

Meaningful Participation of TB Communities in National Planning

This Guidance Note on Meaningful Participation of TB Communities and Key Affected Populations (KAP's) in National Planning has been prepared to enable a consolidated understanding of this in the context of TB and to maximise the contribution of communities, civil society organisations and 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.

Appreciating the need to work differently with Communities

By their very nature, communities are organic and diverse, and a great variety of groups and organizations – community actors – arise in response to perceived community needs. At their simplest, they may lack formal structures or capacity for running administrative systems, managing funds or communicating effectively with officials and other organizations. Larger community organizations may have those skills and capacities but may be working in isolation from each other and from mainstream government systems.

In some contexts, community actors operate outside of mainstream systems in order to reach people who are marginalized or criminalized or who do not trust official systems – for example, undocumented migrants, sex workers, sexual minorities or drug users. Sometimes community actors are themselves isolated from the mainstream, due to barriers within the country or to donor processes that prevent them from acting as equal partners in planning, implementation, oversight and assessment of programs.

The TB response has historically been based on a medical model which has often struggled to accommodate and appreciate the contribution that less formal approaches make. However, an effective and comprehensive TB response needs to maximise the skills and knowledge of all stakeholders, both formal and informal. For this to happen, communities need to be involved in all stages of national planning and more flexible approaches need to be embraced to ensure that their engagement is effective.

Who are Communities?

Community is a widely used term that has no single or fixed definition. Broadly, communities are formed by people who are connected to each other in distinct and varied ways. Communities are diverse and dynamic. One person may be part of more than one community. Community members may be connected by living in the same area or by shared experiences, health and other challenges, living situations, culture, religion, identity or values.

Community organizations and actors are all those who act at the community level to deliver community-based services and activities, and to promote improved practice and policies. This includes many civil society organizations, groups and individuals that work with communities, particularly community-based organizations, nongovernmental organizations and faith-based organizations (FBOs), and networks or associations of people affected by particular challenges such as tuberculosis. Community organizations and actors also include those public- or private-sector actors who work in partnership with civil society to support community-based service delivery, for example local government authorities, community entrepreneurs and cooperatives.

What do Communities do?

- Communities play an important role in **TB 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 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.

- In addition to 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 TB 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. Communities 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.
- 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 access to TB treatment . In the Democratic Republic of Congo TB Survivor clubs and outreach groups provide critical support services on TB and challenging stigma, following up patients who are lost to follow up or providing one on one psychological support for MDR-TB patients. Similar models exist in many other countries such as Tanzania, South Africa and Peru.

How to facilitate community involvement in National TB Planning

Each country will have its own processes for national planning of their TB response; some will use an in-country team comprised of experts working on TB in that country; others may call on the services of external experts/consultants to lead the national planning process; while a hybrid, using both internal and external experts may be the preferred option.

Knowing 'what to do' is not the same as understanding 'how' to effectively involve communities. The following is a description of four steps that could be taken that would significantly enhance community involvement.

Situation Analysis:

A comprehensive desk review including recent TB Reviews, HIV Reviews and all other relevant documentation. An in-depth look at the country situation including what Civil Society and Community Based Organisations exist and what aspect of TB work they are involved in? Sources of information would be web based list serves, NTP's, Global Fund Principle Recipients, other health related NGO's and stakeholders (including UNAIDS & WHO Country Offices). Word of mouth, making use of personal contacts is also a useful way of gaining full understanding of the existence and work of less formal groups engaged in TB work within the community. Any external experts/consultants should be fully briefed and should understand the country, the status of the TB response but also the role and contribution that has been made by communities, including community dynamics. This process could be led by the national TB planning team or a civil society organisation that has the capacity to lead such a process or a technical partner that has a strong commitment to community engagement in TB programs.

Community Stakeholder Analysis:

Identify a lead person or organisation to drive this process. This would be a more in-depth analysis of community based organisations, both formal and informal, in the country. Mapping where they work and looking at what they do and understanding what support, if any, they get? Because this will involve groups working with KAP's it is important that the lead on this is sensitive to the legal and social environment that may be problematic for many of these groups. As the process progresses special consideration should be given to outreach to engage specific communities and population groups that might otherwise be excluded from the TB planning process. This is probably most effectively achieved through partnering with an existing, trusted community based TB group, and ensuring they are appropriately resourced to engage with KAP's and other marginalised or hidden population groups, especially women and those whose lifestyle choices see them criminalised or highly stigmatised.

Community Stakeholder Consultation:

Develop clear Terms of Reference for the meeting to ensure that any outcomes are useful and effective for the National TB Planning Process and for Communities. The information from the *Situation Analysis* and *Community Stakeholder Analysis* should be made available and shared at the meeting. This helps everyone have the same understanding and will ensure discussions are focused. Whilst it is not always helpful to pre-empt the outcome from such a meeting there are potential benefits that may emerge. The strengthening of local mechanisms and platforms to negotiate with the National TB Planning Process Convenor; a more comprehensive understanding of the potential that TB communities can bring to the planning process and the national TB response and how NTP's might support this; Perhaps a TB Civil Society Advisory Group may emerge to channel information from communities into the planning process and with support of NTP's (or other entities), the integration of community involvement at a systemic level ensuring this is continuous and automatic in the future. Setting up On-line consultations with TB communities should also be seriously considered. These can be extremely productive in facilitating community input to strengthen national TB planning processes.

Building New Coalitions and Maximising Existing Structures:

Developing mutually beneficial arrangements with key partners who are supportive of community participation will strengthen the role of communities in National TB Planning Processes. Working directly with KAP's or organisations that represent the needs of KAP's ensures that marginalised population groups have an active role in the planning process. Coalitions can be effective vectors for channelling and disseminating information to and from the planning process. Developing coalitions can be a significant step in formalising the engagement of communities in the planning process and also in the national TB response and can be instrumental in avoiding misunderstanding and misconceptions.

- **When resources are limited** it is important to utilise existing TB community structures rather than set up duplicate ones. Bring them into the process and ensure there are recognised channels that enable them to input into the national TB planning process. Supporting any Civil Society forum's that exist, who are able to consider and inform about community TB priorities and needs or providing financial support to convene such a forum is a good investment that will have positive benefits for any national TB planning process.
- **Accessing technical support** for example through Global Fund CSS or technical support agencies willing to focus on community involvement in national TB planning, to establish structures and processes to maximise community contributions and involvement, is an option that should certainly be considered.
- **It is essential that the planning team** has the right guidance, including strong Terms of Reference, to work on TB community engagement.
- **The timeline of national planning activities** need to be prepared and made available to community participants in good time - dates and timings of pre-planning meetings, consultations etc. and financial support should be available to enable community representatives to attend.

Whatever approach is taken the process would be made more effective if a key contact person or focal organisation, based in country is identified. It is particularly important for TB communities and KAP's to have a contact point, an informed point of reference that has an overview of the planning process, to go to for clarification of various processes, timelines and other technical or organisational issues. This would be helpful for both in-country and external people to perhaps influence the process especially around community issues.

Conclusion

Effective participation of communities in National TB Planning is not complex or difficult to achieve. However, it does require commitment, flexibility and a strong desire to have a TB response that benefits the whole population. Participation of communities enriches the process, adding skills, knowledge, diversity and integrity to the final outcome that may not be present otherwise.

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

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