

COMMUNITY SYSTEM STRENGTHENING AND TB

This Guidance Note on Community System Strengthening and Tuberculosis (TB) has been prepared based on the Global Fund's Information Note. It is to enable a consolidated understanding of Community Systems Strengthening in the context of TB and to maximise the contribution of communities, civil society organisations and key affected populations (KAP's) in an effective TB response. It is not a set of instructions but is designed to stimulate critical thinking about the important role that communities play and how they can be engaged and supported to ensure a country's national TB response has the biggest impact.

What is Community System Strengthening?

Community System Strengthening is about **strengthening systems**. It is about investing in the system pillars (monitoring and accountability, advocacy, social mobilisation, community linkages, collaboration, institutional capacity building, planning and leadership development) that enable community organisations to maximise their contribution to all aspects of TB programming. Strengthening community systems means investing in an environment that is enabling for communities and community organisations.

Community systems strengthening (CSS) develops the roles of key affected populations and communities, community organizations and networks, and public- or private-sector actors that work in partnership with civil society at the community level, in the design, delivery, monitoring and evaluation of services and activities aimed at improving health. CSS has a strong focus on capacity building and on strengthening human and financial resources, with the aim of enabling communities and community actors to play a full and effective role alongside formal health and social welfare systems.

The *goal* of CSS is to achieve improved health outcomes. Community systems strengthening (CSS) is therefore an *approach* that promotes the development of informed, capable and coordinated communities and community-based organizations, groups and structures. It involves a broad range of community actors and enables them to contribute to the long-term sustainability of health and other interventions at the community level, including an enabling and responsive environment in which these contributions can be effective.

Why are Communities important in the TB response?

TB is a social phenomenon with severe health implications for the whole population, however there is little understanding of the critical role played by communities in mitigating those implications. The lack of meaningful involvement of affected communities, in all aspects of TB programming, often leads to "morally acceptable targeting" in a country's TB response. For example, LGBT (lesbian, gay, bi-sexual, transgender), IDU's, SW's may not be considered "morally acceptable" by a country and TB programmes can often resort to a supply driven approach which is insensitive to the specific requirements of these affected communities leading to barriers for access to services. Ultimately this undermines a country's TB response.

Engaging with communities facilitates '*Knowing your TB epidemic*' deepens understanding of the contribution of communities and the key populations in which they are most active. This in turn, supports more informed, evidence based, TB response planning processes towards a more effective outcome.

Whatever approach is taken it is vital to bring a critical analysis to enable a change process in the TB response; 'Vital' to avoid stagnation and for pushing the TB response to enhanced success and 'critical' because health systems alone cannot cope and need the skills, knowledge and work of communities to maximise the scope and effectiveness of national plans and a comprehensive TB response.

Who are the Key Affected Populations in the context of TB?

The Global Fund Information Note on CSS (Feb. 2014) describes KAP's as:

Key Affected Populations may be broadly described as those "*most often marginalised and have the greatest difficulty in achieving their rights to health*".

The population faces high risk and high burden of at least one of the three diseases.

- The populations' access to relevant services is significantly lower than the rest of the population, and thus dedicated efforts and strategic investments are required to expand coverage, equity and accessibility.

- The population faces frequent human rights violations, high barriers to services and limited recourse because of systematic disenfranchisement and social and economic marginalization and criminalization. However, in the context of TB it is helpful to understand a more nuanced description. In the context of TB we can consider KAP's under three distinct groups:

1. People at increased risk of TB because of biological and behavioural factors that compromise immune function.

People living with HIV/AIDS and those with other health conditions that decrease immunity for example those on long term therapeutic steroids, those on immune suppressant treatment and people who are malnourished are vulnerable to TB because their compromised immune systems are less able to fight infections.

People with pre-existing medical conditions such as Diabetes, Silicosis and other dust related lung disorders are also particularly at risk and less able to fight exposure to TB.

Certain lifestyle activities which compromise immunity include those who smoke and people who consume high quantities of alcohol (over 40gm or 50mL per day), people who use drugs, increasing their risk of TB infection.

2. People who have increased exposure to TB bacilli (due to where they live or work – overcrowding, poor ventilation)

Examples include:

Health Care Workers who may be exposed to TB bacilli through their day to day work of delivering care and support to TB infected patients.

Contacts of TB patients (in households) are at increased risk of exposure because they might be the primary carer or living in a household prior to a family member being diagnosed. Contacts in workplaces or educational facilities are vulnerable both prior to a TB patient being diagnosed and during the early stages of treatment of TB patients in their environment.

Incarcerated people (prisoners) and staff working in correctional facilities are particularly vulnerable to TB because of the overcrowded nature of correctional facilities and the, very often, low standard of living conditions.

Miners, peri-mining or mining-affected population, Slum dwellers in urban settings and people living in hostels are at risk of increased exposure to TB bacilli for a range of reasons including poor living and sanitary conditions, poor ventilation, overcrowding, malnourishment etc.

3. People who have limited access to health services (due to gender, geography, limited mobility, legal status, stigma)

Women and children in settings of poverty: Women suffer disproportionately the consequences of TB, and children, especially young children, could suffer from severe and fatal varieties of TB.

Remote populations, Deep sea fishermen, because geography and working lives limit access to health services, while those with limited mobility, the Elderly and people living with physical or mental disabilities may not have anyone to help support and supervise their attendance at health services.

Homeless, migrants, refugees and internally displaced people and Indigenous peoples and ethnic minorities often suffer increased stigmatisation and legal status problems making it difficult to access health services.

Sex workers and victims of sex trafficking, people who use drugs, men who have sex with men are often outside of the law which can be a major obstacle to accessing health services.

Many of these population groups benefit from community support and therefore it is important to understand what communities do in the context of the TB response

What do Communities do in the TB response?

In addition to **advocacy**, the **'watchdog' function** and **technical knowledge**, communities bring the **TB 'lived experience'** and an understanding of **what will and what will not work**. Communities are the ones that understand **'how'** to deliver services effectively and to reach marginalised and hidden population groups. For example in certain regions women suffer disproportionately the consequences of TB even though TB affects men and women equally. They are often the last to get medical care and there are cultural and social barriers that negatively impact on a woman's access to TB services in such conditions. Community groups that work closely with women or are run by women are vital for developing interventions that accommodate and address the specific TB needs of women.

Communities provide **TB screening** programmes, including supporting efforts for integrated screening of child health; they support **retention in treatment programmes**, including **adherence support**; they lead on **stigma mitigation** efforts and are often **catalysts for change** in attitudes and practices; they **connect people** to services; are **flexible and responsive** to needs and are **important factors** in what happens beyond the walls of the clinic. Communities support the **continuum of care** – from diagnosis, through treatment and ongoing care and support. Importantly, they **disseminate** TB prevention and risk reduction information in simple and easily understood language and **empower people** to be more TB aware, particularly among key affected populations.

Community System Strengthening in the context of TB

The Global Fund has developed a set of four **Measurement Frameworks** that cover HIV/AIDS, Tuberculosis, Malaria and Health System Strengthening. Each of the measurement frameworks include a CSS module and each CSS module contains four **Interventions** aimed at strengthening community systems. The CSS Interventions provide the opportunity and funding to enable communities and community based organisations to maximise their contributions to the TB response and address any gaps that may impede this.

Intervention 1: Community Based Monitoring for Accountability

Community-based organizations and other community groups are strengthened to monitor, document and analyse the performance of health services as a basis for accountability, advocacy and policy activities. Community-based organizations establish and implement mechanisms for ongoing monitoring of health policies and performance and quality of all services, activities, interventions and other factors that are relevant to the disease, including prevention, care and support services, financing of programs, and of issues and challenges in the environment, (such as discrimination and gender-based inequalities), that constitute barriers to an effective response to the disease and to an enabling environment.

This intervention offers the opportunity to support training for communities, and KAP's groups in particular, around monitoring and evaluation (M & E) and how to translate outcomes into results. It is important that communities gain an understanding of how to accurately collect community feedback regarding TB services and how to translate this meaningfully within various policy and service development structures. Linked to this are building capacities and skills on representation within various structures. 'Knowing your TB epidemic' is not the same as presenting that knowledge to technical committees or policy forum's. Enabling an understanding of TB budget cycles (at all levels) is another important area for strengthening community systems. Inclusion of core funding, such as salaries, rent and equipment to support community based initiatives in ensuring better accountability of TB and health programmes is also essential.

Community systems, networks and organisations are well placed to monitor TB services with respect to their reach, accessibility and quality. They are ideally placed to report drug stock outs, difficulties faced by KAP's in accessing care, lack of patient friendly services etc. They can play an important role in providing feedback about implementation, fixing of accountability and improvement of services. In order to perform these functions effectively their capacity needs to be built and they need to be empowered to perform these functions. TB programmes are often challenged by lack of human resources and capacity to monitor and supervise programme activities, often drug shortages and stock outs are not reported in a timely manner and access barriers continue to prevent patients seeking care. All these can be changed by investing in community resources to empower them to act.

Intervention 2: Advocacy for Social Accountability

Service providers, national programs, policy makers, and local and national leaders are held accountable by community sector organizations for the effective delivery of services, activities and other interventions, as well as for the protection and promotion of human rights and gender equality. Communities and affected populations conduct consensus, dialogue and advocacy at local and national levels aimed at holding to account responses to the disease, including health services, disease specific programs as well as broader issues such as discrimination, gender inequality and sustainable financing, and aimed at social transformation.

Communities play an important role in **advocacy**, a function often misunderstood as negative and confrontational by governments and decision makers. However, advocacy has a positive role in highlighting TB and keeping it visible amongst many competing priorities. It is also important for encouraging legislative reform to remove barriers that impede certain KAP's such as displaced populations, prisoners, sex workers vulnerable to TB to comfortably and safely access TB services, vital in the broader context of public health.

The **'watchdog'** function, so often undertaken by communities, particularly around quality of TB services, procurement and stock outs (of TB drugs), stigma and discrimination mitigation is an important and valuable conduit for reality based evidence that can inform the National TB Planning in service improvements.

There are **community based systems** that work towards making TB services accountable for example in Peru and other countries have community groups that meet and inform TB services such as **Community Advisory Boards** who are active around new TB drugs, assessing plans for clinical trials, overseeing research and advocating for price reductions. At a sub-regional level there may be **Community Health Committees** with a primary focus on ensuring greater access to TB treatment .

Intervention 3: Social Mobilization, building community linkages, collaboration and coordination

Communities and affected populations engage in activities to improve their health and their own environment. Community action, establishment of community organizations and creation of networking and effective linkages with other actors and broader movements such as human rights and women's movements. Strong informal and formal relationships between communities, community actors and other stakeholders enable them to work in complementary and mutually reinforcing ways, maximizing the use of resources and avoiding unnecessary duplication and competition.

This intervention allows for requests to develop partnerships and for regular monitoring and follow up of these partnerships. This intervention could support training and capacity building of partnerships, networks and representatives of key populations, for example partnerships with harm reduction networks to ensure access to TB services for IDU's. Other examples include partnerships with women self-help groups, village health committees, organisations working on migrants, miners associations and organisations working with sex workers and men who have sex with men. This type of outreach work requires funding for transport, accommodation, meeting rooms, materials, and facilitator costs to enable these events to take place. It is also an important intervention to support linkages with human rights and women's organisations and movements. It will support regional TB Forums and the use of social media to facilitate coordination of activities, information sharing, and advocacy campaigns.

Ensure that social mobilization initiatives are supported and has direct impact on health outcomes in TB, for instance in the Democratic Republic of Congo ex TB patient clubs and outreach groups are able to provide critical support services on TB while reducing stigma. They are supporting health care centres track patients lost to follow up and are providing one on one psychological support for MDR-TB patients. Similar models exist in many other countries such as Tanzania, South Africa and Peru

Intervention 4: Institutional Capacity Building, planning and leadership development in the community sector

Capacity building of community sector groups, organizations and networks in a range of areas necessary for them to fulfill their roles in service provision, social mobilization, monitoring and advocacy. Includes support in planning, institutional and organizational development, systems development, human resources, leadership, and community sector organizing. Provision of stable, predictable financial resources for communities and appropriate management of financial resources by community groups, organizations and networks. Provision of technical, material and financial support to the community sector as required to enable them to fulfill roles in service provision, social mobilization, monitoring and advocacy.

This intervention is important for support around training for proposal writing and resource mobilisation for organisation who work on TB issues and this in turn is critical for sustainability. Development of organisational systems for example databases, Monitoring and Evaluation and financial management enable the organisation to make the most of its links with the communities. Human Resource systems are another area, for instance for staff succession as well as an effective system for recruiting, training, managing and retaining TB volunteers. As with other interventions security of salaries, rent etc. are critical and often overlooked as part of a capacity building package. Supporting training schools around developing TB advocacy networks and coalitions would also be something to consider.

For all these interventions it is really important to budget adequately for technical assistance to support training, including on leadership, and skills building. These activities all need to be funded, including core funding for groups and organisations delivering these activities (core funding is often not available through programme funding) and the Global Fund CSS funding stream is designed to specifically support community based activities and programmes by funding the pillars that enable these community led programmes and organisations to thrive and maintain sustainability.

It is important to demonstrate that such activities are linked to positive health outcomes. In this context there are a number of examples to demonstrate the effectiveness of such capacity building and empowerment activities which ultimately lead to better TB care and outcomes. For example, in the Sidama zone of Ethiopia, investment in the community based health extension workers network in the form of training and incentives led to a doubling of TB case detection and improvement in treatment success.

Conclusion

Communities are important to the TB response, globally, regionally, nationally and locally. They do a lot of the work that mainstream TB services are unable to do. They bring to Public Health discourse, planning and decision making, a 'lived reality' and a wealth of skills, knowledge and understanding of the real consequences of TB. But communities cannot make this critical contribution without support. Community System Strengthening can provide the essential support and the benefits derived from this must be maximised. A TB response without the full, integrated involvement of communities will inevitably fall short, but a national TB response that embraces and supports the comprehensive engagement of communities and key affected populations may just achieve a TB free status.

Further Reading and Resources

- Community Based TB and HIV Integration Good Practise Guide http://www.path.org/publications/files/HIV-TB_integration_guide.pdf or http://www.aidsalliance.org/includes/Publication/GPG_TB_HIV_integration.pdf
- Community involvement in tuberculosis care and prevention: Guiding principles and recommendations based on a WHO review; WHO 2008 http://www.stoptb.org/wg/tb_hiv/assets/documents/9789241596404_eng.pdf
- Community Systems Strengthening Framework, August 2011 and Community Systems Strengthening Information Note <http://www.theglobalfund.org/en/fundingmodel/support/infonotes/>
- Global Fund Monitoring and Evaluation Guidelines and Tools <http://www.theglobalfund.org/en/me/documents/>
- Analysis of CSS applications in Round 10 / Global Fund www.theglobalfund.org/documents/civil_society/CivilSociety_Round10CommunitySystemsStrengthening_Analysis_en
- Community Systems Strengthening and Key Populations: A Policy Discussion paper; Global Forum on MSM and HIV 2013 <http://www.msmsgf.org/index.cfm/id/11/aid/8376>
- Southern Africa Regional CSS Framework <http://www.satregional.org/sites/default/files/publications/Southern%20Africa%20CSS%20Framework%20FINAL%20-%2022%20September%20201.pdf>
- Information Notes on Human Rights ; Gender ; Addressing sex work, MSM and transgender people in the context of the HIV epidemic ; Information Note ; Harm reduction for people who inject drugs Information <http://www.theglobalfund.org/en/fundingmodel/support/infonotes/>
- Advocacy, Communication and Social Mobilisation for TB Control: Collaboration of Country Level Good Practices. <http://www.stoptb.org/countries/acsm/resources/tools.asp>

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