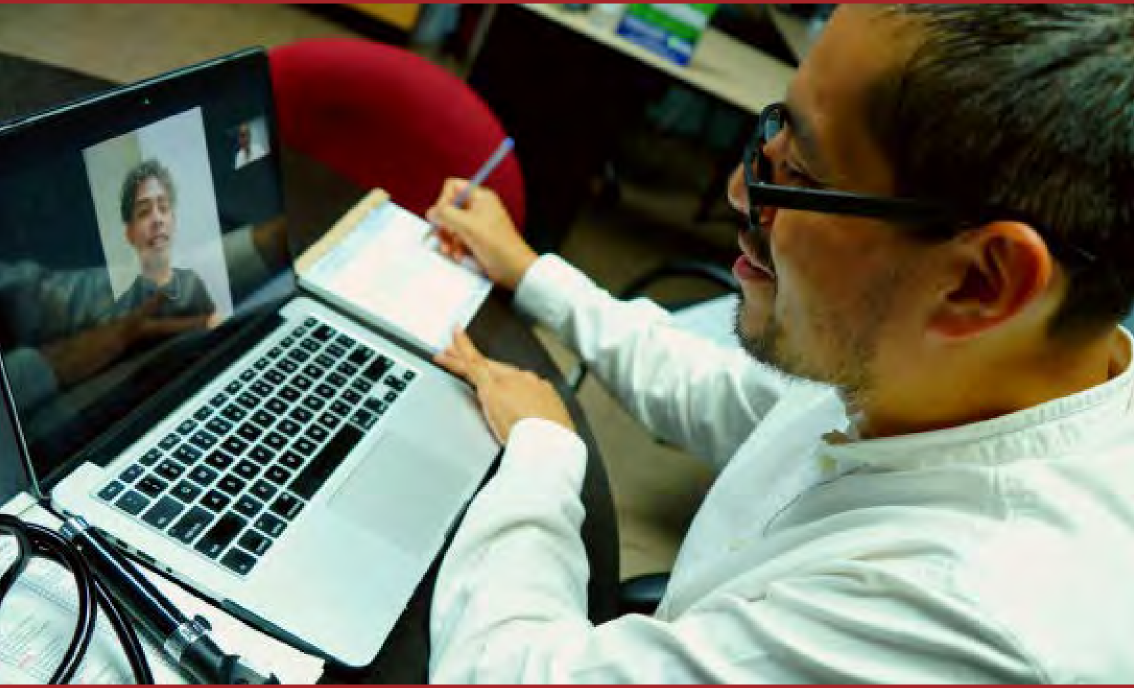
[10] WHO/Europe. (1998). *Therapeutic patient education: continuing education programs for healthcare providers in the field of chronic disease prevention: recommendations of a WHO working group.* **https://www.euro.who.int/__data/assets/pdf_file/0007/145294/E63674.pdf**

[11] Jouet, E. (2009). Le savoir expérientiel dans le champ de la santé mentale : le projet Emilia *[Experiential knowledge in the field of mental health: the Emilia project].* Recherches en communication, 32, 35-52. **https://doi.org/10.14428/rec.v32i32.51593**



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Demetrio Magallanes, a doctor at the Kimirina community center in Guayaquil, Ecuador, provides a remote consultation.

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Prevention and testing in the North of Mauritius by CUT, a PILS partner. Demedicalization of prevention and care measures to communities through trained community health workers increases access to healthcare for marginalized populations.

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In Mauritius, a PILS community health worker performs a rapid HIV diagnostic test on a person contacted via social networks.

Las Vergnas, 2010)[12]. This leads to community-based, i.e., peer-supported TPE. Overall, the expertise of the person being cared for certainly improves relations with care staff, provides an element of *empowerment*, increases self-esteem, and contributes to defending users' rights (Jouet, Flora & Las Vergnas, 2010).

As mentioned in Olivier Maguet and Christine Calderón (2007)[13], by observing current practices, identifying emerging problems, and questioning data from several sources, FAA associations learn, denounce, and propose strategies and reforms to the healthcare system for the benefit of people living with HIV. The expert patients are at the heart of this system, but they are not alone. The multi-competence of those involved in associations, the diverse experience of people living with HIV/AIDS and the multiple sources of information create experiential knowledge generating a unique and pragmatic collective expertise. The only barometer of this expertise must remain the needs of the people living with HIV/AIDS, their responses and their development according to the changes in context, which require permanent observation and adaptation.

Community expertise is most often mediated by community-based organizations (CBOs), which act as mediators, operators and above all, facilitators. As a result of this shift from the community to the CBOs, we will look at how CBOs establish accountability to the community in Chapter 6 on representation.

What community experiential knowledge are we talking about?

- General knowledge of the daily life of the community (geographical location, transport, habits, services available, use of services, opening hours, etc.).
- The practical and daily understanding of life with treatment, access to prevention or testing tools and access to care.
- Cultural knowledge of the community.

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[12] Jouet, E., Flora, L. & Las Vergnas, O. (2010). Construction et reconnaissance des savoirs expérientiels des patients : Note de synthèse. *[Construction and recognition of patients' experiential knowledge: Summary note],* Pratiques de Formation - Analyses, 58-59, 60-61. https://hal.archives-ouvertes.fr/hal-00645113

[13] Maguet, O. & Caldéron, C. (2007). AIDES, une réponse communautaire à l'épidémie de sida *[AIDES, a community response to the AIDS epidemic]*. AIDES.

- Identifying human rights violations in access to healthcare.
- The ability to express and rationalize the community's needs.
- Knowledge of sex and drug use practices.
- Prioritizing the community's needs.

What kind of community expertise are we talking about for CBOs?

It is, in fact, any form of information originating from the community and made operational to improve health conditions. However, many health professionals wonder why it is necessary to go through the community to get this information. After all, sociologists, anthropologists, and public health technicians can resolve these questions with their technical know-how. While this may be possible, it takes time, money, and a lot of external human resources. Obtaining this information through the community implies a guaranteed collaboration since it is chosen, allowing the community to appropriate the solutions found. At the same time, it promotes improvements in community and individual self-esteem, elements of sustainability and best practices that will never be provided by external experts, however empathetic they may be.

As we know from the historical aspects of the FAA in Chapters 1 and 2, several new approaches to community involvement in healthcare systems emerged in the 1980s. Thus creating several types of knowledge:

- the "watchdog" role: reporting of malfunctions, denunciation of conflicts of interest;
- observatory knowledge: data feedback from observing people living with the condition, other users of the healthcare system or those around them;
- knowledge of the feedback and expression of needs: qualitative surveys in addition to large-scale quantitative epidemiological or sociological surveys;
- knowledge of the organization of CBOs' community actions;
- knowledge of technical-medical understanding that complements the lived experience with the condition;
- knowledge for the distribution of technical-medical knowledge for the benefit of the community and sometimes also for the carers;

- mediation skills, especially with the health system;
- research knowledge.

These forms of knowledge have already been circulated *at a minimum* in communities affected by TB or malaria, thanks to funding from the Global Fund. Only the specific technical knowledge related to HIV is discussed here. However, it must also be accompanied by good administrative and financial management, which is crucial for the survival and credibility of CBOs.

The level of recognition for experiential knowledge and community expertise

When reviewing the international medical and social literature, there are two concerns. Firstly, articles dealing with experiential knowledge from people living with the condition, especially on Therapeutic Patient Education. We have cited some of these above. And secondly, work on the knowledge of Community Health Workers (CHWs) and their recruitment and training. These CHWs, as we will explain in Chapter 4, appear to be an effective and low-cost solution to access to care for geographical and identity-based communities in the FAA. When recruiting CHWs, they have in-built community expertise. They are recruited directly from the community they will be working with, most often a key population or a population where people are exposed to HIV. Their expertise is based on their experience with people living with the condition or people belonging to sexual, gender or addiction minorities or those experiencing other social vulnerabilities (young people, women, etc.). These CHWs provide psychosocial follow-up and adherence support for PLHIV and prevention support to key populations, including peer education and, more recently, assisting with community-based HIV testing and pre-exposure prophylaxis (PrEP) support for HIV. CHWs also monitor the prevention of transmission of HIV from pregnant women/ young mothers to their babies and provide information to young people and adolescents. The experiential knowledge of CHWs, whether they are living with HIV/AIDS or belong to a key population or a population where people are exposed to HIV, will need to be developed through

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In Mauritius, PILS community health workers carry out preventive measures in a caravan.

the right training and supervision in order to turn into the quality operational community expertise required.

Regarding the experiential knowledge of people living with chronic conditions recognized by French law on TPE, the process of health democracy seems to have had two divergent effects, as described by Emmanuelle Jouet (Jouet, Flora & Las Vergnas, 2010). Carers see it as a source of cheap and available human resources with the people living with the condition themselves and volunteers from related associations and also cheap representatives in health bodies, compared to nursing staff. On the other hand, people living with the condition hope to gain empowerment through advocacy, which relates to the watchdog function. What is the outcome in 2021?

Recognition of community expertise, defined above as a body of new knowledge, is still in its infancy. Nevertheless, healthcare systems will recognize community health workers in countries with limited resources . Again, we will see the major limitations of this recognition in Chapter 4 on CHWs.

Many CHW training curricula stop at technical-psychological-medical understanding and delivery of basic care, all under the supervision of the public health system. The organization of observatories is valued and encouraged, often with international funding. We support prevention of mother-to-child HIV transmission. Community-based testing has now been introduced in most countries after a long struggle for demedicalization. We are already much weaker on the central issue of the feedback of community needs from their CHWs. But is this all that community expertise offers?

In France, training courses for leaders and managers for community action in health and social work will be created by validating prior learning. This validation of prior learning (VAE), recognized in the 2002 social modernization law, is defined by Wikipedia as follows: “For individuals and employees: means of official recognition of skills acquired through professional, personal and associative experience; help in managing professional careers and their development; easier access to diplomas and the resumption

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In Mauritius, PILS community health workers reach out to marginalized populations with poor access to care.

of studies; saving time and personal and financial investment" ("Recognition of prior learning", 2021, Benefits section, para. 2)[14]. In France, the FAA has led to the creation of at least two diplomas for professional and volunteer field workers, initially with the *Centre National des Arts et Métiers* and *AIDES*[15]:

- a professional certificate as a community health facilitator in health and social work;
- a certificate of competence as a community health manager in health and social work.

Despite these still rare diplomas, we need to discuss recognition for community health and social work facilitators and managers. How do these new professionals fit into the health and social system? What are their potential career paths? This is not yet clear. Furthermore, what happens to watchdog knowledge, mediation, and the potential for involvement in research?

In fact, community expertise created in the FAA, i.e., as a counter-power to the established healthcare system, does not get the recognition it deserves, but can it?

The limits and constraints of creating a body of knowledge recognized as community expertise in the fight against AIDS

As we have just discussed, the *watchdog's* role and expertise as an early warning system are at odds with its integration into a system that is organized to remain operational and effective.

Furthermore, a standardized approach to spreading community knowledge is an oxymoron of the community approach. In today's world, where researching standards are important, creating a "modular" body of knowledge does not fit well with the different needs of specific communities.

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[14] Recognition of prior learning. (2021, July). In Wikipedia. https://en.wikipedia.org/wiki/Validation_des_Acquis_de_l%27Experience

[15] AIDES has since withdrawn from this collaboration with *Arts et Métiers.*

Finally, creating community expertise with different experiential knowledge and facilitator skills takes time. Moreover, this approach is too often based on voluntary work, which is not realistic in the context of survival in developing countries or even in the social precariousness of rich countries.

What community expertise should be shared in countries with limited resources?

While international organizations do not "officially" recognize community expertise, it is nevertheless in demand in FAA projects or programs and beyond. The Global Fund to Fight AIDS, Tuberculosis and Malaria (the three pandemics) is its champion and largest user. Here are some examples of the demands on technical support agencies such as Expertise France.

Community expertise in the FAA is required for:

- supporting country dialogue for Global Fund grant applications, particularly for groups where people are exposed to the three pandemics or socially or geographically marginalized in their access to health;
- supporting the meaningful involvement of key populations in the development of country funding requests by helping them to articulate their comprehensive health needs;
- supporting community structures in their involvement in the development of the Global Fund application and also in the negotiation of the grant;
- strengthening access to funding from the Global Fund for small community-based organizations serving socially or geographically marginalized populations;
- building capacity to implement Global Fund grants for Principal Recipients (PR), Sub-recipients (SR) or Community Sub-sub-recipients (CSR);
- strengthening the monitoring and evaluation of grants and impact measurements according to community indicators;
- providing organizational support to community structures involved in the fight against the three pandemics;

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Self-testing is another means of HIV testing for the hardest-to-reach populations. Once you have been tested, you can access treatment and receive a care plan.

- supporting the implementation of innovations in the community field in the fight against the three conditions;
- strengthening advocacy rooted in field experience to promote human rights and gender equality;
- supporting better representation and input from key populations or groups where people are exposed to the three pandemics in a country’s national health coordination bodies (CCMs);
- supporting better quality input from key populations or groups or a population where people are exposed to the three pandemics in a country’s health strategy documents;
- promoting community expertise and experience in the writing of national documents or national health responses;
- promoting networking between complementary community structures in order to pool or synergize their national or regional actions.

Table of expertise required for missions to support AIDS CBOs, including work with the Global Fund (GF)

N°	Type of mission	Type of expertise
1	Assessment of people's needs in the community	•Knowledge of needs assessment techniques (active listening, register studies, focus groups, surveys) •Strategic prioritization of needs •Writing skills
2	Support for country dialogue as a component of the Global Fund application	•Planning •Feedback on the needs of key populations •Facilitation and moderation of meetings with a wide audience •Summary and analysis of issues •Advocacy •Report writing
3	Support for the drafting of the application to the Global Fund	•Knowledge of the request response form •Knowledge of international recommendations on the prevention and management of three diseases •Analysis of community needs feedback •Negotiation of the consideration of needs in the application •Knowledge of community service provision at the national level •Advocacy •The interface between the health system and the community system (issues, vocabulary, strategies)
4	Diagnosis of grant implementation issues with an EU dimension	•Experience in grant management in a community setting •Knowledge and experience of how the GF operates and monitors grants •Knowledge of the constraints on the implementation of community actions •Analysis of the findings and issuing of recommendations
5	Support for the financial and programmatic management of the Global Fund's community-based PRs, SRs and SRHs, monitoring and evaluation, and procurement management	•Experience in grant management in a community setting •Knowledge and experience of how the GF operates and monitors grants •Financial expertise in the non-profit sector •Programmatic expertise in community actions and their monitoring and evaluation •Community pharmacy management •Negotiation and interface between community realities and the requirements of the GF, RP or SR •Report writing •Transmission of knowledge (written and oral)

N°	Type of mission	Type of expertise
6	Capacity building of health workers: by welcoming key populations and human rights, gender approach	•Diagnosis of problems in welcoming health professionals in terms of human rights and gender •Knowledge transfer to professionals •Methodology for monitoring progress on human rights and gender
7	Capacity building of community players in strategy or innovative actions to be implemented in another context	•Knowledge and previous experience in implementing innovation •Situational analysis of innovation in the national landscape •Knowledge transfer •Monitoring and evaluation framework for the actions implemented •Search for funding •Writing a capitalization report
8	Supporting community innovations for scaling up	•Knowledge and previous experience in implementing innovation •Strategic knowledge of scaling up •Framework for monitoring and evaluating the actions implemented •Search for funding •Writing a capitalization report
9	Support for project drafting from justification to evaluation framework	•Knowledge of project methodology in the community framework (involvement/validation) •Knowledge transfer
10	Support for the capitalization of community experiences	•Analytical capacity and ability to assist in the analysis of field experiences •Ability to synthesize and assist in the synthesis •Strong writing skills
11	Strengthening community stakeholders in Global Fund Country Coordinating Mechanisms (CCMs)	•Knowledge of how the CCM operates •Knowledge of the mandates of representatives on the CCM •Knowledge of CCM eligibility •Organizational diagnosis of community constituencies •The organization of the community group and its representatives •Writing framework documents •Performance Assessment Framework for Representatives
12	Support for the selection of community representatives to the CCM	•Mastery of the principles of good governance •Knowledge of CCM eligibility •Diagnosis of the possible selection choices according to the country context and the actors in place •Writing an election protocol •Setting up and organizing the elections

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In Mauritius, people living with HIV are organized within the Hope Committee to carry out advocacy work. Key populations or those disproportionately affected by HIV are included in the decision-making processes that affect them.

N°	Type of mission	Type of expertise
13	Organizational diagnosis and strengthening of community organizations. Example: “Support for the governance and management of staff and community volunteers” or “Assistance in writing a multi-year strategic plan”	•Analysis of the institutional environment •Associative governance •Supervision of community programs •Administrative and financial management •Advocacy/Communication
14	Support for networking of community organizations at the national or regional level	•Experience in organizing and managing a network •Organizational strengthening of the non-governmental sector •Advocacy/Communication
15	Helping community organizations to find funding	•Analysis of the donor environment •Advocacy/communication techniques •Writing skills

Not to mention the operational research aspects of community health which have not been included here.

It must be emphasized that in 2021, community organizations have staff that are as qualified as expert consultants. The expertise listed in the table above is all embedded in large CBOs. It goes beyond Global Fund support by addressing the needs of national disease programs or cross-cutting programs such as maternal and child health, mental health or addiction in a broad sense, to name a few.

Regarding advocacy and human rights, some of which are gender-related, community organizations have a real edge that could be passed on to other public health institutions. Their unique expertise in reaching the most difficult populations is vital to modern public health, especially in the fight against epidemics.

Let us add that, from a universal health coverage perspective, the contribution that civil society can make through community-based organizations, but also user associations and citizens’ expertise on health will guarantee the success of this global effort to serve all.

Finally, community-based organizations provide a unique *mentoring* and South/South cooperation opportunity that could further strengthen and support weaker but indispensable structures in some countries.

As an example, we report on[16] the experience of the transfer of South/South skills from ARCAD Santé PLUS, coordinator of the West Africa Platform (PFAO)[17] of Coalition PLUS, to the Nigerian Network of People Living with HIV (RENIP) in Niger. This need to strengthen the structure was financially supported by L'Initiative (Expertise France) within the technical assistance framework to strengthen RENIP, an association that receives funding from the Global Fund. The request was carried out by RENIP with the Global Fund's Program Management Unit within the Niger Intersectoral FAA Committee (CISLS) and referred to ARCAD Santé PLUS for expertise with the agreement of the Initiative. The reinforcement focused on the needs and expectations of RENIP. Over time, the mission and skills transfer process was carried out in three phases (organizational diagnosis, strengthening plan, and project writing). The methodological approach was built around the involvement of RENIP and the strategic partner CISLS. Indeed, for better sustainability, this support was, above all, based on a good appropriation of the approach and training of the members of the Network and not on external support implemented through a human resource established in the structure. The asset of a South-South cooperation is that the associations providing and receiving support share similar societal, cultural and contextual elements. Thus, the knowledge of the national context for one, and

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[16] From an interview with Dr Adam Yatassaye, PFAO co-coordinator, ARCAD Santé PLUS. It carried out this technical assistance mission for RENIP.

[17] The West Africa Platform is supported by ARCAD Santé PLUS (Mali), a member of Coalition PLUS. It is a sub-regional mechanism aimed at strengthening capacities and developing synergies between twenty AIDS associations from eight countries (Mali, Burkina Faso, Senegal, Guinea, Côte d'Ivoire, Togo, Benin and Niger). The decisions and strategic orientations of the West Africa Platform are taken within a steering committee which ensures its governance.

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The issue of human rights and the legal provisions in force in Cameroon are key to respecting the dignity of key populations.

the recognized experience at a sub-regional level for the other, generated a partnership dynamic to move forward together in the implementation of the assistance. The fact that they have the community in common, experience the same realities on the ground and carry out similar actions allowed for adapted and personalized support that the beneficiary could appropriate.

This support has enabled RENIP to be supported in its reflection on governance, to be strengthened in its search for funding and, above all, to benefit from a different perspective in Niger on the part of the various institutional players. RENIP was supported in developing a strategic plan (identified in the strengthening plan). However, the resources allocated to this support did not allow for the longer-term support needed for optimal follow-up. Of course, remote monitoring has been carried out through a dashboard of the reinforcement plan. Still, it remains insufficient, according to ARCAD Santé PLUS.

Conclusion

Expertise derived directly from the community presents an opportunity for both public health and community health systems. Because of the increasing number and growing competence of CBOs, we can now call it a community health system. Therefore, it is clear that the community expertise created by the FAA cannot and must not disappear. Instead, it must be formalized and shared.

We also know that the community possesses intrinsic knowledge essential for improving access to healthcare for everyone in areas without any professional health infrastructure or human resources. It alone provides access to marginalized populations with poor access to healthcare. This is a fundamental reason for valuing community health workers and recognizing them as essential human resources for a well-organized healthcare system based on equitable access to care and prevention.

Community-based organizations have found opportunities to become more technical and thus play their role, placing them on the front line between communities and the mainstream public health system. Their advocacy work to recognize their expertise should be better promoted and respected. It should be shared, along with their unique knowledge of daily life with HIV/AIDS, the risks taken by certain groups of people, and their knowledge of human rights and gender. Due to lack of mutual recognition, their expertise will be enriched by better interaction with sometimes hostile parties, such as the public health system. As Ulrich Beck said, there is room for improvement in recognizing the complementarity of scientific and social expertise. In the long run, more effective links between the community health system and the public health system can be established, supporting universal access to care.

4

Community health workers in the worldwide fight against AIDS are an asset to global health

“Everyone, without any discrimination, has the right to equal pay for equal work. Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity and supplemented, if necessary, by other means of social protection”. (United Nations, 1948, Article 23)[1]

Introduction

This chapter focuses on peer educators in the fight against AIDS (FAA) by considering them to be community health workers (CHWs)[2]. First, we will discuss the broader framework of CHWs in the Sustainable Development Goals (SDGs) and then analyze how these community health peer educators/workers are a tremendous asset to the sustainability of strong healthcare systems. We will also see how they have succeeded in shifting the boundaries of healthcare systems which were previously out of reach to populations living on the margins of society and how they embody the relevance of a human rights-based approach to health as advocated by Jonathan Mann at the WHO Global Programme on AIDS as early as 1985 *(see Chapter 1 on concepts and definitions)*. This chapter elaborates on the previous chapter on community expertise, justifying the promotion of the work of these CHWs/peer educators, which are so unique to the FAA.

Unfortunately, this peer-to-peer approach is hardly mentioned in the CHW expansion projects to which healthcare systems in developing countries are now turning, mainly for economic reasons or because of the shortage of “classic” healthcare professions, such as doctors and nurses.

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[1] United Nations. (1948). *Universal Declaration of Human Rights*. (217 [III] A). https://www.un.org/en/about-us/universal-declaration-of-human-rights

[2] They are also sometimes called health mediators.

The use of CHWs, whether linked to a particular area[3] or a particular population, is not a stop-gap measure. It is a comprehensive response to improving the performance of healthcare systems. However, it is important to understand that the FAA, caught up in more important advocacy issues, has not taken the time to gain widespread acceptance on this issue. CHWs remain linked to projects mostly funded by international sponsors with little spin-off into national healthcare systems. How then can their added value be emphasized, and how can they be sustainably linked to healthcare systems? We will try to propose long-term solutions to "gaining widespread acceptance".

The general framework on the role of CHWs in the healthcare system in relation to the SDGs

A review of the recent literature on the history of CHWs and their implementation in waves of varying magnitude suggests that there is little evidence of strong political support for CHWs and that there is no plan for their successful implementation into healthcare systems in the short term.

In a 2007 paper commissioned by the World Health Organization *(see Chapter 1 on concepts and definitions),* Lehmann and Sanders provide an overview of what was known about CHWs at that time. They note the extreme diversity of CHWs worldwide and attribute this to the need to respond to societal and cultural norms and, above all, to the need for CHWs to be integrated into and accepted by the community to which they belong. The article warns that CHW programs are neither a perfect solution nor an illusion but that there is a lack of data on the conditions for their effectiveness. For them, successful CHW programs owe their success to the fact that the program is strongly rooted in an already mobilized community. At the time, there were few examples of sustainable CHW programs that were not highly institutionalized or even nationalized, such

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[3] We will refer to CHWs linked to an area, either a village or district, as geographical CHWs and those linked to a key population, including MSM or people who inject drugs, for example as identity-based CHWs.

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A transgender woman visits the Kimirina Community Medical Centre in Quito, Ecuador, for the first time for a sexual health consultation.

as in Brazil, Bangladesh and Nepal (Perry & Zulliger, 2012)[4]. In fact, most of the projects employing CHWs would disappear if the community disengaged or demobilized, mainly because project funding had run out.

Schneider et al. (2008)[5] attribute the renewed interest in the FAA to the CHWs in South Africa. In the early days of the FAA in the North, and later in some countries in the South, volunteers in close proximity to HIV emerged and supported self-support and prevention programs and later treatment adherence and testing programs. The massive influx of funding to developing countries in the 2000s made it possible to pay some of these volunteers to become CHWs. They were placed under the supervision of healthcare staff and were more often care oriented, focusing more on the distribution of medication and compliance with treatment rather than prevention.

Other articles[6] confirm the renewed interest in CHWs due to a need for FAA staff in the 2000s with the arrival of antiretroviral therapy, while many CHW programs in primary health care had lost their appeal since the 1980s (Hermann et al., 2009). It is also the prospect of achieving the Millennium Development Goals (MDGs) by 2015 that prompted the WHO to revisit “task-shifting” from healthcare workers to the community by reconsidering CHWs (Campbell & Scott, 2011)[7], especially in the FAA in developing countries.

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[4] Perry, H. & Zulliger, R. (2012). *How effective are community health workers?* Johns Hopkins Bloomberg School of Public Health. **https://www.childhealthtaskforce.org/sites/default/files/2019-07/How%20Effective%20are%20CHWs_Evidence%20Summary%20Condensed%28JHSPH%2C%202012%29.pdf**

[5] Schneider, H., Hlophe, H. & van Rensburg, D. (2008). Community Health Workers and the response to HIV/AIDS in South Africa: tensions and prospects. *Health Policy and Planning*, *23*(3), 179-187. **https://doi.org/10.1093/heapol/czn006**

[6] Hermann, K., Van Damme, W., Pariyo, G. W., Schouten, E., Assefa, Y., Cicera, A. & Massavon, W. (2009). Community health workers for ART in sub-Saharan Africa: learning from experience - capitalizing on new opportunities. *Human Resources for Health*, *7*(31). **https://human-resources-health.biomedcentral.com/articles/10.1186/1478-4491-7-31**

[7] Campbell, C. & Scott, K. (2011). Retreat from Alma Ata? The WHO report on task shifting to community health workers for AIDS care in poor countries. *Global Public Health*, *6*(2), 125-138.

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A PILS community health worker in Mauritius performs a screening test in a caravan during methadone distribution at the Vacoas police station.

These pre-2015 articles (MDGs) point in the same direction, with reports of diversity in recruitment and training and often a lack of supervision and pay insecurity, all of which lead to instability for CHWs and doubts regarding their effectiveness. Their recommendations are the same concerning recruitment—which must be carried out within the community of origin—, training—which must be adapted—rigorous supervision, effective remuneration of CHWs, and their strong roots in their community of origin.

From 2016 onwards, with the adoption of the Sustainable Development Goals (SDGs) and the publication of the WHO's Human Resources for Health reports, things are changing. In 2016, the WHO launched a strategic consultation on human resources for health by 2030[8], recognising that the SDGs would only be achieved with a strong focus on human resources (HR) for health (World Health Organization, 2018). There is a chronic under-investment in HR and a real plundering by richer countries of HR trained in poorer countries. This is all the more worrying as the WHO predicts an increased demand for healthcare workers worldwide in the coming decades. The WHO emphasizes a patient-centered healthcare system reform at the community level in this document.

In 2018, at the 40th anniversary of Alma-Ata, the WHO issued guidelines on the role and use of CHWs in health policies[9]. It states that progress towards universal health coverage will be achieved by harnessing the potential of CHWs by improving their working and living conditions. These guidelines place CHWs on the frontline between the community and the healthcare system. They also confirm that in HIV counseling, treatment and care, CHWs have shown their effectiveness, as have CHWs in other areas of primary health care. However, the WHO (2018) notes that there is a lack of evidence in this largely unexplored field of CHWs, such as qualifications or work contracts, career progression, typology and size of the target population, lack of economic evaluation and in-

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[8] World Health Organization. (2018). *Human Resources for Health: Global strategy on human resources for health: workforce 2030*. World Health Organization. **https://apps.who.int/iris/bitstream/handle/10665/250368/9789241511131-eng.pdf**

[9] World Health Organization. (2018). *WHO guidelines on health policy and system support to optimize community health worker programmes*. World Health Organization. **https://www.who.int/publications/i/item/9789241550369**

depth longitudinal studies on their effectiveness. This is reflected in the fact that the recruitment and use of CHWs have often been on a project basis rather than in larger programs. However, there are now large-scale projects such as the Village Workers in the fight against malaria in the Mekong area of South-East Asia[10], where they have proved successful (The Global Fund, 2019). Their response throughout the country, as in Ethiopia[11] (Zulliger, 2021) or in Rwanda (World Health Organization, 2013)[12] as part of primary health care in rural communities, is now recognized as a model for organizing healthcare systems in countries with limited resources, leading to improved population health indicators.

The WHO's policy recommendations within these guidelines are clear and generally recognized by all (World Health Organization, 2018), but, unfortunately, they are still poorly applied. It is necessary to:

- select CHWs with the community and require them to belong to that community[13];
- train CHWs with a balance between theory and practice;
- manage, i.e., give an institutional link to CHWs, and pay them;
- supervise CHWs;
- provide for career progression;
- integrate their work both in the community and in the healthcare system;
- provide relevant community data via CHWs while respecting confidentiality and ensuring feedback from health services to CHWs on the quality of the data and its use;
- involve community representatives in decision-making, problem-solving, planning and budgeting processes;

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[10] The Global Fund. (2019). *Regional Artemisinin-resistance Initiative (RAI)*. **https://www.theglobalfund.org/media/6509/publication_regionalartemisininresistanceinitiative_focuson_en.pdf**

[11] Zulliger, R. (2021). *Ethiopian Community Health Workers Programs*. CHW Central. **https://chwcentral.org/ethiopian-community-health-worker-programs/**

[12] World Health Organization. (2013). *Assisting community health workers in Rwanda: MOH's RapidSMS and mUbuzima*. World Health Organization. **https://apps.who.int/iris/handle/10665/92814**

[13] CHWs often cannot be employed in the healthcare system, partly for legal reasons. Public law in many countries prohibits hiring on the basis of sex, gender or race. Belonging to an identity association helps to avoid this pitfall and they can be retained as peers and not just as technicians.

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Some community-based organizations provide antiretroviral therapy to patients who cannot travel.

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Internal and external condoms and lubricants are part of the prevention materials distributed by community associations.

- strengthen links between the community and healthcare institutions;
- establish a job description based on an assessment of community needs and also on possible means of action (supplies, drug supply chain, new communication technologies, etc.);
- invest in CHW programs; and
- develop their role in line with changing community and healthcare system needs.

In addition, in the same year, the WHO published a practical guide for introducing CHWs, which provides guidance on the recruitment, training, supervision and remuneration of CHWs and community involvement in these processes[14].

In 2017, UNAIDS and the African Union, aligning with the WHO strategy on human resources for health, also published a report entitled "2 million African community health workers"[15]. The report, which claims to be inspired by the successes of the HIV response, particularly at the community level, calls for an increase or redeployment of funding to community staff. In fact, this report is completely aligned with the technocratic aspects of the WHO guidelines without any real analysis of the specificities of CHWs in the FAA, without any mention of their contributions to HIV risk prevention, nor of their commitment to human rights, let alone to key HIV populations and a peer approach. This is a missed opportunity to defend the place of peer educators/CHWs in the FAA and will have consequences for the future.

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[14] World Health Organization. (2018). *WHO Guideline on Health Policy and System Support to Optimize Community Health Worker Programmes*. World Health Organization. **https://apps.who.int/iris/bitstream/handle/10665/275501/WHO-HIS-HWF-CHW-2018.1-eng.pdf?ua=1**

[15] UNAIDS & African Union. (2017). *2 million community health workers in Africa - Harnessing the demographic dividend, ending AIDS and ensuring sustainable health for all in Africa* UNAIDS & African Union. **https://www.unaids.org/sites/default/files/media_asset/African2mCHW_en.pdf**

Another practical guide to optimizing CHWs within community systems[16], written by six US international organizations, reinforces the WHO guide on CHWs with practical advice on managing and supervising CHWs (Ballard et al., 2017). However, this guide does not address the fundamental problem at the heart of this issue, namely its financing. The lack of political will and the lack of imagination about financing CHWs, in this sense analogous to universal health coverage, i.e., left to the state's prerogative to find the resources, makes the scaling up of programs and, of course, their sustainability uncertain.

Also of note is a very interesting article by Modeste Konan (2019)[17] which makes our simplistic understanding of identity-based CHWs more complex in contrast to primary health care CHWs linked to geographical communities. His anthropological study aptly draws attention to the fact that the ruraliz ation of the HIV epidemic in high-prevalence countries can put the CHW's chosen identity community at odds with, or even in opposition to, the geographical community of a village. This implies strong tensions between community and health obligations. He concludes that CHWs need to be better trained and more closely supervised by the healthcare system on issues with high community stigma, HIV in particular.

Specific aspects of CHWs' skills in the FAA

In Chapter 3 on the community expertise of the CHW, we described what makes up the community expertise of the CHW, but we mainly discussed it at the institutional level of community-based

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[16] Ballard, M., Schwarz, R., Johnson, A., Church, S., Palazuelos, D., McCormick, L., Sall, E. G. & Fiori, K. Jr. (2017) *Practitioner Expertise to Optimize Community Health Systems: Harnessing Operational Insight.* **https://chwcentral.org/wp-content/uploads/2018/01/Practitioner-Expertise-to-Optimise-Community-Health-Systems-Harnessing-Operational-Insight.pdf**

[17] Konan, M. (2019). La problématique de l'implication des Agents de Santé Communautaire dans la gestion du VIH/Sida – Analyse anthropologique d'un récit dans l'ouest de la Côte d'Ivoire *[The challenge of the involvement of Community Health Workers in the management of HIV/AIDS – An anthropological analysis of a story in western Côte d'Ivoire]. European Scientific Journal*, 15(6),33-45. **https://dx.doi.org/10.19044/esj.2019.v15n6p33**

organizations. Now, we need to address it in terms of individual skills.

Technical skills: a CHW as a key asset in the continuum of care for people living with or at risk of HIV

What can we expect from community health workers/volunteers in rich and developing countries?

All forms of CHWs in the FAA in the world have self-support in common, more specifically self-support groups, as this cannot be an individual exercise. These are not necessarily groups formalized by an association or other institution. In order to form a self-support group, there must be more than two people who share one or more of life's challenges and who talk about them regularly. Also, their discussions must be absolutely confidential.

Members of self-support groups should be able to progressively express their life experiences within the group and build their own individual responses to the difficulties shared by the group or even build a collective response to the group. The group usually has a facilitator. When a member of the self-help group or specifically the facilitator feels able to support others outside the group, they become an excellent candidate for recruitment as a CHW or volunteer.

Does this mean that only by going through a self-help group can you become a CHW or volunteer? No, but in several tasks that we are going to list, it is a great asset for peer education, with all the credibility that a lived and shared experience brings to end the isolation or to convince people of the care and prevention approach. As recommended by all the institutions mentioned above, CHWs must belong to the community they work with. In the FAA, as we frequently point out in this book, the community is often identity-based, linked to key populations but not always, especially in high-prevalence countries, where epidemic spread extends beyond key populations to groups exposed to HIV/AIDS, such as women, children and young adults.

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Presentation of the CUT needle exchange programme, a PILS partner, in the Baie-du-Tombeau neighborhood of Port Louis, Mauritius

Thus, there are CHWs/peer educators who specialize in the following:

- setting up peer support groups for target populations (men who have sex with men, sex workers, people who use drugs, transgender people, adolescents, transport workers, people living with disabilities, sexual partners of people from key populations, etc.);
- support for sexual risk reduction and drug use, e.g., through condom distribution, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis, exchange or distribution of syringes or injection kits, etc.;
- support for the prevention of mother-to-child transmission of HIV;
- pre- and post-test HIV counseling in institutional settings;
- community-based testing in specific settings;
- support for treatment compliance: therapeutic education, nutritional support;
- support for the delivery of treatment at home or in decentralized locations;
- social support;
- home support and palliative care;
- support for people in hospital;
- searching for persons lost to follow-up;
- family and community bereavement support;
- surveys in research programs targeted at key populations.

As CHWs possess important and unique knowledge about the population and communities, they must report this knowledge to their supervisor in an organized and confidential manner to facilitate appropriate action. This means that the institutional link of CHWs must be strong and rewarding for their work so that the information they hold is useful and a source of action adapted to the needs of communities and healthcare systems. The CHW is, thus, as the Boston University Research and Innovation Center[18] puts it, "a bridge" between the various institutions that care for people, such as hospitals, social services when they exist

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[18] Boston University Center for Innovation in Social Work & Health. (n.d.). *Community Health Worker Role on the HIV Care Continuum*. Boston University Center for Innovation in Social Work & Health. https://targethiv.org/sites/default/files/supporting-files/Community_Health_Worker_Role_on_the_HIV_Care_Continuum_Fact_Sheet.pdf

and associations, families and communities. CHWs build bridges between different aspects of life *and* care for people living with or at risk of HIV. Their practical work enables what is known as the continuum of care.

CHWs: agents of community change

Their day-to-day work puts CHWs on the frontline for accessing information that the healthcare system does not have because it is often undisclosed by the community. Therefore, it is essential to help them shape this knowledge and experience to enable beneficial changes for individuals and communities. Few experiences capitalize on this knowledge. In relation to the healthcare system and their home institution, CHWs should thus be able to play a key role in the following activities:

- health education and community information on sexual and drug-related risk reduction for target populations and prevention of mother-to-child transmission of HIV. The information provided by CHWs is firmly placed at a level that the community understands and accepts, with a necessary human rights dimension, and above all, with a progression towards a community support objective;
- keeping records of rights violations and discrimination. Too often, these aspects are lost or under-utilized to enable progress towards legislative change, changes in the behavior of communities or police forces, or even, most frequently, healthcare staff. The objectification of unacceptable situations in terms of respect for people is a key tool for change as it allows realistic objectives to be set for actions to improve people's rights. In this context, CHWs are essential assets for the improvement of human rights thanks to the trust that allows people to speak out about the unacceptable, and then as spokespersons and the link with the institutions;
- assisting in the assessment of community needs. This missing link in most projects aimed at target populations can be found if CHWs are used in a relevant and rewarding way to create and monitor projects. They do not need to have a degree in public health, nor do they need to create projects, but they can and should work in multidisciplinary

teams that listen to them and put their qualitative experience and knowledge on an equal footing with quantitative studies of the population's needs;
- helping to identify solutions for project sustainability adapted to community contexts in order to promote a community "takeover" of projects that are ending.

CHWs' unique experience and knowledge

As mentioned in Chapter 3 on community expertise, the community has intrinsic knowledge, much of which is ignored by the healthcare system. The community-based CHW is on the frontline between the community and the healthcare system, and they need to work together to enable better access to care.

This role is even more important when dealing with marginalized populations affected by HIV.

Until then, this knowledge has had little recognition while projects are being funded, and then it remains unused until the next project. However, if we are to achieve the MDGs by 2030 and end the AIDS epidemic, CHWs and the medical and nursing knowledge they expand upon will need to be given lasting recognition for sustainable results. The SDGs will not be achieved without recognized CHWs and a comfortable alliance between the community and the healthcare system.

Finally, it is important to remember that the main source of community activism through advocacy comes largely from the feedback from CHWs/volunteers on the community's needs. This is because they are at the heart of the lives of people affected by HIV and their environment. Is this still the case?

The challenges of the current CHW model for the FAA

A longitudinal study in Zimbabwe published in 2018 looked at CHWs involved in randomized research on child-friendly antiretroviral

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In the north of Mauritius, the CUT caravan travels the streets at night offering HIV testing and distributing prevention materials and sterile syringes.

therapy (Buzsa et al.)[19]. This qualitative study used the framework proposed by the WHO (2018) in its practical guide cited above to recruit CHWs and then collect their perceptions of how the project was structured and managed to enable them to do quality work. Their feedback was also collected to potentially scale up the project in other settings. The way CHWs were recruited, trained and supervised aligned with the 2018 WHO recommendations. CHWs reported high satisfaction with their work. They particularly appreciated the intense supervision and follow-up that gave them long-term value for their work. They also appreciated the access to supplies to support their work, as well as the training standards, the continuous training sessions and the formalized links with the health centers.

On the other hand, CHWs found their remuneration too low and found it difficult to cut ties with families when the number of home visits planned in the project was reached. They also criticized the project's lack of sustainability at the end of the research. The authors conclude that, while the CHW management model does exist, it does not sufficiently anticipate the difficulties of project sustainability, particularly with regard to task-shifting.

A peer educator at Espace Confiance in Abidjan, Côte d'Ivoire, who has been involved in a multi-country research project in French-speaking sub-Saharan Africa since 2015, shared his experience with us. The project focuses on preventing HIV diagnoses among men who have sex with

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[19] Busza, J., Dauya E., Bandason, T., Simms, V., Chikwari, C. D., Makamba, M., Mchugh, G., Munyati, S., Chonzi, P., Ferrand, R. A. (2018). The role of community health workers in improving HIV treatment outcomes in children: lessons learned from the ZENITH trial in Zimbabwe. Health Policy Plan, *33*(3), 328-334. **https://doi.org/10.1093/heapol/czx187**

men (MSM)[20] and was extended in 2016 to include pre-exposure prophylaxis (PrEP)[21]. Since 2008, he has been educating his peers about HIV and referring them to a community health center to manage their health. Driven by the need to share his knowledge about HIV and to get his peers to adhere to care and accept regular follow-ups, Thomas is an activist who loves his job. The successes and achievements in the projects he leads, especially in these research projects, give him great satisfaction. He can recruit people, find those whom we have lost track of in the research project, replace them, publicize the indispensable role of community workers for the success of a research project[22], participate in the implementation of access to PrEP and share experiences with other peer educators to make him better at his job.

However, the job of a peer educator is not without its difficulties. The first is the lack of recognition, which translates into a salary that does not allow for a decent living or provide job security. If the peer educator works according to their job description five days a week from 8 a.m. to 5 p.m., they are on duty permanently, including evenings, nights and weekends, for the entire duration of the project (three years). Beneficiaries contact him at any time to discuss doubts or questions. He does not have enough time to find another paid job that would allow him to get by.

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[20] This research project, commissioned by the ANRS and the Bouisson Bertrand Institute (Institut Bouisson Bertrand)/L'Initiative, aimed to "assess the feasibility and value of comprehensive quarterly preventive care for men who have sex with men (MSM) in sub-Saharan Africa, in order to help reduce the incidence of HIV in this key population, in their female partners and in the general population." **https://sesstim.univ-amu.fr/projet/cohmsm https://www.anrs.fr/fr/presse/communiques-de-presse/267/afrique-de-louest-la-prevention-contre-le-vih-chez-les-hsh**

[21] The project "Access to HIV pre-exposure prophylaxis (PrEP) for men who have sex with men: acceptability and feasibility study in West African community clinics" (MSM-PrEP) commissioned by the National Agency for Research on AIDS and Viral Hepatitis, Bouisson Bertrand Institute (Institut Bouisson Bertrand) in France, ran from 2017 to 2020.

[22] The MSM project presented at the ICASA Conference in Abidjan in December 2017 explained "the multiple and essential roles of peer educators in a research project involving MSM in West Africa".

The second is a personal investment. To be a peer educator, you need to come from a community, be recognized and legitimized by it and be committed to that community in order to be able to carry out the work. This requires a degree of maturity and experience to put people at ease; it also means expressing yourself and being open with your family and friends. It also represents a social exposure that can lead to safety issues. There is no distinction between private and professional life.

The third is the lack of training (which was very short on this project). Quality training should take place over several weeks and be integrated into the research project at an early stage.

“When a person likes their job, you have to help them succeed”, says this peer educator. However, the most frustrating thing for him is his profession’s lack of recognition. “The donor imposes everything, and we are not involved in the decision-making process”, he explains. The project owner imposes salaries, protocols, and procedures, which are not always the most appropriate for the community. “Why do you lose track of a person? How do we get in touch with them when we do not have direct access to the file? We know the reasons for discontinuation, but we do not have the opportunity to act beforehand because the protocol is that we have to go through the doctor to get the information”, he explained.

The results of community-based research work are based on the ability to recruit and follow up with those enrolled in a trial. This work relies on the peer educators, their community knowledge, their ability to inspire confidence and their committed activism and personal commitment. This “big brother or sister” role is the key to success.

Even though the association in Côte d’Ivoire has called on the Ministry of Health to highlight the essential role of peer educators, no status would allow peer educators to be recognized, legitimized, and make a living from their work. For this peer educator, the first recognition should come from the research project leaders. They know what peer educators bring to the projects and, therefore, they should value their crucial role in the success of a project.

As the article and the example above illustrate, CHWs need:

- sustainability to optimize their work as community change is slow;
- stability with decent pay and living conditions to keep them in their jobs. Until now, we have relied too much on the mobilization of activists who work hard for little compensation;
- recognition of their role in order to value their work in relation to the healthcare system and healthcare staff, but also in relation to the community;
- recognition of their profession in order to consider career development (see the chapter on community expertise on the validation of prior learning);
- recognition of the knowledge and experience they have accumulated over time as a basis for community health development. However, like any institutional sector, the voluntary sector tends to move away from this essential source of information toward advocacy issues that are less in touch with the daily reality for people affected by HIV. Increasingly, we hear that CHWs/volunteers feel marginalized by activists' decisions in the HIV community.

Mainstreaming aspects of CHWs' work in the FAA for primary health care CHWs

There are, of course, aspects of CHWs' work that can benefit primary health care. The most obvious aspect of this issue is human rights. CHWs in the FAA could train other CHWs, especially health professionals and police and legal experts, on anti-discrimination and anti-stigma. This breakthrough is crucial for the future of the CHW profession:

- to improve the tolerance of geographical communities towards marginalized populations; and
- to promote health professionals and other types of health professionals to acquire specific knowledge about marginalized populations in order to do their job better by accepting the different lifestyles of these populations.

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In Guayaquil, Ecuador, Centennial Park is a place of work for sex workers. Kimirina's "brigadistas" carry out prevention and testing activities.

©Coalition PLUS/Régis Samba Kounzi

Confidentiality, trust and respect are essential when dealing with people who are disproportionately affected by HIV and often marginalized and discriminated against.

This is interesting because marginalization and discrimination are not just a matter for PLHIV or those at risk. Every community has members who feel like outsiders, and even healthcare professionals who belong to these geographical communities can sometimes mimic community responses that reinforce stigmatization and, therefore, barriers to access to care.

Although imperfect, the least professional hierarchy between healthcare professionals and CHWs in working collectively with populations living with HIV is still found in the voluntary CHW sector. This rather integrative model for identity-based CHWs should benefit other CHWs.

Coming from self-support, identity CHWs have a lot of experience of active listening and empathy that persists despite their multi-tasking, and this active listening training could benefit the PHC.

The potential future of CHWs in the FAA

What often differentiates CHWs/peer educators from identity communities from those from geographic communities is an increased commitment to their work emanating from their direct and personal connection to the condition or increased risk of the condition.

Many CHWs say that their work is 24 hours a day, seven days a week, with inadequate pay, with all the risk of burn-out that this entails. Therefore, it is necessary to provide for developments in their work because turnover is often high.

The associations that involve them and on which much of their work in the field is based should place greater value on their CHWs. The financial aspects of their value are linked to the projects and funding bodies that are not very generous with them. This will have to change in the long run, as too many projects rely on these behind-the-scenes human resources from marginalized populations who are happy to have a job, however low paid. The voluntary sector that employs CHWs must also act as their advocate in relation to funding bodies and highlight their essential and professional nature. This is a good subject for advocacy!

The major difficulty we mentioned is that of linking their work to projects that must be time-limited, thus giving rise to employment spurts depending on whether or not a funded project exists. In this sense, associations also rely too much on the CHWs' commitment to activism by not integrating them into the permanent staff teams as part of the association's team. This needs to change, particularly in associations' advocacy with regard to its funding and, more generally, on the indispensability of CHWs for the FAA, the survival of the association and the achievement of the results expected by the international community.

Is it necessary to foresee a “bureaucratization” of identity-based CHWs like the one discussed for geographical CHWs? Probably not, and their commitment to activism, which makes them so valuable, would also be likely to disappear.

Instead, there needs to be more of a focus on career development in the voluntary sector. Although it may already exist to a certain extent, it needs to be better structured and more innovative.

CHWs are a valuable source of field experience that are not utilized to their full potential. Therefore, they must be used by aligning them with social capital and advocacy activities.

CHWs must be able to become more systematic trainers of healthcare professionals, international organizations, legal and police experts, new recruits to associations, health and justice ministry staff, etc. They must therefore be trained to formulate and transfer their knowledge. They should be key and recognized players in the scaling up of successful projects in which they have been involved. This can also be done by training other CHWs when needed as projects are scaled up.

CHWs should also be responsible for supervising field projects. They must be fully involved in the monitoring and evaluation of projects, from their conception to their completion. This will improve the indicators.

More systematic support for their careers will enrich community health by recognizing their contribution and moving CHWs into other aspects of public health and human rights.

Conclusion

CHWs in the FAA have demonstrated, more than for any other condition, that experiential knowledge is an asset that can be used directly by the healthcare system and the community.

Their proximity to people affected by HIV, either by living with it or being at risk of it, comes from self-support and has provided real recognition for their work in larger and smaller projects. This recognition has enabled them to 1) follow up on antiretroviral therapy to encourage compliance, and 2) to be in contact with people who are at risk of exposure who are far removed from the healthcare system, and not to carry out "classic" health promotion, but to reduce risks by respecting the practices of people at risk in order to help them move towards greater protection of their health. These identity-based CHWs or CHWs living with HIV are credible sources of information to protect the populations they work with. This is a model that can be rolled out for other conditions and other social issues.

In countries with generalized epidemics, all CHWs working with geographical communities must understand the anti-stigma aspect if the FAA is to be integrated into PHC, particularly in rural settings.

For CHWs, their credibility in relation to the healthcare system needs to be deepened to find a coherent, effective and sustainable role for them. This credibility could be broadened with more open and in-depth training by other healthcar professionals who do not necessarily work in the FAA and with rigorous supervision, which they also seek.

Funding for CHWs' work must be systematized and promoted, and the survival of this model is to "gain widespread acceptance", both literally and figuratively. A training school for basic CHWs and supervision of more experienced CHWs would pave the way for a quality approach to recognition and an avenue for sharing the knowledge gained from the FAA with other CHWs. Such a place would also provide a physical network where health professionals could share and develop ideas in order to create the community health of the future from the ground up.

5

Integrating community-based responses from the fight against AIDS into healthcare systems: broadening the contributions of the fight against AIDS to other aspects of health or society

Those involved in the fight against AIDS want to share their experiences without giving up on what they have already achieved.

Introduction

After nearly 40 years, it is time to gradually move the focus of the fight against AIDS (FAA) away from its exceptionality, mainly due to its community involvement, towards national and local responses for people living with HIV (PLHIV) and populations at higher risk of HIV transmission.To do this, integrating the FAA into "ordinary" healthcare systems, specifically the public system, but also the private system, is now on the agenda for reasons of funding and, above all, a better organization of healthcare in the countries. To save millions of people, large domestic and international financial flows (see UNAIDS)[1] have been devoted solely to the care of PLHIV. This funding has often led to an imbalance in the already fragile healthcare systems of developing countries by displacing staff, often funding them differently, creating specific health bodies with their own organizational structures, and establishing particular methods of accountability and control. This imbalance has also happened by creating specific care pathways in general healthcare facilities for people living with HIV, resulting sometimes in even more stigmatization of HIV/AIDS patients and an increased workload for staff. This is known as a vertical health service approach because it focuses on a particular population with a specific care organization. Moreover, beyond health responses, the FAA has shown that it has both social, economic, and legal causes and consequences that require a broad multi sectoral response that involves the vital input of people living with HIV or populations at higher risk of HIV transmission and those around them.

Under the umbrella of the United Nations's Sustainable Development Goals (SDGs), there is renewed interest in community

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[1] UNAIDS. (n. d .). Big shift to domestic funding for HIV since 2010. https://www.unaids.org/en/resources/presscentre/featurestories/2020/march/20200331_domestic-funding-hiv#

health responses to people's basic healthcare needs (Blanchet, 2016)[2]. This is based on the success of Ethiopia's healthcare system (Wang et al., 2016)[3], which produced interesting results for a low-income country. This is a horizontal approach because primary health care (PHC) is accessible to everyone in basic facilities. Unfortunately, these two community approaches, vertical and specific for HIV, and horizontal and generalist for PHC, have generated competitive rather than harmonious effects[4]. Their differences in geographical and horizontal approach as in Ethiopia and belonging or identity and vertical approach as in the case of the FAA seem to create a gap. This is unfortunate because the energy generated by the well-considered integration of the FAA could revive geographic community health which would benefit a greater number of healthcare users.

In 2018, and following the publication of the 2015 SDGs, the International AIDS Society (IAS) published a report in The Lancet on the mainstreaming of responses to the FAA within the concept of global health (Bekker et al., 2018)[5]. The report lists and analyzes a wide range of healthcare facilities where the FAA response, which includes putting the cared-for at the heart of the health response, respecting rights, gender equality, including communities in participatory mechanisms, equal access to care, but also access to medicines, can be integrated, ranging from sexual and reproductive health, maternal and child health, to adolescent health, etc., and primary health care. Nevertheless, the report calls for careful integration of specific services for key populations, such as men who have sex with men and people who use drugs. This is because

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[2] Blanchet, K. (2016). La santé communautaire, enjeu essentiel *[Community health is a key issue]. Le monde diplomatique, 63*(4), II-III. **https://www.monde-diplomatique.fr/2016/04/BLANCHET/55240**

[3] Wang, H., Tesfaye, R., Ramana, G. N. V. & Chekagn, C. T. (2016). *Ethiopia Health Extension Program: An Institutionalized Community Approach for Universal Health Coverage*. World Bank. **http://hdl.handle.net/10986/24119.**

[4] See the report of the African sub-regional community health forum held in Dakar, Senegal and published in March 2018.

[5] Bekker, L-G., Alleyne, G., Baral, S., Cepeda, J., Daskalakis, D., Dowdy, D., Dybul, M., Eholie, S., Esom, K., Garnett, G., Grimsrud, A., Hakim, J., Havlir, D., Isbell, M. T., Johnson, L., Kamarulzaman, A., Kasai, P., Kazatchine, M., Kilonzo, N., Beyrer, C. (2018). Advancing global health and strengthening the HIV response in the era of the Sustainable Development Goals: the International AIDS Society. *The Lancet Commissions, 392*(10144), 312-358. **https://doi.org/10.1016/S0140-6736(18)31070-5**

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At Alternatives Cameroun's Access Center (Raïssa), the nurse carries out follow-up consultations and antiretroviral therapy renewals.

the health services and the general population are not ready to accept them without real work on human rights and more social acceptance.

Analyzing the lessons learned about the community aspects of the FAA allows for reflection on the possibilities of integrating the FAA into healthcare systems, without being naive about its limitations. The FAA remains unique in its community-based approach and probably more so than before because of the marginalized populations it primarily focuses on and with whom solutions are found.

Furthermore, the COVID-19 pandemic has also led to a re-examination of global health and an analysis of its successes, including the international FAA. More than ever, the lessons learned in this area must be made clear, or they will disappear and we will reinvent the wheel of global health. In this sense, community involvement must support local responses designed for the context of the areas affected by an epidemic in an intelligent way.

We will use “mainstreaming” in the sense of “integration” or horizontalization as it is called in public health. This concept will be used here to refer to the process of integrating the FAA into primary health care. Please note, however, that the term “mainstreaming” is often also used to refer to the multisectoral aspect of healthcare approaches, such as the “gender” approach (Elsey et al. 2005)[6]. We will use the word “multisectoral” when referring to actions that take place with sectors other than health.

This chapter will briefly review the process of mainstreamingin public health over recent decades and the more recent concept of universal health coverage. We will then try to analyze why the FAA has been seen, since its creation, primarily as a vertical and exceptional approach, with its own administrative policies and organizations, its own staff and its own premises and control mechanisms. For more than 10 years, efforts have been made to integrate it and horizontalize it into the “ordinary” healthcare

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6 Elsey, H., Tolhurst, R. & Theobald, S. (2005). Mainstreaming HIV/AIDS in development sectors: Have we learned the lessons from gender mainstreaming? *AIDS Care*, *17*(8), 988-998.

system. The Global Fund to fight AIDS, Tuberculosis And Malaria (the Global Fund) has also proceeded with caution. We will focus exclusively on mainstreamed community aspects of the FAA (UNAIDS, 2004)[7,8]. We will also investigate which community-based aspects of the FAA are already integrated into healthcare systems and could be used for other health or prevention issues. This chapter may seem more complex to those who are not familiar with the world of international development. We will discuss the Global Fund's role in international community mobilization and the role of other donors and international bodies in more depth. However, it seemed to us that in order to understand the global challenges facing the FAA with a real risk of disengagement, it was necessary to provide some insight into what our colleagues in the South have to deal with.

Elements of the public health context concerning the multisectoral and mainstreamed nature of the FAA

The concepts of multisectorality and mainstreaming of the FAA are not new. They are rooted in the creation of the first World Health Organization (WHO) FAA program, the Global Program on AIDS (GPA) created by Jonathan Mann in 1988. As early as 1989, it called for a strong link between FAA programs and other healthcare programs[9] with a clear focus on human rights. The United Nations program on AIDS, UNAIDS, succeeded the GPA in 1995. Under the leadership of Peter Piot, UNAIDS has strongly promoted the multisectoral nature of the FAA on the institutional front:

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[7] UNAIDS. (2004). *The "Three Ones"* [Flyer]. UNAIDS. https://data.unaids.org/una-docs/three-ones_keyprinciples_flyer_en.pdf

[8] Other aspects can also be standardized, such as staff training, procurement and supply management and, of course, monitoring and evaluation of HIV programs. Monitoring and evaluation of HIV programs in national public health evaluation frameworks is already integrated in some countries under the umbrella of the "Three Ones" promoted by UNAIDS.

[9] Mann, J. (1989, October). Global AIDS in the 1990s. *World Health*, 6-7. https://apps.who.int/iris/bitstream/handle/10665/49286/WH-1989-Oct-p6-7-eng.pdf?sequence=1&isAllowed=

- on a global level by the very composition of UNAIDS, made up of 10 UN agencies and the World Bank[10];
- and on a national level by pushing, alongside the World Bank, for the creation of National FAA Committees (National AIDS Committees) in developing countries whose institutional roots are no longer at the level of the Ministries of Health but at an inter-ministerial level, often the Prime Minister's office, also including the private sector and civil society.

Since the early 1990s, there has been a growing interest in multisectoral health responses under the World Bank's healthcare programs and a desire to mainstream the FAA. Here are two notable initiatives which, in greater or lesser proximity to the FAA, have enriched the concepts of multisectoral health responses and are pushing to mainstream the FAA.

An example of multisectoral approach: SWAps[11]

Sector-wide approaches (SWAps) were developed by the WHO in the early 1990s to bring greater coherence to the various programs funded by international sponsors in the long term. This multisectoral coordination approach was the responsibility of governments. It aimed to bring more complementarity between the various health programs, avoid duplication of funding and generate more harmonization in the funding process, in the supervision of health programs and more transparency from both donors and recipient states.

With the multiplication of large-scale international health initiatives in the 2000s, the relevance of SWAps as a platform for consultation, coordination and harmonization of funding should have been stronger, especially as the trend among donors has been towards increased country ownership of aid. However, a major drawback of SWAps is the centrality of governments, leaving little

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[10] The list of UNAIDS Cosponsors is available on the following website: **https://www.unaids.org/en/aboutunaids/unaidscosponsors**

[11] Peters, D. H., Paina, L. & Schleimann, F. (2012). Sector-wide approaches (SWAps) in health: What have we learned? *Health Policy and Planning, 28*(8), 884-890.

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After the reception, the beneficiaries enter Alternatives Cameroun's Access Center building to continue their care. Raphaël Tsogo is at the reception.

room for non-state players whose involvement and influence have increased considerably in the last two decades, including private foundations and players from the voluntary sector.

As a matter of fact, there has also been an increase in vertical initiatives over the last 20 years, which has made joint reviews of national strategies more complex. This is where SWAps would have been useful. However, the two major international donors to the FAA, the Global Fund, and the President's Emergency Plan for AIDS Relief USA (PEPFAR), select countries for funding according to their own criteria (Peters et al., 2012). They rely little on local programs or on the specific characteristics of the country being financed, thus limiting the interest of SWAps.

Thirty years after their creation, SWAps have not generated much enthusiasm in the global health sector, but they still make sense and could re-establish their value, especially if they are integrated into national healthcare systems. SWAps have earned their place in a long-term approach to health investments with the current international will to move away from emergency and short-term healthcare programs. They could thus re-establish their relevance ibyo integrating non-state players, such as civil society and private foundations. This could be illustrated in the responses to COVID-19 which should use a multisectoral approach that automatically includes the country's health and economic players. Unfortunately, this has not always been the case.

An example of mainstreaming all health services: Universal health coverage

You may recall that the goal of "Health for All by 2000" was included in the Alma-Ata Declaration in 1978 *(see Chapter 1 on concepts and definitions).* This was to be achieved through the spread of primary health care until the arrival of AIDS, among other obstacles. Furthermore, in 2001 the African Union countries committed themselves in the Abuja Declaration to devote 15% of government expenditure to health, which has hardly been achieved[12]. In fact, the increase in the health budget in the 2000s was achieved for many countries by increasing dependence on international aid, which accounts for an average of one-fifth of health expenditure in Africa (Gatome-Munyua & Olalere, 2020)[13]. It cannot be stressed enough that households are the main contributors to health in poor countries. Eight hundred million people worldwide spend more than 10% of their income on it and 179 million people spend more than 25% (World Health Organization & The World Bank, 2018)[14]. Moreover, there are concerns that the economic consequences of the COVID-19 health crisis will further delay an increase in national health budgets. The burden of health expenditures will be even greater in the coming years.

In the face of these major failures, the United Nations (UN) resolution on Universal Health Coverage (UHC)[15], adopted on December 12, 2012, calls on governments to accelerate the transition to universal access to quality and affordable healthcare services. It marks the beginning of political investment in this issue globally[16].

As a result, the UHC was endorsed in the Sustainable Development Goals (SDGs) in 2015[17] to achieve them by 2030. The aim "is to ensure that the entire population has access, without discrimination, to nationally defined basic services for health promotion, prevention, treatment and rehabilitation, and to safe, affordable, effective and quality basic medicines, while ensuring that their cost does not cause financial hardship to users, especially the poor, vulnerable and marginalised"[18]. This access is, of course, through primary

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[12] By 2011, only Tanzania had achieved this goal.

[13] Gatome-Munyua, A. & Olalere, N. (2020). Public financing of health in Africa: 15% of an elephant is not 15% of a chicken. *Africa Renewal, 34*(7). **https://www.un.org/africarenewal/fr/magazine/octobre-2020/financement-public-de-la-santé-en-afrique-15-dun-éléphant-nest-pas-15-dun**

[14] World Health Organization & The World Bank. (2017). Tracking universal health coverage: 2017 Global Monitoring Report. **https://apps.who.int/iris/handle/10665/259817**

[15] Also known as universal health coverage.

[16] **https://undocs.org/fr/A/RES/67/81**

[17] United Nations. (2015). Goal 3: Ensure healthy lives and promote well-being for all at all ages. **https://www.un.org/sustainabledevelopment/health/**

[18] **https://undocs.org/fr/A/RES/67/81**

health care, which is the most effective and efficient approach to achieving these goals and UHC. As an interim target, one billion people are expected to benefit from it by 2023.

As part of the thinking behind the establishment of the UHC, the WHO coordinated “The Global Action Plan for Healthy Lives and Well-being for All”, now known as “Stronger Collaboration, Better Health”[19], launched during the UN General Assembly on 23 September 2019 on UHC. This plan brings together 12 international health organizations[20] and aims over the ten years to ensure UHC in the context of achieving the health-related SDGs.

The plan aims to align the actions of health players at both international and national levels to accelerate progress in health and establish an accountability framework.

The mobilization of States

Dr Ghebreyesus, the Director-General of the WHO, states that “Universal Health Coverage (UHC) is a policy choice” (United Nations, 2019)[21]. He says that the need “to double healthcare coverage by 2030 and prevent nearly 5 billion people from going without healthcare” is real.

Regarding the financial sustainability of UHC, this will probably only be achieved through different health financing systems, tailored to each country.

The definition of the minimum care package covered by the UHC has not been established. Of course, each state decides this according to global recommendations. Within this framework, UHC will have

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19 World Health Organization. (2019). *Stronger Collaboration, Better Health: Global Action Plan for Healthy Lives and well-being for all. Strengthening collaboration among multilateral organizations to accelerate country progress on the health-related Sustainable Development Goals*. World Health Organization. **https://apps.who.int/iris/handle/10665/327841**

20 World Bank, GAVI, GFF, Global Fund, WHO, UN-Women, UNAIDS, UNDP, Unicef, Unitaid, UNFPA, WFP.

21 United Nations. (2019). UN welcomes ‘most comprehensive agreement ever’ on global health. **https://news.un.org/en/story/2019/09/1047032**

to respond to the aging population and to maternal and child health. However, it is still too timid to respond to the health needs of marginalized and vulnerable populations due to discrimination in the healthcare system. These populations, and in particular the key populations for HIV and hepatitis (men who have sex with men, sex workers, people who use drugs, migrants, transgender people, people held in places of detention), are far from care and are not given much consideration in the States' priorities for access to healthcare. Their economic vulnerability is an additional barrier for them accessing the care they need.

Communities and civil society engagement[22]

It is noted that this plan does not significantly integrate civil society and communities, which are consulted via the CSEM[23], the civil society representation structure of the UHC2030[24]. The space given to them is not commensurate with the plans that will potentially affect their health.

The active presence of civil society arises at two levels:

- nationally: to bring about community representation and engagement on a national level. An essential element for patient-friendly healthcare;
- internationally: to inform global health agencies to help governments establish sustainable primary health care on a community level.

The FAA has undeniable achievements that must be protected and generalized in the thinking around the UHC, including:

- the role of the person requiring care in the construction of responses to their health needs;

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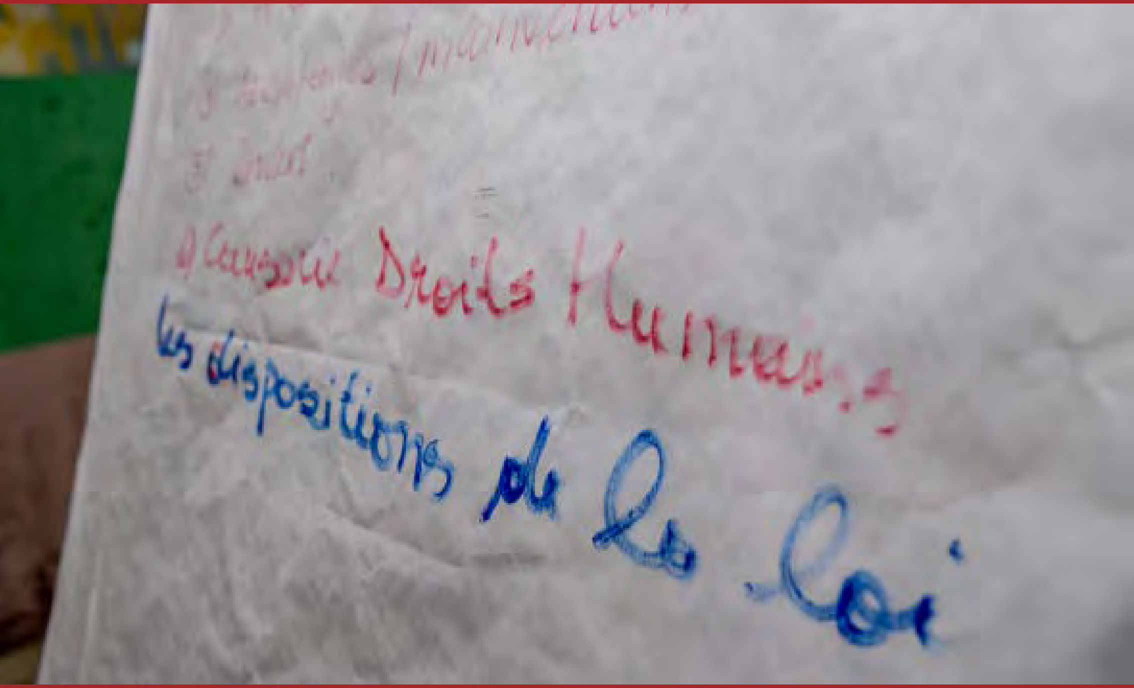
[22] Among the 7 accelerator themes in the Global action Plan: Sustainable financing, frontline healthcare system, civil society and community engagement, health determinants, research and development, innovation and access, data and digital health, innovative programs in fragile states and for epidemic responses.

[23] CSEM: Civil Society Engagement Mechanism is a mechanism for civil society engagement.

[24] https://www.uhc2030.org/about-us/governance/



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The issue of human rights and the legal provisions in force in Cameroon are key to respecting the dignity of key populations.

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Awareness-raising workshop for men who have sex with men and bisexual men at the Turiho centre in Bujumbura, Burundi, to discuss HIV/AIDS and sexually transmitted infections prevention and the associated risk behaviours.

- the multisectoral and inclusive approach at national level (government, private sector, international bodies, civil society and representatives for the person requiring care);
- the commitment and funding of civil society and community bodies for their role in the healthcare system for the populations furthest from care, and their effective participation in the design and implementation of healthcare programs;
- the human rights dimension by preserving and strengthening the right to health of every person.

The state funding is not increasing, not to mention that civil society and community engagement are not high on the agenda of UHC or governance bodies, we can add the social justice and human rights response to HIV do not receive enough attention.

Therefore, it is necessary that the implementation of the UHC in countries can ensure that the right to health is embedded in health debates and programs. It highlights the crucial role of civil society and communities (as mobilizers, gatekeepers, advocates, and service providers and experts). Communities should also remain vigilant in protecting and promoting the health, rights, and *empowerment* of key and vulnerable populations. The UHC, as it is intended, also effectively focuses on the poorest and most vulnerable in terms of access to healthcare. Without the vigilance of those involved, as well as national and international bodies, there is a risk that key populations and other vulnerable groups to HIV and other stigmatizing conditions will not receive sufficient attention or resources in the context of UHC.

Is the fight against AIDS vertical or horizontal?

Since the beginning of the epidemic, the creativity of populations marginalized by HIV to access care has been significant. This has been done with a tendency to create new specific services (that have sometimes opened up to others), because of a lack of access to care in the mainstream healthcare system *(see box below on Halles Clinic – ARCAD Santé PLUS).* Nevertheless, even if barriers persist in the mainstream healthcare system, the voluntary sector is fighting to integrate it by rejecting any kind of ghetto mentality *(see box below on 4 Baz Project – PILS).*

Halles Clinic – Bamako/ARCAD Santé PLUS – Mali[25]

In Mali, ARCAD Santé PLUS manages more than half of the active cases of people living with HIV. It does this through four support and care centers (CESAC) and 13 Support and Counseling Care Units (USAC) located throughout the country. As early as 1996, when the first CESAC in Bamako was created, the aim was to develop an acceptable care response for people living with HIV and stigmatized individuals who did not feel comfortable in the mainstream healthcare system. CESAC has become a refuge and a space where there is no judgment but instead opportunities for discussion, and solidarity. Similarly, people ostracized from Malian society because of their lifestyle and sexuality also wanted a safe place to receive care, with suitable opening hours, because it was impossible for them to use the mainstream healthcare system, particularly when rejected by healthcare staff. Therefore, the Halles Clinic opened as a sexual health center in 2010, from 4 p.m. to midnight every day, for key populations more at risk of HIV (sex workers, men who have sex with men, etc.) and people living with HIV. This clinic is located where there is a large population (market, brothels, bus station, etc.). It has enabled people to benefit from care and responses better suited to their health needs (e.g., treatment of sexually transmitted infections previously treated by self-medication). It also responded to the strong demand from key populations for a place where like-minded people could come together.

Its success quickly became apparent for several reasons:

- **the responses provided are better suited to the needs of the people for whom the center is intended. Then, the beneficiaries become more involved in the center 's work, in the sense that the key populations are more involved in**

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[25] From an interview with Dr Bintou Dembélé, Director of ARCAD Santé PLUS.

fieldwork, welcoming and giving orientation to their peers in the center, etc.;

- the clinic has developed a strategy that is both fixed (people attend the center) and mobile (reaching out to the population through work in the field) with peer educators, or paired up with the nursing staff on outings;
- since its creation, the municipal authorities, community leaders (market managers) and the community police have been involved, allowing the center to be integrated into the municipal landscape.

However, national authorities, embarrassed by the lifestyles of key populations, have never been willing to participate in, replicate or integrate the model, although they have never actively blocked it. The center relies exclusively on external funding. What would happen if ARCAD Santé PLUS had to depend on national health authorities for funding?

4 Baz Project - Republic of Mauritius[26]

This project originated in Port-Louis in 2019 as part of a study by associations involved with key populations into their care needs. Many of the people concerned stopped going to the hospital because they were stigmatized and discriminated against and received inadequate care. This pilot project aims to create a consistent community presence in six Mauritian hospitals. It is supported and the hospital presence is shared by a group of associations, PILS, AILES, CUT, Parapli Rouz, all of which are involved in the response to HIV and aim to provide a quality response to the care of PLHIV, in particular by combating stigmatization and identifying people lost to follow-up.

The healthcare system in Mauritius is free of charge for users. The aim here is to supplement the quality of services provided through peer support within the public healthcare

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[26] Based on a joint interview with Annette Ebsen Treebhoobun, Director of PILS, Melissa Antoine, co-coordinator of the Indian Ocean Platform, and Ashvin Gungaram, coordinator of the Nou Vi La Community Center.

system through community action. In other words, the aim is to combine the public response with the community response in order to find a response better suited to the people who require care.

After intensive advocacy, the Mauritian government provided a space within the public hospitalfor this additional support, with annually renewed authorizations. Peer educators provide inpatient services from Monday to Friday. This collective approach requires coordination between the associations involved within a community health committee, which is also a decision-making forum. A shared vision for action has been developed with and for people who require care in a context where the State is aware of the contribution of the community response but is sometimes suspicious of the integration of communities into the public healthcare system.

However, despite the difficulties of coordination, as in any project involving several partners and the management of day-to-day difficulties, the inpatient services have made it possible to resolve certain conflicts between healthcare staff and people who require care through specific support provided by the peer educators in the field of therapeutic education for people who require care, something that healthcare staff, doctors or pharmacists in the public system do not always do. This was achieved by creating an intermediary space between the people who require care and the nursing staff. This approach has also made it possible to find beneficiaries lost to follow-up by the associations, meet new people who require care at the hospital, and identify new pockets of infection to carry out information and awareness-raising activities. The initial difficulty was to get the hospital healthcare staff to accept this community presence. However, the associations note that healthcare staff's approach to people who require care has been improved thanks to their presence. A mutual interest between healthcare staff and peer educators allows for better care conditions, for example, in the event of a shortage of medication, the associations can launch advocacy efforts. From this ongoing experience, we learn about the need for continuous dialogue between

community bodies around clear objectives such as the needs of the relevant populations. This requires a link with healthcare authorities for good coordination and feedback from those directly concerned.

Whatever one may say, the FAA has always been multisectoral in its approach to society and mainstream in its management, more so than any new condition until its arrival, even in the fight against tuberculosis, the management of diabetes, and more so than any other universal public health issue, such as maternal and child protection. The FAA has, by virtue of its broad approach, always worked in broad and inclusive partnerships:

- in its causes and societal consequences: human rights, labor rights, gender, sexuality, drug use, marriage for all, etc.;
- in the medical issues addressed from HIV infection: the multifaceted nature of opportunistic infections or immunodepression, which meant that several medical specialties had to collaborate in order to care for a single person in good conditions. A link then had to be made between prevention and management of the transmission of the virus, first with condoms, but also with treatment as prevention such as PrEP and PEP. This has continued and extended to other related issues such as the management of sexually transmitted infections, hepatitis with drug use, and also maternal and child protection with the prevention of vertical transmission, not forgetting mental health and psychiatry;
- through a holistic approach to solutions: information-awareness, prevention, risk reduction, treatment, psychosocial care, nutrition, research, etc.;
- in its social aspects with access to healthcare for the poor, migrants and those with so-called risky jobs (sex work, truck drivers, etc.);
- in its types of organizations: multidisciplinarity, medical and public healthcare players, and non-medical players such as PLHIV, peer educators, community health workers, researchers, sociologists, anthropologists, politicians, etc. with networking.

Why then do we blame the FAA for being vertical?

Dogmatically, in the late 1990s, SWAps advocated for an FAA that focused solely on HIV prevention as part of a horizontal approach to all health issues for low-income countries. In 1997, the World Bank and the European Union even argued that putting PLHIV in Africa on treatment was not cost-effective. As a result, what emerged from such a finding was the idea that we should focus on prevention and maintain SWAps. These institutional players predicted that putting PLHIV on treatment would “verticalize” the FAA. Their rejection of a vertical and specific approach to the FAA with the treatment of millions of people was mainly for economic reasons, as these institutions did not consider this approach to be cost-effective. While history has proven them right regarding the increased imbalance in already weakened healthcare systems on one side, from a humanitarian perspective, on the other side, they have been shamed for their purely economic approach to access to care for PLHIV, and for a good reason! The G8 in 2000 and 2001 and the UN did not agree with their reasoning and created the Global Fund to fight AIDS, Tuberculosis and Malaria (the Global Fund), which is primarily a financial and vertical instrument.

However, to “deverticalize” this massive international AIDS fund from the outset, the fight against tuberculosis and malaria was added to take advantage of the FAA’s energy and recognize the strong link between AIDS and tuberculosis, especially in the South. This was a good idea.

The creation of the Global Fund in 2001 was intended to make up for the delay in giving lifesaving antiretrovirals to millions of people living with HIV around the world. At the time, taking a vertical approach to the care of PLHIV through specific programs was the only solution in an emergency situation. This approach saved millions of people, but it could only be temporary. As a matter of fact, emergency responses cannot be sustained for years, even more so in more than a hundred countries, without the risk of imbalance in the healthcare systems.

Several elements have thus been added in the past decade to the Global Fund’s approach:

- a strengthened human rights approach to protecting key populations from HIV;
- progression in the joint response to TB and HIV ;
- the recent introduction of common strategies for all three diseases in some countries;
- a substantial effort to prevent the vertical transmission of HIV, thus integrating it in the world of maternal and child health;
- strengthening healthcare and community systems; and
- a willingness to address gender inequalities in the 3 pandemics care.

However, some of these developments were more theoretical than practical. Still, symbolically, they paved the way for integrating the care of PLHIV. Mainstream advocates, including SWAps advocates, continue to criticize the Global Fund for not working through direct budget support to states such as low-income country governments or for working with overly specific decision-making or implementing bodies, such as CCMs and Global Fund Principal Recipients *(see Chapter 6 on representation).*

Since 2007, the Global Fund has recognized the community's contribution to the fight against AIDS, tuberculosis, and malaria. It defines the strengthening of the community system through investments in the following areas:

- "community-based monitoringto assess the accessibility, responsiveness and quality of services;
- community-led advocacy;
- social mobilization, community building, collaboration and coordination between communities and other health players;
- institutional capacity building, planning and leadership."[27]

The Global Fund organizes community responses into three categories according to their proximity to the healthcare system:

- those who operate under the umbrella of the "formal" healthcare system, such as community health workers, for example;

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[27] Global Fund. (2007). *Community systems and responses.* https://www.theglobalfund.org/en/community-responses-systems/

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Methadone distribution at Vacoas police station, Mauritius. Advocacy by associations led to the introduction of this substitution programme.

- those that act partially under the umbrella of the “formal” healthcare system, such as support for treatment compliance;
- those that operate currently outside the “formal” healthcare system, such as support for populations with criminalized behavior, and other innovations, e.g.community-based testing, and will join the system later.

In a 2019/2020 thematic review in five African countries on the impact of its investment on community health[28], the Global Fund notes, among other successes, definite progress on better linking community aspects with the healthcare system, especially in malaria, and more partial progress on AIDS and tuberculosis regarding collaboration with the formal healthcare system. Nevertheless, the Global Fund’s recognition of the concept of “community health systems” has made progress in changing the mindsets of public policymakers, but there is still a lot to be done. Above all, the Global Fund implicitly recognizes that not everything can be integrated into the formal healthcare system, hence its support for communities and key populations.

Many other questions also arise, such as: how can the experience of prevention of mother-to-child transmission of HIV, when successful in one country, benefit maternal and child protection? And perhaps the most fundamental question is: how do we move away from the exceptionality of the FAA while preserving the formidable mobilizing and reforming work that it has carried out? No one has found the solution yet, but we can suggest several avenues.

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[28] Global Fund. (2020). *Global Fund Thematic Review on Community Health: Synthesis Report*. **https://www.theglobalfund.org/media/10128/core_endasantecommunityhealthsynthesis_review_en.pdf**

Applying the useful lessons learnt from the FAA to other issues

If mainstreaming the FAA has any chance of becoming a reality, then responses that could prove to be useful for other conditions must be identified.

We will all have been struck by the constant reference to public health experts[29] and community-based organizations (Kay & Musgrove, 2020)[30] from the FAA to find responses to the COVID-19 pandemic, with varying degrees of success. Very little was actually transferable in purely biological terms, except for the general hygiene measures applicable to everyone in the healthcare system. Such things need to be reiterated during every pandemic. In terms of infectious risk, there has also been an increase in the risk or lack of access to care for socially poorly integrated populations (migrants), marginalized people (homeless people) or economically vulnerable people (cashiers, delivery staff, etc.), and also in the transmissibility to healthcare personnel. So, why the frequent reference to HIV?

In its online course on COVID-19[31], the World Health Organization explains the importance of community involvement in the fight against the COVID-19 pandemic. However, this is still carried out passively by the community, which remains the recipient of good information and does not appear as a player in their own right, as, for example, in the transfer of information carried by the community itself or by contact-tracing actions in which the community is strongly involved. In this case, we are thinking of the former patients of COVID who, through their experience, are surely credible sources of prevention or testing messages for people at

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[29] Dr Anthony Fauci in the United States, Professor Delfraissy in France, and many others.

[30] Kay, E. S. & Musgrove, K. (2020). From HIV to coronavirus: AIDS Service Organizations Adaptative Responses to COVID-19? Birmingham, Alabama. AIDS and Behavior, 24(9), 2461-2462. **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7180637/**

[31] The course, entitled "Introduction to COVID-19: methods for detection, prevention, response and control", is available at the following link: **https://openwho.org/courses/introduction-to-ncov/items/6mKUQt2OvrLCP8pNjulB3l**

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Screening test carried out by a health worker, the nurse supervisor, among sex workers in Bamako.

risk of catching the virus. What role did the families of older people institutionalized in retirement homes play?

In contrast, UNAIDS was quick to issue a “Human Rights in the Time of COVID-19” summary at the beginning of the COVID-19 pandemic that illustrates how much has been achieved in human rights with HIV that can be translated into the 2020 pandemic situation[32]. With regard to the “community at the center” [of the response], UNAIDS is, unfortunately, most evasive. What does this really mean in practical terms? However, once again, one can be struck by the rapid mobilization of community-based FAA players in the context of COVID to provide the necessary responses for PLHIV and also for populations exposed to HIV and isolated by the pandemic, to ensure the continuum of care and, in this case, treatment.

Non-communicable diseases (NCDs) could also benefit from the lessons learnt from the FAA. Just as chronic medical conditions such as HIV can now, the management of NCDs can also benefit from community outreach, psychosocial support, peer adherence support, and multisectoral approaches to daily life (e.g., workplace, school) of people living with NCDs. This has already started in some countries with regard to the management of diabetes and high blood pressure, but never in all community aspects. Similarly, support for people living with disabilities could also benefit from a human rights approach similar to the FAA’s approach developed with community support.

The mainstreaming and multisectoral aspects of community involvement already in place

a. The holistic approach to health

There can be no community involvement in healthcare without recognition and a practical approach to the holistic health of individuals. This was evident in theory since the Alma-Ata Declaration, and in practice since the holistic management of HIV,

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[32] UNAIDS. (n. d.). *Rights in the time of COVID-19: Lessons from HIV for an effective, community-led response [Brochure].* UNAIDS. https://www.unaids.org/sites/default/files/media_asset/human-rights-and-covid-19_en.pdf

which, beyond strictly medical care[33], very quickly took an interest in the psychosocial health of PLHIV and treatment compliance. This included self-support, nutritional health with user-friendly aspects in all FAA organizations, family care with the fight against mother-to-child transmission, sexual risk management with sexual health clinics, risk reduction related to drug use, legal and judicial aspects to fight against barriers to access to care, aspects of professional reintegration, and income-generating activities. The list is far from exhaustive and above all, is evolving, but we can see in concrete terms how PLHIV have helped to guide the new responses that had to be put in place to ensure the proper management of their health.

b. High-quality training

From the very beginning of the movement of people living with or affected by HIV, the training of peers and volunteers has been crucial in establishing the credibility of their commitment and their will to change. Initially starting in the United States, in San Francisco and New York, this training approach spread to England and then to France and Germany with the creation of the large FAA association bodies. It also spread to developing countries by creating association elites who found it more difficult to spread their knowledge to less literate populations. It is surely the biggest impression that the FAA has made on community involvement; a demanding and permanent training that pushes or should push the players in the fight against AIDS to always act as quality spokespeople on the issues that concern their health.

The success of HIV training in addressing a comprehensive approach to the needs of PLHIV has been marked by the involvement of PLHIV or key populations as trainers in training healthcare professionals, police professionals, lawyers, and journalists. The relevance of individual and community experiences of living with the condition has become essential when training professionals who become open to human rights and the daily realities of living with HIV.

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[33] Or because the medical management of HIV was initially impotent, forcing the search for other sources of well-being or mitigation of the effects of the disease.

c. The demedicalization of certain care or prevention responses

The transfer of prevention, testing, or drug distribution tasks to communities via trained community health workers (ideally peers from the target populations) has undoubtedly increased access to healthcare for marginalized populations or those unwilling to be recognized as key populations. It all started in the North, with needle exchange or needle distribution programs as part of harm reduction related to drug use in the late 1980s and 1990s. This gradually extended to more traditionally "medical" activities, but not without a long and difficult struggle with the health authorities.

The most symbolic of these victories remains the possibility of community-based testing for populations that are difficult to access because of factors related to their lifestyle or being isolated geographically. Although it is still difficult to accept in some countries, this shift towards community care is a start. It could even be expanded and better structured thanks to the community prescription of pre-and post-exposure prophylaxis for HIV alongside a genuine syndromic approach to the management of HIV treatment, similar to that put in place for sexually transmitted infections (Belec, 2007, p. 454; World Health Organization, 2008)[34,35] or should be (Tran Van et al. 2014)[36]. This last possibility, which has yet to be implemented, would allow community care to be clearly integrated into the health pyramid, decisively improve the road to the UNAIDS 95-95- 95 targets, and relieve the overcrowding of healthcare professionals who are often too few in number.

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[34] Belec, L. (2007). *Sexual transmission of HIV*. John Libbey Eurotext.

[35] World Health Organization. (2007). Module 2 : Introducing STI syndromic case management. *Training modules for the syndromic management of sexually transmitted infections*. World Health Organization. http://apps.who.int/iris/bitstream/handle/10665/43275/9241593407_mod2_eng.pdf?sequence=3

[36] Tran Van, B., Pham Minh, K. & Strobel, M. (2014). Prise en charge des infections sexuellement transmissibles dans les pharmacies privées à Hanoi *[Management of sexually transmitted infections in private pharmacies in Hanoi]*. Santé Publique, 26(4), 491-498. https://www.cairn.info/revue-sante-publique-2014-4-page-491.htm#

d. The operation of multidisciplinary networks, particularly in research

Task-shifting in the FAA is probably one of the best known and is already recognized as being readily applicable, and indeed already applied, to the management of other conditions. There is still a great deal of progress that needs to be made in ensuring that community players participate on an equal footing with other participants in all these networks. However, there are few examples of true equality of community members in networks or multidisciplinary bodies, especially when it comes to public health decisions. Country Coordinating Mechanisms (CCMs) at the country level still have a long way to go in this regard, as does the Global Fund itself. The day that a community representative is elected to the presidency of the Global Fund, or a director of an international health body comes from the community sector, then the recognition of equality in the complementarity of experiences will be truly recognized.

Examples of collaboration with research networks exist with mutual recognition of each other's contributions, including community outreach knowledge, without which research with key[37] HIV populations would not be feasible.

Community-based research players[38] have an opportunity to promote community-based research and access key populations. This would make it feasible to implement the many research projects, but it is also true that more interesting collaborations than just making community field workers available for academic research are possible.

Here are some examples:

- **The ANRS-SEXTRA project, whose principal investigators are community players, the Coalition PLUS**

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[37] Demange, E.; Henry, E. y Préau, M. (2012). From collaborative research to community-based research. research. A methodological toolkit. ANRS/Coalition PLUS. **http://www.coalitionplus.org/wp-content/uploads/2012/07/GUIDEgb.pdf**

[38] Community-based research involves collaboration between researchers and community players, from the choice of topic to the publication of articles, the development of a methodology and the collection and analysis of data.

community research laboratory and its Bolivian member IDH, collaborates with academic laboratories. This project, which aims to identify the HIV-related determinants and sexual health needs of cis or transgender men and women using the internet to find sex-economic exchange partners (Canada, France, Bolivia, Ecuador, Republic of Mauritius, Morocco, Romania and Portugal), shows that such research projects can be funded with community-based scientific support;

- **the ANRS-Ipergay project, which ran from 2012 to 2016. This community-based biomedical prevention trial aimed to evaluate the efficacy of on-demand PrEP for men who have sex with men with a high risk of HIV exposure in France and Canada. The trial results were very successful and there was a 97% reduction in HIV incidence during the open phase of the trial. This trial developed a new type of support, combining medical and community players. This trial was an opportunity to evaluate the benefit of support based on the collaboration of doctors and community support workers in the field of biomedical prevention. Since then, PrEP has been authorized for use in France;**

- **ANRS-PRÉVENIR, in France, aims to reduce the number of new HIV infections in the Île-de-France region by promoting access to PrEP for HIV-uninfected at-risk individuals, in which AIDES is responsible for community support. The community coordinator (Coalition PLUS) is a member of the Scientific Council of the study, and AIDES was included in the executive committee (decision-making body) which met monthly. Academic researchers have understood the value of the input provided by community players at all levels, including decision-making, to conduct this research. It also showed how research and advocacy could be effectively linked;**

- **Flash! PrEP in Europe (2016), in conjunction with 15 community-based organizations and two universities, one of which has an overall coordination role with AIDES and Coalition PLUS. This online survey aimed to collect**

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Community-based AIDS organizations operate alongside actions taken by the public health system.

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information on knowledge, interest and use of PrEP among key populations in the HIV epidemic in 12 European countries. For this survey, a Scientific Council was set up with representatives from associations and the medical, institutional and academic fields to ensure shared decision-making on the valorization strategy (scientific and advocacy). The results of the survey are used by researchers and representatives of associations at international and national conferences, as well as in national advocacy work;

- **Stigma Index (2016) in Morocco. The Stigma Index study in Morocco by ALCS is part of an international initiative to document, analyze and report on HIV-related stigma and discrimination. This study, conducted between March and June 2016 in eight cities in Morocco, was carried out by ALCS association players, in perfect collaboration with a professor from the National School of Public Health in Morocco. From the beginning of the collaboration, the ALCS Research Officer participated in the study, took part in the data analysis and, for the first time in the Coalition PLUS countries, participated in the drafting of the national results;**

- **The PARTAGES project is an international research project led by Coalition PLUS that focuses on sharing your HIV status among people living with HIV. The aim is to understand the individual, psychosocial and contextual determinants in order to implement targeted responses for people. This first project carried out by Coalition PLUS (Morocco, Ecuador, Mali, Romania, DRC, France and Canada) is also a good example of an equitable partnership between academic teams and community players, both at the international coordination level and in each country.**

e. Citizen involvement of FAA players

Over the last ten years, citizen observatories on the supply of medicines in particular and on the organization of the health pyramid have become methods of action that potentially rebalance public health decisions. By combining community experience in access to care with systematic monitoring of the realities on the ground, and by comparing them with national standards of care, the observatories have become a response mechanism that provides credibility to advocacy and allows for collaborative efforts with the public authorities in the search for solutions.

It is clear from the above that the FAA has gone far beyond a vertical and specific interpretation of the care of PLHIV, or people exposed to HIV by challenging other structures or institutions using research, for example, and by creating a more open approach to the care system, through the demedicalization of certain responses for example. The FAA has also given care networks pride of place to improve the continuum of care.

Community involvement strategies ready to be mainstreamed

a. Integrating human rights into access to healthcare

This is the most obvious acquisition of the FAA, which can be integrated immediately into any new or old health issues, including the fight against the stigma of disability and the management of mental health, to name but a few. As mentioned above, UNAIDS immediately took it upon itself to keep this in mind with COVID-19.

b. Local access to health services

The promotion of community health workers involved in the FAA could be transformative for other conditions as well, as these staff are generally better trained than “traditional” CHWs. Often coming from the peer education sector, these CHWs can also help with other local health and social issues that are often neglected. These include, for example, the sexual health of young people, maternal and child protection for marginalized populations such as sex workers, health promotion in prisons, mental health promotion for people who use substances, etc.

c. An extension of the healthcare services

The demedicalization of prevention, testing and drug distribution in the FAA should provide a more open interpretation of disease management where those requiring care and their families can play an active role in the healthcare system as players in their own right. These neglected human resources can become extremely valuable if they are trained and treated as valid spokespeople in the health choices of local communities, a Bamako initiative revisited and truly supported by the community this time. This was true in the 2020 COVID pandemic, where CHWs distributed methadone in Mauritius and ARVs in Morocco (to name just two examples) to prevent interruptions to treatment.

d. Mainstreaming prevention and care for PLHIV on the road to total de-stigmatization of populations directly or indirectly affected by HIV

If the stigma is eradicated and it may not take much effort to achieve this, then HIV care in the broadest sense will become mainstream. There is no need for a specialist center to diagnose and prescribe first-line HIV treatments. However, for quality care, the care pyramid needs to be solid with a good referral system to regional care centers and a good counter-referral from regional centers to community care centers . What is needed is to secure the care pathway for PLHIV in the healthcare system, but this applies to anyone who requires treatment for any pathology. Because of these shortcomings in the care pathways, mainly due to discrimination from healthcare workers rather than any difficult medical technique, the FAA has become isolated from the rest of the “mainstream” healthcare system.

e. Mainstreaming FAA funding on a national level for better sustainability

There will be no integration of responses until there is a mainstreaming of funding, and this is probably what scares HIV specialists and PLHIV the most. Despite its desire to do so, the Global Fund has not even properly aligned its funding with the government budget cycle in some countries out of concern for short-term results and for the security of the funding granted. Under these conditions, the integration of HIV, malaria and tuberculosis care remains a pious hope. Will the UHC succeed in aligning all external funding in the state budget and in increasing the domestic share of health funding while addressing the needs of all vulnerable populations? The issue remains unresolved and is very much linked to the respect for and advancement of human rights.

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Involving community members who share the same social values fosters open dialogue and improves access.

Conclusion

Is it possible to mainstream the FAA in the future for the benefit of healthcare systems without losing momentum regarding its current achievements?

The answer to this question is central to moving towards more mainstreaming. In fact, if PLHIV and key HIV populations remain under the impression that healthcare systems are not yet ready to accommodate them in conditions that they feel comfortable with, the integration of HIV care in the ordinary healthcare system will be delayed or, worse, it will fail.

The following are some of the conditions or responses that would support the inclusion of the response to HIV in mainstream healthcare systems, including community-based systems, and how the community-based system could also benefit from the achievements of the FAA.

Cultural:

- bringing a human rights and gender perspective to all aspects of health;
- active contribution of people who require care to their health solutions for all conditions;
- willingness of States to allow this contribution;
- rebalancing the doctor-patient relationship;
- a holistic understanding of well-being and illness that includes the community.

Practical:

- pooling of resources, particularly on the UHC (see pp. 4-6 on the UHC), and for the establishment of citizen observatories;
- pooling of patient networks;
- knowledge sharing: extension of joint training courses on holistic disease management (specialists/people being treated).

However, the move towards mainstreaming the FAA remains difficult

- for personal reasons. Indeed, many PLHIV or key populations would fear the loss of personal benefits “from the HIV system”, such as better remuneration and personal recognition. This applies to many individual and institutional FAA players, including peer educators, large or small associations of PLHIV in developing countries, leaders of international FAA bodies, etc. It is also up to them to collectively emphasize their added value to healthcare systems, without false modesty or sycophancy. In fact, the solution is also collective in these individual fears. We need to extract and analyze the added value for healthcare systems of these amounts of personal experience: the value of the courage of testimony, the value of creativity in the solutions proposed, the value of networking, the value of sharing experiences, of being able to listen to others, of speaking out in hostile environments, of questioning ineffective or dubious practices, etc. Yes, the FAA activists were and still are extraordinary, but they want to share their experience without giving up on what they have made progress on so far;

- for collective reasons. Marginalized HIV populations are afraid that they will no longer be cared for in a mainstream system, without respect for their right to health. There is also a real fear on the part of the association players, in particular, that the achievements and resources of the FAA will be “watered down” in the “sea” of healthcare systems which are globally underperforming and whose practices in terms of governance and accountability are mediocre. This is a real risk, but it is also a short-term vision that can only create weariness on the part of health decision-makers, especially international ones. Moreover, it is important to remember that the most fundamental achievement of the FAA has always been to adapt and be creative when faced with obstacles in order to propose solutions without having them imposed. It is precisely because the FAA is no longer at the top of the agenda of decision-makers that this creativity and willingness to be part of the solutions is more important than ever. We hope that this analysis contributes to this.

6

Community representation in the fight against AIDS: the frontline between the community & the healthcare system

Community representation is based on a personal commitment that is transformed into a collective commitment thanks to the close ties of community members

Introduction

The issues associated with community representation are naturally very significant, i.e., who “speaks for the community”. They play out between the legitimacy to speak “on behalf of the community” and the skills to express as clearly as possible the way of life, the needs and the priorities chosen, as well as the need for constructive involvement of the community in the projects that affect it.

Therefore, quality representation is about having a good link between the community and the healthcare structure or institution (most often in our case). The credibility of the community’s representation is at stake.

Chung et al. (2012)[1] describe how community representation in local health authorities works in the United States and find that local elites often take on this role. The article raises the question of the legitimacy of representation, particularly of key and marginalized populations. The authors conclude that the issue of representation is often poorly explored, and their study also found that communities often struggle to define their criteria for good representation, i.e.:

- meet the needs of the affected groups;
- promote *empowerment* through greater community involvement.

Based on the example of the “Riposte” project cited below, we will also see that, sometimes, the competence of the representation poses a problem because legitimate but incompetent representation

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[1] Chung, P., Grogan, C. & Mosley, J. E. (2012) Residents perceptions of effective community representation in local health decision-making. *Social Science & Medicine*, 74(10), 1652-1659.

undermines the credibility of the community's input. This implies a major effort to support and train representatives.

Therefore, we will look at how to approach the best quality of representation in the current institutional context where the Global Fund continues to play a leading role on this issue. We will spend a lot of time analyzing the Global Fund "model" as it is the richest and clearly the most reformable and adaptable.

However, the evaluation of representation is never carried out in any of the institutions we will mention, giving a subjective character to this aspect, which is nevertheless crucial to community progress in the health field.

Criteria for good representation

It isn't easy to be a good community representative.

The mandate of community representatives is to represent the specific interests of their community and not their own interests.

To represent these collective interests, it is, therefore, necessary to:

- be a recognized leader in their community, and have their support through a clear selection and nomination process;
- put forward the views of their community on the issues discussed in the representation;
- provide a strategic vision;
- influence decisions;
- understand the consequences of decisions taken;
- report on the decisions and strategic elements used to achieve or fail to achieve a decision.

The representatives must, therefore:

- devote time to preparing for the representation activity;
- improve their understanding of the issues under discussion;
- seek input from community members to form an opinion;
- assume their representation by their presence and active involvement in the bodies where they represent the community;

- maintain strong links with the community outside of times when they represent them.

They also need to:

- be a leader or spokesperson recognized by their community;
- have a personal commitment to the issues surrounding representation but approach it from a collective perspective rather than a personal perspective;
- understand the global issues in the fight against AIDS (FAA) or any other health or research topic;
- have good analytical skills and public speaking skills.

Encompassing all the community legitimacy and skills mentioned is very often difficult for one person, or at least it was when the concept of international community representation came into play in the 1990s with UNAIDS, and then in a clearer and more recognized way since the creation of the Global Fund. So often, and ideally temporarily, community facilitators have been used to play this role in close proximity to the community. This was necessary as some communities were ostracized or criminalized, and some still are in many countries.

International representation of communities

Community representation in UNAIDS

The first health institution to have community FAA representatives was UNAIDS.

The creation of GIPA/MIPA[2], the principle of meaningful involvement of people living with HIV, coincided with the creation of UNAIDS in 1994. In its Programme Coordinating Board, acting as a board of directors, community representatives are recruited as non-voting members in a ratio of 22 governments, 10 UN cosponsoring agencies to five representatives of FAA civil society, three from

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[2] The GIPA principle – Greater Involvement of People with AIDS – is about the increased involvement of PLHIV. MIPA – Meaningful Involvement of People with AIDS – refers to the meaningful involvement of PLHIV.

the South and two from the North. It is not specified whether or not these representatives should be people affected by HIV/AIDS. However, it is the responsibility of the UNAIDS Executive Director to approve the appointment of these representatives. This is where we see a bias against communities, which for the UN is not surprising given the supra-governmental nature of this institution. The community aspect of the FAA is probably best expressed in the UNAIDS Secretariat team. In any case, this is inappropriate governance for an institution that is intended to be at the heart of the community aspects of the FAA.

Community representation on the Global Fund Board

The Global Fund to fight AIDS, Tuberculosis and Malaria was intentionally placed outside the auspices of the United Nations largely because of its particular governance, and its model must continue to evolve. Together with donor and recipient governments and NGOs, the community participated in designing the Global Fund governance in 2001 in the Transitional Working Group (TWG). The latter was established after the 2001 UN Special Session.

As we have already mentioned, the governance of the Global Fund is still unique. However, it still needs to be refined and must therefore evolve in order to do so.

The community constituency on the Global Fund Board has significantly improved the organization[3] since its creation. It has obtained the means to organize itself, but has it increased its influence beyond declarations of intent?

Further analysis would require an assessment of the influence of community views on Global Fund Board decisions, an analysis of the alliances made to obtain decisions carried by the community constituency, and an analysis of the forces that opposed them and their reasons. However, there are some common-sense questions. Why, when the Global Fund claims that communities of people affected by or vulnerable to the three diseases are central to its

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[3] More information at: https://communitiesdelegation.org/about

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This person sits on the Global Fund's Country Coordinating Mechanism as a representative of men who have sex with men and bisexual men.

mission, is there only one constituency of communities at the board and not two or three (one per disease)? The issues, challenges, and contexts of the three diseases are very different, and confusing them delays the empowerment of those affected by the diseases, their prevention, treatment and particular vulnerabilities. Of course, one might think that this will strengthen the vertical side of the Fund, but it will empower communities to really move in their direction. Moreover, the distribution of these two or three seats does not necessarily have to be done by disease; it can be done quite differently, depending on what the communities decide.

Would it be better to remove the NGO seats to avoid transforming the Board too much? This is another valid question. Too many NGOs, especially international ones, have used their presence at the Global Fund to advocate for their own interests, their PRship[4] or funding in other capacities. Their absence from the Board would make things clearer. However, to take it a step further, one wonders whether the money from the Global Fund is used to finance NGOs from developed countries, inevitably to the detriment of governmental and especially non-governmental players in the recipient countries. This may have been necessary in the Global Fund's early years but after nearly 20 years, it is unacceptable, as is having UN principal recipients in countries that are not at war.

If Global Fund money were to go to NGOs in developed countries, it should only be for the long-term capacity building of their Southern counterparts. It should definitely not be for project implementation in recipient countries.

In order for the Global Fund to make progress in implementing its discourse focused on community players, it is time to re-examine the distribution of seats on its Board. With its dynamism and spirit of reform, this structure is capable of doing so. It is capable of coherent changes in its governance after a rigorous assessment of the gap between its rhetoric and its actions on the centrality of people affected by diseases and in its fight against conflicts of interest.

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[4] PRship means being a main recipient of the Global Fund in the countries.

The limits of communities' role in the Global Fund at the central level

When the Global Fund was established in 2002, communities representing people affected by the three diseases (HIV, TB, and malaria) did not have voting rights on the Board. This right was acquired in 2004 as a matter of course for everyone. Now, one might also ask how it is that the presidency of the Global Fund's Board, which changes every two years, has never yet been given to communities in the Fund's 20-year history when everyone is singing the praises of community involvement.

This limitation is also reflected in the small share of the Fund Secretariat's teams and the budget allocated for the issue.

The Communities, Rights and Gender (CRG) department in the Global Fund Secretariat remains marginal, with an allocation of $16 million for strategic initiatives over three years to support communities around the world in three diseases[5,6]. In addition, there are two complementary strategic initiatives for Human Rights ($5 million) and one under the COVID-19 mechanism (CLM SI) for $3 million. The CRG is also more focused on the English-speaking world than the French-speaking world in Africa, where the greatest difficulties in the FAA at the community level still lie. This is partly because the national contexts of French-speaking African countries are generally countries with concentrated epidemics rather than generalized ones as in many English-speaking countries. Widespread epidemics have led them, despite unfavorable political and societal environments for communities, to consider the needs of people affected by HIV. They represent a significant proportion of the population.

The lack of human resources in the Global Fund Secretariat involved in community, rights and gender equality issues is blatant.

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5 Global Fund. (updated in 2020). *The Community, Rights and Gender Strategic Initiative* [Brochure]. Global Fund. **https://www.theglobalfund.org/media/9948/crg_2020-06-strategicinitiative_update_en.pdf**

6 The other strategic initiatives launched by the Global Fund for the period 2020-2022 are available at: **https://www.theglobalfund.org/media/9228/fundingmodel_2020-2022strategicinitiatives_list_en.pdf**

This imbalance is easily seen compared to the strategic ambition endorsed by the Board, which covers all Global Fund financing. Its 2017-2022 strategy has four priorities, one of which is the promotion and protection of human rights and gender equality.

There is a paradox in the accountability of country fund management teams, which is based on the achievement of key quantitative results such as the number of people on ARVs or the number of nets distributed. Nonetheless, the inclusion of CRG themes, which allows for greater sustainability of results, would be fundamental. This could be reflected in the Fund's new strategy for 2022-2027.

As the Global Fund has grown, it has developed complex and sometimes contradictory procedures. A member of the Secretariat summarized this concept, "we are slaves to the Global Fund's procedures, not to the beneficiaries". This is because grant implementation procedures leave little room for communities. The current trend is to reduce the number of principal recipients (PRs) and sub-recipients (SRs). However, it is necessary to work with community-based organizations that work closely with people. As a result, a specific system has been set up to ensure that these bodies can integrate the Global Fund's procedures.

Finally, the more recent and renewed tendency to position Global Fund management closer to a private sector structure also reduces the internal understanding of key CRG issues and the minimum services this should cover in grants.

While the Global Fund is seen as a civil society and community-friendly body, the growth of the Secretariat has not maintained this dynamic, which is now more theoretical or politically correct, as is the case with other international organizations that are historically or culturally less community-oriented (e.g., GAVI or the WHO). One could also question the role of the main donors and, therefore, the administrators in this imbalance and which, like France, have historically supported rights issues.

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Self-help groups and conversations help identify people's real needs and provide psychological support, particularly when they have just been diagnosed with HIV.

The perspective of a stakeholder in the field[7]

The Global Fund's theoretical model has allowed for the visibility of key populations and communities. There is an opportunity to point out what is not working in implementing the programs.

However, the quality of this representation is fundamental to this visibility. The training of representatives is, therefore, a necessary asset. You have to be able to argue, make a documented claim and act as the spokesperson for a group of people. The power given to countries by the Global Fund, through its principle of country ownership, is great. In practice, however, we find that in many countries, particularly those less inclined to recognize key populations, the voice of communities is not heard. Their involvement remains only a guarantee of "good" functioning. The CCM is only a body for approving national decisions made by the highest authority. The Global Fund should do more to support communities in their representation through technical and financial means to ensure the community's voice is heard.

While the Global Fund has established a set of procedures for the involvement of civil society, there is evidence of a lack of decisiveness in applying its own procedures. This was discussed at the 2021 Africa Partnership Forum, including the request to "leverage the position of the GF to advocate its core principles and strategic objectives with stakeholder groups at national and global levels including on human rights, equity, gender equality and other structural determinants of the three diseases".

Let us hope that the next Global Fund strategy for 2022-2027 will result in a strong repositioning of Communities, Rights and Gender, including in its operationalization. Let us also hope that the Secretariat is accountable for managing the allocated grants by allowing the communities to have real involvement, which allows for better qualitative results.

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[7] From an interview with Serge Douomong Yotta, former Director of Affirmative Action – Cameroon, spokesperson for AGCS PLUS and current Advocacy Director of Coalition PLUS.

Shouldn't the Global Fund be stricter with countries on these issues? We can see that, while state ownership is crucial, it is nonetheless an obstacle to progress in terms of rights and community representation/involvement, as is the case with PEPFAR, for example, which is more inflexible in its relations with countries regarding the involvement of communities in the implementation of programs.

At country level, community representation is numerically stronger in CCMs, but often not very effective, limiting communities' impact on public policy.

Community representation in Global Fund Country Coordinating Mechanisms (CCMs) in countries

Community representation in CCMs still has a long way to go.

CCMs in Global Fund recipient countries are still relatively new institutions that are still finding their way, and this is normal for such a revolutionary partnership. Each CCM brings together all the representatives of the structures, institutions or communities that are part of the country's response to the disease programs that the Global Fund finances in the country. It is the CCM's role[8], in theory, to make strategic decisions about the use of Global Fund financing in each country. This means that it coordinates the funding application, oversees its use, and chooses who implements the funding. Its responsibilities are therefore very important.

Surprisingly, CCM membership is more demanding than that of the Global Fund in terms of community representation since at least one representative of people living with HIV or TB must be on the CCM. Representatives of key and vulnerable populations must also have at least one representative. In practice, there are often two or three representatives.

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[8] The quality of CCMs varies greatly, ranging from the most effective, which knows the needs of the country's population and translates them into programs, to the least effective, which allows its demands to be dictated by either the main recipient, often the Ministry of Health, or the Global Fund Secretariat. There are all possible intermediaries between these two extremes. But in the Global Fund model, the CCM is the decision-maker on the funding request.

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Self-help groups, such as those in Morocco, are also an opportunity to discuss prevention strategies, PrEP (preventive treatment for HIV), testing and human rights in a confidential environment without any taboos.

There have been changes to the representation of communities since the creation of CCMs, which have always required at least one representative. Initially, for practical reasons and because country policymakers often preferred it, this community representative, most often a man living with HIV, was chosen or, at best, strongly suggested. This allowed the Fund to meet their requirements and the experience of the person affected by HIV to be used at best and instrumentalized more often than not.

It took several years for representatives of PLHIV and HIV-affected communities to be chosen by their own communities and to be truly included in the country's response to HIV under pressure from the Global Fund. This required a type of organization and collaboration that the community-based organizations (CBOs) were not prepared for. Over time, the networks have learned to elect their representatives and move beyond the concept of individual representation preferred by governments toward representation of groups (sick and vulnerable people or key populations) and their needs.

However, progress must be made in order to ensure that community representatives' involvement in the CCM is considered just as important as the involvement of other stakeholders. Let us be clear: there will be no sustainable empowerment of communities, nor an end to epidemics, without this meaningful representation and involvement. Community members must bring up the needs of their peers and implement decisive and sustainable actions where they alone can act through the knowledge and trust of their peers. This strengthens community systems. However, to implement it, you need to be at the decision-making table, with your head held high and with the data needed to convince, implement, and monitor responses.

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Psychosocial support is part of the ANSS comprehensive care model, as seen here at the Turiho center in Bujumbura, Burundi.

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Most community clinics offer general health services and the management of sexually transmitted infections and gynaecological and proctological services.

The current limits of community representation on CCMs

Unfortunately, on this aspect, the Global Fund, either through timidity (but this is unlikely) or through lack of determination, remains too focused on intentions and success stories. We need more than success stories at this stage, more than favorites and more than short-term successes. We need a bold strategy that is truly focused on embedding community involvement in healthcare systems, starting with quality community representation on the CCM.

Sixteen million dollars in Global Fund Strategic Initiatives will not be enough. Community groups worldwide need to be trained, mentored, organized, and evaluated to advance their representation on the CCM. It is also because of a lack of funding that groups are tearing each other apart for a spot on the CCM, and it is because of this lack of funding that they cannot really come together to take the time to strategize, collect data, formulate long-term advocacy plans, etc.

In fact, the lack of resources and the lack of long-term strengthening of all willing communities, not just those in the Global Fund's Strategic Initiatives, have long undermined the credibility of the community world. Yet, the Global Fund remains the only international institution that has so far supported community health, albeit on the surface. We need to make a serious effort in the next few years to end the AIDS, TB and malaria pandemics by 2030, i.e., tomorrow.

While the Global Fund has been quick to embrace communities, the priority given to the community dimension in implementing programs is not entirely commensurate with this ambition; there are structural barriers to a real scaling up of the rights issue in its grants.

All of the above applies even more strongly to the representation of communities in the drafting and monitoring of national strategic plans[9] (NSPs) of countries' ministries of health. Community involvement is often mentioned in the NSPs, but in very little detail, and the minimum is implemented at best. Community representatives may be invited to write the NSPs, but how many can monitor their implementation?

If we do not address this quickly, this representation of convenience could, in most cases, end there. We will include a few stories or statements from people who have succeeded in their projects, because some have. However, we cannot dwell on this issue of representation without improving its equality for all communities. This will come at the cost of funding to support this representation, evaluation of representation and a major investment in research into these processes. The FAA communities are ready for this and can still lead the way on these issues.

"Riposte: the voice of key populations" is a multicountry project (Burkina Faso, Burundi, Mali, and the Republic of Mauritius) supported by L'Initiative/Expertise France and carried out by the NGO REVS PLUS in Burkina. This three-year project aims to strengthen the capacities of representatives of key populations within national bodies (the CCM in particular) to improve their access to prevention and care. Therefore, the aim is to train, inform and structure the community's voice to ensure the effective involvement of these representatives. The first year of this project has taught us that the people concerned have become aware that they need to be "better equipped", both in terms of advocacy techniques and technical aspects, to participate in a dialogue with the authorities and other bodies in the countries. There is a need to recognize the need to include local players in implementing health policies. The various workshops held in the countries and between

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[9] The national strategic plan is a document that describes the planning of the management of a disease (AIDS, tuberculosis, malaria, etc.) over several years. This document details, among other things, the needs and implementation choices of the country's response to the disease to which it is responding. The NSP is fundamental because the Global Fund is supposed to finance it, or at least finance the funding gaps in the plan.

countries enabled the training of community leaders and representatives of key populations. This training invited them to draft national strategic frameworks to prepare funding applications to the Global Fund. Burkina, a representative of the key populations at the CCM, confirms that: “Today, I am satisfied because before it was not like that. People spoke on our behalf, but now we are prepared, and the positions reflect reality because they come from the key populations themselves”.

Community representation in NGOs where there is also room for improvement in terms of community input and action

The GIPA/MIPA principle applies to everyone, and NGOs without a community base should also apply it. Here, this is expressed not so much in the project implementation as in the governance of the associations, both in the NGOs of the North and the South. As we saw in Chapter 2 on the origins of associations, not all FAA NGOs originate from the same reasons for mobilization.

For these, too, there is room for improvement in the representation of communities for different reasons, which we have already discussed in a previous chapter.

- For FAA NGOs created by doctors or other health professionals, it is necessary to make an effort to be inclusive in the governance of their associations by reserving positions for community members and giving them access to the leadership hierarchy of these structures. Indeed, none of the examples cited in the chapter on the origins of the associations have so far been led or chaired by a person who is openly living with HIV, which would in itself be a major cultural transformation in the perceptions of these associations. This attitude discredits the community claim of these NGOs, which is a pity because their work with communities is often excellent.

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Community-based sexual health services developed and implemented by and for people living with HIV, with the support of trained and educated health professionals, are essential to ensure that key populations have access to and remain in care.

- For community-based organizations, the turnover of the hierarchy is lagging behind. Too often, these CBOs are still chaired by their founders, which prevents the “rise” of new people and the enrichment of new ideas. Moreover, it also tends to hamper partnerships and alliances with an ageing perspective on the environment and issues. In the long term, this will lead to the weakening of structures that have been linked for too long to the names of the founding individuals. Careful consideration of the turnover of leaders would considerably strengthen these structures.

The scope for improving community representation is much greater for international charitable or humanitarian NGOs from the North, which later became involved in the FAA with a different culture: humanitarian emergency and poverty alleviation. They then evolved more towards “sustainable humanitarianism”. Their role is crucial in the development landscape and in the management efficiency of funding. Historically, however, they often do not have the same approach to community involvement (Verna, 2007)[10] and are often distant from it.

Although progress has been made in involving communities in these international NGOs’ projects, it is clear that the pace at which they respond to the problems faced by people affected by HIV is often too fast. It is also far from the broad consultations of community members, who are not part of the management staff or decision-making bodies of these structures, which are highly medical or technical (Rilkoff, 2016)[11]. For reasons of managerial efficiency, it is these structures that the Global Fund has often chosen to become principal recipients at the expense of community-based organizations. This is all the more true because many of these international bodies have neglected their capacity-building role in relation to local players and favored a form of sustainability of Global Fund financing.

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[10] Verna, G. (2007). *The behaviour of NGOs involved in humanitarian aid according to their culture of origin and political pressures. Anthropologie et Sociétés, 31*(2), 25-44. **https://www.erudit.org/en/journals/as/1900-v1-n1-as2394/018681ar.pdf**

[11] Rilkoff, N. (2016, December 5). *Are we ready? How organisational culture needs to change to put people at the center.* Sphere. **https://spherestandards.org/are-we-ready-how-organisational-culture-needs-to-change-to-put-people-at-the-centre/**

In fact, Southern NGO and community constituencies at the Global Fund should object to the fact that the Fund, in its next round of funding, still accepts international players as PRs, whether they are NGOs or UN players, to manage national grants.

Community representation in other conditions or global health issues: the FAA's very heterogeneous legacy

As we saw in Chapter 3 on community expertise, the FAA has, in France at least, really opened the door for movements involving people living with HIV/AIDS and to "health democracy". This was thanks to the notable contribution of Pierre Lascoumes, a former volunteer from the early days of AIDES and founder of the late Collectif interassociatif sur la santé (CISS), which was transformed and expanded and is now known as France Assos Santé[12], in 2017. However, if patient organizations in France are represented in all national and regional public health bodies since the law on health democracy, their approach is more about defending the rights of "ill" individuals than about community contribution to public health. These broad groupings of associations take a "user" perspective of the healthcare system in a consumerist approach. The community approach has almost disappeared by shifting as a social movement from the FAA to a broader interpretation of health system "users".

Let us move to another continent and look at what communities in the CESCOMs in the Malian healthcare system have achieved. In this "community" approach to health, community representation has been used mainly for managerial and financial reasons with limited success (Foiry, 2001)[13]. There is currently talk of making the

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[12] More information can be found at **https://www.france-assos-sante.org/presentation/positions/**

[13] Foiry, J.-P. (2001). L'Initiative de Bamako : quels bénéfices pour les populations africaines ? *[The Bamako Initiative: what are the benefits for African populations?]* In Rainhorn, J. & Burnier, M. (Eds.), La santé aux risque du marché – Incertitudes à l'aube du XXIe siècle. *[Health at the Risk of the Market - Uncertainties at the Dawn of the 21st century]* Graduate Institute Publications. **https://books.openedition.org/iheid/2521?lang=fr**

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The community organizations offer free peer testing in health centers or off-site in completely confidential and safe environments.

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Counseling and empowering people are an integral part of the care plan offered by community associations.

community health workers attached to them more official, probably losing much of the community involvement.

In the field of global health, we have observed the representation of civil society in the Universal Health Cover by 2030 process. Associations in the English-speaking world are much more represented than in the French-speaking world, and the community world of the FAA is very poorly represented. Based on these observations, we should not expect lessons on community involvement approaches to be applied to universal access to health — a community issue that is both geographical and identity-based.

Conclusion

The representation of communities is an important and complex issue, as we have just seen, but they are in the process of finding their voice, and this will only have to improve.

Everything we have described regarding the selection criteria for community representation is entirely valid for local, national or international representation of communities in health or research bodies or institutions and, of course, in associations. It is a lot of work, but it is surely one of the best things that a community player can do.

Much has been learned in recent years about finding good representatives and how to train them. However, the most important thing is how to support them. If there is one lesson to be learned from this chapter, it is that representation is difficult, but it should not be personal or carried out in isolation as it too often was in the early 2000s. It must rely on the community or, more practically, on a community support group with a variety of expertise. In our complex world, no representative is omniscient, and community expertise *(see Chapter 4)* must prevail, be recognized, and be shared by these representatives and their support group.

The representation exercise is also very much linked to advocacy, and it must now focus on recognizing the community approach to HIV, especially for key populations and PLHIV. This advocacy must also focus more on research into this community representation and on evaluating it in order to remove the subjectivity that does not allow for substantial progress. Again, communities can pave the way for evaluating the representation for all representatives, wherever they come from. This could not be a more democratic exercise.

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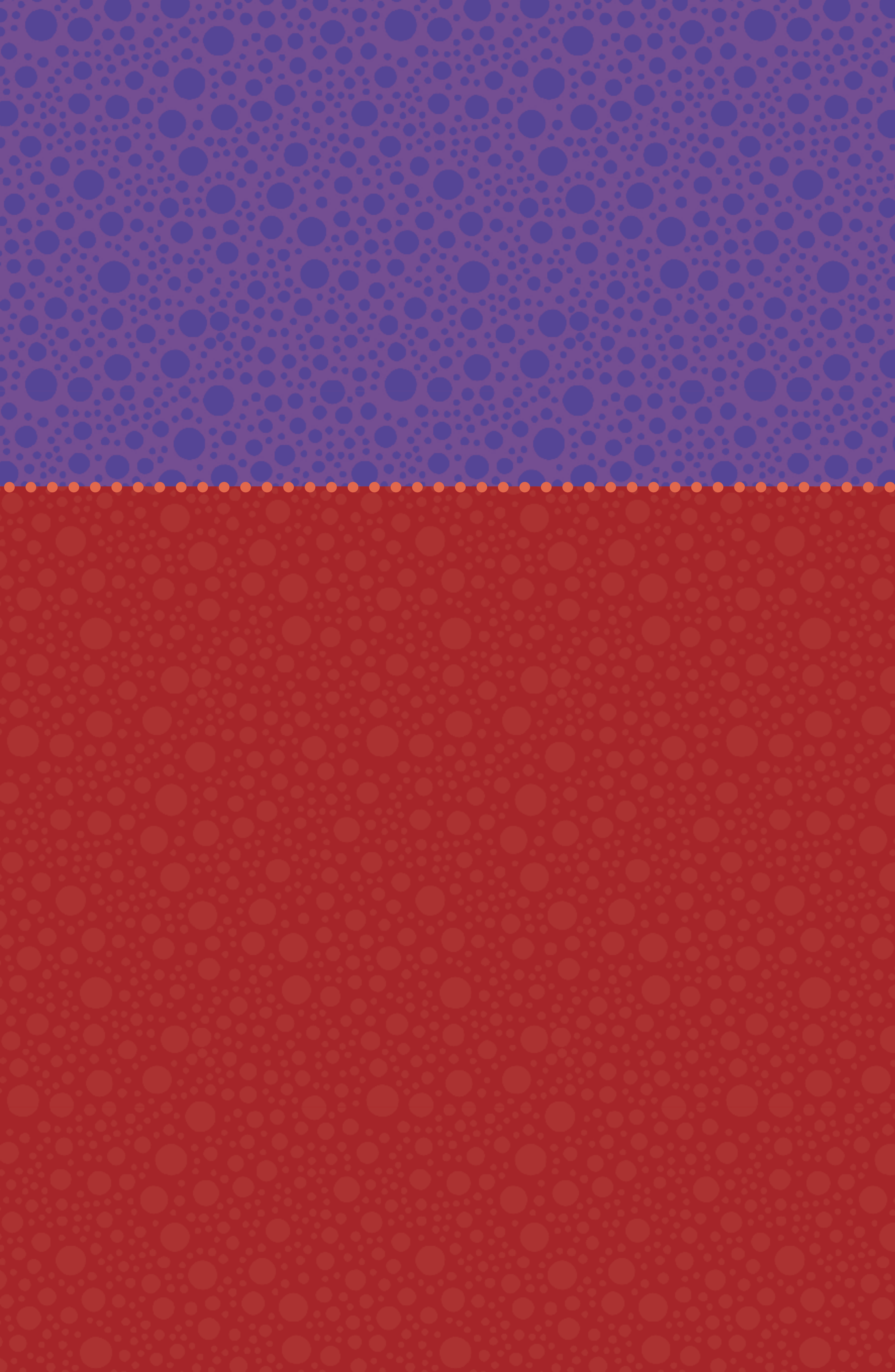
Different aspects of the power of community players in the fight against HIV, their limitations, and the implications for other players



The fight against AIDS in the community has gone beyond what the Alma-Ata Declaration and the Ottawa Charter stipulated.

Introduction

In this final chapter, we will explore and analyze different aspects of community power that have been instrumental to the success of the fight against AIDS (FAA). We will try to learn from experience and apply this to global health and, above all, capitalize on the achievements of the FAA in case they quickly disappear in a world caught up in other epidemics.

We will explore the power base of FAA players, people living with HIV (PLHIV) and communities affected by HIV in particular. By identifying the principles on which the FAA is based, we can analyze its limitations, but above all, we will compare them with the main declarations and charters on which international community health is based to see if the FAA can really claim to be based on them.

FAA players are known for their effective advocacy work that addresses a variety of issues in different ways: universal access to the best treatment and prevention, respect for human rights, better quality of care, good use of FAA funding, information sharing, etc. The communities will then develop **community monitoring tools** to ensure that what has been achieved through advocacy is actually put in place.

Finally, we will see what consequences this activism has had on other conditions and, eventually, on global health.

The power base of the FAA players: innovative principles

1. The centrality of the involvement of those affected by HIV (PLHIV, their communities, families, and allies)

As discussed in Chapter 1 on concepts and definitions, volunteer work has been the foundation of the FAA since the beginning of the HIV epidemic. This volunteering was based on the premise that volunteers from the community of men who have sex with men in the US and England were best placed to care for members of their own community (National Research Council [US] Panel on Monitoring the Social Impact of the AIDS Epidemic, 1993)[1]. The National Research Council (US) Panel on Monitoring the Social Impact of the AIDS Epidemics noted in 1993 that the first advocacy activities for appropriate public policies arose from these community-based organizations (CBOs), particularly in San Francisco. In the 1980s, it was clear that these public policies, especially health and social policies, were designed for legally married heterosexual couples. Men who have sex with men and women who have sex with women, whether single or in couples, were neglected in insurance, inheritance, tax benefits and all other rights granted to heterosexual couples (National Research Council [US] Panel on Monitoring the Social Impact of the AIDS Epidemic, 1993). In order to obtain better care, community-based organizations(CBOs) first used their volunteers to supplement failing health services and to obtain legal and social recognition for the lifestyles of men who have sex with men and women who have sex with women or other marginalized people in society. Their advocacy work has spanned decades, informed by their field experience, and continues around the world, often now supported by professional advocates attached to community-based non-governmental organizations (NGOs). Support activities are now often implemented by community health workers (CHWs) in the South or by professional psychosocial workers in the North.

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[1] National Research Council (US) Panel on Monitoring the Social Impact of the AIDS Epidemic (1993). *The social impact of HIV epidemic in the US*. 1993. National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK234572/

For the original CBOs of the early 1980s, the issue of MIPA, i.e., meaningful participation of PLHIV, was not a real concern because these CBOs were composed of peers, PLHIV and people affected by HIV in close proximity to the epidemic. However, as we saw in Chapter 2 on the origins of associations, not all FAA organizations from the late 1980s onwards had the same roots, and even more so in the 1990s or 2000s. The need for the MIPA principles was thus felt and, in the background, the issues of representation of the interests of PLHIV remained *(see Chapter 6 on representation)*.

One principle of the FAA's power is the involvement of people affected by HIV and their organizations, both in the care and prevention and in the societal aspects of AIDS.

2. The involvement of people living with HIV and CBOs in care and treatment

From the beginning of the AIDS epidemic, volunteers and other community players have made tireless efforts to educate themselves and share medical information in order to have a seat at the negotiating table on new treatments and prevention. They had to understand drug research and development and the organization of therapeutic trials. They also had to challenge the speed at which new drugs were evaluated, understand the way drugs are distributed in the North and South, and the financial choices made by the private and public sectors.

Initially, this was carried out with the involvement of doctors, especially those who were living with HIV. This was followed by close collaboration with other activist health professionals who would never have been able to achieve the level of effectiveness required to move quickly towards better access to quality care worldwide without the close support of communities. Communities living with HIV soon became involved in pre-and post-test counseling as well as changing the standards of good testing. End-of-life support, and later nutritional aspects, have also been the work of community organizations.

This was followed by community-based treatment compliance support in collaboration with prescribing teams, community-based testing which demedicalizes the act of testing people, and more recently PrEP, where monitoring by CHWs is an essential element of its effectiveness. And no doubt this will continue.

There was also this objective of **"making and making known"**, which led, in a language that everyone could understand, to sharing acquired knowledge. This created a mass movement.

Understanding care systems and approaches has been achieved through intensive self-training of people affected by HIV on the condition and its treatment, and through collaboration with activist health professionals in order to disseminatee broadly this medical knowledge from the perspective of people living with HIV or at risk of HIV infection.

3. The importance of human rights in the international response to the pandemic

It cannot be overstated how decisive it was in shaping the response to AIDS when Jonathan Mann, the first director of the WHO Global Programme on AIDS, later replaced by Peter Piot at UNAIDS, immediately positioned the response under the umbrella of respect for human rights. This created an opportunity for the world of human rights activists, lawyers, and legislators, going far beyond a purely health and social response that would fail.

The immediate opening up of the FAA to human rights protection has led to much needed societal reforms to protect marginalized people in society.

4. Various partnerships

The contribution to societal reforms and changes in stigmatizing attitudes has also been made with unusual partnerships for a health topic.

Initially, the FAA reached out to politically aware and often activist intellectual and artistic circles. Their influence and involvement in the decision-making sectors of Northern countries to create changes in mentality has been quite "natural". This has seen famous intellectuals, artists and sportspeople declare that they are living with AIDS, fund the FAA and its research, and help build strong FAA organizations.

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Véronique Coulibaly

Integrating the policymaking community in the North and South has been made possible by individuals, men and women of courage[2], who were not afraid to go against the grain of the attitudes of the time.

FAA players have established partnerships with influential people in political and artistic institutions.

5. The internationalization of the FAA

The principles of GIPA/MIPA have been developed, implemented, and disseminated through international networks of PLHIV, affected people, and then of FAA NGOs, whose discussions and common struggles have very often taken shape during international AIDS conferences. Initially reserved for researchers and doctors, PLHIV were able to make themselves heard from the beginning. As some PLHIV had become real experts on their condition and their community, everyone quickly understood the value of this fusion of people and ideas in order to make rapid progress.

The internationalization of the FAA has been facilitated by regular international conferences where PLHIV, their networks and HIV-affected communities participate and meet.

6. Creating patient solidarity between the North and the South

The response to FAA in the South has been increasingly driven by and towards people living with HIV in these countries, often through activist health professionals attending international conferences. Access to medicines then showed its true colors and pushed for reforms in international trade laws to ensure fairer access to medicines worldwide. New institutions, smaller than the UN system (the Global Fund, Unitaid) , have been set up to respond to the pandemic.

As the momentum for reform was strong in the late 1990s and early 2000s, the founders of these institutions wanted to bring to light other life-threatening conditions and neglected access to care and prevention in the wake of the FAA. This is the case, for example,

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[2] Examples include Michèle Barzach in France, Nelson Mandela and Justice Cameron in South Africa.

for tuberculosis, malaria, and co-infections such as hepatitis *(see Chapter 5 on integrating community-based AIDS responses into healthcare systems).*

The arrival of effective treatments for HIV/AIDS has highlighted the unacceptable differences in access to care between those living with HIV/AIDS in the North and the South, ultimately leading to the creation of new international institutions to promote access to treatment for AIDS and other conditions.

Coalition PLUS and Humana People to People[3] are pioneering models of balance between Northern and Southern NGOs in this delicate balance of funding/actions.

Vincent Pelletier, former CEO of Coalition PLUS

“When I was head of AIDES in France, we experienced a surge in international action created in the 1990s thanks to a few pioneers and their commitment to activism. However, we had no funding. We relied on private funding or French benefactors, such as the Ministry of Foreign Affairs and the Agence française de développement. The question quickly arose as to the legitimacy of the AIDES directors (24 French people with some knowledge of the work financed in Africa) to decide on programs and means of action without involving the people concerned. In this case, the associations financed in this process, as has always been the case at AIDES for national action. This is why we created Coalition PLUS; an organization registered in France, able to receive donations in France and institutional funding, but whose governance would be ensured by the people affected by the action. AIDES would have a voice like the other Coalition PLUS Board associations. The member associations of Coalition PLUS are all financially and legally independent. AIDES, which receives donations in France, had decided, in accordance with the message given to its French benefactors who fund the FAA in general rather than a particular body, to allocate part of its funding

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[3] You can find more information at **https://www.humana.org/who-we-are#our-partner**

to international work. Therefore, it was the first to fund Coalition PLUS through part of its resources acquired by its private benefactors and continues to do so in the long term for substantial amounts.

The success of separating the source of the funding from the decision on the action to be financed — which decision is taken by those it serves, or more accurately those who represent them —should be an example to continue along this path. Who is better placed to decide on actions than those who benefit from them? To quote Gandhi: “Do not do anything for us without us”. The Global Fund’s Board is an example that seeks to move in this direction, by involving donor and recipient countries, but the place of communities is probably still too weak. In reality, we have not yet accomplished what we set out to achieve, as donor countries still have a major say in decision-making.

It is a bit like how taxes work. All taxpayers are benefactors according to their means, but the Members of Parliament represent the citizens as a whole and decide how the money will be used. In principle, it is not the Ministry of Finance that decides on the action. In the same way, one should imagine that states should contribute 0.7% of their Gross Domestic Product as they have pledged to do to international solidarity in the form of a tax, the use of which would be decided by the beneficiaries themselves and not by a national agency in each country that would only serve to operationalize this aid and, at the same time, to conduct a policy of influence based on money. It is as if Bernard Arnault, a French multibillionaire, or any other taxpayer, could decide what the tax they pay should be used for, on the pretext that they pay more than others. This would be unacceptable. Why should it be any less so in the case of international solidarity? Therefore, this solidarity must be expressed at all levels, and this utopia drives us in Coalition PLUS.”

7. Creating equitable partnerships in health development

Caught up in the spirit of reform created by non-governmental FAA players and linked to developing and rich country governments, UN players and the World Bank, the Global Fund for FAA, TB and Malaria was created in early 2002, which changed how development aid should progress in the 21st century.

The financial support provided by the Global Fund is, therefore:

- made up of donations;
- based on the performance of funded programs;
- based on programs proposed and implemented by the recipient countries; and
- includes the government contractors and governmental and non-governmental prime contractors;
- focused on moving countries away from aid dependency by pushing for a greater national contribution from aid-receiving countries.

The Global Fund is governed by a Board whose governance is unique in that it is:

- inclusive of patients and communities of people vulnerable to disease;
- balanced with an equal ratio of recipients to donors; and
- also allows for alternating leadership between recipients and donors.

Two international health bodies, GAVI and Unitaid, were created at the same time as the Global Fund and were dedicated respectively to the distribution of vaccines worldwide and the development and distribution of innovations in the health sector. They do not approach equality in the distribution of donors and recipients, nor the strength of non-governmental representation in their governance. These two bodies are still governed by fairly classical models, even if they have representatives in associations or the community (Global Fund, 2015)[4].

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[4] Global Fund. (2015). *Review of the adequacy of the resources available to implement constituencies of the Global Fund Board*. https://www.theglobalfund.org/media/2630/oig_gf-oig-15-13_report_en.pdf

In contrast to the United Nations model, bilateral players, and many international NGOs with in-country representation, the Global Fund has chosen a recipient country ownership and management of funding model to propose, implement, and monitor funded programs. In return, the country is responsible for management in relation to the Global Fund, which expects effective and efficient programs in which community-based organizations must be involved as workers in the field and, increasingly, as those implementing the program.

The governance of Global Fund in-country funding applies the same principles of inclusion and balance of representation in recipient countries: mandatory inclusion of PLHIV and people living with TB, vulnerable communities and civil society and the private sector. This is done within the framework of the national coordination bodies, often called “CCMs”[5]. In theory, the CCM decides on funding priorities for the three diseases (AIDS, tuberculosis and malaria) and is also responsible for the proper implementation of the programs and the proper use of the funds granted by the Global Fund.

CBOs logically have a fundamental and innovative role in this, especially those representing people who are marginalized or vulnerable to the three diseases *(see Chapter 6 on representation)*.

The Global Fund is the only international organization working in the FAA that respects the principle of inclusion of people affected by diseases and civil society (NGOs) and the principle of balanced governance between donors and recipients. At the country level, CCMs must also adhere to the same principles of inclusion of people affected by the diseases and balance in governance between government public sector representatives and civil society and the private sector.

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[5] CCM stands for Country Coordinating Mechanism.

The limits of these community-based AIDS principles: still a long way to go

1. The limits of MIPA: persistent obstacles to people's involvement

In a 2009 paper, Kim et al. describe the experience of applying MIPA in Uganda, a country heavily affected by HIV, to facilitate access to treatment for PLHIV [6]. The article recalls the challenges of implementing MIPA in many African countries due to the lack of basic education for PLHIV, communication difficulties and the persistent difficulties people encounter when making their HIV status public in countries with high stigma. The authors note real progress in self-support and in the recruitment of PLHIV in peer education activities for access to treatment and monitoring of antiretroviral therapy. However, this assessment also notes persistent difficulties involving PLHIV in information campaigns, public speaking, public policy reform, and project/program development and implementation.

Furthermore, there are international networks of PLHIV who think that putting people living with HIV in the spotlight everywhere is a "miracle" solution, without considering their training and, above all, their understanding of collective issues. There is a real risk of manipulating people who are experts in testimonials. This "model" of MIPA has led to obvious abuses, by putting forward PLHIV, often the same ones, who have made it their business to represent only themselves, without any strong link with PLHIV communities and their interests.

2. The limits of community involvement in care and prevention. When will community health workers receive the recognition they deserve?

In the North, the decrease in voluntary work has now transformed the responses, which are carried out in close collaboration with salaried staff from the associations. However, it does not appear

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[6] Kim, Y. M., Kalibala, S., Neema, S., Lukwago, J., & Weiss, D. C. (2012). Meaningful involvement of people living with HIV/AIDS in Uganda through linkages between network groups and health facilities: An evaluation study. *Psychology, Health & Medicine*, 17(2), 213-222.

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Dr Adam Yatassaye *(right)* is the co-coordinator of the Coalition PLUS West Africa Capacity Building Platform, supported by ARCAD Santé PLUS.

that the community involvement approach has suffered[7]. Yet, the validation of acquired experience is still in its infancy. There is still progress to be made to allow career progression in this community field or transfer of experience to other pathologies.

In the South, community involvement takes place through CHWs and peer educators, but there is a real problem recognizing this function *(see Chapter 4 on CHWs).*

3. The limits of anti-discrimination and anti-stigmatization and respect for human rights and gender equality: cultural changes that take time

As we have seen over and over again, the FAA is inextricably linked to the struggle for human rights. While there has been a great deal of progress in human rights, especially in relation to men who have sex with men, women who have sex with women and people who use drugs in the North, there is still a lot to be done in the South on these issues.

The subject of human rights[8]

The human rights approach to health highlights an important paradox. Most of the human rights efforts in the FAA have focused on access to healthcare. As a result, the discussions and efforts were mainly directed toward the Ministries of Health. However, the fundamental and overriding element is respect for human rights, yet the Ministry of Justice is hardly ever the target of this advocacy for rights.

The importance of progress in the South remains to stabilize the achievements. We can see that the advances in health are significant. Thanks to the Global Fund's recommendations in setting up health programs, people living with HIV have access to care, especially through establishing community health centers that have gained expertise and where people

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[7] See AIDES' 2019-2023 association project: **https://www.aides.org/dossier/aides-en-france**

[8] From an interview with Franz Mananga, CEO of Alternatives Cameroon, a member of GATS PLUS.

feel safe. However, these achievements are weak. National programs promote the health of populations, especially key populations, but other laws criminalize certain sexual practices in the same country, effectively impeding access to healthcare. From one day to the next, community centers can be closed down by one simple decision made by a zealous official. The culmination of years of work has now been brought to its knees. Therefore, it is essential to take a legal approach to this fight so that human rights are respected in the broadest sense, not just in regard to the right to health.

Progress and successes have been achieved through national and sub-regional community mobilization, such as that embodied by AGCS PLUS (see the box in Chapter 2, p. 68). In this network, MSM activists from various countries in the West, North and Central African sub-regions are inspired by each other to improve the situation in their countries. This mobilization of men who have sex with men has made it possible to set up actions to prevent sexually transmitted infections (STIs), starting with HIV. Secondly, community health centers provided support for care, including providing antiretroviral (ARV) drugs, education on HIV and STIs, and strengthening sexual health support for minorities, most of which were then developed in several cities in the same country. However, there are still limits.

Activists agree that rights issues and challenges need to be internal to the country if they are to be sustainable and not driven by external bodies. The fight over rights remains primarily a discussion between civil society and the national authorities of a country. Through these discussions, the topic of human rights is put on the table with ministries of justice through the dialogue on barriers to access to healthcare. Advocacy on this issue is carried out on the fringes of access to health, without any structured and specific means, which slows down progress considerably.

Another limitation is that of technical assistance providers. Players and activists in the South have legitimate expertise based on their environment but they are not given the means to pass on this experience. Thus, technical assistance providers continue to send experts from other

backgrounds, without being able to make a real difference in the countries. Let us allow local players to transfer their expertise to their peers to change the effects of Global Fund or PEPFAR grants.

A recent and no less disastrous development is the COVID-19 health crisis, which has led to significant human rights setbacks in many countries. The curfew and lockdown measures, while necessary to control the pandemic, have unfortunately led to a significant increase in human rights abuses and violence. In Cameroon alone, 2031 cases of violence and rights violations of sexual and gender minorities were recorded in 2020 compared to 1380 in 2019 (Unity Platform, 2021)[9].

The feminization of the HIV epidemic, the vulnerability of men who have sex with men and transgender people have also brought gender inequality and its associated vulnerability to the fore.

UNAIDS highlights the vulnerability of women worldwide, but particularly young women in West and Central Africa (Avert, 2020)[10]. Most married women aged 15-19 cannot make decisions that affect them personally, and, therefore, cannot make decisions about their healthcare. This is further exacerbated in this age group if the women belong to a key HIV population (sex workers, people who use drugs, transgender women, migrants or women living with disabilities), which puts them at risk of gender-based violence, including rape. Patriarchal laws and traditions sometimes make them even more vulnerable, and it will take a long-term commitment to improving gender relations around the world.

In a 2014 article, Odette Ky-Zerbo et al. conducted a quantitative study on discrimination of PLHIV in Burkina Faso and found that the

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[9] Unity platform. (2021). Transphobie : le visage d'une nouvelle crise – Rapport annuel 2020 des violences et violations faites aux MSG au Cameroun [Transphobia: the face of a new crisis – 2020 Annual report on violence and violations of the rights of sexual and gender minorities]. Unity platform. **https://healthymboa.org/download/rapport-annuel-2020-de-violences-et-violation-des-droits-des-minorites-sexuelles-et-de-genre-msg/**

[10] Avert. (2020). *Gender inequality and HIV.* **https://www.avert.org/professionals/social-issues/gender-inequality#footnoteref12_5n2jcey**

primary cause of discrimination is self-discrimination, especially among women living with HIV who feel excluded and marginalize themselves from society[11]. The article concludes that there is a need for more support for PLHIV to **empower** them. An ALCS/Coalition PLUS study, conducted by Moussa et al. (2021)[12], notes the multifactorial nature of self-stigmatization among PLHIV in Morocco, which affects professional and personal lives as well as access to care and calls for different levels of responses to combat it.

Charlotte Pezeril from the Université Libre de Belgique made similar remarks about discrimination against PLHIV in Belgium[13]. These mainly concern access to insurance, entry, retention and advancement in employment and vocational training, access and conditions of residence for foreign nationals, interpersonal relations, and access to medical care. She thinks the phenomenon of self-discrimination is important, and that stigmatization is very much linked to social perceptions among the PLHIV studied in Belgium.

The history and conclusion of these two articles remind us of the lack of research on this issue and the need to investigate it further.

The criminalization of HIV is a major threat to human rights and has grown around the world since the 2010s. It concerns situations of HIV transmission, exposure to HIV or lack of information about a person's HIV status.

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[11] Ky-Zerbo, O., Desclaux, A., El Asmar, K., Makhlouf-Obermeyer, C., Msellati, P., & Somé, J.-F. (2014). La stigmatisation des PVVIH en Afrique : analyse de ses formes et manifestations au Burkina Faso [*The stigmatization of PLHIV in Africa: analysis of its forms and manifestations in Burkina Faso]*. Santé Publique, *26*(3), 375-384.

[12] Moussa, A. B., Delabre, R. M., Villes, V., Elkhammas, M., Bennani, A., Ouarsas, L., Filali, H., Alami, K., Karkouri, M., & Rojas Castro, D. (2021) *Determinants and effects or consequences of internal HIV-related stigma among people living with HIV in Morocco*. BMC Public Health, 21(1), 163. https://doi.org/10.1186/s12889-021-10204-1

[13] Perezil, C. (n. d.). *Processus de stigmatisation et de discrimination des personnes vivant avec le VIH/sida [Processes of stigmatization and discrimination of people living with HIV/AIDS]*. Observatoire du sida et des sexualités. https://www.observatoire-sidasexualites.be/recherches/processus-de-stigmatisation-et-de-discrimination-des-personnes-vivant-avec-le-vihsida/

The British NGO NAM studied the map of HIV criminalization in the world in 2020 and found that every continent has laws criminalizing the transmission or risk of transmission of HIV (Webb, 2020)[14].

In this respect, sub-Saharan Africa is the worst and best continent. It has the most laws criminalizing the transmission or risk of transmission of HIV, even though the rate of criminalization is low compared to the HIV prevalence rate. This is also the continent where such laws have been repealed in several countries, notably on the criminalization of mother-to-child transmission, as the counter-productive effects on prevention were immediately evident. In 2018, in the Democratic Republic of Congo, it was thanks to community pressure that laws specific to the criminalization of HIV were repealed (HODSAS-RD, 2019)[15]. This process is underway in Zimbabwe and Kenya.

4. Limits to the internationalization of the FAA and North/South solidarity

This is a complex issue which involves a paradox because community action is inherently local, but the internationalization of the FAA protects communities that are exposed. Finding a balance between local and international aspects is a challenge that few non-governmental bodies have mastered so far, mainly for financial reasons, as the donors for community action are mostly in the North while the action is located in the South.

However, it should be noted that in the vast majority of cases, the governance of FAA actions by most international NGOs lags behind that of international bodies such as the Global Fund in this sense.

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[14] Webb, R. (2020). *HIV criminalisation laws around the world*. NAM. **https://www.aidsmap.com/about-hiv/hiv-criminalisation-laws-around-world**

[15] HODSAS-RD.Congo. (2019). Vulgarisation de la loi portant protection des droits des PVVIH et le PA en RD.Congo (Brochure) *[Popularization of the law on the protection of the rights of PLHIV and people affected in DR of Congo* (Brochure)]. HODSAS-RD.Congo. **https://toolkit.hivjusticeworldwide.org/wp-content/uploads/2019/09/Dépliant_HODSAS_JWW_Juillet2019.pdf**

In 2016, the Global Network of people living with HIV (GNP+) published a *checklist* of questions to help FAA NGOs ensure that they were complying with two core MIPA principles[16]:

- Their organization advocates for the most meaningful involvement of PLHIV and affected communities in all aspects of the response to HIV/AIDS;
- Their organization is committed to the MIPA principle in its work for PLHIV and affected communities.

Regarding second principle, the problem often arises because humanitarian NGOs still tend, for reasons of lack of time and the search for funding, to write or do things "in place of" the people affected by the project in question.

The very publication of the **checklist** attests to the awareness of the larger PLHIV network of the possible distancing of FAA NGOs from community concerns, hence the provision of tools to ensure the permanence of MIPA. This is certainly not enough to allow for significant changes in the governance and methods of action for international humanitarian or charitable NGOs.

It is clear from these limitations that the FAA still has a long way to go.

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[16] The Code for Good Practice for NGOs Responding to HIV/AIDS. (2008). *Self-Assessment Checklist: Meaningful Involvement of PLHIV and Affected Communities (MIPA)* [Brochure]. The Code for Good Practice for NGOs Responding to HIV/AIDS. **https://livingpositivevictoria.org.au/wp-content/uploads/2016/09/Meaningful_Involvement_of_PLHIV_and_Affected_Communities_MIPA.pdf**

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Positioning of community principles in the FAA with regard to international community health statements

Let us now compare the three main statements and principles of community health that we discussed in the chapter on concepts and definitions. Let us see, after our analysis, if the FAA respects them, and at their coherence. Let us take the time to list some of them so that no one who claims to be a community activist forgets all that the FAA has contributed through commitment, work, and solidarity.

With regard to the Alma-Ata Declaration (1978)
The FAA has worked hard to provide scientifically and socially acceptable care with full community involvement. PLHIV and key HIV populations around the world have made it their duty, when allowed, to participate individually and collectively in the planning and implementation of their healthcare. They have also claimed the right to do so, as stated in the Alma-Ata Declaration.

It is also the FAA players who have made the most progress in providing essential medicines through their mobilization.

The FAA went further than Alma-Ata on the need for teamwork, including the community, whereas the Declaration only defines the team as health professionals and CHWs.

With regard to the Ottawa Charter (1986)
The FAA, if one refers to the principles of the Ottawa Charter *(see the chapter on concepts and definitions)*, adheres to these principles and sometimes exceeds them:

- it goes beyond health promotion and also addresses caring for the ill and implements the concept of harm reduction in the areas of drug use and sexuality;
- it has enabled the acquisition of individual skills and collective reinforcement, with equal access to information. It has gone beyond this, sometimes allowing community involvement in the training of healthcare professionals;

- it has enabled the creation of recognized multisectoral institutions and approaches in the healthcare sector, moving from the principle of cross-functionality to its implementation daily and around the world.
- since its creation, it has focused on non-healthy public policies that impede the health of PLHIV or those at risk of becoming infected, thereby addressing the determinants of health;
- finally, and perhaps most importantly, the FAA has promoted, as stated in the Ottawa Charter, "community as the main voice for health, living conditions and well-being" (World Health Organization, 1986, Section on Commitment to Health Promotion).

With regard to the most recent Astana Declaration (2018)
There has been a setback with the Astana Declaration, with little mention of community or CHWs in human health resources. Human rights, which the FAA had clearly introduced in its founding principles, are barely mentioned. We are witnessing the great return of healthcare professionals and national sovereignty.

It is clear from this brief review that the FAA is an exceptionally successful model of community engagement and involvement. So why doesn't it own up to this, or risk seeing these community assets disappear over time?

The power of community action: a focus on community monitoring and observatories

In the FAA, all aspects have community involvement, even research has been opened up to the community, but this has been done to provide much-needed assistance to biomedical and social science research. There is still a lack of "purely" community-based research interested in the communities themselves, their driving force for mobilization, their current and potential positioning in the healthcare sector, their current and potential operating modes, their partnerships, etc. This entire field of research is rarely discussed, and this leaves room for dogmatism and methods which are detrimental to the stabilization of the community world in the health field.

Nowadays, it is rare to find field projects on HIV that do not involve **at least** the people concerned, but it is often in an operational mode, much less conceptual, and more so in the French-speaking than in the English-speaking world. In the French-speaking world, communities of PLHIV and key populations often have little understanding of objective needs assessment. This considerably weakens their ability to "launch credible projects" and puts them at the mercy of more technical international and national NGOs. Let us look at two recent and related aspects of the FAA's community mobilization work that can benefit other conditions and healthcare in general.

Community monitoring is a practice that originally dates from the mid-2000s, and it was developed by the National Rural Health Mission (NRHM) across India. It aimed to provide equitable and affordable access to quality healthcare while being accountable and responsive to the population's needs, especially rural populations, and particularly women, children and the poor (Shrivastava et al., 2013)[17].

Together with internal monitoring of healthcare programs, regular studies and surveys, community monitoring consists of, according to Shrivastava et al.:

- ensuring that healthcare programs are linked to the needs and rights of communities;
- promoting community-driven actions on the ground.

The first means of action has been to monitor delocalized actions, public health services and care pathways.

Community monitoring in this context involves a partnership between healthcare services, the community and CBOs and NGOs

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[17] Shrivastava, S. R., Saurabh, P., & Ramasamy, J. (2013). Community monitoring: A strategy to watch out for. *Gateways: International Journal of Community Research and Engagement*, *6*(1), 170-177. **https://www.researchgate.net/publication/272397158_Community_monitoring_A_strategy_to_watch_out_for/fulltext/5641c0c008aec448fa61d08b/Community-monitoring-A-strategy-to-watch-out-for.pdf**

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Annette Ebsen Treebhoobun, the CEO of PILS in Mauritius, speaking at an international conference organized by the association in Mauritius in 2020.

in a constructive way based on evidence rather than on fault-finding (Garg & Laskar, 2010)[18].

Community monitoring has five phases:

- preparatory activities: identification of stakeholders and composition of the **task force** members must include representatives of civil society, politicians and members of the healthcare system;
- capacity building and training of trainers;
- development of tools and techniques for community needs assessment and community service evaluation;
- discussion of data and community feedback on data;
- evaluation of **feedback** received.

Based on the number of publications found on the internet, structured community monitoring is a process that is becoming common in the English-speaking world, but is still unusual, in this structured form, in the French-speaking world.

Nevertheless, the Global Fund has taken up the concept of community monitoring in 2020 to help applicants for Global Fund grants draw on examples[19].

Based on the examples cited by the Global Fund in its preparatory work on community monitoring published in 2020[20], there are no examples that address all aspects of care and prevention in its structured form in the fight against the three diseases. Will there be examples of this in funding examples from the 2020 Global Fund applications?

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[18] Garg, S., & Laskar, A. R. (2010). Community-based monitoring: Key to success of National Health Programs. *Indian Journal of Community Medicine: official publication of Indian Association of Preventive & Social Medicine*, *35*(2), 214-216. **https://journals.lww.com/ijcm/Fulltext/2010/35020/Community_Based_Monitoring__Key_to_Success_of.4.aspx**

[19] Global Fund. (2020). *Community Monitoring: Overview*. **https://www.theglobalfund.org/media/9622/core_css_overview_en.pdf**

[20] Global Fund. (2020). *Towards a Common Understanding of Community-based Monitoring and Advocacy*. **https://www.theglobalfund.org/media/9632/crs_2020-02cbmmeeting_report_en.pdf?u=637319005551530000**

In contrast, community-based observatories with a narrower view on aspects sensitive to the care of communities and the people who require care for the three diseases exist around the world. They originally had a priority interest in distributing drugs (ARVs), prevention tools, and stock-outs. Their interests have since expanded to include human rights, public policy implementation including free healthcare patient satisfaction surveys, monitoring and control of budgets and resources of Global Fund-supported bodies, etc.

Their principles are similar to those of community-based monitoring, but probably less open to joint working groups with health professionals. They are also more directly oriented towards advocacy, without fear of denouncing dysfunctions to improve the quality of care and the governance of healthcare systems (Expertise France, 2019)[21].

The limitation of observatories is their continuity, and their dependence on funding from outside the countries where they are located which also weakens their credibility in the countries. One might ask whether it would not be better to internationalize them in order to have monitoring standards for civil societies in different countries. However, their lack of integration into broader community monitoring could eventually cause them to disappear.

The power of community advocacy

The strength of advocacy is surely the most distinctive feature of the FAA communities since the beginning of the response. This has changed over time as the challenges faced by PLHIV have evolved.

If you look at the websites of the San Francisco Aids Foundation[22] and AIDES[23] in France nowadays , you will find the same advocacy

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[21] Expertise France. (2019). Observatoires communautaires en santé *[Community health observatories]*. [Brochure]. Expertise France. **https://www.initiative5pour100.fr/sites/default/files/ressource-doc/2019-11/Initiative5%25-4-Observatoires%20acces%20soins-FR-v4.pdf**

[22] **https://www.sfaf.org/**

[23] **https://www.aides.org/**

themes of equal access to care and new prevention and screening techniques, the fight against discrimination, with the same activist pressure coming from the field. In San Francisco, there is more emphasis on access to housing and reducing the risks associated with drug use. At AIDES, they place more emphasis on women, transgender people and hepatitis C.

As seen through the websites of these two important historical bodies, the advocacy is clear and unsurprising. The community aspects are implicit because there is no advocacy on these relatively unpopular issues.

In a paper published in 2016, Sunguya et al.[24] confirm in a meta-analysis of 25 publications on the outcomes of AIDS advocacy programs that advocacy has been able, in different countries and targeting different populations, to influence social norms and have an impact on reducing HIV transmission and adherence to ARV therapy. We suspected it, but it is still good to read, especially when the authors identify lessons that can be applied to advocacy in other non-communicable diseases, namely:

- putting those most at risk at the center of advocacy responses;
- using members of the relevant community to pass on messages to their peers and continue the messages over time;
- targeting specific practices with clear messages;
- basing them on scientific results.

The constituency of the three disease communities on the Global Fund Board issues regular position papers on Global Fund policy and strategy[25]. However, it is still very much tied to the vocabulary and concerns of the Fund, without much creativity or strength of proposal. It has to be said in chapter 6 that a single constituency representing people affected by three of the biggest pandemics on

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[24] Sunguya, B. F., Munisamy, M., Pongpanich, S., Yasuoka, J., & Jimba, M. (2016). Ability of HIV Advocacy to Modify Behavioral Norms and Treatment Impact: A Systematic Review. *American Journal of Public Health*, *106*(8), 1517. **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940638/**

[25] These publications are available at: **https://communitiesdelegation.org/publications**

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all continents would need to compromise a lot to keep everyone happy, and in doing so runs the risk of watering down its message too much.

The limits of advocacy on community aspects of the FAA

As we have seen throughout this book, the community aspects of the FAA seem obvious to everyone. Yet they are not mentioned, analyzed, or researched as such. This situation is dangerous because, by not singling them out, these community aspects of the FAA cannot be defended or improved, and they risk disappearing in favor of more medico-technocratic approaches.

These technocratic aspects already exist when you look at the websites of the community delegation to the Global Fund, the UNAIDS website on the place of CHWs in the Sustainable Development Goals, the Global Fund and the crowd of international FAA advocates around the Global Fund.

The dreaded search for funding for institutional survival has taken its toll in a soft consensus, hidden behind complicated words and concepts that are not very explicit.

Everything is still possible with community advocacy illustrated by actions. The community aspects of the FAA can be saved and highlighted at the price of a real evaluation of these actions according to terms chosen by the communities and not their donors but also at the price of an enormous research effort on community involvement to reproduce its successful aspects for the benefit of global health.

Conclusion

The community-based response to AIDS has often been built based on opposition to “mainstream” healthcare systems around the world with a desire for rapid reform and improvement for the benefit of people who require care and communities. In addition, the community-based approach has also helped bring communities closer to healthcare services, support health processes, build confidence and improve self-esteem in communities. It has set up actions that complement public healthcare systems, especially for access to care for marginalized and even criminalized populations.

The community approach has generated proposals for healthcare system reform in record time, focusing on those that are ill and at risk. More forward-thinking healthcare professionals and politicians have accepted these reforms. The community-based response to AIDS has promoted equal access to care and enabled advances in human and gender rights around the world that had not been achieved through reproductive health and primary health care. This response showed the strength of the approach in terms of powers and creativity.

The FAA is already well on its way to becoming mainstream *(see Chapter 5 on the integration of the FAA)*, but the most pressing thing to do to safeguard it is to learn more about its achievements, assets and limitations, as outlined in this book. The FAA, with its breakthroughs, is now out of step with the global health mainstream, which is currently focused on universal health coverage (UHC). It is a pity that this disregards any capitalization on the community assets from the past few decades that could tremendously support access to UHC.

Unfortunately, and also, fortunately, times have changed. However, old enemies such as healthcare professionals controlling healthcare and disease have returned with the therapeutic control of AIDS in particular and therapeutic improvements in malaria and tuberculosis. The generation which included the first members of the AIDS community is disappearing with their indignation, their strength of proposal and their constant and constructive challenge to the established order. Yet the advocacy topics of the last 20 years have not championed the community-based approach of the FAA, considered as implicit.

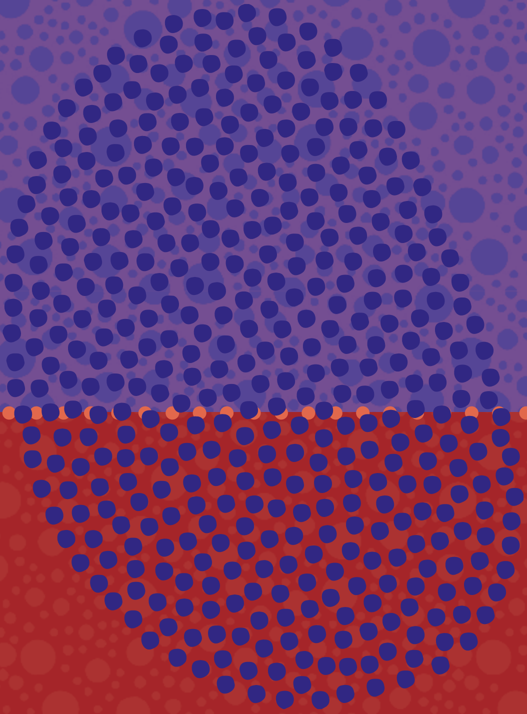
Through the financial flows it has been able to generate, the FAA has made many enemies and caused frustration for which it is now paying dearly. However, the main cost is that it has not capitalized on its achievements or analyzed its community model, which is more dynamic and more reformist than traditional community healthcare. The FAA community has not learned from its experience, and this is to its detriment and to the detriment of global health, which may be stripped of this unique experience in the next decade. It is clear to us that the approach taken by community health in the context of the FAA will only be sustainable and transform public health in the long term if an independent school for community health is created. Housing community health in schools of public health will never allow it to flourish because professional control will prevent it. Furthermore, the validation of the experience of community players in the FAA remains a largely insufficient response. The recognition of CHWs, which takes the future of the health of marginalized or poor populations well beyond the FAA, must be achieved through a unique school based on the community expertise developed by these marginalized or poor groups.

There was a naive assumption that access to care via antiretrovirals would be the most difficult step in the FAA, but this is not the case. All the practical and successful community principles and achievements that we have reviewed in this book that have modernized community health must now inspire global health for greater social justice. These FAA achievements must now be defended and promoted by a different, but no less intense, advocacy for the recognition of community expertise embedded in independent schools linked to public health systems.

Abreviations

AFD	French Development Agency (AFD)
AIDS	Acquired immunodeficiency syndrome
ARV	Antiretrovirals
BI	Bamako Initiative
CBO	Community-based organization
CCM	Country coordinating mechanism
CESAC	Centre for Counseling, Support and Advice (CESAC)
CH	Community health
CHW	Community health worker
CSS	Community system strengthening
DU	A person who uses drugs
FAA	Fight against AIDS
GDP	Gross domestic product
GF	Global Fund to Fight AIDS, Tuberculosis and Malaria
GIPA	Greater Involvement of People living with HIV/AIDS
GMHC	Gay Men Health Crisis
GNP+	Global Network of People living with HIV
GPA	Global Programme on Aids
HCV	Hepatitis C virus
HIV	Human immunodeficiency virus
HR	Human resources
HSS	Health system strengthening
IDU	A person who injects drugs
IRD	Institute for Research and Development
MDGs	Millennium Development Goals
MIPA	Meaningful Involvement of People living with HIV/AIDS
MoFA	Ministry of Foreign Affairs
MSM	Men who have sex with men
MTCT	Mother-to-child transmission of HIV
NACC	The National AIDS Control Committee
NAP	National AIDS Programme
NCDs	Non-communicable diseases
NGO	Non-governmental organization
NSP	National strategic plan

PEC	Support
PEP	Post-exposure prophylaxis
PEPFAR	President’s Emergency Plan for AIDS Relief (USA)
PHC	Primary health care
PLWHIV	People living with HIV
PR	Principal Recipient
PrEP	Pre-exposure prophylaxis
SDGs	Sustainable Development Goals
SR	Sub-recipient
SSR	Sub-sub-recipient
STIs	Sexually transmitted infections
SW	Sex worker
SWAps	Sector-wide approaches
TB	Tuberculosis
THT	Terrence Higgins Trust
TPE	Therapeutic patient education
TRP	Technical review panel
TWG	Transitional Working Group
UHC	Universal health coverage
WHO	World Health Organization



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A 40-year community mobilization against AIDS

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Dr Hélène Rossert has been firmly committed to the international fight against AIDS for nearly 30 years and contributed to the provision of universal access to HIV treatment including access to healthcare for marginalized groups. She promotes a deeper understanding of the Denver Principles, “do not do anything for us without us”, articulated by people living with AIDS in 1983. She details the contribution of the fight against AIDS to community health in the 1970s and 1980s. Based on the success of the community-based approach taken by key players in the fight against AIDS, she charts the way forward for universal healthcare access as part of the Sustainable Development Goals.

She adopted her activist approach at the AIDES organization in France, where she ran the first international program. Dr Rossert also draws on her experience as Vice Chair of the Global Fund to Fight AIDS, Tuberculosis and Malaria to apply the lessons learned from the fight against AIDS to other health conditions. She wants to convince public health decision-makers that universal access depends on community health systems accepted and valued as part of overarching healthcare systems.

By using specific examples from Coalition PLUS’s member associations, this book demonstrates that community health and its peer educators are the vital links between access to healthcare and prevention for the poorest and most marginalized people in our societies. As the fight against AIDS has shown, we cannot develop a rigorous and long-term strategy without involving them in the healthcare system and in the fight for their rights

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