

## In-depth Thematic Studies

During the month of October 2016, a Community Action and Leadership Collaborative (CLAC)-affiliated researcher<sup>1</sup> conducted 19 extensive independent interviews with key and vulnerable populations and community respondents. CLAC members themselves identified the interviewees to ensure representation of all disease cohorts and geographies relevant to the Global Fund, and their involvement in the thematic areas of exploration. Interviews averaged 90 minutes in length and were, by necessity, flexible to ensure capture of the dynamics specific to respondent experiences. A vetted list of qualitative open-ended questions guided the discussions. The views presented here are not necessarily CLAC's, but represent those of the respondents, further endorsed by in-country community consultations.

To maintain confidentiality, as requested by interviewees, quotes are anonymous, and editorial liberties taken to further mask identity and ensure narrative flow.

*The CLAC is a unique collaboration between AIDS and Rights Alliance for Southern Africa (ARASA), the Global Network of People Living with HIV (GNP+), Global Action for Trans\* Equality (GATE), the Global Forum on MSM and HIV (MSMGF), the Global Network for Sex Work Projects (NSWP), the International Network of People Who Use Drugs (INPUD), and the International Treatment Preparedness Coalition (ITPC). The collaboration between these regional networks supports a deep understanding and connection with key populations to strengthen expertise in the areas of HIV and tuberculosis, treatment access, human rights and community engaged. [www.clac.cab](http://www.clac.cab).*

### Thematic Study 2: Taskforces: Building Resilient and Collaborative Systems for Health Advocacy

#### Summary

Community groups have long struggled to gain meaningful entrance and participation in national disease responses. Over time, certain groups in certain contexts have risen up and advocated successfully for their priority needs. Overall, however, even the strongest community groups or national networks are often overpowered by larger stakeholder influence, and particularly that of governments.

A variety of homegrown and field-tested initiatives are working to overcome these challenges, improving and strengthening engagement in grant and evidence generating processes from the outside-in. This thematic study explores these sustainable community systems for health, variously labeled and hereafter-called community taskforces. Through respondent interview quotes, it presents rationale and method examples being used by civil society and community-led organizations to come together across diseases, population, and thematic issues as one voice to coordinate engagement, information sharing, and advocacy.

Respondents applauded the Global Fund as unique from other donors in their insistence on engaging community stakeholders in all aspects of funding, not just as periodic consultants or beneficiaries “not smart enough to fully participate.” The approach is not without **challenges**, however, including:

1. Lack of skilled, empowered, and motivated **community leaders**
2. **Distrust** within and between discrete communities, and between communities and other stakeholders (particularly government)
3. The need for a clear **communication framework**

Areas for **replication** found to facilitate the building of resilient and united systems for health advocacy include:

1. **Recognize and appreciate the diverse willingness and ability to engage** in grant processes

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- 1.1 Tailor support for skills and leadership strengthening based on individual population and organizational needs
- 1.2 Acknowledging conditions causing malaise and demobilization
- 1.3 Facilitating community dialogue around fissures
- 2. **Identify common themes and issues for communities to mobilize around** including (but not limited to) human rights, stigma and discrimination, drug stock-outs, funding shortfalls, programmatic exclusion, unfriendly and discriminatory services, gender-based violence and inequality, legal and policy barriers, harmful cultural and traditional practices, and the desire to effect change, and to follow:
  - 2.1 Dial down common themes and issues to community group-specific interests
  - 2.2 Develop priorities to jointly advocate around
- 3. **Support official formation of homegrown community taskforces**
  - 3.1 Explore and promote taskforce opportunities
  - 3.2 Establish a comprehensive communication framework
  - 3.3 Provide technical support and resources
  - 3.4 Exercise patience with the process, working strategically even if slowly towards goals

Ultimately, taskforces provide a legitimate, organized entity serving as a single point of community contact appealing and relevant to donors, government, and other key stakeholders. They make it easier for stakeholders to interface with all community groups, and direct resources and technical support to build community capacity and skills.

## 1. Recognize and Appreciate the Diverse Willingness and Ability to Engage

Many community respondents share their sense that not all communities are ready to engage “fully,” or able to engage at the same level as other communities.

### 1.1 Tailor support for skills and leadership strengthening based on individual population and organizational needs

**“Networks and institutions need to be prepared and ready to engage for engagement to work.** When resources are really limited, and there are so many issues to address, and organizations are working so hard just to get a little bit done with almost nothing, they are not attracting the kind of staff or volunteers with the technical skills, the language skills, and the educational background and practical experience to be able to engage.” Another noted, “At the end of the day, nobody from the community really has a clue what is going on in the Global Fund processes. They don’t understand, don’t know how to engage better, don’t know how to navigate even their own government given changes and turnovers and strikes and corruption.” Communities feel demoralized. Further, the **government and most principle recipients (PR) do not trust communities to manage grant funds or programmatic activities.** “Given appropriate technical assistance and support, and with financial and managerial systems in place,” community groups can potentially pursue grant-funded activities “better than anyone else, for they know their communities.” **There is a huge need for technical skills development and capacity building within community organizations, so that they are ready and able to engage and make a difference.**

### 1.2 Acknowledge conditions causing malaise and demobilization

Some respondents complain that **stakeholders and decision-makers exhibit a general weariness for community issues** “People got tired of me harassing them about TB issues,” said one. “Those living with HIV and malaria had the same experience. People just stopped listening to us.” The weariness goes both ways. “There is demoralization experienced by key populations after repeated disappointments.” Some **communities feel disenchanting** by the entire experience. “The process is spelled out to be participatory, and looks participatory, but the implementation of it as being led by the government, and

finalized by the government... is not participatory.” Further, “there are issues of the manner of presenting, the lack of data to back up prioritization, a single voice speaking out for all, lack of leadership skills,” and more, all hindering community ability to enter into the process, and be heard, in many country contexts.

Ironically, **in countries where prevention and treatment are working well for key and vulnerable populations, community mobilization is weakening** because “there is no longer a need to maintain a high level of mobilization and advocacy.” With no fight anymore, there is less drive and interest. “The issues driving communities have been mitigated and without them they are demobilized and becoming inactive. Funding is decreasing, and as they become smaller, many organizations are folding. Policy advocacy and watchdogging in these situations are at risk of extinction.”

Demobilization is occurring for a multitude of other reasons. In some countries, **it takes years to establish systems for civil society organizations working with/for ‘criminalized’ populations to formally register.** In other countries, **strict donor funding requirements, including those of the Global Fund, weaken community engagement where they do not have the capacity to comply.** Indirectly, this is a “success for governments seeking to block funding flows to civil society.” **Some feel that the Global Fund is shifting towards more government, and less community, support.** “In the early days [before the New Funding Model/NFM], there were more consultation meetings with key population communities. One thing that worked very well was dual track funding... it was a chaired process with civil society and government stakeholders. It still is, but the government is always stronger than civil society, and this needs to [be better] accounted for.” **The perceived shift towards more governmental funding and less community investment has discouraged some activists.**

### **1.3 Facilitate community dialogue around fissures**

Many respondents complained that **as a whole, communities are fractured, competitive, adversarial, and distrustful of other groups.** With the global trends to capacitate and include ‘safe’ groups over ‘controversial’ ones, shrinking budgets, and new and reemerging fundamentalism, it is no wonder different populations resist working together. “As funds have shrunk there is lots of competition for remaining funds, and the capacity of organizations is very poor. Leadership is not always positive. It is hard to negotiate without trust, and hard to coordinate efforts when one population is jealous of another. Informal communication and gossip is rampant, and [groups] are divided on every topic. The only thing that brings them together is fundraising and bitching about funds.” Generally, “they all tend to focus on their own issues. It has been a mistake to view them as a homogenous group. Rather, they are quite diverse, and that is what gives them strength... But, **where there is money [involved], there is always going to be a lack of trust.**” Given the complexity of the Global Fund and other grant mechanisms, most communities “don’t know what is happening at different levels and it is hard to follow that much information. They cannot track activities accurately. They are very diverse and not organized, and don’t present as one voice, while the government is very organized and has lots of opportunity to prepare and push their own agendas through.”

## **2. Identify Common Themes and Issues for Communities to Mobilize Around**

Despite discord and discouragement, respondents also share examples of diverse groups and leaders organically finding common ground to work together. **In many examples, crosscutting human rights mandates prove to be the glue that holds and brings all populations and disease communities together.** “We realized after many discussions that our human rights issues were common and we needed to work together better.” **Other binding factors include stigma and discrimination, drug stock-outs, funding shortfalls and exclusion from programming, unfriendly and discriminatory services, gender-based violence and inequality, legal and policy barriers, harmful cultural traditions and practices, and, most importantly, a desire to effect proactive change.**

### **2.1 Dial down common themes and issues to community group-specific interests**

Of course, **finding common ground takes time, investment, and strong leadership, and does not work well when imposed (forced) from the outside in. It is better to let communities “find where the common ground is themselves,”** and encourage them. With strong leadership, communities are able to “look at big picture issues common to all and merge around that as an advocacy agenda before dialing down to the sex worker or person who uses drugs or other community, otherwise there is no value seen... There is always fear that by defining a common agenda some people will not ‘fit’ into it. **There is a strong need to spend time talking about alignment areas, how things spell out differently for groups, while keeping in mind the underlying issue.**” The reality is that “none of the networks alone can address even their own issues.”

“We realized that no matter how much streamlining we did, [resources] were never going to be enough and we needed to work together” to ensure efficiency and effectiveness. This did not overlook the fact that there were issues community groups did not agree on, “but we did agree on one thing, and that was that if we united as a single body we would be stronger advocating within the CCM (country coordinating mechanism).”

### **2.1 Develop priorities to jointly advocate around**

Despite the need to recognize individual needs and priorities, the **CCM and the government is perceived as more willing to accept broader packages with more expansive interventions for communities than those narrowed down to discrete—and potentially controversial—populations.** Respondents feel this is why PLHIV often ended up at the forefront, for they “tend to make discussions easier because you can’t argue the needs of PLHIV.” The moment criminalized or socially excluded and stigmatized groups are involved, conversations get tougher.

**The beauty of united communities is that there are safety nets in numbers, and it is less likely that an issues or disease population will be left out as the process moves from concept note to budgeting, work planning, and implementation.** Jointly establishing priorities and then holding individual meetings to move groups forward with consensus around the joint priorities works well. There is realization that “CCMs work better when all key (and vulnerable) populations come together around issues as one voice and push jointly for endorsement and to be heard.”

## **3. Support Official Formation of Homegrown Community Taskforces**

Amongst respondents, mobilized community taskforces were variously called Secretariats, consortiums, *Observatorios*, coalitions, community consultative groups, and community technical committees. **They work best when homegrown, bottom-up systems for health advocacy that are democratic and transparent, meet monthly, have an agenda, vote in a facilitator, and establish strong ties with CCM community representative(s).**

According to one respondent, when recalling taskforce formation, “We got together and discussed how to get issues moving for all populations. We requested technical assistance to bring together civil society organizations to design a roadmap around our involvement in the country dialogue process.” Another said, “We decided we needed to formally bring together malaria, HIV, TB, and key populations including sex workers, men who have sex with men, PLHIV and TB, and people who use drugs. This led to the formation of a consortium of 15 organizations to advance the rights of key affected organizations... The purpose was that whatever happened on the CCM, we would all advocate with one voice.”

**Eventually, taskforces may become a body to “augment SRs in implementation.** We believe engagement should not end with consultation because we have a vested place and interest in implementation and must be part of the ongoing process, not just there for the sake of being counted. Our member representatives form an important part of implementation. We provide a way to get information and to share information and data and processes about the grant itself (with communities). Key population representatives on the CCM report (back) to us.”

## 2.2 Explore and promote taskforce opportunities

Following formal organization, many new taskforces issue press statements to announce their presence, invite key stakeholders to roundtable discussions where they present prioritized issues, or formally present priorities to the CCM for endorsement. This draws attention to themselves as legitimate, and organized, entities to **serve as a single point of community contact**. In all cases, **taskforces are appealing and relevant to donors, government, and other stakeholders alike, particularly if they cut across diseases, populations, and thematic issues**. In fact, they make it easier for stakeholders to interface with all community populations under one umbrella, and provide a single place to direct resources and technical support to build community capacities and skills. Respondents note that their participation is sought more post-taskforce formation. “Suddenly, things began to change. Before nobody was interested in talking to us. Now they are. We are invited into strategic planning development and other meetings and working groups. We were even invited to participate in the NSP. The more we participated, the stronger our united voice became.”

**IIPC’s community consultative groups are one noteworthy example of unification as a mechanism** to promote i) social accountability, ii) community-based monitoring and sensitization, iii) consultations among discrete populations, those living with disease, women and youth, and iv) advocacy. “They represent all networks and will eventually become an SR mechanism... Because they include key population organizational representatives, CCM representatives, and (in this case) ministry of health representatives, action can be taken immediately (to offer) immediate solutions.” Taskforces pursuing a process of **joint capacity assessment and situational context mapping, followed by issue prioritization and CCM endorsement, ensures that they will not easily be ignored**. Respondents note that, “Community consultations and endorsement of priority recommendations were a key to success. All key population and civil society came together with recommendations and pushed as one voice to get CCM endorsement.”

## 3.2 Establish a comprehensive communication framework

**A key to successful taskforces is successful communication** – with community representatives to the CCM, and with other key stakeholders, government, civil society members, and multilateral partners. As seen in Thematic Study 1, communication between community representatives and their constituents was challenging given the lack of sufficient (or any) funds to support meetings or information exchange. As a unified platform, however, taskforces pool resources and even apply for grant funding to support communication activities, which they deem “necessary to ensure accountability [to all constituents], and transparency.”

Communication spans regular meetings to raise and discuss issues, follow-up on issues, provide information on process and progress, and gather information from constituents. Given all the various networks and community bodies linked in to successful taskforces, communication can be challenging. “We are currently building a communication strategy to communicate more effectively with members,” said one respondent, and endorsed by several other respondents as a key element of any successful unified engagement. Accordingly, a good communication framework must take into consideration the mechanism of communication (*how* including Facebook, WhatsApp, email, SMS, phone calls, face-to-face meetings and forums, and community focal points to relay information) to both share and gather information and mobilize people (*where*), with *whom*, according to what schedule (*when*), and for what purpose (*why*). One respondent volunteers that they have a newspaper where they publish CCM activities. “**Open communication means greater involvement in processes and procedures that make decisions.**”

As a side note, a comprehensive **communication framework must also identify what CCM representatives may share with taskforces, and subsequently constituents**. “Conflicting messages come from the Global Fund Secretariat about how far community representatives can and should consult their constituents about CCM activities. It is confusing to most representatives.” Further, “CCM members

don't know what to do after meetings are concluded. There is no formal network or method of communicating with civil society, no formal method of back and forth and debate." This is where taskforces play such an important role, as they ultimately have reach into all geographic areas, as well as across all community sectors.

### **3.3 Provide technical support and financial resources**

To support the growth and development of successful taskforces takes resources. **Many community organizations are unaware that technical assistance or capacity strengthening support is available, or how to apply for it.** "It is easy to respond to once it is known about. But [without taskforces], it often goes to those already linked into processes and who get preferential treatment and have multisectoral relationships," and is thus potentially divisive. **"The Global Fund needs to see beyond organizations that are long established and those that are nascent and could have the ability to do more if only their capacities were built up in needed areas."**

Current technical support has limitations. Nearly all respondents mention the perception that it "ends once the grant is signed, leaving key populations hanging." Unanimously, respondents request that **support and resources be provided continuously, and consistently, throughout the grant cycle, not just during grant development.**

Overwhelmingly, the Community Rights and Gender Department (CRG) is hailed as the champion of community-directed technical assistance, though "they [seem to] have very little influence on implementation. They are the ones with the most technical and tactical experience. **The Global Fund should... give the CRG them more authority and funds to reach communities and continue to do what they do best.**" Currently, "the CRG cannot handle all technical assistance needs (requests), and the budget isn't really effective on a wide scale."

### **3.4 Exercise patience with the process, working strategically even if slowly towards goals**

Respondents with taskforce experience caution that, "It takes time. We had the passion and the time and we knew it was the right thing to do and it would pay off in the end. And it has." Further, **"There needs to be recognition [and acceptance] that you can't have everything at once.** With help from external consultants and technical expertise, work on ticking one box at a time and getting that done, and done well, so you are prepared to move on to the next task." For example, **strong taskforce champions prepare and plan strategically for the time, leadership commitments, and organizational structures needed to mobilize and properly unify. They solicit targeted technical support, and tackle issues one at a time with quality and thoroughness,** knowing that the results of others nearly guarantee their success. Some are now positioning themselves to be SRs and even PRs, identifying the capacity and skills needed to meet requirements, and proactively seeking technical support to fill those gaps. All agree that having a specific mandate around which to focus communities in solidarity support their ongoing engagement across all phases of country dialogue, from national strategic plan (NSP) development, to concept note, grant making, implementation, evidence generation processes, and even beyond the Global Fund-related activities. "The results are unparalleled."