

# INVOLVEMENT OF THE COMMUNITY

Hi, my name is **Nurse Community!**

My job is to ensure that patient-centered approaches are prioritised in the TB/HIV response. This includes investing in the core pillars of our society, the community. These pillars include monitoring and accountability, advocacy, social mobilisation, community linkages, collaboration, institutional capacity building, planning and leadership development. Strengthening community systems means investing in an environment that is enabling for communities and places the communities at the centre of TB programming.



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### How can communities be involved with treating and preventing TB/HIV?

Since HIV and TB infection can occur in communities, community members (and not only health care workers) can help to prevent TB and HIV and support people with the diseases.

Community involvement can greatly benefit communities where people have been involved in the prevention and treatment of HIV and TB.

Examples of the different ways in which communities have been involved in TB/HIV care and prevention are provided in this document. In low- to middle- income countries, there is a shortage of health care workers which may limit provision of services for TB and HIV prevention and treatment. Given the human resources for health challenges in many regions, the WHO has recommended that 'task-shifting' be adopted in health facilities. This is where certain tasks that were traditionally performed by doctors are now performed by nurses and certain nurses' tasks are performed by community health workers or lay people.

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### What are some examples of how communities can be involved in TB and HIV activities?

Anyone can be involved in TB and HIV treatment and care. Some of the ways that communities have become involved in TB and HIV treatment and care include:

- Advocacy
- Awareness-raising
- Training
- Peer education
- Contact tracing
- Home visits or assisting in the delivery of medication
- Treatment support
- TB infection control



## ADVOCACY

Advocacy involves people or a group of people (such as professionals, the media, patients and community members) speaking up against an issue or for purposes of gaining support in order to change policies or get support for an idea or movement.

Progress in the global and national fight against HIV was driven primarily by advocacy, yet TB has not received as much advocacy support.<sup>96</sup> Advocacy can take many forms such as getting community support for petitions or memorandums, marches, sit-ins and meetings with decision-makers. Advocacy work often involves several key stakeholders, each with unique ways of providing leverage around issues, working together on one or more issues.

### CASE STUDY: CALLING SA GOVERNMENT TO INCREASE EFFORTS ON COMBATING TB

In South Africa, the Treatment Action Campaign (TAC), Section 27, Oxfam and Médecins Sans Frontières (MSF/Doctors without Borders) identified important steps to be taken in fighting TB at the 2012 South African TB conference. The groups delivered a memorandum containing interventions critical for the reduction of TB cases and mortality in South Africa, such as diagnosing all people living with TB and drug-resistant TB (DR-TB), ensuring access to the best available medicines, improving the affordability of medicines, reducing crowding in prisons, the mines and other congregate settings and implementing active case finding and infection control measures.

### CASE STUDY: MULEIDE'S ADVOCACY WORK

The Mozambique HIV, TB and Human Rights Training Advocacy Programme (MULEIDE) is a group of Mozambiquan actors and civil society organisations that formed in 2012 to fight for better access to treatment and health funding. During 2012 there were many drug shortages in Mozambique. MULEIDE met with the Minister of Health and campaigned for;

- Increased knowledge about what goes on in the health system
- An increase to the national health budget
- Improvement in the management of the supply process of drugs

Through its advocacy (fighting for the above things) it has got a commitment from the government to order more drugs and to work with the World Bank for emergency supplies when needed.

Source: <http://www.wlsa.org.mz>

<sup>96</sup> Seti, B. *Effective Partnerships: A Civil Society Perspective. TB/HIV Workshop. Aids and Rights Alliance for Southern Africa (ARASA). Maputo, Mozambique. 10-12 April 2013. S 7.* Available at: [http://www.who.int/tb/challenges/hiv/arasa/effective\\_partnerships.pdf](http://www.who.int/tb/challenges/hiv/arasa/effective_partnerships.pdf)

## AWARENESS

Awareness involves making sure that your community knows about the risks of contracting TB and HIV and how and where to get treated. This can be done in many ways such as giving talks at schools, churches, the workplace, taverns or in sports teams. You could ask your local radio station if you could be allowed to talk about TB and HIV on the radio. You could also hold community events or attend community events and ask if you could speak about TB and HIV. Most importantly, remember that even just speaking informally with people around you about TB and HIV is one of the most effective ways of spreading a message.

There are many useful tools that you can use to assist in raising awareness- this toolkit is one of them. Raising awareness is a valuable part of overcoming and challenging health issues.

It's important that people understand all the information about TB and HIV – this might mean speaking in the language most understood by people or getting someone else to talk to people in the most understood language within an area.

### CASE STUDY: DHAT'S DISABILITIES AWARENESS WORK

**Disabilities, HIV and AIDS Trust (DHAT) is a regional organisation working in southern Africa. It was formed in 2007 to promote the rights of people living with disabilities. DHAT started a programme on the Rights and Needs of Persons with Disabilities in Zambia. The project visited six clinics to inform health care workers (HCW) about DHAT's work and to talk about issues experienced by women with disabilities who have HIV. HCW were very interested in this work and agreed to send two HCW to a workshop with DHAT. DHAT has also held awareness-raising workshops which have been attended by women with disabilities, doctors, nurses and Health NGO workers, in order to spread their message.**

*Source: <http://www.dhatregional.org/>*

## TRAINING

Training about HIV and TB can cover many topics and should be suited to the specific skills or knowledge needs of the people being trained. It gives people skills and knowledge which means they are better informed and better able to fight HIV and TB. You can be involved in the community as a trainer and as a participant in training. Attending training sessions is a good way to get knowledge, which will help you in raising awareness to those around you. This Toolkit is a useful tool for training – one or more people could teach the material in this toolkit to the participants of a TB training session.

It is important to have clear goals you want to achieve in your training and make sure you remember this when leading the sessions. One of the goals of training must always be that participants understand the issues you are discussing. It is important to remember that not everyone has the same knowledge and/or experience. You may also need to change the speed at which you explain things if you are training people who do not know a lot about HIV and TB. The number of training sessions needed will depend on how complex the issues covered are. Also, if there are lots of people who need to or want to attend, you may need to give the same training in several different locations.

## CASE STUDY: YORD'S TRAINING

Youth Outreach on Rights and Development (YORD) was started by youth in Namibia. They have held training workshops on Reproductive Health Rights, in the Ohangwena region with HIV support groups. There were three workshops in total. The workshop was put together with information gathered from brochures and pamphlets on HIV prevention, TB and Sexual and Reproductive Health Rights (SRHR) from NGOs, ministries and organisations. This information was handed out at the training. After the workshops, participants recommended for more workshops and materials on topics that had not been discussed. The support groups are still in existence and these workshops have instilled a desire to learn within the groups.

Source: <http://www.arasa.info/images/Reports-may-2013/ARASA%20Annual%20Report%202012%20.pdf>

## TREATMENT SUPPORT

People who are taking TB or HIV treatment take their medication for a very long time.

There are many ways in which you can support people taking treatment:

1

Start a **Support Group**: A support group of people with the same disease can be formed. This can be used as an opportunity to provide training to people on treatment, answer questions and assist people in taking their treatment. MSF in Khayelitsha uses its community support group to provide ARV treatment to patients who are stable on their ARV treatment.<sup>97</sup>

2

Be a **Treatment Buddy**: Treatment buddies are people who support patients on treatment or in the early stages of treatment. This can involve attending the clinic with the patient, collecting their medication at the clinic, reminding patients to take their treatment and supporting people through taking treatment.

3

**Delivery of Treatment**: Patients who are very sick cannot attend the clinic to collect their own medication. Many people support patients on treatment merely by delivering a person's medication to their home.

4

**Support with Chores**: People who are starting treatment may experience side effects or still be too ill to attend to their daily chores. By helping someone on treatment to do simple tasks like doing their grocery shopping, cleaning their home, running some errands, taking care of their children or cooking them a meal can allow people on treatment to rest and recover.

<sup>97</sup> [http://www.msf.org.za/sites/default/files/publication/documents/ART\\_Adherence\\_Club\\_report\\_toolkit.pdf](http://www.msf.org.za/sites/default/files/publication/documents/ART_Adherence_Club_report_toolkit.pdf)

### CASE STUDY: PIH TREATMENT SUPPORT

For every 100 000 people in Lesotho, 633 are infected with TB each year. The co-infection rate of MDR-TB and HIV is 70%. It is clearly important for TB and HIV treatment to be addressed together. Staff working for Partners in Health (PIH) in Lesotho are trained in both HIV and TB treatment. The Botsabelo Hospital (which has 24 beds) caters for people who are having side-effects from MDR-TB drug. PIH, through assistance of community health workers closely track Botsabelo patients and the integrated HIV and TB treatment they receive, which includes Directly Observed Treatment (DOT). A Community Health Extension Worker manages one unit (1000 households) and links the unit to a health facility. One community health worker is assigned to 20 households. Houses were visited once a month or more and residents were screened for ailments, including TB symptoms using the TB screening algorithm.

Source: <http://www.pih.org/country/lesotho/about>

### PEER EDUCATION

Peer education is an important part of community involvement. It means that people who share similar experiences, or have had a disease before, educate others on how to manage their illness. This is a very powerful education model, as people with TB or HIV learn more from others who have the diseases and have first-hand experiences on the disease(s). This type of education is different from attending a training workshop and learning information from a doctor or nurse. It is a way for lay people to teach those in their community about health issues.

### CASE STUDY: PEER EDUCATION IN ZAMBIAN PRISONS

TB prevalence is very high in Zambian prisons with 10 to 20 times higher infection than in general society. TB control guidelines are being developed to combat this. Peer education happens among prison inmates, facilitated by Prisons Care and Counselling Association (PRISCCA). Fellow prisoners who have either had TB or HIV or who have received specialised training on TB/HIV, share knowledge with fellow prisoners. Prisoners are motivated to become counsellors or to learn from counsellors because many fellow inmates contract TB while in prison. The programme is sustainable as new peer educators are trained annually, allowing for new educators to take over if fellow inmates are released. The skills and experience gained through the peer education and training are applicable to other employment opportunities when they leave prison.

Source: <http://www.osisa.org/law/zambia/prison-care-and-counselling-association-prisca-zambia>

## CONTACT TRACING

TB contact tracing involves finding out whether someone has come into contact with TB disease (through a person infected with TB disease). Contact tracing may involve screening the household contacts for TB disease and providing treatment or IPT (to prevent TB) where necessary. This is a further way of being involved in your community's fight against TB and HIV, where people assist by going to the homes of contacts and do TB screening and education with household contacts.

## DELIVERY OF MEDICINES AND HOME VISITS

Delivering medication to those with HIV and/or TB and making home visits is another way to be involved in supporting those with TB and/or HIV. You do not have to be a qualified doctor or nurse to deliver medication. Getting medication delivered to people's homes makes life much easier for them. If people are sick it is important for them to rest. Decreasing the times they need to leave home helps in their potential recovery.

### CASE STUDY: COMMUNITY HEALTH STRATEGY

Kenya's National Guidelines for HIV Counselling and Testing (HCT) includes home -based testing as well as workplace programmes for testing and treatment. This was developed in 2006 with the goal of improving the country's health. HCT is part of "routine patient care", meaning all patients get tested and counselled.

Community Health care workers do door-to-door delivery of health services (deliver medicine, check people are taking medicine, do tests and conduct TB screening).

Houses are visited once a month by a community health worker or more if ailments are serious. One HCW is allocated 20 households. The country is divided into units made up of 1000 households in some regions Each unit is managed by a community HCW who provides a referral to a health facility where the person can begin treatment if they are diagnosed with HIV and be provided with adherence support.

This initiative is government supported, but is reliant on scarce donor funding. The amount the Government of Kenya's proposed to pay per home-based testers was is not enough to support the livelihoods of staff. Therefore insufficient salaries or stipends lead to demotivation and attrition of community health workers and an unsustainable programme. Sustainability challenges will have to be addressed with adequate resources allocated to the programme to ensure the continued success of HIV/TB prevention, care and support.

Source: <http://kenya.usaid.gov/programs/health/77>

Source: <http://www.tbonline.info/posts/2013/7/23/kenyan-government-now-sets-pace-war-against-tuberc/a>

## INFECTION CONTROL

Infection control is very important when dealing with TB. It is a practical way to stop new TB infections. Infection control can be done in a number of ways such as monitoring the hospital and clinic environment. This can be done by making sure people are not too close together or coughing on each other. One of the steps identified by civil society at South Africa's 2012 TB conference was to reduce crowding in prisons and put in place infection control measures.<sup>98</sup> This shows how important infection control is in fighting TB and HIV.

### CASE STUDY: TB TESTING IN PRISONS IN SWAZILAND

**It is easy for TB to spread in the prison environment , because often prisons are overcrowded and it is very easy one for TB to spread. 3570 out of 100 000 prisoners have TB in Swazi prisons, and 1900 per 100 000 officers. "TB is one of the most important opportunistic infections among inmates with HIV/AIDS"**

**Swaziland for Positive Living (SWAPOL) and Swaziland National Tuberculosis Control Programme (NTCP) are trying to get TB prevention on the Correctional Services' agenda along with treatment and care programmes SWAPOL recommends all prisoners with HIV should be tested for TB. TB testing policy needs to be developed in order to establish infection control in prisons.**

**The WHO recommends that all prisoners should be tested for TB before they enter prisons and at least annually, including when they leave prison.**

*Sources: [http://www.who.int/hiv/pub/idu/tc\\_prisons/en/index.html](http://www.swapol.net/World Health Organization, 2009, HIV testing and counselling in prisons and other closed settings. Available at: <a href=)*

### CASE STUDY: TB INFECTION CONTROL AT BUS STOPS IN SWAZILAND

**Bus stops and buses are another place where infection can easily spread, as people crowd closely together. SWAPOL, in collaboration with the NTCP, convened three meetings with various partners to plan the Stop TB campaign.**

**SWAPOL conducted TB infection Control (TB IC) campaigns in 5 bus ranks around the country over 5 months. Bus conductors, drivers, travellers and people from the surrounding areas were able to access HIV HTC services and were empowered on accurate information on TB IC. 345 people got tested and were screened for TB by MSF on site.**

*Source: <http://www.swapol.net/>*

<sup>98</sup> Smart, T. *The TB activist agenda in southern Africa: more from the South African TB conference. 18 June 2012.* [www.aidsmap.com](http://www.aidsmap.com). Available at: <http://www.aidsmap.com/page/2397011/>



### ASSESSMENT OF NEEDS

In order to assess the needs of your community you need to be aware of the issues relating to HIV and TB. Different people (age, sex, diagnosis) and different communities have different health problems and needs. Therefore, assessment of needs must be done carefully. A good way to assess the needs of your community is to go out individually or in a group and ask people questions about what their problems are, if they have HIV or TB (if they are happy to talk about this), whether they are getting the correct medicine and in the right dose, what they feel they need, what has helped them, what has not helped them, etc. You could also ask those who are receiving treatment at the clinics in your community a series of questions on HIV and/or TB. Questions could also be asked through an anonymous survey. Asking questions allows you to see the 'gaps' within the community and enables one to identify what is still needed in the community. A needs assessment can help you decide what is most important to work towards in advocacy or what areas need to be taught in training to the community.

### IDENTIFICATION OF PEOPLE WHO CAN ASSIST

After you have done a needs assessment, it is very important to identify who can help fill the gap(s) you have identified. These people may be community leaders, members of the municipality, NGO workers (who may have connections higher up in government and the health ministry) and media representatives (radio, newspapers, television, etc.). This involves approaching people you know who will be able to help and telling them about what you need. It may also involve getting contact details for people you do not know, meeting with them and explaining what you need.

### TRAINING/EDUCATION/AWARENESS RAISING AS NECESSARY

Once needs have been identified, the next steps can be taken. These steps will be different for each need but may be a combination of training strategies, peer education and awareness raising. Handing out written and/or visual information or getting community radio stations to talk about the needs you have identified is a way of doing this. Always remember the problem you are trying to solve. Even though you are working towards fighting TB and/or HIV you must be clear on what exactly you are working on. Doing a needs assessment will define the most priority areas to work on. The training and awareness raising you do will be based on the needs you identified. Asking people who are experienced for help is a good way to make sure your project is successful.

## **TOOLS/RESOURCES**

Doing a needs assessment and getting into contact with people who can help means you should know what resources and tools are needed to address your community's need(s). These resources and tools take many forms and can be brochures, t-shirts, more information about new drugs, funding, etc. It is a good idea to have a group of people in charge of getting the tools and resources needed. This group can also be in charge of awareness raising and education. Having a strong team with good leadership who remember the needs you are trying to address in the community is important if you are going to get tools and resources and then use them properly.

## **MOBILISATION (IF NECESSARY)**

You may need to gather support and get people together to address the needs you have identified. This is possible if you explain what you want to do in a way that is easily understood by the whole community. If you tell them why a problem needs to be fixed and how each individual and the community will benefit, you may be able to mobilise people and communities. This means people will support the idea and join together to fix the problem.

## **ACTION**

This is the final stage of community involvement. Action means putting in place your plan for addressing the need and using the people you have identified to help. Again, it is important to remember the needs you are addressing, even in the action stage. It is complicated to deal with issues around HIV and TB, not only because you are dealing with diseases but because you are dealing with different sorts of people who have different reactions to these topics. Some people who may be in a position to help will not be helpful. It is important to stay positive and carry on fighting for what your community needs, even if it does not happen immediately and is not easy.