Regional Platform
Latin America and Caribbean
Support, Coordination and Communication

vialibre

REGIONAL Alliance technical support

SOCIAL DIALOGUES

SUSTAINABLE CIVIL SOCIETY

A proposal to support civil societies of HIV, Tuberculosis and Malaria in the transition processes of Latin America and the Caribbean countries

by Joan Tallada
Consultant
March 2017

This document and the methodological tool hereby described were devised by Anuar Luna (Mexico), Alfredo Mejía (Colombia) and Miguel Martínez (Peru), who commissioned its materialization to the consultant Joan Tallada (Spain): the four of them worked closely together to conceive a pilot version that was implemented in Panama, Paraguay and Belize during the period between November 2016 and February 2017. The author acknowledges the work and contributions of Diego Postigo (Panama), Inés López (Paraguay), Martha Carrillo (Belize) and Carmen González (Global Fund to Fight AIDS, Tuberculosis and Malaria; Switzerland) who certainly have enriched the final version.

Why a proposal to support the sustainability of civil society?

The dawning of a new period that evolves towards self-sustenance with national resources in a number of countries receiving support from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM), together with the implementation of the corresponding GF's transition, sustainability and co-financing policy, has driven the proliferation of proposals and facilitation tools as of lately.

Among other tools are included the "Transition Preparedness Assessment Framework Tool" developed by **Curatio International Foundation**, the "Social Contracting Tool" by **APM Global Health**, and "Transition Readiness Assessment Tool" by **Eurasian Harm Reduction Network** with the collaboration of **AMPG Health**, which have already begun to be applied in several places.

Such instruments are certainly useful because, one way or another, they help to better understand the gaps and opportunities to sustain the response within the scope of current HIV/AIDS, Tuberculosis and Malaria relations. However, its application may be limited or even halted if civil society is not duly prepared with a process of cultural and organizational transition that provides the understanding on how the expectations of general society are changing with regards to the use of domestic resources, in which ways the latter redefines the rules of the national political game, and how all this forces civil society to rethink and reposition itself as key players in the sustainable responses.

In other words, it is necessary, albeit not sufficient, to equip civil society with technical instruments for the demand and management of services in HIV, Tuberculosis and Malaria. Previous or simultaneously, it is also necessary to increase their capacity for

analysis and action on how to sustain the social legitimacy of such services and how to ensure a timely political and budgetary response that complies therewith.

The whole society is in transition

The Latin America and the Caribbean (LAC) region, just like the rest of the planet in varying degrees, is undergoing fundamental changes in several areas that will determine the setting, opportunities and challenges for an effective response to HIV, TB and Malaria. These changes require civil society to undergo a process of reflection and critical adaptation into a new framework of relations with general society and with those who design, approve, implement and evaluate public policies in their countries for health or other related sectors. This document and the methodological process proposed hereby are aimed at supporting and stimulating civil society in the LAC region in order to encourage taking an active role and making a significant contribution to ensure that those changes fully integrate the effective response to the three diseases abovementioned.

The term most commonly used to designate transformations in progress is ''transition'', which may be ambiguous, since it designates an intermediate step between two conditions, a previous one and a subsequent one, which is intended to be well defined, but that not always fits reality. However, its use has become widespread in academic and official documents as well as in international meetings, and it is therefore used in this document. Its application to specific countries must be done with the due precautions and nuances.

Four interlinked transitions are changing the health landscape in LAC: The transition of funding sources for HIV, TB and Malaria programs (among others), the transition from international commitments to health, the transition of diseases or epidemiological transition, and the population or demographic transition.

Subsequently, we will explain briefly each of the abovementioned transitions, commenting on the implications for the region and for civil society action and sustainability strategies for HIV, TB and Malaria. This exhibition aims to provide analysis tools of a changing environment wherein community groups must conduct, analysis that argument the subsequent proposals for action.

In a second part, we propose the basis of a methodology for critical reflection on the environment and the definition of an action plan, including the identification of support and training needs which will facilitate civil societies of HIV, TB and malaria to meet the challenges and take advantage of the opportunities offered by these new scenarios as they become evident in their respective countries. This methodology was tested in a pilot project implemented in Paraguay, Panama and Belize during the period between November 2016 and February 2017. The implementation experiences in these three countries have been used to evaluate and improve the methodology. The results of these processes can be obtained through the following links:

- Transitioning and sustainability of civil society in the HIV/TB response of Belize

- *Report on Technical Assistance Risks and Needs of Civil Society in the Context of Sustainable Transition in Panama*

- *Sustainability of Community Response Actions to HIV, TB and Malaria in Paraguay*

This guide aims to applyiing the methodology, as detailed by local consultants hired for this purpose and conducted as by the pilot experience, at the end of the document. However, there are no restraints to yjis methodology from being adapted and applied by the initiative of the interested organizations in the countries where they decided to do so.

Transition of funding sources for HIV, TB and Malaria programs

Although the economic data for the past two years are negative, if taken from a three decades perspective Latin America and Caribbean countries have been gradually increasing their average income per capita[1]. While this indicator does not reflect how equitably the income is distributed among the population sectors, the average value is adequate to progressively cease to being considered eligible to receive total or partial aid from entities such as **GAVI(the Vaccine Alliance)** or **The Global Fund to Fight AIDS, Tuberculosis and Malaria**, or other bilateral agencies from high-income countries.

The expectation of the international community is that the governments of countries that until now were recipients are now able to raise more revenues from taxes from an upward economic activity and to use it to provide better basic social services, for example, education and health. The source of such taxes is often an emerging middle class that is increasingly connected, more involved and more demanding towards their governments.

Thus, the countries of the LAC region are increasingly dedicating more of their own funds to their own health systems, while donor countries are contributing less. This combined phenomenon also implies a change of legitimacies: While international agencies respond to boards of directors that include representatives of multiple actors, national leaders must be accountable to their own complex, unequal and hierarchical

[1] *"América Latina y el Caribe: panorama general". The World Bank: http://www.bancomundial.org/es/region/lac/overview#1 (accessed on 11/16/2016).*

societies, where the preservation of the human rights of minorities does not necessarily have the adequate support.

This raises the need for the civil society of HIV, TB and Malaria to reconsider its strategy, which until now has often been focused -regarding the financial sustainability of the response of civil society- in the relationship with bilateral or multilateral donors, shifting towards the dialogue and the advocacy in the field of local public institutions and in the society as a whole to which they are accountable to.

The transition of international commitments in health

In 2000, the United Nations General Assembly unanimously approved the so-called Millennium Development Goals (MDGs), an international commitment that resulted in an unprecedented transfer of resources from high-income countries to low and middle-income countries. Out of the 8 goals, 3 were related to health, and one in particular, namely **number 6**, was focused on the fight against HIV, malaria, and other diseases, such as tuberculosis. The commitments related to these MDGs formally expired in 2015.

In September of 2015, the 193 countries that make up the same General Assembly of the United Nations, among which are those from Latin America and the Caribbean, adopted the so-called Agenda 2030 and the commitment to adhere to the **Sustainable Development Goals** (SDGs). These are 17 goals, of which **number 3** refers directly to health: "Ensure healthy lives and promote well-being for all at all ages." A guarantee that is the responsibility of all governments, regardless of their level of wealth.

Thus, the international agenda to which the countries of the LAC region have adhered transits from a perspective focused on the reduction of mortality associated with specific diseases or populations (the so-called vertical approach) to another one, that although it still mentions them[2], puts greater emphasis on improving the general health of all people (the so-called horizontal approach).

[2]Of the 13 targets of the said goal number 3, the third one is committed to "put an end to AIDS, tuberculosis, malaria epidemics and neglected tropical diseases, and fight hepatitis, waterborne diseases And other communicable diseases by 2030"

This generalization of the international health agenda requires changing the discussion of the actors that until now have been involved in its implementation, including civil society, as it modifies both the number as well the interests and the framework of their relationship.

The transition of diseases or epidemiological transition

In the past 25 years, the profile of the diseases with greater weight[3] among the general population for the whole of the LAC region has been varying: whereas in 1990, communicable diseases and maternal and child diseases were most prevalent, nowadays their place has been taken by non-communicable diseases, although closely followed by firearm assaults and the persistence of lower respiratory tract infections[4].

Scenarios may vary when analyzing the situation in each country, each population group and each disease. In the case of HIV, the burden of disease compared to the set of health problems that cause death and disability is very high in Belize[5] and Dominican Republic, and significant in Panama, whereas, compared to the rest of ailments, it is not the case in Ecuador, Peru or Paraguay, where it does not appear in the list of the top 20 diseases with greater burden. As for tuberculosis or malaria, neither of them is listed in any of the countries mentioned.

Although the analysis varies and gives greater weight to the three diseases if specific groups are taken, such as the indigenous population or the reproductive age (15-49), and mortality is used as an indicator, we must remember that health policies and systems are shifting their focus towards increasing health gains for the general population rather than to reducing deaths in specific groups. The fact that this generates questions of inequity does not prevent it from being taken into account when determining the viability of action strategies.

---

[3]The burden of disease is expressed in "Disability Adjusted Life Years" or DALYs, which expresses the years lost due to premature death and the reduction of optimal quality of life as a result of a health problem. There is agreement among experts that all public health policy should aim at reducing the burden of DALYs in the population.

[4]Burden of disease expressed in DALYs in Latin America and the Caribbean for 1990 and 2015. Source: *vizhub.healthdata.org/gbd-compare*

[5]It has gone from being the first to the second disease, behind diabetes, in DALYs for the population as a whole, although it continues to be first in both DALY and premature mortality for adults between 18 and 49 years of age. Source: *vizhub.healthdata.org/gbd-compare*

Changes in the epidemiological profile of the region as a whole, and the way in which they reproduce or not in each sub region, country, or population group, have important consequences on where the focus of public health policy stands and the expectations that general society has about them.

Where the data shows a persistence or an increase in the burden of disease, as is the case of HIV in Central America and the Caribbean, the civil society's strategy must be different from that of the other nations, such as in South America, where these particular diseases have a much lower weight, and the demands of the general society about which should be public priorities for health intervention do not necessarily take them into account.

In addition, in the case of HIV, the evolution experienced by its approach should be taken into account given the expansion of the antiretroviral treatment coverage, the effect of such treatment on the transmission risk and the potential use of pre-exposure prophylaxis. In this regard, the emphasis shifts towards ensuring early detection and the **treatment cascade** rather than reinforcing behavior change programs or policies for modifying risk determinants among vulnerable populations.

Population or demographic transition

Parallel to the transition of diseases, LAC is experiencing the transition of populations, also called demographic transition: in 1990, the younger age groups had a much higher weight in the population as a whole, while in 2016 this weight is distributed more evenly, a trend that is accentuated in the projections for the coming years (see Figure 1).

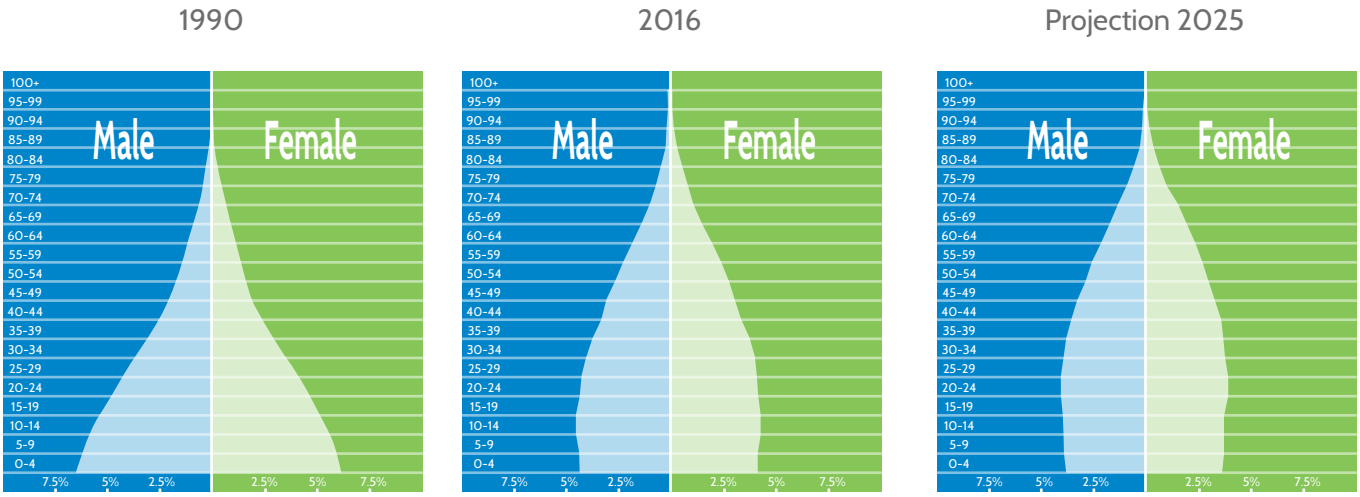

Figure 1: Population pyramid in Latin America and the Caribbean expressed by age and gender groups in 1990, 2016 and the forecast for 2025.
Source: **www.populationpyramid.net**

These projections point to an increase in life expectancy and the consequent aging of the population, which runs parallel to the increase in non-communicable diseases observed in the previous section.

It is true that, as it has been discussed, the impact of the three diseases by age group, the burden of HIV or tuberculosis among people of reproductive age (15-49 years) moves up several positions in some countries; but it is also true that the demographic composition will condition social expectations regarding the priorities that health systems must set forth.

Identifying the Challenges of Civil Society in Transition

The transitions described in the previous section compel civil society to exercise reflection and analysis about what are the big changes taking place in their environment and how they stand and act thereon.

This exercise is further driven by the Global Fund's **transition, sustainability and co-financing policy** to Fight AIDS, TB and Malaria, which supports sustainable transition processes, including the preparation of civil society and communities to participate in such processes through collective reflection, the identification of needs and the planning of the corresponding actions.

Objectives

The following sections offer a number of tools that civil society groups on HIV, tuberculosis and malaria in each country can use to achieve these two goals:

1. Building a shared vision on changes in the social, political, and financial environment and the challenges and opportunities that this entails for civil society in HIV, TB and malaria.

2. Develop an action plan that lays the foundations for addressing the challenges and take advantage of the opportunities presented by the transition processes. This action plan should detail the training and support needed to carry it out.

Methodology

This process shall be conducted following a participatory methodology using the analysis and interpretation of the available evidence, the opinion of experts and key players, and dialogue and agreement among peers.

Final products

At the end of this process in each of the countries where it is applied, the following products shall be available:

- The shared vision of civil society groups on how the transition is developing in their country, what the challenges and opportunities are.

- A plan with proposals for action, responsible people and institutions, and the corresponding implementation schedule. Said plan will have a section that defines the support and training necessary for its implementation and shall be accompanied, to the possible extent, by a corresponding budget prepared with the help of local consultants.

Process to Support Civil Society during Transition:

Orientation Guide for Local Consultants

This methodological guide proposes the steps to be taken to fulfill the two objectives described above:

- Build a shared vision

- Define an action plan that includes the necessary training and support to conduct it

Based on his/her knowledge and experience on the local dynamics, each consultant should assess the extent to which each activity is relevant in their country, and propose the corresponding specific and reasoned plan.

1. Build a shared vision

To build a shared vision requires the following components: To obtain the best available and most relevant evidence for the analysis of the environment and its foreseeable evolution, gather the opinion of experts and key actors in this regard, and analyze it in groups.

Activities to be performed:

1.2. For his/her presentation before the members of civil society, the consultant should obtain and systematize the following information for their country, where available:

- Current and future situation regarding international assistance for health, in particular the Global Fund.
- Current situation regarding financing with domestic resources to tackle the three diseases: amounts and priority areas.
- Government health action plans, including HIV, TB and Malaria, and other related sectors such as gender and human rights[6]. In particular, determine whether those plans include processes involving civil society.
- Evolution of the burden of disease in the country within the last 10 years using the database **vizhub.healthdata.org/gbd-compare** (also available in Spanish) or other sources deemed equally reliable.
- Current population pyramid and future projections (2025). The United Nations database hosted in **www.populationpyramid.net** may be used or other national sources deemed equally reliable.
- Experiences of existing political and financial sustainability of civil society, including intersectoral initiatives that are directly or indirectly related to health.

1.3. The consultant should identify and interview other experts and key stakeholders to gather additional information and opinion, such as members of the government (including those responsible for national HIV, TB and malaria

[6]In addition, it can be determined whether such plans are associated with the implementation of the Agenda 2030 of the Sustainable Development Objectives.

programs), UNAIDS or other multilateral agencies representatives, representatives of civil society entities other than the health or academics sectors, etc, with special attention to counting on the contribution of Country Coordinating Mechanism (CCM) members.

1.4. The consultant should identify and convene a meeting of civil society members on HIV, TB and Malaria, and CCM representatives, where he/she will present their findings and facilitate a dialogue on the following issues:

- How is my country evolving in relation to the most prevalent diseases? What are the forecasts for the future in the short and medium term?
- Is the withdrawal of international donors offset by an increase in domestic resources for health in general and for these diseases in particular? Do priorities vary as the donor moves to self-financing?
- Which areas of the response to HIV, TB and Malaria were financed by international cooperation, and what impact their withdrawal may have if not replaced by national resources?
- How are these changes affecting civil society?
- How does general society take in such changes? Is it sensitive with regards to respect for the human rights of minority groups, including the right to health?
- Is there a risk that HIV, TB or Malaria will be perceived as already receiving sufficient resources and that the priorities should now be different? What may civil society do about it?

The meeting should set apart a space for reflection, exclusive for the civil society, to address the following questions:

- Are local authorities in favor of having civil society to design, implement and evaluate health projects in general, and for the three diseases in particular? Are there adequate legal mechanisms for this?
- What role should civil society play in the context of transitions? How can it be critically adapted and contribute to that process?

- As a service provider: Are the same services still needed? How do we optimize them? How do we make the general society value the benefits it obtains from them?
- As advocates: What strategies are needed in the transition scenarios?

The consultant may use the following example to develop sustainability strategies in countries where HIV, tuberculosis or malaria have a low disease burden.

Elements for dialogue 1: From competence to cooperation

In discussing with the local authorities about the allocation of domestic resources for HIV, TB or malaria, it is often the case that we are met with the following answer: Money is limited and many needs must be met. The instinctive response is usually to raise the tone of the claim and present one's own need as the most pressing one. This strategy does not usually work, as it falls into the dynamic of opposing some diseases against other (divide and rule) instead of focusing on the amount and management of the resources available to the health system as a whole.

On the contrary, the defense of sufficient, transparent and sustainable financing of the entire health system allows HIV, tuberculosis and malaria groups to gain social prestige and influence capacity, what we call political capital, which will help them ensure that prevention, care and treatment of these infections can continue to be part of national health plans, now with local resources.

They can also offer other patient organizations to collaborate so that the accumulated experience in defense of human rights and against stigma and discrimination for HIV or TB, for example, extends to the entire health system and protects all its users. It is through defending what is common that will cover the specific.

2. Defining an action plan, and its required training and support

The consultant will help define the action plan, and the training and support needs, which will be defined at a second meeting of the same group of civil society members as in the first meeting. It is appropriate that this meeting takes place shortly after the first one.

The consultant will propose a meeting structure in order to allow the group to orderly respond the following questions:

- In light of the reflection on the transition's challenges and opportunities conducted previously, how do we make HIV, TB and/or malaria to remain on the political agenda and be part of the social demand during and after the transition period? Two possible scenarios:
    - If our country continues to have high or medium-high HIV prevalence but low TB and malaria;
    - If our country has a low disease burden in any of the three diseases.
- How do we ensure that these agendas count on the effective participation of civil society, especially in the post-transition context, both in their design, as well as in their execution and evaluation?
- How do we make civil societies of each of the diseases, different in dimension, to transfer knowledge and successful experiences to each other?
- What steps should we take to achieve this? Some examples:
    - Advocate on the public policies for health and other sectors that affect them.
    - Advocate on the implementation models for those public policies.
    - Advocate on budgets for health and other relevant areas of government action.
    - Weave or strengthen alliances with other concerning groups of patients or entities in order to advocate for a system of equitable health for all.

- Weave or strengthen alliances with intersectoral networks addressing the risk determinants to general health, and in particular for the three diseases and most vulnerable populations.
- Determine the added value of civil society's contribution to the response to HIV, tuberculosis and malaria.

- Who should conduct each activity and how do we get coordinated?
- What is the execution schedule?
- What resources do we need?

    - In terms of training: for example, in political and parliamentary advocacy, analysis of the budgetary cycle, health system financing models, social contract models, cost-effective analysis of services, etc. Specifically, the identification of training needs will take into account the following issues:

        - What is the lowest common denominator of this or other knowledge that we must all possess?
        - What are the expertises that can coexist independently in co-operative groups?
        - What is the existing know-how and where is it located? How can it be shared and put to common service?
        - Who can provide the know-how we need but do not have, and how much does it cost?

    - In terms of technical and financial support: What is the approximate cost of carrying out the action plan (including training), detailed according to activities to the extent possible.

The consultant may use the following exercise to discuss the most effective strategies for sustaining the social and political legitimacy of national responses to HIV, TB and malaria.

Elements for dialogue 2: Count the benefits before the amounts

Civil society is often tempted to demand from governments the replacement of the exact monetary amounts left out in national budgets by international donors. Such vision emphasizes the volume of expenditure, which may be unrealistic to get, instead of focusing on its optimal management, which would be more intelligent. The experience in other countries shows that the same services that were previously provided with international funding may be offered, or even increased, with less domestic resources thanks to better purchase agreements, a reduction in the number of intermediaries, increasing collaboration with civil society, or adjusting wages to the local labor market, among other measures.

Society in general will be more likely to support demands that make domestic resources more profitable and that are focused on the benefits obtained, rather than requiring public financing economic figures inherited from donors.

At the end of the consultations meetings, the consultant will draft a preliminary report containing the following information with regards to the corresponding country:

- The progress made in the shared vision about the transitions affecting all three diseases.

- The action plan and the support and training needs that participants from civil society have agreed to, where applicable, in accordance with the terms set out above. The steps to take in order to incorporate key aspects from the civil society action plan into the transition plan negotiated by the CCM with the Global Fund.

This preliminary report should be prepared based on the format proposed in Annex 1 and shared for via email to be validated by the participants . Once validated, it will be sent to the project coordinators for discussion and agreement on the final version.

Annex 1: Country report format (maximum of 15 pages, excluding appendices)

- First page: identification of the project, the country and the author of the report
- Index
- Acronyms
- Executive Summary (maximum 400 words)
- Background
    - Rationale of the project
    - General and Specific Objectives
- Methodology
- Results of the Desk Review
    - Situation of HIV, TB and Malaria in the country, and in relation to the general burden of diseases.
    - Country plans in response to HIV, TB and Malaria.
    - National and international funding of the response to the three diseases: recent developments and future projections.
    - Experiences of political and financial sustainability of civil society.
- Results of Consultations with Experts
    - Consulted experts
    - Main points in common and possible discrepancies
- Results of the Meeting to Build the Shared Vision
    - Participants
    - Definition and key elements of the shared vision

- Results of the Meeting to Agree on the Action Plan:
    - Strategic Objectives of the action plan
    - Short, medium and long term specific objectives
    - Activities to be conducted and their timeline, according to a short, medium and long-term prioritization.
    - Monitoring indicators and impact assessment of activities.
    - People and institutions responsible for its implementation.
    - Training required for the implementation of activities.
    - Approximate costs of the activities of the action plan, as possible.

- Incorporation of the Action Plan into the Country's Transition Plans: Challenges and opportunities, and steps to take.
- Conclusions and recommendations.
- Annexes (if applicable).
- Bibliography, references and online resources.