

Behaviour Change Communication and Social Mobilisation Guidelines

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Guidelines developed by Professor Harry Hausler¹ and Ms Caroline Wills on behalf of URC/
TASC II Project.

¹ School of Public Health, University of the Western Cape, Email: hhausler@uwc.ac.za

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Acronyms

ACSM	Advocacy, communication and social mobilisation
AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
BCC	Behaviour change communication
CBO	Community-based organisation
DoH	Department of Health
DOTS	Directly observed treatment short course
FBO	Faith based organisation
HIV	Human immuno-deficiency virus
MDR-TB	Multi-drug resistant tuberculosis
MRC	Medical Research Council
NGO	Non-governmental organisation
NTCP	National TB Control Programme
PHC	Primary health care
SM	Social mobilisation
TADSA	TB Alliance DOTS Support Association
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation
XDR-TB	Extensively drug-resistant tuberculosis

1. Introduction to these guidelines

Tuberculosis (TB) has a profound impact on communities in South Africa. The National TB Control Programme (NTCP) of the Department of Health (DoH) recognizes the potential role community members can play in successfully combating TB.

1.1 What is the purpose of these guidelines?

These *Behaviour Change Communication and Social Mobilisation Guidelines* aim to assist in the development and implementation of a programme to change behaviours and mobilise communities to increase TB and HIV case finding and case holding. They were developed as a practical and user-friendly resource to assist those wishing to plan and implement appropriate and effectively managed social mobilisation processes in their communities.

These guidelines therefore provide an overall understanding of what social mobilization is, how it is implemented, with whom and how its success is measured.

1.2 Who will use these guidelines?

These guidelines have been developed primarily for

- District and facility level managers who are responsible for managing TB and HIV.

However they can be used by anyone who wishes to get involved in addressing TB in their community. This guide can therefore also be used by:

- People in various community structures, namely community based organisations (CBOs), non-governmental organisations (NGOs), faith based organisations (FBOs)
- Health promoters, DOTS supporters, home based carers, community health workers
- Traditional healers
- Employee Assistance Practitioners or TB and HIV co-ordinators in the workplace

1.3 Why were these guidelines developed?

The motivation underpinning the development of these guidelines is to build the capacity of managers to strengthen district and facility level programmes to plan and implement effective TB/HIV social mobilization strategies so as to address the following four key challenges;

- Improving TB case detection and treatment adherence
- Combating stigma and discrimination
- Empowering people affected by TB
- Mobilizing political commitment and resources for TB.

1.4 What does this guide contain?

This guide focuses on assisting the reader with information about how to plan, implement and evaluate a social mobilization process to reach communities affected by TB. The guide is structured in the same order as a planning framework. This process includes establishing goals and objectives, conducting a situation analysis including a stakeholder analysis, establishing partnerships, developing a budgeted plan of activities, mobilizing resources for the plan and monitoring and evaluating the plan. The guide consists of TEN chapters:

Chapter One introduces the guide and describes for whom and how it could be used to guide the reader to plan, implement and evaluate a social mobilization process.

Chapter Two provides basic facts about TB, background information regarding the prevalence of TB locally and worldwide making the link to the HIV/AIDS epidemic as well as an outline of the international and national efforts to address TB.

Chapter Three introduces the reader to the concept, principles and goals of social mobilization in the context of TB.

Chapter Four provides information on how to establish successful community partnerships so as to build support to address TB at the local level.

Chapter Five gives guidance on coordination of community workers and defines the roles and responsibilities of community workers providing TB services. It goes on to provide information on how to maximize the benefits of having such people in place to provide quality TB services.

Chapter Six focuses on different TB and TB/HIV messages that could be shared with the community.

Chapter Seven focuses on ways that information about TB can be communicated to communities, from one-to-one education to mass communication campaigns.

Chapter Eight looks at advocacy as an important tool to ensure that change is effected to address TB. Tips on how to implement an advocacy campaign are shared.

Chapter Nine focuses on resource mobilisation to ensure that sufficient financial and human resources are in place to ensure the success of a comprehensive TB programme for the community.

Chapter Ten provides a case study to show how chapters 7, 8 and 9 are all linked to ensure a successful programme outcome.

Chapter Eleven provides key information on monitoring and evaluating (M&E) the success of a social mobilisation process. It does not provide in-depth information on M&E but rather looks at key indicators and tools to measure success.

Chapter Twelve highlights the importance of operational research in improving TB care in communities towards improved programme outcomes.

Chapter Thirteen provides the reader with potential resources to assist them in their work.

2. Setting the Scene

2.1 TB/HIV Fact Sheet

This fact sheet can be used to inform community members or the media about TB and HIV.

What is TB?

Tuberculosis (TB) is caused by bacteria (germs) called *Mycobacterium tuberculosis*, which are spread through the air when a person who has TB coughs, sneezes or breathes. TB can occur anywhere in the body, but only TB in the lungs can infect other people. Anyone can become infected with TB, but all people with HIV are at greater risk of becoming sick with TB disease. **TB can be cured whether a person is infected with HIV or not.**

What is the difference between TB infection and TB disease?

TB infection (latent TB) means that the bacteria are inside your body but they are not active. People who are infected with TB usually have no symptoms and most of them do not become ill. They also do not pass the disease on to other people. TB disease is also called active TB. Active TB means the infection has become active in your body and will make you sick. People with active TB have symptoms and can pass it on to other people. Therefore active TB must be treated, cured and where possible prevented. If TB is left untreated it can be fatal.

What are the signs and symptoms of active TB?

TB symptoms depend on where in the body the TB germs are growing. TB germs usually grow in the lungs but can also occur in other parts of the body including the lining of the lung (pleura), lymph nodes, brain, heart, abdomen, bones, kidneys and skin. TB in the lungs may cause:

- A bad cough that lasts longer than 2 weeks
- Pain in the chest
- Coughing up blood

Other symptoms of TB (whether it is in the lungs or in other parts of the body) are:

- Sweating at night
- Weight loss
- Poor appetite
- Weakness or fatigue
- Fever

How can health workers tell if I have active TB?

Health workers can test for TB in different ways. The most reliable test for TB is a sputum test. A chest x-ray may also be necessary.

Can active TB be cured?

People diagnosed with active TB can be treated and cured with medication taken for six to eight months. TB medication must be taken until the doctor says that TB is cured. Stopping or skipping TB medication just because you feel better might lead to recurrence of TB. By not finishing your medication you could also develop drug resistant TB. Treatment of drug-resistant TB is more difficult and much more expensive than treatment of TB that is not resistant. It is extremely important for TB patients to take their medication for as long as the nurse or doctor recommends.

Why do some people with TB not complete their treatment?

Some people start feeling well early on during treatment and they stop taking medication before all the TB germs are dead. Other patients forget to take their treatment or delay going back to the clinic or hospital. If patients miss any doses of their treatment, they should not be afraid to go back to the clinic (TASC II TB Project, n.d).

Dangers of not taking TB medication:

- You will not be cured and may eventually die
- You may develop resistant strains of TB that are not curable
- You will spread the disease to those around you.

Am I at greater risk of getting TB because I have HIV?

Yes. HIV weakens your immune system and increases your chances of developing other infections. These infections are called 'opportunistic infections' because they take the opportunity of attacking you when your immune system is weakened. TB is the most common opportunistic infection. HIV also promotes both the progression of latent TB infection to active disease and recurrence of the disease in previously treated patients.

How do I protect myself from getting TB?

- If you have been 'in contact' with a person who has active TB, for example if you live with, work with, travel in the same vehicle (including public transport), or have been in the same environment with someone with active TB AND you have developed any symptoms of TB, it is strongly advised that you go to the clinic to be tested for TB.
- If you are HIV-positive, avoid working in conditions that expose you to TB germs such as health facilities servicing active TB patients;
- Ensure that you have daily adequate nutrition to strengthen your body's defences against TB;
- Encourage people who are coughing to cover their mouths when they cough. This helps prevent the cough from spreading germs in the air.

What is the impact of co-infection with TB and HIV?

TB and HIV speed up the progress of each other, and TB considerably shortens the survival of people with HIV and AIDS. TB accelerates the progression of HIV disease and shortens survival, killing up to half of all AIDS patients worldwide. People who are HIV-positive and infected with TB are up to 50 times more likely to develop active TB in a given year than people who are HIV-negative. TB is the leading cause of death in HIV-positive people.

Many people infected with HIV in developing countries develop TB as the first manifestation of AIDS. The two diseases represent a deadly combination, since they are more destructive together than either disease alone.

- TB is hard to diagnose on HIV-positive people
- TB progresses faster in HIV-infected people
- TB in HIV-positive people is almost certain to be fatal if undiagnosed or left untreated.
- TB occurs earlier in the course of HIV infection than many other opportunistic infections.
- TB can be cured in HIV-positive people using the same drugs for the same length of time as in HIV-positive people.

I am on antiretroviral therapy (ART) to fight HIV infection. Can I also take medicine to cure TB?

Yes. Your doctor will decide which combination of medicines will work best for you. ART is for life and TB treatment is taken for at least 6 months.

What is the impact of TB/HIV on women?

Worldwide women bear a disproportionate burden of poverty, ill-health, malnutrition and disease. TB causes more deaths among women than all causes of maternal mortality combined, and more than 900 million women are infected with TB worldwide. Once infected with TB, women of reproductive age are more susceptible to developing TB disease than men of the same age. Women in this age group are also at greater risk of becoming infected with HIV. Although the majority of TB cases are in men, a growing proportion of TB cases are in women as a result of the HIV epidemic.

What is MDR-TB?

TB can normally be treated with a course of four standard, or first-line, anti-TB drugs. If TB patients interrupt their treatment, multi-drug-resistant TB (MDR-TB) can develop. MDR-TB can take up to two-years to treat with second-line drugs, which are more expensive and have more side effects than first-line drugs. Drug-resistance can be reduced where strong TB control programmes are in place to ensure that TBpatients complete their treatment.

What is XDR-TB?

Extensively drug-resistant TB (XDR-TB) can develop when the second line drugs used to treat MDR-TB are also misused or mismanaged and therefore also become ineffective. It can also occur when a person is infected with TB from a person with active XDR-TB. Because XDR-TB is resistant to first- and second-line drugs, treatment options are seriously limited. It is therefore vital that TB is managed properly to prevent the occurrence of drug-resistant TB (WHO, 2006a).

2.2 Magnitude of the problem

In a recent report by the WHO (2006b) they state that in 2004, there were 9 million new TB cases and approximately 2 million TB deaths worldwide. The Directly Observed Treatment Short-course (DOTS) strategy remains at the heart of the new Stop TB Strategy (WHO, 2006) and in 2004 was being applied in 183 countries, including 44 countries in Africa. Despite this, the incidence of TB is continuing to grow in Africa. This is especially driven as a result of the HIV epidemic. The burden of TB is especially felt in sub-Saharan Africa and Asia, home to 80% of all TB patients.

Expanding areas of work within the next Global Plan to Stop TB 2006-2015 include; community and NGO participation in TB care, advocacy, communication and social mobilization and improved management of MDR-TB and TB/HIV.

A recent report by UNAIDS and WHO (2006) states that almost two thirds (24,7 million) of all persons infected with HIV are living in sub-Saharan Africa. It further highlights that in 2006;

- the HIV prevalence of HIV in the region was 5.9%,
- there were 2.8 million new HIV infections amongst adults and children in the region,
- the number of deaths due to AIDS was 2.1 million.

South Africa has a population of approximately 47 million people and the incidence of TB is 718/100 000 people/year, which makes it a high burden country. With an estimated 339,000 TB new TB cases in 2004, South Africa has the 5th highest TB burden in the world. The high incidence and prevalence of TB is attributed to the HIV epidemic, where 60% of TB patients are also living with HIV. The relationship between TB and HIV has had a negative effect on the management of TB, because the high levels of TB-related stigma have now been attributed to HIV, preventing people from accessing TB treatment. In South Africa, some 5.5 million people, including 240 000 children younger than 15 years, were living with HIV in 2005 (UNAIDS, 2006).

The DoH commissioned the MRC (2004) to measure the extent of MDR-TB in South Africa. The study found 1,6% of new patients with MDR-TB, with the prevalence varying across the provinces, with the lowest prevalence recorded in the Western Cape (0,9%) to the highest in Mpumalanga (2,6%). Furthermore, the study recorded a prevalence of MDR-TB of 6,6% amongst those who had prior TB treatment, showing that unfavourable outcomes of previous treatment (failure or default) are strongly associated with MDR-TB.

27 countries have reported XDR-TB cases (WHO, 2007). At the beginning of 2005, XDR-TB was detected in KwaZulu-Natal and highlighted the lethal combination of HIV and TB in South Africa. Of the 53 patients initially diagnosed with XDR-TB at a district hospital in the KwaZulu-Natal province, from January 2005 to March 2006, 44 tested for HIV and each of them was found to be HIV-positive and 15 were on ART. All but one (52) of the XDR-TB patients died with a median survival from sputum collection of 16 days. These cases highlight that XDR-TB is an important cause of death in TB/HIV co-infected patients even where ART is available. It has also highlighted the need for improved drug resistance surveillance, contact tracing and infection control in health care facilities (Grimwood et al, 2006).

2.3 Management of TB globally and locally

Communities are not alone in trying to address TB. Many communities across the world have similar challenges and the problem is so large that in 2000, the Stop TB Partnership, an international effort to address TB, was established.

The Stop TB Partnership is a coalition of 400 organisations and individuals committed to short and long term measures required to control and eventually eliminate TB as a global public health problem. As part of the

practical implementation of its work, the Partnership has divided itself according to 7 working groups, and one of these strategies is that of Advocacy, Communication and Social Mobilisation (ACSM)(WHO, n.d).

Since its inception in 2000, the Stop TB Partnership has had many international meetings, where priorities are set out and commitments made. To add further focus, the Stop TB Partnership developed a Global Plan to Stop TB 2006-2015 (WHO, 2006c). This Global Plan outlines a vision of a TB-free world and their "mission is;

- to ensure that every TB patient has access to effective diagnosis, treatment and cure,
- to stop transmission of TB,
- to reduce the inequitable social and economic toll of TB,
- to develop and implement new preventive, diagnostic and therapeutic tools and strategies to stop TB" (WHO, 2006c).

In 2005, an ACSM working group was established to mobilise political, social and financial resources; to sustain and expand the global movement to eliminate TB; and to foster the development of more effective ACSM programming at country level in support of TB control. The ACSM sub-group have developed a 10-year framework for action to contribute to the Global Plan to Stop TB 2006 – 2015. The vision of the work plan is one where 'all communities at all levels are empowered to remove the threat of TB to human health'(WHO, 2005) By applying ACSM strategies from health-care settings to households, TB patients are supported and treated effectively with dignity and respect.

The Global Plan to Stop TB is also committed to meeting the Millennium Development Goal relevant to TB '[Goal 6, target 8] to have halted and begun to reverse the incidence of TB by 2015.' (WHO, 2006c)

On August 25, 2005, the WHO-AFRO Regional Committee Meeting in Maputo culminated in a unanimous declaration of TB as an emergency in Africa by 46 Ministers of Health. The resolution from the meeting warned that 'unless urgent extraordinary actions are in place, the situation will worsen and the 2015 Millennium Development Goal TB targets will not be met'. (Department of Health, 2006)

In response to the Maputo Declaration, the South African government has developed a National Tuberculosis Crisis Management Plan (Department of Health, 2006) which was released in March 2006. As part of the crisis plan, each province is responsible for (amongst nine strategies);

- the implementation of a high visibility social mobilisation campaign
- the implementation of a high intensity media campaign
- the implementation of a strengthened supervision system to ensure facility and community-level staff receive adequate mentoring and support to improve performance of the TB programme.

These guidelines seek to empower district and facility level managers to implement these elements of the National TB Crisis Plan.

3. Goals of social mobilisation

The ACSM recognised that social mobilisation is a process of bringing together all feasible and practical intersectoral allies to raise awareness of and demand for a particular programme, to assist in the delivery of resources and services and to strengthen community participation for sustainability and self reliance. Allies include decision and policy makers, opinion leaders, NGOs such as professional and religious groups, the media, the private sector, communities and individuals.

Social mobilisation generates dialogue, negotiation and consensus, engaging a range of players in interrelated and complementary efforts, taking into account the needs of people. Social mobilisation, integrated with other communication approaches has been a key feature in numerous communication efforts worldwide.

Social mobilisation recognises that sustainable social and behavioural change requires many levels of involvement. Isolated efforts cannot have the same effect as collective ones.

Key strategies of social mobilisation include;

- partnership building and networking
- community participation
- media and special events to raise public awareness
- advocacy to mobilise resources and effect policy change

Each of these key strategies are discussed in more depth in subsequent chapters.

In the context of TB, a social mobilization programme would try to address the following four key challenges;

- Improving case detection and treatment adherence
- Combating stigma and discrimination
- Empowering people affected by TB
- Mobilising political commitment and resources for TB.

4. Establishing community partnerships to build support

As previously recognised 'working together achieves more than working alone'. When initiating a social mobilisation campaign, different stakeholders should be identified and involved in the process from the planning phase. Below is a table identifying potential stakeholders, what they could contribute, how they should be approached and what resources they may have to offer. Approaching an organisation for support may be facilitated if you are accompanied by a member of that organisation who is supportive of a TB campaign.

Stakeholders	Role	How to approach	Resources
Schools	<ul style="list-style-type: none"> - Provide education to school children about the symptoms of TB, the importance of TB treatment and the link between TB and HIV. - Identify TB suspects. - Mobilise children to be involved in TB campaigns. - Assist in being DOTS supporters for children/teachers with TB. 	<ul style="list-style-type: none"> - Through the school governing body or through the principal. - Through teacher unions. 	<ul style="list-style-type: none"> - Skilled in teaching/training. - School has hall/classrooms that could accommodate dramas, meetings, workshops etc. - Have existing relationship and trust of children and parents so easy to access a large group of people and gain their attention easily.
Traditional healers	<ul style="list-style-type: none"> - Potential DOTS supporters. - Assist in raising awareness about TB. - Have good relationships with the community so have high influence. - Identify TB suspects and refer them to health facilities. - Encourage people to know their HIV status. 	<ul style="list-style-type: none"> - Traditional healer's council. 	<ul style="list-style-type: none"> - Community leaders with influence so can encourage members to adhere to treatment. - Trained health professional so can refer TB suspects to health facilities and encourage HIV counselling and testing. - Provide complementary care for TB patients.
Traditional leaders	<ul style="list-style-type: none"> - Assist in raising awareness about TB. - Encourage community members to know their HIV status. - Have good relationships with the community so have high influence. 	<ul style="list-style-type: none"> - Traditional leader's forum/council 	<ul style="list-style-type: none"> - Community leaders with influence so can encourage members to seek care for TB symptoms, adhere to treatment and to test for HIV.

Faith based organisations/ leaders	<ul style="list-style-type: none"> - Leaders to send out messages and share information regarding TB. - Encourage members of church groups to become involved in TB prevention activities, and the delivery of TB/HIV care. - FBOs have a value system that encourages care and support and could go a long way to addressing stigma and discrimination against people with TB and TB/HIV. 	<ul style="list-style-type: none"> - Approach the faith leader to get their buy in. - Faith leader then gets support of the leadership of the FBO, and they develop a communication strategy to mobilise their faith group. 	<ul style="list-style-type: none"> - Human resources. - Financial resources. - Buildings and facilities for meetings, workshops, fundraisers.
Local businesses	<ul style="list-style-type: none"> - To provide support to ensure their employees remain healthy – TB/HIV prevention and care. - To support local initiatives and promote their business, through providing financial resources. - Implement workplace TB programmes. - Enter public-private partnerships. 	<ul style="list-style-type: none"> - Local chamber of business to be approached to support social mobilisation campaign. - Large businesses could be contacted directly, especially if they have a business that makes their employees more vulnerable to TB and HIV i.e mining companies. 	<ul style="list-style-type: none"> - Financial resources. - Human resources. - Material resources such as company vehicles, office space etc.
Non-governmental organisations	<ul style="list-style-type: none"> - Assist in TB social mobilisation campaigns, by implementing door-to-door campaigns, developing popular media, implementing rallies. - Assist in promoting case detection. - Assist in DOTS support strategies. 	<ul style="list-style-type: none"> - Approach NGOs directly to get their buy-in and assistance. - Could enter into a memorandum of understanding (MOU) and provide funding to the NGO to implement particular activities. 	<ul style="list-style-type: none"> - Human resources. - Capacity to mobilise community members. - Commitment. - Strong relationships in the community.

5. Coordination of community workers and volunteers

The successful delivery of TB programmes to the community can be greatly enhanced through developing partnerships in the community, using treatment supporters, non-governmental organisations (NGOs) and community based organisations (CBOs). Broadly, the advantages of this approach are that of sustainability, skills development and cost saving.

ROLE AND RESPONSIBILITY OF THE DEPARTMENT OF HEALTH OF PROVINCIAL GOVERNMENT:

The model of leveraging community resources has the full support of government, and through provincial governments, NGOs and CBOs can apply for funding to implement TB programmes in the community. If the application for funding is accepted by a provincial government, it will enter into a service level agreement with the NGO/CBO effectively buying a service from the organisation. Organisations are given clear guidance as to what functions the funds are intended to support and organisations are accountable for the funds to government. The agreement stipulates minimum standards that need to be adhered to by the NGO/CBO receiving funds. These can include specific duties of TB treatment supporters, minimum wages to be paid and reporting procedures.

ROLE AND RESPONSIBILITY OF DISTRICT MANAGERS AND HEALTH FACILITIES:

Prior to any partnerships being initiated, health facilities should ensure that a successful DOTS strategy is being achieved. According to the TB Alliance DOTS Support Association (TADSA), several prerequisites need to be in place prior to introducing community based DOTS (TADSA, 2007):

1. District management recognises TB as a priority
2. Health facility is able to achieve a sputum turn-around of 48 hours or less
3. Health facilities receive a regular, uninterrupted drug supply
4. At least one person is responsible for TB at the health facility
5. Standardised recording and reporting procedures are in place in the health facility.

With these 5 systems in place, health facilities can begin to consider expanding their TB service into the community.

Introducing community based DOTS creates opportunities and challenges for health facilities and TB Clients:

Opportunities	Challenges
Increases the reach of the TB service	Focus of the TB service at the facility shifts to include managing the delegation of tasks to treatment supporters
Health facility spends less time with patients and allows more time to concentrate on other TB activities e.g record keeping, operational research, resolving systems issues	Different levels of capacity of treatment supporters means that the TB manager at the clinic needs to monitor and support treatment supporters to ensure services rendered are of a high standard
Role of health facility evolves to include TB programme management and does not solely focus on the patient-provider relationship	Ensuring quality service is rendered at community level
Clients save resources (time and money) because they don't have to travel to the clinic as regularly	
Tracing TB contacts, defaulters, and treatment interrupters becomes easier with treatment supporters based in the community	
Involving community based treatment supporters is cost effective (Sinanovic, 2003)	

TADSA has a wealth of experience and provides tailor-made technical expertise to assist health facilities to initiate and maintain functional community-based TB treatment, to help them tighten the TB control systems at clinic and sub-district levels. In TADSA's experience, health facilities need to realise that the responsibility of patients receiving community treatment still remains the responsibility of the health facility. For this reason, one person at the health facility should be delegated the responsibility for TB and act as the primary liaison between the facility and the NGO/treatment supporters in the community. The health facility should (TADSA, 2007);

- Know their treatment supporters by meeting with them on a regular basis (at least monthly)
- Make sure the treatment supporters are in close proximity to their TB patient
- Keep up-to-date records regarding their patients and monitor their progress
- Monitor compliance to identify possible defaulters
- Decide and be clear about whether treatment supporters trace their own patients only or clinic patients as well.

ROLE AND RESPONSIBILITY OF NGOs, CBOs OR COMMUNITY VOLUNTEERS:

It is ideal for NGOs and CBOs to provide community DOTS support as it provides a formal employment structure for treatment supporters. Depending on the community (deep rural communities), this may not be possible. In this case, treatment supporters receive their stipend directly from government.

In the case where the organisation is present, the organisation is responsible for;

- Recruiting and training treatment supporters
- Providing a contract stipulating terms of employment and scope of work for treatment supporters
- Providing mentoring and support to the treatment supporter
- Supervision and monitoring of the treatment supporter

EXAMPLE OF A WELL ESTABLISHED NGO PROVIDING TB CARE:

TB Care Association aims to respond to the needs of the community with regard to TB control. Managing a very successful community-based TB care programme, approximately 500 TB treatment supporters administer directly observed TB treatment to almost 4000 patients per day. TB Care has a tiered management system to ensure proper coordination of the treatment supporters consisting of 3 district coordinators, 5 area coordinators, and 44 area treatment supporters.

Not only does TB Care provide support in the community, but also work in health facilities. A recent initiative has seen the introduction of TB clerks and TB assistants to assist in the proper administration of TB care in high burden facilities. TB assistants are particularly helpful in visiting patients who require follow-up at the clinic, a critical part of effective TB care.

In recognition of the dual epidemics of TB and HIV, new initiatives are needed to best support one patient with 2 diseases. Here is a common scenario being played out in many communities in South Africa:

A patient tests positive for TB at the clinic and is then offered an HIV test. The patient consents for an HIV test, and tests HIV-positive, and is found to have a very low CD4 count. Before starting ARVs, the patient has to start TB treatment.

In response to such a scenario, an NGO could be asked to provide a treatment supporter to assist with TB treatment. Once the TB has been treated and ARVs can commence, there is much value in the same treatment supporter remaining in place to provide adherence support for their ARVs. Models of care are being explored in different communities to try and find ways of providing effective care to patients. These need to be shared so that managers in the health service and of NGOs are aware of different models and can pilot them locally – TADSA calls this 'finding local solutions to global challenges'.

Treatment supporters are real advocates at community level – whether they are in patient's homes, providing workplace support or in health facilities - they have knowledge and expertise to raise awareness and visibility regarding TB and HIV. Opportunities are created, such as World TB Day, World AIDS Day, or particular health drives initiated by communities or workplaces, where treatment supporters provide health

information. This kind of work is invaluable to support the work of the health facilities in case finding. It also goes a long way to ensuring diseases such as TB and HIV are talked about in communities to break down barriers such as stigma and discrimination that prevent people from accessing treatment.

The examples highlighted above may appear simple on paper; however in practice they require huge support to ensure the best care for the patient. Proper communication between NGOs, CBOs and managers at all levels of the health service will ensure that successful projects are able to continue to perform and provide services in the community. It will also ensure innovative ideas and new models of care are created.

Staff turnover is an ongoing challenge for the health service and NGOs/CBOs alike. It is therefore critical that processes are in place to ensure that issues of training are addressed. Health facilities and organisations need to maintain a strong relationship in order to ensure that an optimal human resource plan is being implemented to ensure that a quality TB service is being provided in the community.

A capacity building plan needs to be in place that includes;

1. Tools for capacity building for all relevant stakeholders that includes standardized training materials, flowcharts and checklists of activities with sequence of events,
2. A training plan, that includes methodology appropriate for adult education and tools for the community,
3. Identification of persons responsible for conducting training,
4. Ensuring ongoing training to address staff turnover and maintain good quality services.

Some training can be standard, but health facilities and organisations need to provide ongoing mentoring and supervision to identify and respond to specific training needs of individual staff members to assist them in doing a good job.

6. Standard TB communication messages

Communities need to be given simple information about TB that improves their knowledge, demystifies myths and misinformation and improves their health seeking behaviour. It is not always important for people to understand in-depth information about a disease but knowledge of the signs and symptoms, treatment options and care can go a long way to ensuring people seek help early, and are able to complete their treatment. These messages can be incorporated into social mobilisation activities as part of mass communication initiatives.

PREVENTION

- STOP TB, because you can
- Anyone can get TB
- Go and get tested for HIV
- If you have a persistent cough, weight loss and night sweats, you should get tested for TB
- Anyone can contract TB, whether rich or poor, young or old, male or female
- TB is curable through DOTS, the internationally recommended TB control strategy

CARE

- Support your family, friend and community in the fight against TB
- Don't isolate people with TB, help them!
- Your DOTS supporter can help cure you of TB by reminding you to take your treatment every day.
- If you were cured of TB, your voice is crucial in letting TB patients know!

TREATMENT

- You will only be cured if you complete your treatment
- Prevent TB from spreading to others by getting treatment
- Receive free quality treatment from local public health clinics
- Interruption of TB treatment can lead to multi-drug resistant TB (MDR-TB)
- Do not stop your TB treatment until you are told to by your health care worker

TB/HIV MESSAGES

- Know your status, get tested for HIV
- If you have TB, get tested for HIV
- If you have HIV, be aware that you are at greater risk for contracting TB
- You can take TB treatment with ARVs
- TB drugs can cure you whether you are infected with HIV or not
- Do not stop your TB treatment until you are told by your health care worker

7. Activities and methods of communication

In a recent publication developed by The Panos Institute they said that "our failure to respond to TB is largely a communication failure. People suffering from TB symptoms often think they have a cough rather than TB. Likewise, those affected, and their caregivers, often do not know where to find help. The media and civil society largely leave the problem of TB to the medical community" (Sarker, S & Scalway, T, 2005).

It is estimated that only 78% of TB cases are detected and notified in South Africa, presenting a major challenge for communication (WHO, 2006b). Even among the cases that are detected and treated, there is very often a long delay between the onset of symptoms and diagnosis. This highlights one aspect where communication can play a large role in educating and mobilising people to be aware of TB. Most often we only hear about TB around World TB Day. This needs to change so that awareness of TB goes beyond World TB Day and is made relevant every day to keep the public informed, motivated and conscious of the disease.

Everyone has a role to play in sharing information about TB, as highlighted below:

7.1 Health education in clinics

Health education in clinics can be provided by health educators, DOTS supporters, counsellors or nurses, who can give talks in the waiting room of public health facilities about TB and the interaction of TB and HIV. This is an excellent opportunity to share information as patients in waiting rooms are a captive audience, and they often have to wait for extended periods before they are seen. These talks can be supported with the distribution of print media including; pamphlets, displays and videos for people to look at while they wait.

EXAMPLE: Mindset Health Channel was launched in October 2003, and targets health care workers and the public. Mindset Health sources and creates digital health educational content such as video, multimedia and print media in multiple local languages and has prioritised its initial focus on HIV and AIDS and Tuberculosis (TB). It delivers the content into the users' immediate environments, including hospitals and clinics, through satellite broadcast (daily 07h30 to 17h30). Currently it broadcasts to 110 sites in South Africa and has the potential to reach the rest of Africa. (Mindset, 2006)

7.2 Door to door campaigns

Health facilities and NGOs can develop campaigns targeting specific communities, and with the assistance of DOTS supporters and volunteers develop a campaign where they personally visit homes to share information with families, to deepen their understanding of TB. The advantage of door to door campaigns is that it brings the information into the home and makes it real for those living there, and it provides an opportunity for people to ask questions.

EXAMPLE: In 2005, the City of Johannesburg announced that the City would embark on a five-day door to door campaign, starting on 28 November, and running until World AIDS Day. "The City of Johannesburg will once again embark on a door to door campaign to deepen awareness about HIV and AIDS. This year we are going to vigorously target Alexandra but other parts of the City will not be neglected." Masondo, the Executive Mayor, said. More than 3 000 volunteers will go from door to door handing out condoms and information pamphlets, and encouraging people to get tested. They will also help counsel people infected with or affected by the virus. (*Door-to-door campaign kicks off World AIDS Day, 2005*)

7.3 School education

Schools are an excellent environment where health education can be shared. WHO have an initiative called the 'health promoting schools' (WHO, 2006e) initiative, where a health promoting school is one that constantly strengthens its capacity as a healthy setting for living, learning and working. Amongst its 6 objectives it strives to prevent leading causes of death, disease and disability. Schools can use many different settings as opportunities to educate the children about TB and can share TB information through drama, story-telling, worksheets, quizzes, video/DVD material and inviting speakers to talk about TB, especially those who have successfully combated TB. By forming partnerships with NGOs and health facilities, schools can be assisted in accessing the necessary resources to implement quality programmes.

EXAMPLE: The Maldives felt the need for social mobilisation was with their children. Schools across the islands held workshops, parades and TB quiz contests and there was a meeting with higher officials and secondary (level) schoolchildren chaired by an Atoll chief (social advisors). The next day, 74 schoolchildren attended a workshop on TB awareness so they could organise awareness campaigns in their own communities. In the Russian Federation a children's poster competition was organised and prizes awarded during a TB day press conference (Stop TB, 2002).

7.4 Peer education

Peer educators are people who have been trained to inform and educate their communities about TB. Community can be understood to mean any group of people including your neighbourhood, work colleagues, church group or youth group. Peer educators are there to provide information, refer people to services, initiate awareness activities and be a role model to their community.

EXAMPLE: In 1996 Brenda Chego started nursing again at Burgersfort Community Health Centre in Mpumalanga and immediately found herself plunged into a health crisis. In every village, there are Peer Educators, who have been trained to inform and educate the community about TB and HIV and AIDS. The peer educators serve as her eyes and ears, since many of Brenda's patients live far from Burgersfort in rural villages (Smallhorne, M, n.d).

7.5 Meetings and Workshops

Workshops are an ideal space for people to be given information and proper training about TB. Furthermore, workshops can also be a space where multi-sectoral partners can come together to discuss the development of joint TB initiatives.

EXAMPLE: In Hlabisa, 25 traditional healers volunteered in 1999 to attend two one-day training workshops on the management of TB. "The information we got from the training taught us a lot about TB and the treatment of patients, says traditional healer Jack Nyawuza. "We were also taught about the symptoms of TB, so that when we pick them up in any of our other patients, we can refer people for a TB test. This information added to what we learned in our training as healers" (Department of Health, n.d)

Panel discussions can also be established, where TB specialists are invited to discuss different nuances of the TB epidemic. The reach of these discussions can be extended by broadcasting the information on TV and radio and having phone-in sessions.

7.6 Mass Media

Banners and posters can be developed raising awareness about activities or with a focus on educating people about TB. These should be developed in the local language to ensure information is well understood. The STOP TB Programme developed an international poster that they made available on their website [www.stoptb.org] for any to use and access. This is another option to reduce the cost of developing your own poster, and also pushes the global theme for that particular year.

[EXAMPLE: INSERT ACTIONS FOR LIFE POSTER – WORLD TB DAY 2006]

Posters and pamphlets are also available locally by the National Department of Health, via the mass communications campaign, Khomanani and accessed through their website: www.health.gov.za. Information can be downloaded or ordered in different languages. Posters and pamphlets can be widely distributed to health facilities, non-governmental organisations, faith based organisations, sports clubs, health facilities, schools, taxi ranks, bus stops and libraries. Other forms of media one could distribute are; stick on tattoos at rallies and bumper stickers.

Community radio stations provide an excellent source of information. In many rural communities written information is scarce, and so communities rely on radio for information. Radio also provides some anonymity to speakers who may not be ready to disclose. Radio shows can do interviews with TB patients and interviews with health promoters so they can share simple messages on TB. On an ongoing basis, radio stations can be provided with media briefs about TB to regularly raise awareness.

EXAMPLE: In India, radio programmes were produced for media, briefings were prepared and local media guides appeared in local languages (Stop TB Partnership, 2002).

Television is also extremely powerful and can use investigative documentaries, TV soaps, chat shows, and the newsroom to highlight TB, and/or to integrate TB messages.

It is important that if you organise a parade or rally, you should invite the media (newspaper, TV or radio) to try and raise additional coverage. The media have a powerful effect on influencing public perceptions and are a vital partner.

The Internet has become an important source of information for people who are able to access it. Clear, concise information should be easily available for internet surfers.

7.7 Concerts

In recent years, concerts have become a popular means for fundraising and raising awareness about certain issues. Worldwide, members of the entertainment industry, singers and actors, are role models and icons and are very influential. They recognise this and more and more they are using their influence positively.

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EXAMPLES:

In Moscow, Doctors without Borders held a 'contagious concert' in which young musicians performed works by composers who suffered from tuberculosis, such as Chopin, Liszt, Shostakovich and Stravinsky (Stop TB Partnership, 2002).

46664: The Concert - A sell-out crowd of over 40,000 witnessed the 4½ hour concert live, the highlights of which were then heard or seen by an estimated record 2 billion people. It was broadcast live in South Africa, then worldwide on MTV as a 90-minute special on World AIDS Day.

A wonderful array of the world's great performing artists gave freely of their time and performed unique collaborations. Performers included Anastacia, Angélique Kidjo, Annie Lennox, Beyoncé, Bob Geldof, Bono, Danny K, David A Stewart, Jimmy Cliff, Johnny Clegg, Ladysmith Black Mambazo, Peter Gabriel, Queen, The Corrs, The Edge, Watershed, Youssou N'Dour, Yusuf Islam, Yvonne Chaka Chaka and Zucchero.

It was not just the music community that answered the rallying call of Mr Mandela, but the business world too. Some of the world's biggest brands supported the cause by giving resources, manpower and money to enable the concert to happen. Global media partners for the event were MTV's Staying Alive, Tiscali and BBC World Service. Global event partners included Coca-Cola, FedEx, Virgin Atlantic, SABC and The Fleming Media Group, who were supported by BMW, Nissan, Sennheiser, Motorola and Sheraton Hotels locally (Nelson Mandela Foundation, n.d).

8. Advocacy

Advocacy has been defined by the Advocacy, Communication and Social Mobilisation (ACSM) Working Group of the Stop TB Partnership as:

"Activities to place TB control high on the political and development agenda, foster political will, increase financial and other resources on a sustainable basis and hold authorities accountable (Stop TB Partnership, 2006) "

Advocacy therefore aims to influence individuals (decision makers, leaders, policy-makers and people in positions of influence), groups or institutions to change policies, the implementation of policies, laws and practices and to invest in TB control activities.

Advocacy work can target people with influence at all levels

- local level: community, village, district, city
- national level: the whole country
- international level: more than one country

Depending on the target audience, advocacy can take many different forms. For example, it can be written, spoken, sung or acted. Advocacy can vary in the time it takes – it can take one hour or several years depending on the issue you are trying to address. We can do advocacy work on our own or with others but remember that some of the most powerful advocacy methods are led by the people affected by the problem or issue, or directly involve them for example by people with TB or cured of TB.

A successful advocacy campaign requires planning. The following process of 8 steps is recommended to plan your advocacy campaign:

- **Step 1: Select an issue or problem you want to address**
This step requires you to consider the different issues that could be worked on and to select one that is realistic and which will benefit from advocacy. Once you have done this, define the selected problem or issue clearly.
- **Step 2: Analyse and research the issue/problem**
Once you have identified your issue, you need to analyse the issue, find information about it and suggest possible solutions. The information you find during this process can help to influence and inform your target or ally, to provide evidence supporting your position, to disprove statements by people who oppose you, to change perceptions of a problem, to disprove myths, rumours and false suggestions, and to explain why previous strategies have not worked.
- **Step 3: Develop specific objectives for your advocacy work**
Once you have a clear understanding of your problem, you need to have a clear vision of what you want to achieve. This can help in deciding what changes are necessary to reach a solution that will solve the problem you have identified. Once the vision is in place identify your aim and your objectives.
- **Step 4: Identify your targets**
This step requires you to identify who you are advocating to. Most institutions/ organisations have limited resources available for undertaking advocacy work. Therefore it is important to focus advocacy efforts on the individuals, groups or institutions that have the greatest capacity to take action and to introduce the desired changes. At a local level there are often charismatic people who have power and influence at an informal and/or formal level. In identifying your target, it is important to understand the decision making process as it may be necessary to work through others to reach your target. Identifying targets will help you to plan strategically, and help you to choose the most appropriate activities.

- **Step 5: Identify your resources**
Successful advocacy requires resources such as people, money, skills and information. It is important to be realistic about what resources you have or can raise.
- **Step 6: Identify your allies**
This step requires you to identify people who you will advocate with. In some cases a coalition of people or organisations can achieve more together than individually, however coalitions can take time and energy.
- **Step 7: Create an action plan**
This step requires you to select advocacy activities and making a detailed plan for these activities. At the end of this step you should have developed a plan that has objectives, targets, activities, resources, persons responsible, timeframes and expected outcomes.
- **Step 8: Implement, monitor and evaluate**
This step will enables you to see whether your chosen activities had their intended impact. You do this through monitoring your activities and evaluating your results. Monitoring is the measurement of progress towards achieving objectives and helps you to note which activities are going well. Evaluation is about making judgements about the quality and impact of your activity. In order to measure progress you will have to develop indicators, which are signs that indicate whether you have succeeded or not. You will then have to determine how you are going to collect information that assists in measuring your indicator. This could be through qualitative (case studies, stories, opinions, feelings) or quantitative methods (surveys, routine programme data). Whatever methods you choose, try to only collect information that will be useful in relation to your indicators.

For more information about each of these steps visit www.aidsalliance.org to download the manual.

Example of International TB Advocacy Effort:

Stop TB Partnership

This is a coalition of 400 organisations committed to the elimination of TB as a public health problem. The Partnership has helped keep TB on the agenda of international organisations and donor agencies. The last ten years have seen most TB advocacy efforts, and associated activities in the media, directed at building high-level political commitment in the international development arena and mobilising resources for global TB control. These efforts have been largely successful.

TB was deftly placed on the global health agenda in part through strategic leverage of the media during TB outbreaks in New York and areas of London in the early 1990s.

In 2000, strategic advocacy with the media in the run-up to a landmark conference of health and finance ministers from 20 high burden countries in Amsterdam, followed by the G8 Summit in Okinawa the same year, which made specific reference to TB, firmly established TB as a global public health threat deserving high-level attention and large-scale financing. The creation of the Global Fund for Fight AIDS, TB and Malaria provided further impetus.

A simple but rather crude indicator used to measure political commitment is the level of funding committed by international agencies and national governments for TB control (Sarker, S & Scalway, T, 2005).

Example of National TB Advocacy Effort:

Gender AIDS Forum (GAF)

The main objective of the GAF project was to develop a gendered understanding of TB and its links to HIV in South Africa by examining all factors that may increase the vulnerability of women to these diseases and hinder their access to care, treatment and support. Through a research process culminating in the publication of a position paper, GAF sought to increase in-house awareness of salient issues related to TB/HIV as a first step in developing a strong advocacy agenda. In February 2006, GAF convened a community experts meeting in Durban to discuss and solicit feedback on the research findings. Thirty women and men from a range of support groups and civil society organisations attended the meeting, as did several municipal officials and staff from government agencies. Participants discussed how to build an effective TB/HIV advocacy agenda that would feed into GAF's "Claim back the right" campaign, which focuses on influencing policy at both the national and community levels and on monitoring at the grassroots level to obtain full access to all HIV prevention and treatment options for women and other marginalised individuals.

Based on the research process and findings, as well as the February 2006 community experts meeting, GAF identified the following recommendations for all stakeholders involved in advocacy efforts regarding HIV, TB and gender:

1. Review existing health policies to identify where and how strategies to improve access to integrated HIV and TB services for women could be incorporated.
2. Support community-led social research to examine the ways in which women are especially vulnerable and to advocate for TB/HIV services that are responsive to the special needs and vulnerabilities of women.
3. Train health care workers to be more responsive to the needs of women in provision of TB diagnostic and treatment services.
4. Encourage civil society organisations working on health issues to integrate TB and the specific gender issues related to co-infection into their existing advocacy agendas (Open Society Institute, 2006).

9. Resource mobilization

Mobilising resources is an important skill whether you are working in the public sector or in the non-profit sector. In the context of social mobilisation, public/private partnerships can be entered into to fund specific activities in communities. Alternately, NGOs, CBOs and health facilities can work independently to access resources for TB programmes.

Mobilising resources to support the implementation of sustainable health programmes is a task that requires careful planning to ensure success. Many organisations use more traditional fundraising methods such as; appeals through direct mail, bequests, corporate donations, capital campaigns and annual events. Funds are also raised through cost recovery ventures where organisations sell products that have been made such as bead work. On the whole, funds raised using these methods provide short-term relief responding to immediate needs.

An alternate strategy is to look at fund development, which is a more long term strategy for raising funds, and requires one to look to the private and/or the public sector for funds as they generally have the capacity to commit more money over a period of time. The private sector consists of individuals, corporations and foundations and the public sector is the government (national, provincial or local). Finally funding can also be accessed through bilateral (country to country) and multilateral aid agencies (eg. United Nations) and organisations.

Most potential donors want to know how funding your request will move both their and your organisation towards achieving each of your missions so a three phased approach is advised to ensure you have a comprehensive strategy in place:

Phase 1: Conduct an organisational assessment to determine organisational and development goals

Phase 2: Identify potential donors and develop a programme proposal

Phase 3: Donor relations

Phase 1: Conduct an organisational assessment to determine organisational and development goals

This phase requires you to clearly state your organisational goal, purpose and objectives. This step may require some analytical thinking to ensure your planning takes stock of the current situation both internal to the organisation and externally. Once this is complete, you are in a strong position to clearly describe your cause – i.e the development of a vision that your project seeks to address for a better future related to specific improvements in the health and welfare of a particular population.

Phase 2: Determine potential donors and develop a programme proposal

Potential donors need to be sought out and researched. It is important to identify and evaluate those funding sources likely to give support. It is important to know the priorities of potential funders and match your programme needs to their interests.

Most major funders have specific formats for proposals. Before writing a proposal, determine whether guidelines have been set out, as a proposal incorrectly formatted will normally not be considered. If no template is provided, a well accepted template for a proposal is one that is no more than 15 pages, single spaced and includes the following sections:

1. Cover letter
2. Executive summary
3. Background of the organisation
4. Problem statement/ needs assessment
5. Programme goals and objectives
6. Methodology
7. Evaluation
8. Budget
9. Appendices

Phase 3: Donor relations

After submitting any proposal wait a reasonable period of time and if you have had no response,

- Telephone the donor representative to ask how the application is doing and by when you could expect a response or
- Follow up in writing to ask how your application is doing, and by when you could expect a response.

Ensure your follow-up is politely worded and pleasant as well as persuasive rather than aggressive. If you are notified that your proposal was successful, the process is just beginning.

Managing donor relations is an important activity in any organisation. It is critical that loyal donor relationships are developed as small donors may become large donors in the future. When dealing with donors remember these guidelines for developing successful donor relationships:

- Communication – ensure regular communication with your donor/s
- Involvement – involve donors in your work and invite them to special events
- Professionalism – adhere to deadlines, be responsive, conduct yourself professionally and pay attention to details
- Regular reporting – send regular reports that update the donor on the progress and status of the project
- Accountability – be accountable for your actions and take responsibility when problems develop
- Respect and trust -
- Enthusiasm – be enthusiastic about what you are doing – enthusiasm is infectious!
- Planning – write out your goals, make action plans and implement them
- Competence – ensure you do an outstanding job of service delivery
- Appreciation – express your appreciation periodically and give them public recognition

Planning for, applying for and receiving donor funds is a big management undertaking for any organisation, and despite being a lot of work, it can assist in expanding your project in exciting ways. Set aside resources to assist in the management of donor relations to ensure you have the support necessary to ensure sustainable partnerships with your donor(s).

10. Case Study: Addressing low TB cure rates in the XYZ sub-district

The district management team of ABC district were requested to attend a meeting called by the provincial TB co-ordinator, Thembi Majola. Thembi made a presentation highlighting her concern at the poor management of TB at 4 of the health facilities in the XYZ sub-district, with the intent of advocating to her team that community based TB care was the way forward.

As part of the introduction to her presentation, Thembi recognised that TB is a complex disease to manage, and that she believes that the health facilities are working extremely hard in identifying TB cases and that they use every opportunity to raise awareness in the clinic (pamphlets, posters and health education talks in the waiting room) and in the community (on days such as World TB Day and World AIDS Days) they have door to door campaigns and concerts that integrate health messaging to teach the community to recognise the signs and symptoms of TB. Thembi said that these strategies go a long way towards case finding.

However, there are many challenges facing the health facilities and TB patients. Thembi explained that her TB adherence rates and cure rates are low due to;

- low levels of supervision of treatment in the patient household: support is not even available in the critical first days of treatment
- poor tracing of defaulters.

Thembi attributes these challenges to the lack of resources of the health facility and the TB patients. There are long distances between the health facility and the client's homes, making walking a tedious and tiring journey especially by sick patients, and public transport is not easily available or affordable. Thembi has been monitoring the XYZ TB stats and believes that they reflect that the district is not meeting the acceptable norm in terms of TB cure rates. Thembi completes her presentation with one recommendation: *to implement community based TB care.*

Thembi explained to the team that she has done some initial research into this strategy and has seen that it has had remarkable results in effectively and efficiently managing TB. Specifically, she showed findings by WHO (2002) that community based TB care;

- Is normally well received
- Provides relief to health services, because of the HIV epidemic, the levels of TB have increased enormously and many health facilities find themselves overwhelmed with TB caseloads
- Has had a positive effect on treatment outcomes among patients cared for in the community and treatment outcomes are either equivalent to or (more frequently) improved, compared with patients treated through health facilities.
- Has a positive impact on costs, as costs associated with community care are often far less than health facility based care
- Can include the full range of activities including; case finding, directly observed treatment, defaulter tracing, as well as the establishment of TB support groups.

The district management team listened carefully and were impressed with the presentation. After some questions and discussion, they fully supported her recommendation. They suggested she contact TADSA, a national organisation with expertise in the implementation of Community Based TB Care. They were careful to highlight that even if Thembi were to implement such a strategy, ultimately the 4 health facilities still need to manage and take responsibility for the outcomes of their respective TB programmes.

Thembi felt very encouraged and motivated after her meeting and immediately contacted the Director of TADSA. The Director asked Thembi many questions about how TB was being managed locally and after some discussion said that she would discuss Thembi's request with the National TB Control Programme (NTCP) to ensure that TADSA's support of the XYZ sub-district was in line with the priorities of the NTCP. Within a week, the director called Thembi with positive news that TADSA had been given permission to form a working relationship with the XYZ sub-district.

TADSA's director and Thembi agreed to the following 3-phased work plan as a way of initiating community based TB care, a model that TADSA has tried and tested across many South African communities with much success;

Phase 1:	Phase 2:	Phase 3:
Focus is to introduce and set up community based DOTS by conducting a formative assessment, using the findings to plan the intervention based on local context, training appropriate personnel and establishing operating systems. Activities include a formative assessment, training workshops and the start of the process evaluation.	Focus is to introduce HIV/AIDS and quality improvement into established community based DOTS and set up monitoring and feedback systems between health facilities, the district, TADSA and the province that interface with existing TB recordkeeping. Activities include identifying 'best practice' & continue with process evaluation.	Systematically introduce independence (from TADSA) in the implementation of community-based DOTS, and support the district in working towards sustainability of community based DOTS within the district. Activities focus on concluding the process evaluation and impact evaluation.

Through the process of the 3-phased project an organisation was identified to manage, coordinate and employ the treatment supporters. The organisation was able to access subsidies through the Department of Health which paid the stipends of the treatment supporters.

With some training from TADSA on proposal writing, the organisation successfully applied for additional funds from a large company in the area that owns many of the local farms in the community. The company provided the support through their corporate social investment programme and even provide DOT support to employees as part of their workplace wellness programme.

In each of the four health facilities, the facility managers identified one of their staff members who was tasked to be the direct liaison between the facility and the organisation. This ensured smooth communication, monitoring and team work in the delivery of community based care.

The process of establishing community based care took three full years, and the investment in the community is noticeable with the programme being implemented smoothly. Much time was spent on establishing systems especially for monitoring purposes. However, through training health staff and treatment supporters have been able to understand the value of these statistics in measuring progress.

Thembi and the health management team of the ABC district were able to review their TB stats at the end of the project. In particular, they were proud to see that the XYZ sub-district TB stats had improved dramatically, due to the substantial investment in the training of treatment supporters, coordinators and health professionals, there has been a significant improvement in the number of people reached with community based DOTS.

This has indirectly had a positive effect on the;

- treatment outcomes of TB,
- awareness in the health district on the prevention and treatment of TB, HIV and AIDS

11. Monitoring and Evaluation

Through the delivery of a social mobilisation and communication process, monitoring and evaluation targets are important to ensure progress is being made. This can be done through the development of a monitoring and evaluation plan. This chapter does not seek to cover every aspect of monitoring and evaluation as much has been written on this subject. Instead, it focuses on ACSM indicators to assist you in thinking about what it is that you can measure and how.

11.1 Indicators

There are a number of levels at which social mobilisation can be measured but importantly, practical indicators need to be chosen that reflect the results of the activities at community level. The ACSM divide their indicators according to two main goals, that is 70% case detection and 85% TB case cure. The indicators can be divided into **inputs**, **outputs**, **outcomes** and **impact** indicators. Below, figure 1 breaks down the kinds of things that can be measured by the different indicators. Baseline information collected prior to implementing an ACSM plan would be able to assist measuring progress later in the project. All the different types of indicators can be used in the delivery of a strategy however the indicators tend to be time sensitive so can only be collected at different times in the life of the project.

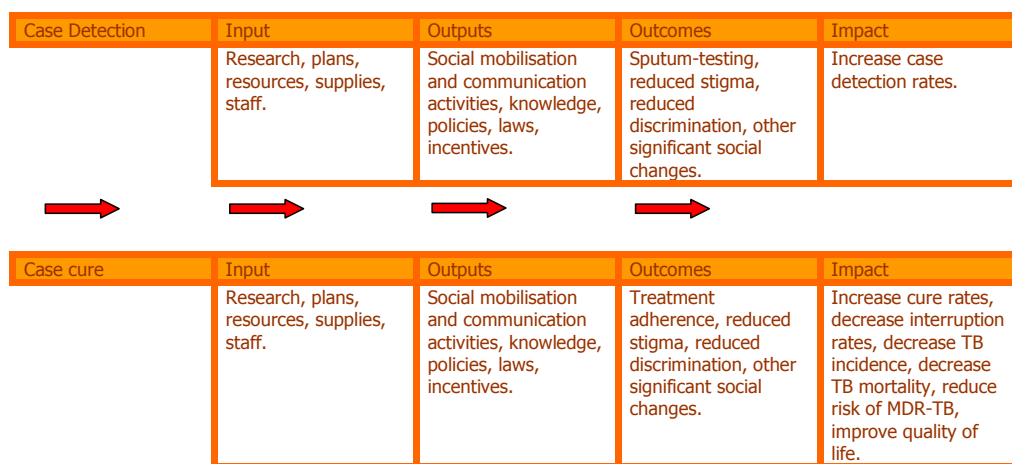


Figure 1: Taken from WHO (2005)

Input indicators reflect what resources such as research, planning, staff, supplies and resources required to design, implement and evaluated ACSM activities.

For example

- Written TB social mobilisation and communication plan with clearly stated behavioural goals
- % of health facilities with sufficient funding to conduct planned activities

Output indicators, which measure the delivery of the inputs, could include the following (WHO, 2005), for example:

Example of activity	Indicator
Use of radio, TV and print media to promote information about TB	# of public services announcements produced
Point of service promotion	# of brochures listing locations of TB services distributed
Civil society engagement	# of organisations reached # of organisations active # of community-based organisations distributing information # of community workshops/ forums

TB patient activism	# of TB support groups # of workshops for public/private/professional and NGOs promoting patient centred care
Use of radio, TV and print media	# of TV, radio and print programmes produced # of broadcast time or newspaper space purchased
Press conferences	# of press conferences organised # of articles generated # of journalists trained in TB
World TB Day promotional materials	# of promotional materials distributed
Support or expand local networks of advocates and champions	# of champions reached # of organisations reached

Other output indicators that could be used could include the following (WHO, 2005);

- % of the population who are aware that a chronic cough could be a sign of TB
- % of population who know that sputum testing is the best way to diagnose TB
- % of population who know that sputum-testing is free at DOTS facilities
- % of population who know the location of their nearest sputum-testing facility
- % of population who know that TB is curable
- % of population that know that completing TB treatment is essential to remain healthy and to avoid developing MDRTB
- % of population who know that TB treatment through DOTS is free

The National Tuberculosis Management Crisis Plan has developed indicators to assist in monitoring the progress of the plan. The following indicators could also be used to measure the success of the social mobilisation activities (Department of Health, 2006);

- # of TB stories published in a month
- # of NGOs and private entities linked to PHC facilities providing TB services
- # of awareness campaigns held in a quarter

With regard to outcome measurement, the following indicators could be used (WHO, 2005):

Example of activity	Indicator
Assessing sputum testing	# of people who present at DOTS facilities requesting a TB sputum test
Assessing treatment adherence	% of new smear-positive cases cured % of new smear-positive cases who completed treatment % of new smear-positive cases who interrupt treatment % of all TB cases who have a DOT supporter
Assessing stigma and discrimination	% of people expressing accepting attitudes towards people with TB % of formal sector employers with non-discrimination policies and non-discriminatory practices in recruitment, advancements and benefits for employees with TB. # of communities that have established a legal framework to protect the human rights of people with TB. # of communities that organise communication activities to empower communities to understand and use policy and the law to obtain the care and support they require for TB patients.
Measuring significant changes	Expanded public and private dialogue and debate. Increased accuracy of the information that people share in dialogue and debate. Increased leadership role by people disadvantaged by the issue of concern. Linked people and groups with similar interests who might otherwise not be in contact.

Impact indicators that look at measuring longer terms change in relation to ACSM include (WHO 2005);

Dimension of work	Indicators of change and longer term impact
1. Policy change	<ul style="list-style-type: none"> Changed policy Change in legislation Policy/ legislation change implemented Positive change in peoples lives as a result of the policy change
2. Strengthening civil society by working with NGOs/ networks/ CBOs etc.	Civil groups active in influencing decision-makers in ways that will benefit poor/ sick people
3. Enlarging democratic space or the space in which civil society groups can effectively operate in society	<ul style="list-style-type: none"> Increased participation of civil society groups in influencing decisions Change in accountability and transparency of public institutions
4. Supporting people-centred policy-making	Improved access to basic rights such as health, housing, food and water

11.2 Means of collection

Identifying indicators is just one part of the planning process of setting up a monitoring and evaluation plan, however another important aspect is to identify tools that will assist with measurement. Identifying tools that are already in place, or easy to add to your day-to-day routine are the best ways of capturing routine data. For example using data already captured by the TB register, the VCT register etc. Other measurement tools could include interviews, surveys, observations, and audits.

12. Operational Research

Operational research is very important in answering general and context-specific questions about the contribution of communities to TB control. As part of one's professional practice it is important to maintain an 'enquiring mind' about how you could improve your programmes performance to ensure successful TB results.

This could be done by designing research to explore (Stop TB, 2007);

- with (ex-)patients their experience of TB services,
- documenting good practices (both quality and acceptability),
- making a strong link between operational research and M& E. For example using stats for case detection, laboratory monitoring, adherence, and treatment outcomes,
- Identify relevant themes based on challenges or opportunities

Most of the time, operational research can feel like an additional burden that is not an essential part of service delivery. Many health workers spend much time completing TB registers for the purposes of statistics however this is mostly a tiresome task. Presenting the statistics once it is translated into useful data, allows staff to begin to think more critically about the management of TB by the health service in the community.

One way to make operational research more manageable is to partner with research institutions so that they act on the research needs and priorities of the TB programme. The responsibility for managing the implementation of the research remains with the health facility so ongoing supervision is necessary to ensure the research is being implemented as planned and proper outcomes are achieved.

Strong synergies between health facilities, research institutions and community groups can create a spirit of learning and motivation to continue to improve TB services. Operational research allows TB programmes to network with other organisations, share the lessons learnt and feature their work at national and international conferences.

13. Resources

1. **Civicus.** Civicus have developed planning tools for civil society, aimed at helping people to deal with a variety of organisations to develop media, planning, monitoring and evaluation, proposal writing and budgeting. This information can be downloaded from <http://www.civicus.org/new/default.asp>
2. **International HIV/AIDS Alliance.** This international organisation has developed a number of extremely useful Toolkits that can be used to support the implementation of programmes in the community. These toolkits can be downloaded or ordered from www.aidsalliance.org. The following toolkits are recommended to support social mobilization:
 - All Together Now! Community mobilization for HIV and AIDS.
 - Advocacy in Action – A toolkit to support NGOs and CBOs responding to HIV and AIDS.
 - Resource mobilisation – A toolkit to support NGOs and CBOs responding to HIV and AIDS.
3. **Khomanani Mass Communication Campaign.** This campaign is an initiative of the South African National Department of Health. As part of the campaign a number of mass media tools were developed including posters, pamphlets, booklets that relate to HIV and AIDS and TB. These tools can be downloaded or ordered from the Khomanani website that can be accessed from www.health.gov.za
4. **Stop TB Partnership.** This Partnership have developed excellent tools to assist in the development of strategies to address TB, as well as information documenting 'best practice' TB projects from across the world. Stop TB Partnership have the latest information and statistics on TB including MDR-TB and XDR-TB. This information can be downloaded from www.stoptb.org
Latest documents of interest [http://www.stoptb.org/resource_center/documents.asp];
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 - Ngamvithayapong-Yanai J, 2007. *HIV testing for life....HIV testing for all tuberculosis patients.* TB/HIV Research Foundation, Thailand and The Research Institute of Tuberculosis, Japan Anti-Tuberculosis Association.
[http://www.stoptb.org/resource_center/documents.asp]
5. **TADSA.** A South African national organisation providing technical support to the health service to manage TB. Contact details: Tel +27 21 918 1556 or go to www.tadsa.com
6. **TB Care Association.** TB Care Association provides care to TB patients by training and employing treatment supporters to provide directly observed treatment. Contact details: Tel + 27 21 692 3027 or go to www.tbcare.org.za
7. **UNAIDS.** The Joint United Nations Programme on HIV/AIDS has documented all aspects of the HIV and AIDS epidemic. They have documents that describe the scope of the epidemic, as well as how it can be prevented, and treated. The website also makes reference to TB, as a result of the strong link between HIV and AIDS and TB. This information can be accessed from http://www.unaids.org/en/Issues/Prevention_treatment/tuberculosis.asp
8. **WHO.** The World Health Organisation has generic tools to assist in social mobilization and behaviour change communication. This information can be accessed from www.who.org.

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