



# Handbook

for community based organizations on **tuberculosis** services for people who inject drugs





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TUBIDU 2011–2014
Empowering the Public Health System and Civil Society to Fight the Tuberculosis Epidemic among Vulnerable Groups
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# **Abbreviations and acronyms**

AIDS Acquired immunodeficiency syndrome

ART Antiretroviral therapy
ARV Antiretroviral drugs

CBO Community-based organization

(defined as non-governmental and other types of civil society organizations that are usually self-organized in specific local areas to increase solidarity and mutual support in addressing specific issues)

CBT Cognitive-behavioral therapy
DOT Directly Observed Treatment

(a component of TB case management that helps to ensure that patients adhere to treatment. Narrower meaning: a trained health care worker or other designated individual, who watches the patient

swallow every dose of the prescribed TB drugs)

EU European Union HBV Hepatitis virus B HCV Hepatitis virus C

HEPA High efficiency particulate air filtration

HIV Human immunodeficiency virus

INH Isoniazid

IPT Isoniazid preventive therapy
LTBI Latent tuberculosis infection
MDR-TB Multidrug-resistant tuberculosis

MI Motivational interviewing

NTP National tuberculosis programme
OST Opioid substitution treatment

PLHIV People living with HIV PWID People who inject drugs

(sometimes also referred to as injecting drug users - IDU)

RIF Rifampicin
TB Tuberculosis

UVGI Ultraviolet germicidal irradiation system

WHO World Health Organization

XDR-TB Extensively drug-resistant tuberculosis

# Introduction

**Tuberculosis (TB)** endangers the most vulnerable and socially excluded populations in society. People who use illicit drugs, especially **people who inject drugs (PWID)** are considered to be at high risk of contracting TB or other infectious diseases, such as **hepatitis B (HBV)** and **hepatitis C (HCV)**. <sup>10-15, 30</sup> Drug users' TB diagnosis and treatment is often complicated by their complex treatment needs (e.g. comorbidities such as HIV/TB co-infection, drug and/or alcohol addiction), stigmatization of both TB and drug abuse, as well as poor access to healthcare services. This can lead to delayed TB diagnosis, severe and advanced disease, drug resistance, low treatment completion rates, onward transmission and preventable deaths. <sup>3,6,7</sup> Thus, drug users are in need of an integrated and effectively coordinated approach to TB treatment that focuses not only on curing disease, but also on addressing additional psychosocial problems, such as addiction. <sup>35</sup>

TB prevention is an essential public health intervention that requires sustained political commitment and coordinated action between health services and community based organizations (CBOs). CBOs working with vulnerable populations play a key role in making health services (whether TB related or not) more accessible to PWID as their first-hand involvement enables health care professionals and those providing other relevant services for vulnerable populations to understand both the local context and their clients' complex needs. This knowledge is essential to early detection of TB among at-risk population groups, as well as to developing and providing supportive services during treatment (especially at outpatient sites). In fact, community based TB care has been proven to be more cost-effective than hospital-based or other standard ambulatory care models.33 Thus, collaboration between the national tuberculosis programme (NTP), TB, HIV or other harm reduction programmes and CBOs who work with poor, vulnerable and at-risk groups such as PWID is indispensable for developing effective outreach services that meet the target group's needs, enabling these individuals access to high-quality care, achieve early diagnosis and complete treatment, as well as preventing further transmission of TB.

The TUBIDU handbook is intended for CBOs working with PWID and other atrisk populations. The main key interventions in TB control should be as follows:

- Intensified and active TB case finding, contact tracing, active referral to health care services
- TB infection control in CBO and among personnel
- Supporting clients undergoing TB treatment and finding lost to follow-up
- Delivering TB treatment (e.g. implementation of DOT)
- Informing, educating and counselling CBO clients and those close to them on TB, as well as providing education and information within the community.

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# **Process of developing the handbook**

This handbook has been developed in the framework of the project TUBIDU: Empowering the Public Health System and Civil Society to Fight the Tuberculosis Epidemic among Vulnerable Groups. This European Union (EU) project is funded by the "Programme of Community Action in the Field of Health (2008-2013)" and includes seven participating organizations from six EU countries (The Dose of Love Association in Bulgaria, The Estonian Network of People Living with HIV and The National Institute for Health Development in Estonia, The Finnish Lung Health Association in Finland, The Tuberculosis Foundation of Latvia, The Institute of Hygiene in Lithuania, and The Romanian Angel Appeal in Romania). Five collaborating partners are also included in this project, all of them from non-EU countries (The Leningrad Region AIDS Center in the Russian Federation, The International HIV/AIDS Alliance in Ukraine, The National Center for Tuberculosis and Lung Diseases in Georgia, World Vision Albania and World Vision Bosnia-Herzegovina). The general objective of the TUBIDU project is to contribute to the prevention of injecting drug use and HIV-related TB epidemic in the project area. The strategic objectives include empowering the public health system and civil society and enhancing the collaboration of various stakeholders in the field in order to tackle TB.

The current situation of all TUBIDU partner countries has been taken into consideration when compiling this handbook, including legislative issues and health and social care systems. In addition to the handbook, the project has included a cross-sectional study of current PWID; focus groups of drug users and CBO personnel have also been conducted and a guidance document on TB services among PWID has been composed for CBO workers. In addition, international scientific literature and official recommendations and guidance have been reviewed.<sup>a</sup>

The handbook is based on the recommendations of the existing key WHO<sup>7</sup> European Centre for Disease Prevention and Control and European Monitoring Centre for Drugs and Drug Addiction<sup>35</sup> guidelines for TB and HIV prevention, care and treatment. The handbook recommendations which refer to evidence-based and internationally recognized approaches to TB diagnostics, treatment and prevention, have been placed in the context of people who use drugs, taking into account the background and conditions in all partner countries.

a All documents are available at: http://www.tai.ee/en/tubidu/publications

# **Rationale**

The aim of the handbook is to provide information, recommendations and guidelines for CBO personnel on how TB prevention, control and treatment activities could be included in their organizations' work with PWID. The handbook supports CBO personnel in their daily work, providing background information on TB among vulnerable groups such as PWID as well as offering methods to facilitate and make CBO's work more efficient. Thus, the handbook is a working tool, rather than a strategic or policy document. The local legislation and conditions should be taken into consideration when implementing the recommendations and guidelines of this handbook.

In this handbook, CBOs are defined as non-governmental and other types of civil society organizations that work for the prevention of HIV and other infectious diseases and provide harm reduction, health or welfare services for PWID and those close to them. The handbook is not directed at organizations providing primary or specialized health care services, as the profile of these organizations usually requires more strict and specific measures for TB prevention and control. Nevertheless, this material could be helpful to those organizations when collaborating with CBOs and working with clients who are or have been injecting drug users or who struggle to adhere to TB treatment.

# I The basics

# **Tuberculosis**

TB is an airborne infectious disease caused by a bacterium called *Mycobacte-rium tuberculosis*. TB most commonly affects the lungs but can attack almost any organ of the body.

**TB** is **spread through the air**. When a person who has infectious TB of the lungs or throat coughs, sneezes, sings, laughs or talks, tiny particles that contain TB bacteria are released into the air. These particles are called droplet nuclei and are invisible to the naked eye. The droplet nuclei can remain airborne in the room for many hours. When other people inhale air that contains the droplet nuclei, they may become infected with TB.

The greatest risk of transmitting TB infection is in the period prior to diagnosis and at the beginning of treatment. The risk of transmission is significantly reduced within two weeks after commencing appropriate therapy for drugsensitive TB. In multi-drug resistant TB (MDR) and extensively-drug resistant (XDR) TB, the risk of transmitting lasts longer after the beginning of therapy.

TB is not transmitted by touching clothes or objects, sharing food, drinking from the same glass or shaking hands with someone infected with TB disease.

## Transmission of TB

TB is spread from person to person through the air. The dots in the air represent droplet nuclei that contain TB bacteria.

# **Latent TB infection and TB disease**

When people have *Mycobacterium tuberculosis* in their body but do not have active TB disease, then it is called **latent TB infection (LTBI)**. These people are not infectious and do not feel or look sick. Only 10% of people with normal immunity develop TB disease during their lifetime. Conditions and lifestyle factors such as HIV infection, diabetes, malnutrition and smoking challenge the immune system and increase the risk of LTBI progressing to active TB disease.

Latent TB infection (LTBI)	TB disease (in the lungs)	
M. tuberculosis is in the body and a tuberculin skin test reaction is usually positive		
No symptoms	Symptoms: cough, bloody sputum, fever, weight loss, night sweats, fatigue	
Chest X-ray is usually normal	Chest X-ray is usually abnormal	
Cannot spread TB bacteria, not infectious	May spread TB bacteria, often infectious before treatment	
Not a TB case	TB case	
No TB treatment is required (some people can benefit from preven- tive therapy with isoniazid (INH) or other drugs to reduce the risk of developing active TB disease)	Treatment for TB disease is required	

Persons with presumptive TB (i.e. people who have symptoms of active TB and/ or an abnormal chest X-ray) should be considered infectious until diagnostic investigations have been completed.

# TB symptoms

Symptoms of TB disease depend on where in the body the TB bacteria are growing. Symptoms of TB may include:

Pulmonary symptoms	Constitutional symptoms
(only pulmonary TB)	(TB of all forms)
<ul> <li>prolonged cough that lasts more than 3 weeks</li> <li>chest pain</li> <li>shortness of breath</li> <li>coughing up blood or bloody sputum (hemoptysis)</li> </ul>	<ul><li>fever</li><li>night sweats</li><li>weight loss</li><li>loss of appetite</li><li>fatigue</li></ul>

# Multidrug-resistant TB and extensively drug-resistant TB

Drug resistance means that the medicines used to treat TB are no longer effective in killing the TB bacteria. Resistance to drugs is often caused by an incorrect or inappropriate use of anti-TB drugs, use of ineffective formulations of drugs and premature treatment interruption. It is also possible for the initial infection to be a drug-resistant form of TB.

**Multidrug-resistant TB (MDR-TB)** – a form of TB that is resistant to at least two of the most powerful first-line anti-TB drugs: isoniazid (INH) and rifampicin (RIF).

**Extensively drug-resistant TB (XDR-TB)** – a form of MDR-TB that is also resistant to any fluoroquinolones and at least one of three injectable second-line anti-TB drugs (amikacin, capreomycin or kanamycin).

MDR-TB and XDR-TB may develop in a patient who is receiving treatment for active TB when anti-TB drugs are misused or mismanaged. This can happen when patients are not properly supported to complete their full course of treatment; when health-care providers prescribe the wrong treatment, the wrong dose, or when the prescribed period is too short; when the supply of drugs to the clinics dispensing anti-TB drugs is erratic; or when the drugs are of poor quality.<sup>21</sup>

**Drug-resistant TB is spread in the same way as drug-susceptible TB**, so newly infected persons can have drug-resistant TB from the beginning without any previous exposure to TB drugs or TB treatment interruption. There is no definitive evidence that drug-resistant TB is any more infectious than fully sensitive strains of TB. Nevertheless, drug-resistant cases are likely to remain infectious for longer periods after starting treatment (this can be linked to the lower effectiveness of second-line TB drugs)





# **Diagnosis of TB disease**

# All people who are suspected of having TB disease should immediately be referred to a doctor or a TB clinic for medical evaluation.

A complete medical evaluation for TB includes:

- Medical history (history of TB exposure, infection, disease, demographic factors and other medical conditions that increase the risk of LTBI to progress into TB disease, such as HIV)
- Physical examination
- Chest radiograph (i.e. X-ray)
- Microbiological examination (e.g. sputum smear or other appropriate samples are analyzed under a microscope by trained laboratory technicians to see if TB bacteria are present)
- Tests for diagnosing TB infection (TB skin test or TB blood test).

Diagnosing TB among PWID can be more complex due to the higher rate of HIV and additional diseases in this population group. Smear-negative pulmonary TB is more common among people living with HIV (PLHIV) and is therefore associated with late detection, poor treatment outcomes and early mortality. <sup>18</sup> Late diagnosis of TB may also be more prominent among active drug users or those who receive opioid substitution therapy (OST) as some opiates may suppress the cough reflex.

## **Treatment for TB disease**

#### TB is treatable with anti-TB medications.

Treating TB involves taking multiple antibiotics over a long period of time. The four drugs that are most commonly used for TB treatment are often referred to as first-line drugs: isoniazid (INH), rifampicin (RIF), pyrazinamide (Z) and ethambutol (E). These are the best drugs for treating non-resistant TB.

Anti-TB drugs are prescribed by a doctor with training in the management of TB and have to be taken regularly (either daily or three times per week at a higher dose). The duration of the treatment varies according to the site of disease and the resistance profile of the TB organism. **Fully-sensitive TB requires 6-9 months of treatment** (unless the central nervous system is affected in which case 12 months of treatment is recommended).

The duration of drug-resistant TB treatment is determined by the resistance profile of the organism and the patient's clinical response to treatment. **The general duration of drug-resistant TB treatment is two years or longer.** Treating drug-resistant TB is possible, but as the most powerful first-line drugs are no longer effective and patients must be treated with second-line drugs,

the treatment lasts longer. Moreover, second-line treatment of drug-resistant TB is far more costly than first-line treatment, and produces more side-effects.

There are two phases of treatment for fully-sensitive TB: the initial intensive phase and the continuation phase. The intensive phase typically lasts for two months and the continuation phase, when TB is no longer infectious, but still requires treatment, for four months. The World Health Organization (WHO) recommends that patients be treated using mainly ambulatory care which is done in the community or at outpatient sites.<sup>34</sup> Some patients require hospitalization, either for clinical or social reasons, in order that therapy can be closely monitored. In addition, some MDR-TB and XDR-TB patients also require prolonged isolation, either at home or in hospital to prevent transmission in the community.

Most people with TB experience a rapid improvement in their symptoms after they begin treatment. The absence of symptoms can reduce patients' motivation to continue treatment, as they may think that the TB drugs are causing them to feel unwell (TB drugs may have disturbing side effects). However, it is crucial to follow the treatment regimen closely and on a daily basis in order to ensure the successful treatment of TB. It is imperative that patients are supported to complete a full course of treatment as interrupting treatment is likely to cause a relapse and could lead to the disease becoming drug-resistant.

Therefore, it is recommended that all patients with TB receive treatment adherence support and comply with Directly Observed Treatment (DOT) regulations. DOT is a WHO-recommended strategy for TB case management, whereby a trained and impartial DOT worker (e.g. responsible medical personnel or other designated individual) observes every dose of the medication to ensure that it is taken correctly.<sup>1</sup>

#### **FIND OUT**



How is TB treatment financed in your country or region for vulnerable populations such as PWID?

What regulations are applied in your country or region to control communicable diseases? Under what circumstances, if at all, is involuntary treatment possible? How is DOT provided in your country or region?

For more information on the treatment of TB, see:

World Health Organization. 2009. Treatment of tuberculosis: guidelines—fourth edition. Geneva, Switzerland: World Health Organization. WHO/HTM/TB/2009.420. (Available at: http://whqlibdoc.who.int/publications/2010/9789241547833\_eng.pdf)

# **Risk groups for developing TB**

As TB is contagious and spreads through the air, those in close contact with the person with TB disease are at high risk of contracting TB infection. Persons who have been in close contact with a person with TB disease should also be encouraged to be screened for TB.

## Persons at high risk of developing TB disease are:

- children
- the elderly
- PLHIV, especially those not receiving antiretroviral therapy (ART)
- persons in prolonged close contact with TB patients (i.e. family members or colleagues)
- pregnant women
- persons diagnosed with LTBI
- regular smokers
- those who regularly consume large quantities of alcohol
- drug users (especially PWID)
- homeless persons
- people with a history of imprisonment
- people born in countries with a high prevalence of TB<sup>II</sup>
- II See Annex I

# TB in people who inject drugs (PWID)

Drug users, whether injecting or not, are among the most vulnerable and socially excluded people in the society. PWID are often exposed to many TB risk factors such as:

- regular smoking and alcohol consumption
- poor nutrition
- poverty
- overcrowded living conditions
- homelessness
- imprisonment

PWID have a higher risk of TB, MDR-TB and XDR-TB as well as a higher burden of HIV, HBV and HCV.<sup>10-15, 30</sup> Given the numerous obstacles drug users often face in accessing health services, both TB and HIV are much more likely to be diagnosed at a late stage in this population group.

There is often a double stigma surrounding PWID with TB disease, due to common negative perceptions regarding both TB and drug use; moreover, affected individuals are often unaware of their rights. Therefore, **PWID often have complex needs and poor access to healthcare services or other lifesaving interventions, which, in turn, can complicate their TB diagnosis and treatment.**<sup>3</sup> Diagnosing TB as well as HIV among PWID at a late stage can severely impair TB treatment outcome and increase the chance of TB transmission among persons in close contact with the individual concerned.<sup>7</sup>

One of the reasons why PWID are in need of a special integrated approach in TB treatment is that drug use is associated with worse health outcomes and lower rates of TB treatment completion than the general population. This is often due to chaotic lifestyles, addictive behavior and other psychological or social factors associated with addictive drug use. Irregular treatment also increases the risk of developing drug resistance. <sup>67</sup>

In addition, PWID should be offered and receive OST or other narcological care, as their addiction should also be considered a disease that needs to be addressed. Even when drug users do complete TB treatment they may still lose their lives to an overdose if their other problems are ignored. However, many of the drugs used in OST (e.g. methadone) can interact with some anti-TB drugs as well as antiretroviral (ARV) drugs. The main complication of managing OST and TB treatment is that RIF can often accelerate the rate at which opiates are metabolized, so patients/clients on TB treatment may experience withdrawal symptoms. If that situation is not correctly managed, the patient/client may stop TB treatment altogether.

Despite these risks, it is still highly recommended that OST, ARV and TB treatment be made available simultaneously to PWID. CBO's first-hand involvement enables them to understand both the local context and their clients' complex needs. As CBOs have often already founded a trusting and respectful relationship with their clients, introducing so-called basic TB activities into CBOs' activities enables them to detect TB early in at-risk populations, as well as to develop and provide supportive services during their clients' treatment (especially at outpatient sites). Thus, CBOs play a key role in making health services better accessible to vulnerable groups such as PWID (whether TB-related or not), helping clients to adhere to TB treatment and dealing both with side effects and with other social problems that may occur.



# Case study 1

### **ESTONIA**

## Roman's story, as told by a CBO worker

"Roman started to inject drugs during his last year at high school. After his mother's death he was left homeless as the apartment where his mother lived belonged to her partner. He started stealing to get money to buy drugs, which soon led to him being imprisoned for six months. After being released, he went to live at the Ahtme shelter. During his imprisonment, he was able to overcome his addiction. With the help of a social worker, he also found solutions to his most difficult problems and slowly but surely, his life started to get better. Soon, Roman met a young woman and they had a son, but unfortunately their relationship did not last. Shortly after, Roman's grandmother invited him to live with her and he also found a job.

I heard news of Roman again one year later, when his grandmother asked me for help. Apparently, Roman had started to inject drugs again and had begun stealing things from home to get money. He also got into trouble with the police. However, he didn't return to the shelter, but stayed over at his friends' places or in random apartments. As his health started to get worse, he went to see a doctor and was diagnosed with HIV. Roman's attitude towards his treatment was rather careless and he didn't take his medication regularly. His life fell apart, as he was involved in more burglaries, receiving various punishments, including more spells in prison.

After living on the streets for two years, Roman came to Ahtme and asked for a place in the shelter. He was in a very poor state of health – he was weak, had a permanent fever and sweated a lot. He hadn't been to a doctor for a long time. As living in our shelter is conditional on undergoing a TB examination, he went to get his X-ray and other tests done. We have a good collaboration with the local TB hospital and if necessary, a member of the staff will even come to pick up clients who may have TB. That's also how Roman was diagnosed with TB; he then had to stay in inpatient treatment for eight months. In the hospital, he started to receive opioid substitution therapy with methadone. The long treatment in hospital was difficult for Roman and there were many times when he wanted to stop the treatment.. But with the support of hospital personnel and his grandmother, he was able to overcome his depression and managed to finish his treatment successfully. After being discharged from hospital, he continued OST and also received treatment in a psychoneurology hospital. However, his addiction to drugs persisted and in 2012, Roman died of an overdose."

# TB and HIV co-infection in PWID

HIV is considered to be the most significant factor in increasing the risk of progression from LTBI to active TB disease. People co-infected with TB and HIV who do not receive or follow ART are at the greatest risk of progressing to active TB disease, as the virus attacks their immune system.<sup>5</sup> PWID are, in turn, at high risk of getting HIV infection, as injecting drug use is a major mode of HIV transmission due to unsafe injection practices.<sup>11,15</sup>

**TB** is one of the leading causes of mortality among PWID living with HIV. TB and HIV co-infection has sometimes been referred to as "double trouble", because TB develops more easily in people whose immune system has been weakened by HIV, while HIV tends to replicate faster in people who are ill with TB.<sup>5,13-14</sup>

For example, persons who are only infected with TB have a 5-10% lifetime risk of developing full-blown TB disease, whereas persons with HIV co-infection have a 5-10% annual risk of developing TB disease.<sup>4</sup>

TB risk factor	Risk of developing TB disease
	About 10% over a lifetime
TB infection and no TB risk factors	
	About 30% over a lifetime
TB infection and diabetes	
	About 7-10% PER YEAR
TB infection and HIV infection	

With early diagnosis, TB, including MDR and XDR, can be cured in PLHIV, provided the treatment regime is properly followed. It is also possible to prevent the progression from LTBI to TB disease in PLHIV by providing them with ART which has been proven to slow the development of immunodeficiency. WHO recommends that ART be started in all TB patients living with HIV, and that TB and HIV prevention, treatment and control activities be integrated to improve the quality of patient care and the treatment outcome. <sup>16</sup>

HIV and TB co-infection among PWID can also have a negative impact on their adherence to treatment, as clients are required to consume large amounts of medication (i.e. ARV and anti-TB drugs) simultaneously. Those drugs can also interact, thus negatively affecting clients' physical wellbeing during TB treatment. Thus, the additional support, treatment observation and counselling offered to all TB patients by CBOs and healthcare facilities are very important factors in ensuring a positive treatment outcome.



# Case study 2

## **BULGARIA** | CBO Dose of Love

## TB through the eyes of Milen, an injecting drug user and former TB patient

"I am 38 years old and I have been using drugs for more than 10 years. That's why I have known the Dose of Love Association for a long time.

My girlfriend and child live in Sofia. I moved there, too, for a while and tried to get my family back together, but I couldn't. I didn't have any money or enough food, and I was still using drugs. My life was miserable. So I went back to my hometown; there, I started to use even more drugs and lost a lot of weight. I heard that it was possible to be tested for TB at the Dose of Love centre. At first I thought that TB was an ancient disease and I didn't realize that it was possible to get it now, but the team there gave me some information. When I had the screen test I understood that I was actually at risk, and that I had all the symptoms of the disease. But all drug users have these symptoms, right? As I trusted the Dose of Love team and because the nurse from the TB hospital was also at the centre, I decided to get tested for TB – and what a surprise - a few days later I got my results and they were positive. I couldn't believe it! I thought it was the end! I had thousands fears and questions – had I infected my mother? Those who I had been living with? I had met hundreds of people during these two months and I couldn't even remember all of them!

I had several conversations with the team from Dose of Love and the TB nurse during the days that followed. So, after I had calmed down a bit, I made the decision to get treatment, especially as it was free of charge. I knew that I would see the same TB nurse at the hospital and that I could talk with one of the Dose of Love workers on the phone. They would even come with me to the hospital and offered to talk to my mother and some of my close friends, to encourage them to get tested, without revealing that I had the disease. So I was ready. I also had the opportunity to get methadone treatment while I was there. Methadone wasn't free but it was still important for me, as I had to stay at the hospital for at least two months. The drugs weren't pleasant, but I wanted to live. Refusing TB treatment wasn't an option – I didn't want to die!

A year and a half later I can say that I am happy I survived! My life has changed a lot. It was definitely not easy to follow everything, but I got help and now I'm feeling much healthier already. I continue to meet the Dose of Love team. I think it helped that the same TB nurse at the Dose of Love day centre on the day I got my diagnosis was also at the hospital. The doctors were also very nice and explained everything very well. But, to be honest, I wouldn't have made it if I had not received methadone treatment at the hospital. But I'm happy that I made it and that I have been given a second chance."

# II Intensified TB case finding, TB infection control and preventive measures

# **Intensified TB case finding among PWID**

Intensified TB case finding includes regular, targeted symptom screening for any signs or symptoms of active TB disease. The main emphasis is put on early identification of persons who are at high risk of being infected with TB or developing TB disease. Early detection and treatment initiation prevents severe forms of TB disease, increases the rate of successful treatment outcome and reduces TB transmission.<sup>7, 17</sup> Contact investigations should first assess persons who are most likely to have been infected with TB (e.g. at-risk groups).<sup>37</sup>

Implementing intensified TB case finding among PWID can be challenging, as:

- PWID may be reluctant to come forward and engage with TB screening efforts, due to stigmas related to TB as well as mistrust of healthcare facilities (e.g. fear of police);
- PWID may have additional psycho-social problems that need to be tackled alongside TB treatment;
- It is necessary to recruit personnel who have special training (both at healthcare facilities as well as in CBOs) in communicating with PWID in addition to clinical knowledge about TB and drug addiction.

Extra effort is required on the part of medical service providers and CBO personnel to ensure that a complete set of diagnostic procedures are performed and to carry out both regular surveillance of treatment and TB prevention activities among PWID, due to the often erratic lifestyle and addictive behavior of PWID (e.g. active referral to healthcare facilities for further testing, DOT, outreach work).

Early diagnosis and complete treatment of TB among PWID is an essential public health intervention that requires sustained political commitment and efficiently coordinated action between health services and CBOs.

## Intensified case finding includes:

# **Active case finding**

Active case finding seeks to identify signs and symptoms of TB disease at the earliest possible stage among individuals who are at high risk and not yet seeking medical attention. This, in turn, allows suspected cases to be detected early and referred to healthcare facilities for confirmation of diagnosis and treatment. The aim of active case finding is to reduce transmission of TB in the community and to increase the chances of survival following TB diagnosis.

There are several approaches to facilitating active case finding that can be taken by CBOs such as conducting outreach work or integrating active case finding into harm reduction activities. All frontline personnel should receive training to ensure the highest possible awareness of clinical TB symptoms. In addition, all new clients accessing CBOs should be screened for TB symptoms and TB risk factors using a questionnaire<sup>IV</sup> as soon as possible after engaging with the organization. All clients should be screened annually thereafter, in line with the recommended yearly screening of all PWID.<sup>19</sup>

	ACTIVE CASE FINDING				
On	On the client's first encounter with the CBO or at the first suitable opportunity				
STEP	ACTION	DESCRIPTION			
1.	Create a neutral atmosphere	Carry out the interview in privacy and in a comfortable setting. You can use simple incentives, such as providing hot drinks, soft drinks or snacks. Be compassionate and empathic towards the client.			
2.	Interview	Use a short questionnaire about current symptoms suggestive of TB and possible TB risk factors. <sup>1</sup>			
	If any symptoms suggestive of TB appear, refer the client immediately to the nearest TB clinic or health care facility for further tests.				
3.	Educate	Educate the client about TB and outline the importance of regular screening for TB in a non-threatening manner.			

**TB** prevention and control activities need to be integrated into the routine work of CBOs providing support services to PWID such as testing for blood borne viruses and dispensing OST.

Remember that each individual risk factor increases the likelihood of developing TB disease!

# How to deal with difficult and challenging behaviour

Pay attention to the client's behaviour and condition to verify whether the client is under the influence of drugs, as it can be more difficult to manage intoxicated clients. Intoxicated clients are more likely to be aggressive, disobedient and/or delirious, meaning they may have great difficulty understanding what the CBO personnel say. Therefore, if the client is intoxicated, speak clearly and with short sentences. Avoid raising your voice and being moralistic or condescending, but remain firm and direct. If necessary, enlist other CBO personnel to help deal with the client.

If the client is aggressive, try to assess the level of aggression before you go to a separate room for further screening for TB. Make sure that you have easy access to an exit and ensure that there is a fellow CBO worker on hand to provide instant assistance, in case this is necessary. Avoid taking risks. If the client's behaviour remains aggressive and dangerous, question the client at another time. If the client becomes aggressive during screening, speak gently, demonstrate empathy and avoid behaviour that could be interpreted as threatening or ridiculing. Think of alternative reactions and rational responses to the client's provocations. In all cases, debrief to someone within the CBO after the incident.<sup>32</sup>



#### **ESTONIA**

## Consequences of a deficient case finding

In 2011, a 50-year-old man was diagnosed with TB disease and started TB treatment in hospital. Doctors asked the man to inform his family (including two children) that he had TB disease and encourage them to attend a healthcare facility in order to be screened for TB. The father didn't

# Case study 3



follow the doctors' orders and kept his diagnosis to himself. No one in the clinic was aware that the patient's family, friends and others close to him had not been informed about their exposure to TB, as none of the personnel had verified whether the man had told them about his infection and asked them to come in for TB screening.

A year later, the man's son, a 24-year-old student who was last screened for TB in 2007 (see normal X-ray on the left), fell ill with a cough, and temperature. When the X-ray was completed, the son was surprised to be diagnosed with TB (see abnormal X-ray on the right). The son was very angry and disappointed that no one in the family had been informed about his father's TB disease a year ago, because now he had infectious TB and he could not continue his studies at university. Had he been tested a year ago, when his father was first diagnosed with TB, he would have been diagnosed with a less-advanced case of TB that would probably not have been infectious. In this case, he would have been able to continue his studies.

Shortly thereafter, the whole family was screened for TB and the 50-year-old man's daughter also tested positive.

## Active referral to health care facilities

Active case finding can be effective only with an efficient referral system between CBOs and nearest TB clinics (or other health care facilities that provide TB testing). Clients found to have symptoms suggestive of active TB need to be referred immediately to a TB clinic or a healthcare facility for further examination and confirmation of TB diagnosis. There needs to be a **clear agreed referral pathway between CBOs and TB clinics** to ensure timely diagnosis and treatment initiation.

TB diagnosis usually takes longer than HIV diagnosis as there is a greater number of different procedures involved in TB diagnostics, and it often requires several visits to the health care facility. Therefore **it is recommended that the client be escorted to the clinic by a CBO worker or representative from the clinic**, and accompanied throughout the process to ensure that the client will not get discouraged or "lost" on the way.

#### If a client needs to be referred to a TB clinic:

Explain to the client the need for further tests in a calm and non-threatening manner. Emphasize the importance of completing all the diagnostic procedures.

Notify the health care facility of a potential TB case.

Organize transportation from the CBO to the TB clinic.

Have a representative from the CBO or health care facility accompany the client to the TB clinic and support them throughout the diagnostic procedures.

Depending on the material resources and time available, provide the client with specific instructions on how to reach the clinic. If possible, cover travel costs or send someone from either the CBO or the TB clinic to accompany the client from the CBO facility to the TB clinic (or health care facility) for further tests. Without accompaniment (e.g. if the client is given only the contact details and opening hours of the TB clinics or other health care facilities that provide testing for TB),

it is more likely that the client will not attend TB screening due to lack of motivation, postponement, change of plans or other distractions that may occur.

In the event that organizing or covering the cost of transportation is not possible, ensure that the client understands the importance of going to the health care facility and completing the procedures for TB diagnosis. Try to make the transfer process as simple and understandable as possible. For example, contact the nearest TB clinic and inform them about the arrival of a potential TB case so that the personnel know to expect a new client.

If the client fails to attend the initial appointment, try again and consider an accompanied referral to the TB clinic.

Remember that TB among PWID is often further stigmatized due to its association with HIV and addiction. These stigmas may make PWID reluctant to be involved with official institutions and authority figures. An efficiently organized referral system with support from a CBO advocate makes access to essential TB diagnostic services possible for PWID.

To organize an active referral system between your CBO and TB clinic or another health care facility that provides TB diagnostics, you can start with the following points:

- Identify the nearest health care facility that provides TB diagnostics and treatment both for people with and without ID and health insurance.
- Contact them, map the services they offer and ask about opportunities for collaboration.

## When the first contact has been made, agree upon:

- Who will provide the transportation for the client?
- How will this be arranged?
- How to ensure that the client reaches the TB clinic?
- Who will accompany the client?
   (i.e. is the person from CBO or the healthcare facility)
- How is the information between your CBO and the clinic exchanged?
   (e.g. via e-mail, telephone, with the person accompanying the client)
- What information about the client can be collected by the CBO prior to screening? (e.g. social risk factors, symptoms)<sup>2</sup>

If the client is diagnosed with active TB, the following points need to be considered after the completion of inpatient treatment:

 Where will the ambulatory TB services be offered? Will DOT be implemented in the CBO or in the clinic?

V See Annex IV, "Misunderstandings and myths"

## Pre-test counselling

It is recommended that any examination for TB or other disease be carried out with the consent of the client and that pre-test counselling be given before screening takes place.

Pre-test counselling promotes confidence and trust-based relations between the CBO personnel and the client, increases the client's awareness of TB, thus discouraging behaviour which increases the level of risk and strengthening the client's adherence to treatment in case of a positive test result.¹ Confirming TB diagnosis often includes several procedures and is more complex and time consuming than, for example, testing for HIV, (especially among PLHIV). Therefore, if the client does not fully understand the importance of screening for TB, there is a higher risk that PWID will fail to complete all the procedures necessary for a confirmed TB diagnosis, especially given that treatment is likely to require that the client return to the TB clinic.

Pre-test counselling should cover the following points:

- Why is testing for TB necessary?
- What does testing for TB involve?
- How is TB spread? How does a person become infected with TB and develop the TB disease? How might a person transmit TB to those around them?
- The client's right to refuse the TB test without affecting access to other services.
- Personal benefits of TB testing and early TB diagnosis (with regard to the client's personal motivational aspects).
- Clinical benefits of TB testing and early TB diagnosis (with regard to treatment outcome).
- Confidentiality of TB test results and treatment.
- The need for and importance of informing partners and other people who have been in close contact with the client in case of a positive TB test result (in some countries this may be a legal requirement).

All possible measures should be taken to normalize screening and testing for TB, making the procedure routine both among CBO clients and personnel.



### **EXEMPLARY CASE 1**

A young woman S. arrived at the CBO for the first time and insisted on taking a rapid HIV test. She was pale, skinny, and seemed rather nervous. In addition, she said that she had been feeling sick lately; as her partner was an active drug user and infected with HIV, she thought that she might have the virus too. However, she refused to go to a hospital or medical centre, because she was afraid of doctors and, in particular, of the police. During the HIV test, she had several coughing fits and was breathing heavily.

Describe the next steps that you will take when such a client arrives at your CBO.

\* Exemplary case management 1 can be found in Annex V

# Finding clients lost to follow-up

Losing clients to follow-up has been stated as a problem in many regions around the world, affecting as many as 21.3% of all patients in the case of MDR-TB patients whose treatment is longer and more complex. <sup>26-27</sup> Therefore, it is important that CBOs do everything in their power to avoid losing track of their clients and, in the event that clients are missing from treatment, to ensure that they are found as quickly as possible and receive help to continue with the treatment.

Tracing clients who have interrupted treatment and encouraging them to return to service for treatment completion is an essential element of effective TB treatment and TB control.<sup>37</sup>

## When the client comes to or actively visits the CBO

- Ask the client for contact details (e.g. personal address, neighbourhood, phone, contact details of friends/relatives/neighbours).
  - Stress that all contact information is confidential and will only be used to reach the client when necessary.
  - When the person has no fixed address or living space, ask about potential places where s/he might be found (e.g. shelters or abandoned apartments/ houses) and try to obtain details of persons who may know of the client's whereabouts.
- Ask about the client's daily activities, routines or other information that might help to re-establish contact with the client (this information can be collected through discussion with the client during visits to the CBO and does not have to be collected in a formal interview setting).

Gathering personal information from PWID can be difficult, as they may be resistant to questioning or feel uncomfortable giving out personal details. However, if you manage to establish a good and trustworthy rapport with clients, they may be more willing to share their personal contact information.

## When the client has missed two appointments

Try to contact the client by telephone.

If the call is not answered, then:

 Look for the client at his/her place of residence, taking any medicines with you, if these are required and you are able to do so.

If the client is not at home, then:

- Leave a note at the client's place of residence or with the client's neighbour.
- Go to places where the client might be found. Contact members of the client's social network (e.g. family, friends, colleagues), ask for clues and suggestions of the client's potential location and try to trace them. Client confidentiality should be protected during this process.<sup>3</sup>

If the client has permanently moved, try to establish their new location to increase the chance of transferring the client to the care of another CBO and clinic.

Explore other legal possibilities for exchange of patient-related information and, if possible (taking account of legal obstacles), actively seek information about any persons mentioned by the client. Collaboration with NTP and the police can be very helpful in this case.

#### When the client is found

- Talk to the client and the family about the reasons for the interruption of treatment.
- Try to identify causes of problems and look for ways to solve them.
- Remind the client about the dangers of treatment interruption and congratulate
  them on previous successes. Tell the client how much longer it is necessary to
  continue the treatment and emphasize the importance of continuing the treatment, even when the treatment is difficult because of side effects or once physical
  symptoms of TB have improved.
- Discuss the case with other colleagues so as to better anticipate and prevent future treatment interruptions.

## Outreach work

Outreach work means that the services offered by CBOs are delivered in the target group's own environment. In other words, CBO outreach workers (preferably in pairs or in small groups) take their services to areas where their clients live or to places where existing services are insufficient or too distant for the clients to reach.<sup>20, 25</sup> Bilingual and/or bicultural outreach workers can also be effective in mediating between clients, CBOs and the medical system. This helps to facilitate early detection as well as improving health outcomes of members of their community.

#### **Outreach work:**

- is a means of reaching at-risk populations (e.g. active drug users, homeless PWID) who would not otherwise access CBOs or TB services;
- helps to gain information about the target group's social conditions, and their needs, as well as helping them to understand the services on offer to them:
- can also be used to reach out to a wider audience in other areas of CBO's work (e.g. syringe exchange, HIV testing).

Outreach work can therefore be implemented as an efficient way of facilitating the finding of clients lost to follow-up, targeting new cases of infectious TB and monitoring current TB cases. It also helps to make screening for TB and other TB-related services more accessible and more acceptable to PWID, despite the countering effects of stigmas related to drug use, TB and HIV.

If you are interested in performing outreach work in your CBO, find out which other organizations in your region or country have implemented this type of work, and identify those bodies providing the relevant training. Sharing information about work methods and previous experience helps to promote the successful integration of outreach work into CBO activities and to achieve the best possible outcome.



### FOR MORE INFORMATION, SEE:

Mikkonen, M., Kauppinen, J., Huovinen, M., Aalto, E. (eds). **Outreach work among marginalised populations in Europe: guidelines on providing integrated outreach services.** Amsterdam: Foundation Regenboog AMOC, 2007.

European Monitoring Centre for Drugs and Drug Addiction. **Outreach Work Among Drug Users in Europe: Concepts, Practice and Terminology.** Lisbon: EMCDDA, 1999. Available at: <a href="http://www.emcdda.europa.eu/attachements.cfm/att-93520">http://www.emcdda.europa.eu/attachements.cfm/att-93520</a> EN Insight2.pdf



### **EXEMPLARY CASE 2**

P. is 56 years old and has been a long-term client at the CBO. He was diagnosed with TB about a year ago and was admitted to the regional TB clinic for inpatient treatment. After he had been proven non-infectious, he started to receive DOT at an outpatient setting. A member of the CBO personnel was assigned as his DOT worker and he still has an estimated 6 months of treatment left.

Although, initially, he came to the CBO regularly to receive his medication, his attendance became more erratic. Now, he has not shown up for two days. His phone is switched off and, when a designated DOT worker at the CBO went to his given address, it turned out that P. had never lived there, and had given false details.

What else could be done to find P.?

How could this situation have been prevented or the process of finding P. facilitated? In the event that P. is found, what should be done next?

What are the possible consequences when a client does not want to be looked for or to be found?

\* Exemplary case management 2 can be found in Annex V

## TB infection control in CBO facilities

All CBO facilities should be safe for clients and personnel. However, persons with infectious TB can be found both among CBO clients and personnel, thus, TB infection control precautions should be implemented. Although persons with TB who receive adequate treatment are no longer infectious, it may be difficult to determine if the person claiming to have been treated for TB has, in fact, received adequate treatment. In addition, a large number of clients and personnel can be at high risk of developing TB disease, once infected (e.g. PLHIV, former PWID, regular smokers).

As TB is spread through the air, the risk of TB transmission is increased if the facility is cramped, or poorly ventilated and if contact with an infectious person is frequent or of long duration.

The risk of TB transmission in CBO facilities can be reduced by taking the necessary infection control precautions. TB infection control involves using a combination of measures to minimize the risk of TB transmission. These measures should be part of daily practice. WHO recommended TB infection control consists of following elements: <sup>16, 19, 23, 31</sup>

- Managerial activities
- Administrative controls
- Environmental controls
- Personal respiratory protection

TB infection controls are organized into a hierarchy, based on the impact of the measures and the order in which the recommended activities should be carried out.

# **Managerial activities**

Managerial activities concentrate on implementing a set of activities at CBO level.

- Develop a CBO TB infection control plan (i.e. assessing available human resources, drawing up policies and procedures that ensure proper implementation of TB activities and services) to be implemented.
- Rethink the use of available spaces, based on risk assessment, with a view to reducing the risk of transmission. Consider the need to renovate existing facilities or construct new ones.
- Conduct on-site surveillance of TB disease among CBO personnel (e.g. check the medical records of CBO personnel, ensure that these records are up to date. If necessary, refer them for TB check-ups).
- Monitor and evaluate the set of TB infection control measures.
- Conduct training of personnel and inform clients about TB and TB infection control.
- Ensure that an efficient network between the CBO, TB clinic(s) and other centers providing services to PWID in the region has been established.

## **Administrative controls**

Administrative controls help to improve the organization and implementation of activities that aim to reduce the risk of TB exposure. Administrative controls have the greatest impact on preventing TB transmission within CBO facilities.

- If possible, assign someone from the CBO the responsibility of assessing the risks, and planning, supervising and evaluating the implementation of TB infection control.
- Conduct TB risk assessment in the CBO and use this to develop a TB infection control plan.
- Develop work practices to identify clients with TB symptoms and refer them to a TB clinic or another health care facility for further tests:
  - Ensure that an efficient referral system (with accompaniment, if possible) from the CBO to a TB clinic is established.
- Place signs and posters on walls that inform the CBO personnel and clients about TB, emphasizing the importance of cough etiquette and respiratory hygiene.
- Regularly test and evaluate the CBO personnel's knowledge about TB.
- $\bullet$  Organize training on TB and on methods used for TB activities (e.g. motivational interviewing).  $^{\text{VI}}$

- Conduct an annual evaluation for follow-up education and training based on the:
  - o number of untrained or new personnel;
  - o changes in the organization and TB/PWID related services;
  - o availability of new TB infection control information.
- Consider your personnel's medical and personal particularities or other conditions that may impair a person's defence against TB infection and disease, such as:
  - HIV infection
  - diabetes
  - silicosis
  - malignancies
  - cancer
  - malnutrition
  - o ther chronic diseases or immunosuppressive conditions

Protection of CBO personnel should be a priority. As such it is necessary to:

- Provide CBO personnel with up-to-date information.
- Organize regular training sessions about TB, TB infection control and respiratory protection measures for CBO personnel.
- Encourage regular HIV testing among CBO personnel.
- Encourage regular TB diagnostic investigation among CBO personnel.

## **Environmental controls**

Ventilation or airflow must be ensured in areas where clients spend relatively long periods of time such as in waiting areas and rooms where meetings with clients with presumptive TB take place. Therefore, meetings with clients suspected of having TB should be organized:

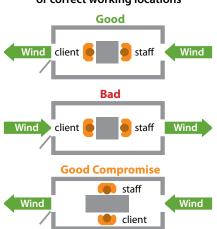
- outdoors
- indoors with an open window
- indoors with special equipment, such as a shielded UV lamp or properly working ventilation

Find out what environmental controls could be applied or are already available in your CBO. Use professionals when estimating and implementing the necessary environmental TB infection control measures to ensure that the airflow is properly controlled and that equipment is being used correctly.

#### **ENVIRONMENTAL CONTROLS**

#### **NATURAL VENTILATION**

Direction of natural ventilation or correct working locations



Natural ventilation can be created by the use of external natural forces such as temperature and wind. Opening a window allows fresh air into the room, thus diluting the concentration of airborne particles which carry *M. tuberculosis* bacteria and allow it to circulate in the room. Windows, doors or skylights should be kept open wherever possible.

As the airflow depends on wind direction, speed, and/or temperature differences, it is often difficult to control. Recirculation of air containing droplet nuclei, however, is to be avoided at all costs!

## **MECHANICAL VENTILATION EQUIPMENT**



Exhaust fan

Mechanical ventilation is created using mechanical equipment to force air exchange and drive airflow. As TB spreads through air, good ventilation can ensure that the risk of TB transmission remains low. Mechanical ventilation and the circulation of airflow should be regularly checked to ensure its safe and proper implementation. Although the costs of mechanical ventilation equipment can be relatively high, it is worth investing in the appropriate apparatus to promote the safety of CBO personnel and clients.

#### **AIR CLEANING**



**HEPA filter** 



Ultraviolet Germicidal Irradiation (UVGI)

Supplementary measures, such as a high efficiency particulate air filtration (HEPA) and ultraviolet germicidal irradiation system (UVGI), can be used to reduce the risk of TB transmission within the CBO. HEPA filters bacteria out of the air, and UVGI kills TB bacteria, if designed and maintained appropriately.



## FOR MORE INFORMATION ON TB INFECTION CONTROL, SEE:

#### Video:

Centers for Disease Control and Prevention (CDC). **Implementing TB Infection Control in Out-Patient Settings**, 2012. Available at: <a href="http://www.cdc.gov/globalhealth/video/tb/tb.htm">http://www.cdc.gov/globalhealth/video/tb/tb.htm</a>

#### Materials:

World Health Organization. **Tuberculosis infection control**. [website] <a href="http://www.who.int/tb/health\_systems/infection\_control/en/">http://www.who.int/tb/health\_systems/infection\_control/en/</a>

World Health Organization. **WHO Policy on TB Infection Control in Health Care Facilities, Congregate Settings and Households**. Geneva, WHO, 2009 (WHO/HTM/TB2009.419). Available at: <a href="http://whqlibdoc.who.int/publications/2009/9789241598323">http://whqlibdoc.who.int/publications/2009/9789241598323</a> eng.pdf

World Health Organization. **Guidelines for the Prevention of Tuberculosis in Health Care Facilities in Resource-Limited Settings**. Geneva: WHO, 1999. Available at: <a href="http://www.who.int/tb/publications/who">http://www.who.int/tb/publications/who</a> to 99 269.pdf?ua=1

# Personal respiratory protection

## Respiratory protection

Personal respiratory protective equipment should be used in situations where the risk of TB exposure is high.

- Implement a respiratory protection programme.
- Educate both clients and CBO personnel on the importance of respiratory protection measures (e.g. cough etiquette, when and how to use respirators), organize training, place posters on walls etc.
- Provide clients suspected of having TB with surgical masks or tissues
  to cover their mouth and nose to prevent the germs from being released
  into the air.
  - NB! Face masks or surgical masks should be worn by those with known or presumptive active TB disease.
  - Face masks or surgical masks reduce the number of droplets being exhaled into the air by persons with infectious TB disease when they talk, breathe, cough or sneeze.
  - Face masks must not be reused!
- Provide CBO personnel with respirators (e.g. models FFP2, N95) to be worn when in contact with a client with presumptive TB or confirmed TB during the initial phase.
  - Respirators should be worn by the person not having TB (i.e. CBO or health care worker).
  - Respirators protect the wearer from inhaling droplet nuclei.
  - Personnel should also be educated about respirator fit testing.

## Respirator fit test

A fit test is a test protocol conducted to verify that a respirator is both comfortable and correctly fits the user. The use of respirators reduces the risk of TB transmission only when the respirator is correctly applied and used.

FOR MORE INFORMATION ON RESPIRATOR FIT TEST, SEE:

http://www.cdc.gov/niosh/npptl/topics/respirators/disp\_part/RespSource3fit-test.html

## **Respirator** for health care workers





- Respirators should be worn by the person not infected with TB.
- **Respirators** protect the wearer from inhaling droplet nuclei.

## **Surgical mask** for persons with infectious TB disease





- Face masks or surgical masks should be worn by the person with known or presumptive infectious TB disease.
- Face mask or surgical masks reduce the number of droplets being exhaled into the air by persons with infectious TB disease when they talk, breathe, cough or sneeze.

## Cough etiquette

Both clients and CBO personnel need to be educated about cough etiquette and checks should be made to ensure that it is followed. These are easy steps to follow and require little material resourses.

- 1. Cover both your mouth and nose with a paper tissue or handkerchief when you cough or sneeze.
- 2. Put the used tissue in the waste basket.
- 3. If a tissue is not available, cough or sneeze into your upper sleeve or elbow, not into your hands.
- If possible, put on a face mask to protect others from getting infected with TB.

In addition, wash your hands often with soap and warm water for at least 20 seconds or use an alcohol-based hand rub.

## Isoniazid preventive therapy

**Isoniazid preventive therapy (IPT)** is an intervention used to prevent high-risk persons from developing TB disease.

IPT is usually set up and controlled by doctors at the TB clinic. However, to improve the treatment outcome adherence support measures, including DOT, if resources are available, should also be applied when the person is receiving IPT.

IPT is often used among individuals with LTBI in order to prevent progression to TB disease. IPT is also used among persons who have spent days or weeks in close contact with a person who has TB disease.

IPT is often given to:

- children (especially those <5 years)</li>
- PLHIV
- pregnant women
- elderly

However, the use of IPT varies between different countries. Therefore, it will be necessary to find out whether IPT is implemented in your region or country and, if so, under what circumstances

CBO can support implementation of IPT by:

- providing adherence support measures for clients;
- helping to implement DOT principles for IPT surveillance;
- dispensing INH with other treatments in opioid substitution treatment (OST);
- observing to identify any side effects.<sup>VII</sup>

# III Case management and psychosocial support

When first diagnosed with TB disease, the client will usually start to receive appropriate inpatient treatment in the local TB clinic. As soon the client is proven to be non-infectious, s/he will be re-admitted to an outpatient treatment. Supervision of therapy and follow-up examinations are generally the responsibility of a TB clinic.

Involvement of CBOs has proven to be of great help in raising awareness about TB, thereby also motivating clients to be screened. CBOs provide considerable support in implementing outpatient TB services for PWID and other vulnerable populations.

## The key to efficient case management is a client-centred approach!

Providing outpatient TB treatment for PWID is challenging but nevertheless feasible. The physical and psychological security and stability of the CBO personnel should also be a priority and should therefore be observed on a continuous basis (e.g. through interaction with peers or by organizing regular meetings).<sup>IX</sup>

# Assessment of clients' social and health situation and need for support

During the first visit to the CBO, some key activities could be:

• Asking clients about their health and social situation. You can use a special questionnaire created for this interview that focuses on establishing any current symptoms suggestive of TB.<sup>x</sup> Education about TB and details about the client's health situation should be given according to their ability to understand and deal with this information.

VIII See Chapter I, Treatment of TB disease

IX See Chapter IV, Preparing CBO personnel for TB activities

X See Annex I

 Getting an overview of social risk factors that would enable the development of better support systems for clients and strengthen their adherence to treatment.

This is especially important for PWID who are more likely to suffer from other (often chronic) illnesses in addition to TB, and whose social circumstances tend to be unstable.<sup>2</sup>

Asking questions about the clients' health and social situation enables personnel to obtain useful information about the need for extra-precautionary measures as well as for other supportive services available for PWID in the region. This, in turn, helps to decrease the likelihood of losing clients to follow-up after they have been directed from a TB inpatient clinic to an outpatient site such as a CBO<sup>XI</sup> to continue their treatment, which is a common problem among PWID. The client's family status and gender should also be taken into consideration as these will influence the client's situation and needs (e.g. if the client has young children who could not be left without attendance during inpatient treatment for TB).

## Informing and educating clients about TB

Informing clients about the basics of TB, as well as symptoms and treatment plays an important role in their level of engagement with the process. When clients take a personal interest in their health (or of that of their friends' and family members', who may also be exposed to TB) and in addressing TB, they are more likely to overcome the challenges that may occur and to complete the full programme of therapy. It is important that the client understands that TB is curable, provided the treatment regime is properly followed.

## The main challenges that clients may face during TB treatment are:

- experiencing side effects;
- facing personal as well as TB-related social and emotional complications;
- forgetting to take medicine or attend check-ups.

Each client should be approached individually, based on his/her current emotional status and personal capacity to comprehend the situation as a whole. Information should be provided on a "step-by-step" basis, as the majority of the content may be difficult for the client to comprehend and digest if presented all at once.

Pay attention to the client's emotional state, pose open questions and try to let the client reflect or retell what has been understood in order to get an overview of the information absorbed, as well as identifying areas which need to be repeated.

Topics that the client should be informed about are:

#### The basics of TB

Inform the client about:

- the symptoms of TB and how to recognize them;
- how TB is cured:
- how TB is spread;
- how further transmission of TB can be prevented and controlled.

Topics that the client should be aware of when starting DOT are:

## Side effects of TB drugs

Side effects are any effects of a drug that may cause additional unwanted symptoms, discomfort or more serious, if not harmful, consequences. They can also be caused by interaction between TB drugs and other drugs, food or alcohol.

The majority of side effects from TB drugs occur only at the beginning of the treatment and subside after a few weeks. Minor side effects may cause relatively little discomfort and often respond to simple treatment of the symptoms. Second-line TB drugs used for treatment of MDR-TB, however, are more toxic and are more likely to cause discomfort to the client taking them. Special emphasis should be given to clients' education both about the side effects of TB drugs in general and about reporting their occurrence.

Discomfort caused by the side effects of TB drugs is often named as a key factor contributing to poor treatment adherence.<sup>2</sup>

Inform the client about:

- common side effects of anti-TB drugs<sup>XII</sup>;
- how long the side effects are likely to last;
- what should be done when side effects occur;
- how side effects are managed.

Clients receiving DOT should be encouraged to report the incidence of side effects, and should be told which specific aspects of the side effect to take note of (e.g. symptoms, regularity, intensity, length and impact on everyday life).

- Regularly ask the client about any new symptoms which may be due to side effects of the medication.
- Remind the client to go to the clinic immediately if they experience any severe or new side effects. If necessary, personally refer the client to a TB clinic or a health care facility.

XII See Annex II, side effects of TB drugs

## **Drug** interactions

Simultaneous consumption of multiple medications, including illicit drugs and alcohol, alongside TB drugs may cause adverse effects and could even have harmful consequences for the client's health. It is important that the client is aware of the dangers of taking TB drugs with other substances, and that s/he seeks prompt medical help in the event of any problems.

Inform the client about drug interactions between:

- ARV drugs;
- alcohol;
- illicit drugs including drugs used for OST such as methadone and buprenorphine;
- other medications.

Comorbidity as well as heavy alcohol use, active drug use and mental health problems should not contraindicate treatment for any of the illnesses being addressed, nor should it lead to any treatment being withheld!

## Consequences of intermittent or discontinued treatment

In addition to raising awareness about possible risks and the importance of following treatment, clients must be made aware of the consequences of intermittent treatment.

Inform the client about consequences such as:

- developing MDR-TB;
- putting others at risk of being infected with TB;
- death.



## Case study 4

## BULGARIA | Dose of Love TB-theme party

"Theme party" has been used by the Dose of Love Association in Bulgaria for many years to increase awareness and motivation among drug users about different problems, including TB. We came up with the idea of a TB-theme party because we thought that a party was the best way to get people involved and to encourage them to enjoy themselves – this is how the party started.

In fact, the information shared at TB-theme parties doesn't differ much from other educative and informative methods such as training, consultations, publishing articles and distributing brochures. The most important difference lies in the way we approach

our clients and in the form that the TB-theme party takes. The main emphasis is put on getting the client's attention, but also on respecting his/her personality, knowledge and experience. We believe that by throwing a TB-party, we help to evoke positive emotions in clients, thereby making them more attentive and active, helping them to be involved for a longer period of time. In order to throw a good party, you need to know what your clients enjoy, but you could also think of things that you enjoy yourself – what activities would encourage you to accept such an invitation?

Tips and steps for organizing a "TB-theme party":

#### Preparation and requirements:

- Set a clear goal, theme and structure for the party.
- Contact the target group.
- Choose a venue where clients feel safe and calm.
- Most theme-parties take place in the low-threshold centre and/or in the organization's rooms. You could hold such parties at other venues, but it is important that clients are comfortable and feel that it is safe to come.
- Announce the time and location of the event approximately one week in advance. Invite clients personally consider the clients' individual style and interests when preparing invitations. This way, the invitations are more personal and the client feels special.
- You can ask the clients to register their participation. This way they will be more
  engaged and excited, making them more enthusiastic about participating.
- Prepare the location for the party at this stage, it is possible to involve one
  or two representatives of the target group. The general atmosphere should be
  cosy, warm and relaxing. Small details such as decorations will help to raise the
  mood. It is a good idea to provide some refreshments at the party. coffee, tea,
  soft drinks, sandwiches, sweets and other snacks are recommended.

#### "Party" time:

It is best to keep the number of participants between 6 and 12.

The party should be organized by no more than two CBO workers to ensure that clients do not feel that they are in the minority. The CBO member is not a lecturer, but is simply there to help start conversations and to make sure that participants stick to the theme and follow the rules.

Conversations should remain informal. The leaders should also encourage participants to share their knowledge and personal experience of TB as well as give recommendations about what could be done to improve TB prevention.

You can include some "interactive games" or find other methods of increasing cohesion in the group and promoting better understanding of the information available. "True or false" type games are a good way of raising awareness and dispelling myths about TB.

The most important thing is that clients leave the party with the impression that they have been involved in a discussion, that their opinions have been heard and respected; and that they themselves made the event possible through their participation.

## **TB case management**

Clients who have been diagnosed with TB disease will be placed in appropriate inpatient treatment by the local TB clinic. The client will remain in treatment there until proven non-infectious. As soon as this has been achieved, the client will be transferred to an outpatient TB service (e.g. to a CBO) where, in collaboration with social and health care facility workers, the treatment will continue on an outpatient basis.<sup>XIII</sup>

It is important to acknowledge that when the client is a recovering PWID and returns to his/her previous surroundings, many social and psychological problems may surface, and could have a negative impact on adherence to treatment. Even if the client successfully completes TB treatment, there is a high risk of that the client may die from drug overdose if drug addiction and other psychosocial problems are not addressed.

This is especially true in the case of PWID who may still struggle with their addiction and are particularly vulnerable to relapse when they return to their previous environment. Therefore, psychosocial support and OST should be provided in conjunction with TB treatment.

The key theme, however, remains the same – use a client-centred approach!

## **Directly Observed Treatment (DOT)**

DOT is a WHO-recommended TB case management approach, in which a health care worker or other designated individual supported by a trained health professional provides the patient with prescribed medication, observes the patient swallowing every dose and offers support throughout the long and difficult process of TB treatment.

DOT means that the **client takes every dose of their prescribed drugs in the presence of a designated DOT worker**. Although strongly recommended, DOT worker does not necessarily have to be a social or a medical worker, though the worker must have received special training in the implementation of DOT. In the current context, previous experience of working with PWID is highly recommended.

A close observation of regular drug consumption and early signs of weak adherence is especially important among PWID who are likely to have other medical or psychosocial problems that also need to be addressed in order to ensure that treatment is completed successfully. Typical predictors of non-adherence include psychiatric illness, substance abuse (alcohol and drugs), homelessness and previous history of non-adherence.<sup>36</sup>

XIII This system may differ between countries. Find out how TB treatment is organized in your country or region.

## DOT programmes can additionally:37

- provide TB treatment at OST and/or CBO sites or OST at TB clinics;
- transport clients to TB clinics or give compensation for transport costs;
- offer social and psychological consultation;
- offer incentives and/or enablers;
- keep track of clients through hospital discharge planning;
- connect clients with specialist support agencies (e.g. social services and other relevant bodies);
- find accommodation for homeless clients etc.

#### What does a DOT worker do?

#### A DOT worker:

- closely observes each dose of medicine swallowed (if necessary, making home visits or tracing the client in the case of a missed appointment);
- · records the course of the treatment;
- checks for early signs of side effects;
- accompanies clients personally to facilities to receive drug supplies;
- supports and motivates clients to attend medical appointments and complete the treatment throughout the long treatment process.

## Why should CBOs become involved with DOT?

The main purpose of DOT is to make outpatient TB services more accessible for PWID. In many cases, it is more convenient for the client to receive outpatient TB treatment in a CBO which specializes in working with PWID as they:

- are more accessible to PWID;
- include other services necessary for PWID.

This eliminates the need to attend multiple sites at different times, allowing PWID to receive treatment for TB and other medical conditions in one facility.

In fact, DOT has proven to have a higher adherence among PWID when combined with other treatment interventions such as:

- HIV care, including ART;
- OST;
- the possibility of screening or receiving care for other medical conditions (e.g. HBV and HCV).<sup>8</sup>

Integrating services aimed at PWID diagnosed with TB together in the same facility means that clients do not need to attend potentially stigmatizing TB-services.<sup>14</sup>

#### How can CBOs become involved with DOT?

As DOT is a medical practice which requires both a regular drug supply and medical observation, CBOs may well encounter legal obstacles to its implementation.

However CBOs can collaborate with TB clinics and integrate DOT into their own activities, thus increasing access to TB treatment for vulnerable populations. CBOs can also play an important role in mediating other services necessary for the client during TB treatment, as they often have more experience working with PWID and have a better overview of their clients' specific needs and circumstances.



#### **FIND OUT**

The first step is to find the answers to the following questions:

- How is DOT implemented in your region?
- How could your CBO collaborate with TB clinics in implementing DOT?
- What kind of additional services can your CBO offer?



## Case study 5

LATVIA | Nurse from the Ambulatory Department of TB and Lung Disease Centre at Riga East University Hospital

Works at Directly Observed Therapy Unit for Adults

"I have been working as TB nurse for many years, and I have seen many different cases. As we know, recovery from TB can be very long and difficult (recovery can take 6 up to 24 months) thanks, in part, to the need for large amounts of medication and the fact that patients must be supervised when taking this medication. That is what the DOT unit is for.

Every day the patient has to go to the DOT unit, where an appropriately qualified nurse administers the medicine. The patient is not allowed to take the drugs home. He or she has to drink the medicine in front of the nurse. The patient has to drink all medicine in one go. To make it easier to swallow the medicine, the patient can have a glass of water. Medical personnel are there to ensure that patients take their medicine without any interruptions. The nurse must record every dose in the special treatment registration list and patients have to sign to confirm that medicine has been taken at that particular day and time.

Every day around 90 people come to DOT unit. Business hours are from 8 a.m. to 7 p.m. every day (except Saturday and Sunday, when the clinic is open 9 a.m.-2 p.m.). The DOT unit has long opening hours to make it more convenient for patients to be treated as they are able to choose a suitable time to take their medicine.

DOT unit workers' strict control over patient has brought positive results. At the same time DOT unit workers have problems with patients who interrupt their treatment regimen for short or long periods of time. In some cases, patients have failed to return to take their treatment for a whole week. Alcohol abuse and drug addictions are the most common problems among TB patients. Sometimes the patient has been drinking so much that s/he forgets to come to the DOT unit. Fortunately, people who work at the DOT unit go and look for missing person(s) immediately.

It is very important to know how our patients feel (both in terms of their physical and mental health). It is our job to remind patients how important it is to attend the DOT unit and to take their medicine. Social support is the main benefit offered to TB patients. They receive food vouchers and money to buy public transport tickets; this is important as sometimes people don't attend the DOT unit because they simply don't have the money to get here or to look after themselves. But, as I said, every case is different and we have to approach them individually.

Working as a DOT unit nurse I do my duties with all my heart, not only for the wellbeing of our TB patients, but also for the wellbeing of our society. It is important to see an improvement in the health situation not only in our own country, but all around the world."



## **Promoting adherence**

Client-specific adherence support measures for PWID are important aspects in ensuring the best possible treatment outcome, helping to reduce the risk of developing resistance to TB drugs and preventing transmission of TB to other people.<sup>9, 14, 16</sup>

## Abstaining from treating PWID because of adherence issues is not justified!

With adequate support, stable care and experienced personnel, drug users can adhere to long-term treatment with clinical outcomes comparable to those of people who do not use drugs.<sup>24</sup>

## Contingency management

Participants are rewarded for positive health behaviour. There are different forms of such interventions:

- vouchers person receives vouchers with various monetary values for engaging in a particular behaviour (e.g. returning for a TB test or TB DOT appointment);
- positive reinforcing medications (e.g. methadone);
- incentives and enablers (e.g. bus tokens, electronic items, food packages).

**Incentives** are small rewards that encourage clients to attend TB screening, outpatient follow-up and DOT appointments. Incentives can be given out on various conditions and at varying intervals. For example, a voucher or a material incentive may be given out weekly to the client receiving DOT, if the client has attended all appointments within the previous 5/7 days. If at least one appointment has been missed, the client will not receive a voucher for the given week. However, incentives must be used to motivate, not to coerce the client.

**Enablers** help the client to overcome barriers to completing investigations and TB treatment. For example, CBOs can provide assistance with housing, transportation, nutrition and other social obstacles, helping the client to overcome barriers and improve adherence.

Incentives and enablers have proven to be successful in contingency management.<sup>28</sup> In order to ensure that enablers and incentives are used appropriately, an individualized needs and/or risk assessment should be carried out to identify the core problems and barriers faced by the client.<sup>37</sup> Family status and gender can also play a role in defining what kind of incentives and enablers the client needs most, as well as in identifying which issues need to be confronted first.

Additional approaches to counselling and motivating of clients for stronger adherence are:

## Group counselling and individual counselling

**Counselling** is a process whereby, through communication and the establishment of a relationship, the participant may come to understand who s/he is, explore possibilities for change and set about initiating these changes. Counselling is motivated by care and concern for the wellbeing of the client. Its aim is to facilitate changes in behaviour and promote problem-solving, as well as bringing about personal growth and development.

**Group counselling** benefits several clients at once, considering the key elements of what the group is looking for, identifying factors which will improve the life of the participants, exploring ways to achieve their goals and looking at alternative options, as well as working out ways to develop a common plan. Group therapy creates a supportive community that helps the person to combat the sense of isolation and exclusion often experienced by drug users. It allows the participants to receive genuine support, get honest feedback and receive useful suggestions for alternatives from peers. Participants can benefit from each other's experiences, and in particular from those who have reached a more advanced stage in their recovery, as these individuals are often seen as inspirational examples. Hope is a powerful tool for resisting relapse and strengthening adherence!

**Individual counselling** gives each client an individual opportunity to explore problematic and painful issues. It gives him/her the chance to get complete confidence and privacy, in case that the client is not yet ready to work in a group environment or simply prefers to approach his/her problems individually. Individual therapy allows the therapist to focus on the client in question and on his/her specific problems, without the possibility of being influenced by peers. It also makes it easier to collect personal information that may help to improve therapy and develop the most suitable approaches for the client to tackle his/her difficulties.

## Motivational counselling and interviewing

Motivational interviewing (MI) is a special collaborative, person-centred method of guiding; widely used in work with PWID, it is used to elicit and strengthen motivation for change. This style of counselling offers a way to interact with substance-using clients to resolve ambivalences that prevent them from realizing their goals.

A central concept of MI is identification, examination and resolution of ambivalence about changing behaviour. Ambivalence means that a person has conflicting feelings about behaviour change (e.g. the client may acknowledge that giving up using drugs is good, but at the same time, hold on to the belief that drugs make him/her feel good, despite all the negative aspects of drug use)

and it is seen as a natural part of the change process. The MI practitioner makes sensitive use of different techniques and strategies that are responsive to the client and attuned to the client's ambivalence and preparedness for change.

## Motivational interviewing:

- Aims to develop an internally motivated change.
- Suggests coping strategies for high-risk situations that are discussed with the client.
- Monitors and encourages changes in behaviour.
- Encourages commitment to change (i.e. TB treatment).

Look for possibilities to organize specialized training on MI for personnel.



## FOR MORE INFORMATION ON MOTIVATIONAL INTERVIEWING, SEE:

#### www.motivationalinterview.org

## Cognitive and behavioural interventions

Cognitive and behavioural interventions aim to identify and correct problematic behaviours of the client by applying a range of different skills that can be used to reduce drug use and to address a range of other problems that often co-occur with it.

## Cognitive and behavioural interventions:

- anticipate problems and enhance the person's self-control by helping to develop effective coping strategies;
- explore positive and negative consequences of behaviour;
- self-monitor to identify early risks and situations that might put the person at risk of discontinuing TB or other treatment;
- help to develop strategies for coping with problems and avoiding highrisk situations.

## Cognitive behaviour therapy

Cognitive behaviour therapy (CBT) is a type of psychotherapy that helps people to change feelings, thinking habits and behaviours that are unhealthy or unhelpful. CBT is used to treat problems such as depression, problems with anger, substance abuse, anxiety etc.

The underlying concept of CBT is that feelings and thoughts play a fundamental role in people's behaviour. The goal is to teach patients to take control of how they interpret and deal with disturbing aspects of their environment, and to encourage them to accept that they cannot control all aspects of their surroundings.

#### In CBT, clients learn to:

- Distinguish between thoughts and feelings.
- Become aware of how thoughts can have a negative influence on their feelings.
- Become aware of the thoughts which seem to have an automatic effect on emotions.
- Evaluate critically whether these "automatic" thoughts and assumptions are accurate or biased.
- Develop skills to notice, interrupt and correct biased thoughts independently.



#### **FIND OUT**

What methods and measures are used in your country to promote and strengthen adherence?

What kind of training is available for CBO personnel on methods and means of strengthening adherence and addressing the client's other psychosocial needs?

## Tips and strategies for adherence support

- Use adherence reminders (e.g. timers, pill boxes).
- Provide adherence counselling.
   (e.g. professional and peer-led support both for PWID and for key individuals in the client's social network).
- Provide social support and social care supportive services that address the extended needs of PWID are likely to have a positive impact on healthrelated outcomes<sup>19, 35</sup>
  - (e.g. housing, food, and low-threshold employment opportunities).
- Address the client's other needs so that adherence to therapy can remain a priority
  - (e.g. syringe and needle exchange, condom distribution, overdose prevention, reproductive health services for women, washing facilities, laundry, clothes and food distribution, access to computers etc. that may motivate the client to (re)turn to the CBO).
    - Integrate similar activities into your CBO or act as an intermediary between different facilities that provide those services to PWID.
- Involve previous PWID in different TB-treatment activities by encouraging them to carry out consultancy work, or take up a role in outreach or CBO work. Former clients' knowledge and input can be very helpful, as they often have relevant knowledge and experience which can be used to improve the accessibility and quality of TB services.



## **EXEMPLARY CASE 3**

A. is a 30-year-old man who previously worked as a carpenter. After was released from prison (he was convicted for selling drugs), he continued to use drugs, got into debt and lost all his belongings, including his apartment. A. has been diagnosed with HIV, HCV and quite recently with MDR-TB. At the TB hospital, he started to receive both methadone and ART, however, he has been experiencing numerous side-effects due to drug interactions and is therefore reluctant to take all of his medications. Now he has started to receive his treatment at an outpatient site, but the nurses and social workers face constant difficulties with his case, as his social conditions are still complicated – he has no income other than disability benefits, no relatives and no place to live, apart from staying in the homes of his friends, most of whom are still using drugs.

How should case management be conducted in this case? What measures could be used to help A. to finish his TB treatment?

\* Exemplary case management 3 can be found in Annex V

## **Challenges of working with PWID**

A long history of drug use may have a negative impact on a person's psychological state as well as behaviour. Therefore, the provision of DOT or other TB related services for PWID may face challenges and difficulties that link to the various psychosocial factors of the client.

However, this does not mean that PWID are not capable of following TB treatment and taking responsibility for their own health, as well as for that of others. On the contrary, the possible challenges presented by the client's psychosocial situation highlights the importance of developing a case-specific approach to encourage the client to develop an interest in his/her health and in the security of those who surround him/her (e.g. family and friends), taking responsibility for personal wellbeing.

Common challenges faced in working with PWID include:9

- difficulties in maintaining long-term contact due to an unstable lifestyle or conditions;
- personal health is often not a priority;
- risk-taking behaviour (e.g. parasuicidal behaviour);
- lack of support from family or friends;
- difficult family situation (e.g. having young children with a partner who
  is also a drug user);
- low socialization (i.e. difficulties in interacting with institutions and society);
- suspicion, lack of trust in CBO and other (non-)governmental institutions;
- comorbidity with other drugs that can cause demotivation;

- self-discrimination, self-stigmatization;
- psychological problems (e.g. depression, anxiety, abrupt changes in general condition) related to using drugs or a withdrawal syndrome.

## How can those challenges be tackled?

- Understand the needs of the target group and what makes CBO services attractive to them (e.g. approach clients through additional services such as syringe exchange, food provision or legal/social counselling, thus establishing contact for further education on TB).
- Realize CBO's limitations in changing the PWID's behaviour.
- Use the services of other professionals (e.g. psychologists, social workers, outreach workers).
- Prevent burnout among CBO personnel.
- Provide supervision and/or intervision among CBO personnel.
- Involve people who have personal experience with drug use/addiction and, if possible, with tuberculosis.

## Client confidentiality

The protection of private client information is commonly referred to as confidentiality and it is an essential issue in many different aspects of TB control among PWID.

Measures to protect client confidentiality:19

- Never discuss a client's case with anyone without the client's permission (including family or friends).
- Do not leave hard copies of forms or records where unauthorized persons may access them.
- Use only secure routes to send client information.
- Be discreet when making client visits.
- Conduct client interviews in private.
- Do not discuss client cases in a public area.



## Case study 6

#### **ROMANIA**

#### Motivating an unmotivated client

A CBO client who had experienced problems with alcohol addiction and depression was diagnosed with MDR-TB. He was married and had two children. The MDR-TB was discovered when he was asked to undergo an X-ray examination for his new job. When he was diagnosed and started his treatment at the hospital, he also began to receive a pension, which was worth more than the salary he would have received had he been working.

However, he soon interrupted his treatment so that he would continue to receive his pension for as long as possible (as he could get it only during his illness). In addition, he was also discouraged from treatment by the side effects. The CBO personnel counselled him to continue with his treatment and explained all the possible consequences, but without success. The client suspected the CBO personnel of being "on the same side" as the hospital personnel and thought that they were exaggerating the consequences just to frighten him.

A few months later, one of his children caught a cold; the child went to the doctor for a consultation and for an X-ray as part of a regular six-month check-up for scheduled contacts. The doctor explained to the client that his children were at high risk of contracting TB disease; this frightened the client and led him to think again about the possible consequences of his untreated MDR-TB.

The CBO personnel (i.e. the psychologist and the peer educator) gave him more information about TB and outlined TB treatment once again; it was only then that the client decided to continue his treatment. Having finally realized the risk which TB presented to his children and other loved ones, he changed his mind about TB treatment. His main aim and motivator for continuing treatment was to avoid TB being transmitted to his children, as he was also afraid that if he passed the disease on to his children, the social protection services would take them away from him.

# IV Action planning and preparing CBOs for TB activities

## **Action planning in CBOs**

The following three-step plan can be used to prepare the CBO to host TB activities: 5

#### **ACTION PLANNING IN CBOs**

#### STEP 1 SITUATION ANALYSIS

contribute to their activities.

What types of TB services are available in your community (e.g. what kind of individuals and groups are involved, what are their motivations, goals and objectives)? Identify the key stakeholders in the community, what kind of knowledge they have about delivering TB services to PWID and other vulnerable groups. Find out more about their attitude and beliefs in this area and assess how your CBO might

Key stakeholders include policy makers, representatives from other projects and like-minded organizations, researchers, scientists etc.

#### STEP 2 | ASSESSMENT OF THE CBO'S STRENGHTS

Assess factors such as available equipment, location, experience, services, current area of expertise etc.

## STEP 3 DESIGNING A SPECIFIC TB PROGRAMME OF ACTIVITY

Based on the knowledge gained from analysis and assessment, design, and implement a specific TB programme that fits your CBO.

## **Preparing CBOs for TB activities**

In order to work with potential TB-infected clients, it is important to assure that your CBO (e.g. rooms, equipment) meets the standards for safe implementation of TB activities.

## Composing and implementing TB infection control

Carrying out TB activities in CBOs puts CBO personnel at higher risk of becoming infected with TB. A TB infection control plan will significantly reduce that risk.

Remember, the safe implementation of the TB programme involves all aspects of TB infection control, including:

- managerial activities
- administrative controls
- environmental controls
- personal respiratory protection.

If any measures which form a part of the TB infection control plan are inadequately implemented, then the risk of TB transmission remains high.

## Establishing a network and a referral system

If the CBO does not have an integrated system to provide care for TB, HIV and addiction simultaneously:

Look up all TB and PWID related organizations and services in your region or country, such as:

- Health care facilities hospitals, TB clinics etc. for TB tests.
- Rehabilitation centres for fighting addiction.
- Other CBOs in the region and across the country these can be useful, for example, if the client lives in another region or plans to relocate.
- Client- or community-based organizations for drug users and PLHIV.
- Contact chosen organizations and agree upon potential activities for collaboration.

Establish a strong referral system between services.

Establish monitoring and recording mechanisms.

 This provides both the CBO as well as the referring facility with information about referrals, such as the proportion of presumptive TB cases being confirmed as having TB disease, additionally received services (e.g. HIV treatment or rehabilitation) etc.

## **Preparing CBO personnel for TB activities**

Before starting with TB activities, it is especially important that the CBO personnel be well prepared. Preparatory activities should include:

- training sessions;
- implementing safety measures, which take account of factors including the mental and physical health of CBO personnel;
- establishing psychological support for workers.

## **Training**

It is crucial to provide CBO personnel with the most recent information about TB, as well as details of available services, new and available methods and information about other organizations' experiences. It is also important to share any additional knowledge which may be useful in improving service provision and ensuring the highest levels of TB infection control.

Education and training of CBO personnel helps to ensure that TB infection control measures are properly followed. It also offers valuable explanations, giving personnel a deeper knowledge of the aim of the TB programme, and helps to promote understanding of how individual roles contribute to its successful implementation.

Trainings should take place before the start of the TB programme and should be continued systematically (e.g. in the form of annual training sessions or lectures).

Topics to be covered in basic TB training and in additional training are outlined in Annex III.

## Physical health and security

The risk of developing TB disease is higher among people with medical conditions that weaken the immune system. Therefore, it is important to **have an overview of the CBO personnel's health status** and to **be aware of conditions that may increase their chances of developing TB disease**, once infected.

Risk factors for TB are:

- HIV infection
- diabetes mellitus
- silicosis
- severe kidney disease
- low body weight
- persons with an organ transplant

- chemotherapy
- corticosteroid therapy
- immunosuppressive therapy
- specialized biological treatment for rheumatoid arthritis, Crohn's disease or other conditions
- previously treated for TB

In addition to implementing TB infection control measures, the following activities must be provided for CBO personnel in order to decrease their risk of contracting TB infection and/or developing TB disease:

- annual TB screenings;
- provision of necessary hygiene equipment (e.g. respirators, surgical masks);
- vaccinations (e.g. hepatitis A, HBV).

## **Psychological support**

Unfortunately, too little attention is given to psychological support measures for CBO personnel who work closely with PWID. Implementing TB activities and supervising DOT can be psychologically exhausting and can increase the risk of burnout among personnel.

Therefore, psychological support measures, such as supervision and other supportive services ought to be made accessible for CBO personnel. These can include:

- psychological counselling (individual or in groups);
- individual or group therapy;
- peer support.

A supportive working environment is essential to avoiding burnout among CBO personnel and helps to prevent conflict and other difficulties arising in the workplace. Establishing supportive supervision among workers (e.g. with peers) can improve the ability of CBO personnel to cope with work-related stress factors, as well as help them to develop more efficient working methods and to adapt to changes.



#### FOR MORE INFORMATION, SEE:

Mikkonen, M., Kauppinen, J., Huovinen, M., Aalto, E. (eds). **Outreach work among marginalised populations in Europe: guidelines on providing integrated outreach services.** Amsterdam: Foundation Regenboog AMOC, 2007.

## Monitoring and evaluating TB activities in CBOs

Monitoring and evaluating TB activities allows the CBO to track progress and successes, make adjustments, and to demonstrate connections between the objectives, activities and outcomes of TB activities.<sup>9</sup>

## Monitoring

Monitoring is the process of routine observation and recording both of implemented activities and their outcomes.

#### Monitoring helps to:

- demonstrate innovative and effective strategies;
- identify difficulties early;
- generate financial and political support for advocacy;
- market related campaigns;
- encourage personnel to support each other by sharing relevant advice and knowledge.

#### CBO personnel could meet regularly (e.g. weekly) to discuss:

- cases that have been referred for further investigation;
- old and new clients who have been questioned for TB symptoms and risk factors, and are at risk of developing TB;
- other socially complex cases;
- difficulties with clients, case management of clients lost to follow-up;
- other work-related challenges and successes.

## **Evaluation**

Evaluation is a systematic review of performance and helps to judge whether TB activities have achieved the desired outcome.

## Evaluating helps to:

- improve the quality of activities;
- improve the design of future activities;
- demonstrate the merits of particular activities.

## Some indicators for monitoring and evaluating TB activities are:

- the number of cases diagnosed with TB;
- the percentage of clients successfully treated (i.e. cured or treatment completed);
- the percentage of clients lost to follow-up and found.



## FOR MORE INFORMATION, SEE:

HIVQUAL Workbook – Guide for Quality Improvement in HIV Care: http://nationalqualitycenter.org/index.cfm/5852/13487 National Quality Centre. Improving HIV Care: http://nationalqualitycenter.org/index.cfm/5852

#### ENSURE FROM THE OUTSET THAT...

...TB infection control and psychological supportive measures are in place to safeguard the personnel as well as other clients.

...the CBO personnel have the knowledge and skills needed to handle clients.

...a strong referral system is in place to ensure that clients can be sent to health care or rehabilitation facilities if additional testing or treatment is required.

Most importantly of all, never give up!

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## **Annexes**

#### Annex I

#### SUGGESTED QUESTIONS FOR SCREENING TB AMONG CLIENTS

#### 1. How to ask?

Before you question the client, make sure that you have put all the necessary preventative measures in place to decrease the risk of TB transmission.

Here is a little checklist:

- Open a window; turn on the ventilation, HEPA or UVGI.
- If it is not possible to take the precautionary measures listed above, question the client outdoors.
- Inform the client about cough etiquette to reduce the risk of TB transmission. In the event of apparent TB symptoms, ask the client to cover his/her nose and mouth with a surgical mask or a tissue/disposable handkerchief. If necessary, wear a respirator.
- Be supportive, empathic and compassionate during questioning. Bear in mind that the client may be sensitive to some stigmatizing aspects whether related specifically to TB or to his/her social status in the society; therefore, try to avoid an interrogative atmosphere. Listen to the client carefully and be respectful.

#### 2. What to ask?

## **TB Symptoms**

Have you experienced any of the following symptoms:

1. Persistent coughing (3 weeks or more)?

Yes No

2. Coughing up blood or bloody sputum?

Yes No

3. Fever, excessive fatigue or night sweats (3 weeks or more)?

Yes No

4. Unexplained weight loss (in the last 2 months)?

Yes No

If yes, please describe:

If any of those symptoms occur, make sure that the client is directed to a TB clinic or a health care facility for further diagnosis and treatment.

## **TB Risk factors**

•	isk ractors	
1.	weakened	been diagnosed with a medical condition that has your immune system? (i.e. HIV, HBV, HCV or other condicould increase the risk of progression from TB infection ase)
	Yes	No
	If yes, how	t was the diagnosis? long ago was the diagnosis made? you received treatment or are you currently undergoing?
2.	Have you	ever been told that you have TB disease?
	Yes	No
	If yes, how	long ago?
3.	Have you disease?	ever been treated with medication for TB infection or
	Yes	No
	•	r long ago? you complete your treatment? Were you cured?
4.		ever been a resident or employee in correctional facilities, care facilities, homeless shelters or other high-risk contitings?
	Yes	No
5.	known to	ever lived with or been in close contact with someone have active TB disease (e.g. family member, friend, shelter roommate, relative)?
	Yes	No
6.	Where we	re you born?
7.	Have you l	nad frequent or prolonged visits to a foreign country?
	Yes	No

Which country?

#### 3. What to do?

Remember that each individual risk factor increases the chances of having TB disease!

The sooner TB is diagnosed, the better the treatment outcome.

If it is suspected that the client has active TB disease, then:

- Inform the client about the next steps to be taken
   (e.g. the need for further testing) and the importance of cooperation.
- 2. Direct the client to a health care facility for further tests and treatment. If possible, ensure that they are accompanied and receive support on the way to the facility.
- 3. Map potential groups of people and areas that are likely to have been exposed to TB for early detection, diagnosis and treatment of new cases.

The information collected via the questionnaire about the client's social and risk factors should be used to develop client-specific adherence support measures so as to ensure a successful TB treatment outcome.

Countries with a high TB incidence are: Afghanistan, Algeria, Angola, Anguilla, Argentina, Armenia, Azerbaijan, Bahrain, Bangladesh, Belarus, Belize, Benin, Bhutan, Bolivia (Plurinational State of), Bosnia and Herzegovina, Botswana, Brazil, Brunei Darussalam, Bulgaria, Burkina Faso, Burundi, Cambodia, Cameroon, Cape Verde, Central African Republic, Chad, China, China (Hong Kong SAR), China (Macao SAR), Colombia, Comoros, Congo, Cook Islands, Cote d'Ivoire, Croatia, Democratic People's Republic of Korea, Democratic Republic of the Congo, Djibouti, Dominican Republic, Ecuador, El Salvador, Equatorial Guinea, Eritrea, Estonia, Ethiopia, French Polynesia, Gabon, Gambia, Georgia, Ghana, Guam, Guatemala, Guinea, Guinea-Bissau, Guyana, Haiti, Honduras, India, Indonesia, Iraq, Japan, Kazakhstan, Kenya, Kiribati, Kuwait, Kyrgyzstan, Lao People's Democratic Republic, Latvia, Lesotho, Liberia, Libyan Arab Jamahiriya, Lithuania, Madagascar, Malawi, Malaysia, Maldives, Mali, Marshall Islands, Mauritania, Mauritius, Micronesia (Federated States of), Mongolia, Montenegro, Morocco, Mozambique, Myanmar, Namibia, Nepal, New Caledonia, Nicaragua, Niger, Nigeria, Northern Mariana Islands, Pakistan, Palau, Panama, Papua New Guinea, Paraguay, Peru, Philippines, Poland, Portugal, Qatar, Republic of Korea, Republic of Moldova, Romania, Russian Federation, Rwanda, Saint Vincent and the Grenadines, Sao Tome and Principe, Senegal, Serbia, Seychelles, Sierra Leone, Singapore, Solomon Islands, Somalia, South Africa, Sri Lanka, Sudan, Suriname, Swaziland, Syrian Arab Republic, Tajikistan, Thailand, The former Yugoslav Republic of Macedonia, Timor-Leste, Togo, Tonga, Trinidad and Tobago, Tunisia, Turkey, Turkmenistan, Tuvalu, Uganda, Ukraine, United Republic of Tanzania, Uruguay, Uzbekistan, Vanuatu, Venezuela (Bolivarian Republic of), Viet Nam, Yemen, Zambia, Zimbabwe.

#### SUGGESTED QUESTIONS FOR SCREENING SOCIAL FACTORS

If you need to get an overview of the client's social factors, the following questionnaire can be used.

- 1. Current place of residence
  - a. Personal residence (apartment, house etc.)
  - b. Rental apartment, social or municipal housing
  - c. Shelter
  - d. No fixed dwellings

#### 2. Current social status

- a. Employed or retired
- b. Student/registered disabled
- c. Unemployed with previous working experience
- d. In employment (including unofficial or casual work)
- e. Unemployed with no previous working experience

#### 3. Current sources of income

- a. Pension (private or state)
- b. Unemployment benefits
- Funding from spouse/partner
- d. Financial support from other family members
- e. Social assistance/welfare
- f. Occasional work
- g. Illegal activities

## 4. Income sufficiency

- a. Sufficient
- b. Insufficient
- c. No income
- d. Insufficient income + debts

#### 5. Social network

- a. Family (children, parents, married or living with a partner)
- b. Relatives
- c. Friends, acquaintances
- d. No social or personal contacts

#### 6. Substance use

- None
- b. Smoking
- Heavy drinking
- d. Drug use
- e. Multiple addictions (e.g. narcotics + alcohol + psychotropic medications)

## 7. Ability to manage in daily life

- a. Can manage on his/her own
- b. Can manage with help
- c. Not at all

## Annex II

## SIDE EFFECTS OF TB DRUGS

## 1. Common side effects of **first-line TB drugs**

Drug	Side effect	Management
Rifampicin	No appetite, nausea, stomach pain	Suggest small meals, particularly before bedtime
	Petechiae*	Refer immediately to a doctor
	Orange/red urine	Reassure patient—this is an expected effect of this drug
Pyrazinamide	Joint pain	Refer to a doctor
	No appetite, nausea, stomach pain	Suggest small meals, particularly before bedtime
	Rash	Refer to a doctor
Isoniazid	Burning/tingling in hands/feet	Refer to a doctor
	No appetite, nausea, stomach pain	Suggest small meals, particularly before bedtime
	Rash	Refer to a doctor
Ethambutol	Eye problems	Refer immediately to a doctor
Streptomycin	Deafness	Refer immediately to a doctor
	Dizziness (vertigo, imbalance and loss of balance)	Refer immediately to a doctor
	Itching, skin rash	Refer to a doctor

<sup>\*</sup> Petechiae: flat round red spots under the skin's surface, with a pinprick appearance, caused by intradermal hemorrhage (bleeding into the skin).

## 2. Common side effects of **second-line TB drugs**

Drug	Side effect	Management
Cycloserine	Seizures	Refer immediately to a doctor
	Psychotic reactions: depression, anxiety, personality changes, psychosis	Refer immediately to a doctor
	No appetite, nausea, stomach pain	Suggest small meals, particularly before bedtime
	Headache	Refer to a doctor
	Dizziness (vertigo, imbalance or loss of balance)	Refer immediately to a doctor
	Rash, pruritus	Refer to a doctor
	Tingling or burning in hands and feet	Refer to a doctor
Ethionamide Prothionamide	Nausea, vomiting	Suggest small meals, particularly before bedtime
	Yellowing of skin or eyes, dark- coloured urine	Refer immediately to a doctor
	Numbness, tingling, pain in hands and feet	Refer to a doctor
	Personality changes: depression, confusion or aggression	Refer to a doctor
	Dizziness	Refer to a doctor
	Problems with eyes: eye pain, blurred vision, colour-blind- ness, difficulty seeing	Refer immediately to a doctor
Fluoroquinolones: Ciprofloxacin	No appetite, nausea, stomach pain	Suggest small meals, particularly before bedtime
Levofloxacin Moxifloxacin Ofloxacin	Swelling or tearing of a tendon or muscle, joint pain	Refer to a doctor
Olioxacin	Yellow skin or eyes, dark-coloured urine	Refer immediately to a doctor
	Diarrhoea	Refer to a doctor
	Anxiety, confusion or dizziness	Refer immediately to a doctor
	Rash, hives	Refer to a doctor

Injectable sec-	Hearing loss, ringing in ears	Refer immediately to a doctor
ond-line drugs: Amikacin	Dizziness (vertigo, imbalance or loss of balance)	Refer immediately to a doctor
Kanamycin Capreomycin	Itching, skin rash	Refer to a doctor
	Decreased urination	Refer immediately to a doctor
	Muscle twitching or weakness	Refer immediately to a doctor
P- aminosalicylic acid (PAS)	Abdominal pain, nausea or vomiting	Suggest small meals, particularly before bedtime
	Black stools	Refer immediately to a doctor
	Unusual tiredness or loss of appetite	Refer to a doctor
	Skin rash, severe itching, hives	Refer to a doctor

## Annex III

#### SUGGESTED TRAINING TOPICS FOR CBO PERSONNEL

#### 1. Basic TB training

for CBO personnel should include the following topics:

- Local TB epidemiology, highlighting at-risk, hard-to-reach groups.
- Causes of TB, how it is transmitted and the signs and symptoms of TB.
- TB/HIV co-infection.
- Common communicable diseases.
- The benefits of early diagnosis and treatment (highlighting the fact that TB is treatable and curable, and that treatment is free of charge for everyone).
- Principles of TB prevention and care:
  - early diagnosis and active case-finding;
  - ways of supporting treatment (including social and psychological support during treatment and the importance of adhering to treatment and DOT);
  - contact investigations following diagnosis of an active case.
- Social and cultural barriers to accessing health services (e.g. fear of stigma and the attitude of personnel).
- Local referral pathways:
  - who to refer, when and how:
  - location and opening hours of testing services;
  - location and opening hours of other PWID related services (e.g. rehabilitation centers).
- Documentation, reporting and evaluation of implemented activities.
- Role of allied professionals and peers in
  - raising client awareness;
  - identifying cases;
  - helping clients complete treatment.
- Understanding and correcting misinformation that causes fear about TB, including addressing concerns about housing people with the condition.
- Topics that reflect the specificity of work with PWID.
- TB infection control in the CBO.

It is strongly recommended that all CBO personnel receive basic training when they are first employed, and that training is repeated every two years.

#### 2. Additional training for CBOs

should be given before starting treatment or providing support services for treatment (i.e. psychological support, treatment adherence incentives) and should cover the following aspects:

- Motivating behaviuor change (motivational interviewing):
  - cognitive behavioural therapy methods to motivate behavior change;
  - o early interventions;
  - o contingency management.
- Basics of case management.
- Practical implementation of DOT.
- Outreach work.
- Common side effects of TB drugs.
- Potential interaction of TB medication with other drugs in the case of simultaneous treatment for other conditions (e.g. OST, especially methadone, and HIV treatment).
- Client confidentiality.
- How to address the stigma associated with TB among clients and in public.

## Annex IV

#### **TUBERCULOSIS: MYTHS AND FACTS**

Myth: TB is hereditary.

**Fact**: TB is not hereditary. It is a disease that is transmitted from person to person through the air. It is spread when those with untreated TB disease of the lungs or throat cough, sneeze or speak, sending the germs into the air.

Myth: TB causes lung cancer.

**Fact**: Lung diseases that cause scarring of the lung tissues, such as TB, can increase the risk of developing lung cancer. There are many causes of lung cancer, with smoking being the number one cause. Radon, asbestos, pollution, and many other materials and chemicals have been known to cause lung cancer.

Myth: Smoking causes tuberculosis.

**Fact**: The cause of the TB infection is the bacterium *Mycobacterium tuberculosis*. Smoking can aggravate TB.

Myth: TB only occurs in lower socioeconomic groups.

**Fact**: In reality, tuberculosis has broken all socioeconomic barriers and can affect anyone irrespective of their socio-financial background and living conditions.

**Myth**: The Bacille Calmette-Guérin (BCG) vaccination prevents individuals from developing TB.

**Fact**: While the vaccine prevents severe forms of TB in childhood, it does not protect adults against TB disease.

Myth: TB only affects the lungs.

**Fact**: TB primarily affects the lungs (in 70-80% of cases) however other parts of the body that can be affected include the lymph nodes, bones, joints, genitourinary tract, heart (pericardium), brain, gastrointestinal tract and the skin; in fact, the disease can affect almost all parts of the body, except the nails and hair.

Myth: TB disease and TB infection mean the same thing.

**Fact**: No. A person with TB infection is not contagious because the germ is inactive or latent. The person does not know he or she is infected because no signs or symptoms are experienced. A person with TB disease is affected quite differently. Someone with TB disease has the active germ within their body; this means that the person may be experiencing signs and symptoms of TB and can be contagious.

**Myth**: An individual who has been infected with *Mycobacterium tuberculosis* will develop TB disease.

**Fact**: A TB infection does not always develop into TB disease. It is estimated that only about 10 percent of infected people will develop TB at some time in their lives. Some other physical and medical conditions may increase the probability of developing TB disease.

**Myth**: A positive TB skin test means that an individual has TB.

**Fact**: A positive TB skin test only confirms that you have been exposed to TB and are infected, but does not necessarily mean you have the disease.

Myth: If I don't have TB symptoms, I don't have TB.

**Fact**: A person with TB disease may have any, all or none of the following symptoms: a cough that will not go away; feeling tired all the time; weight loss; loss of appetite; fever; coughing up blood; night sweats. These symptoms can also occur with other diseases so it is important to see a doctor who will be able to determine whether you have TB disease. It is also important to remember that a person with TB disease may feel perfectly healthy or may only have a cough from time to time.

**Myth**: TB screening and treatment is only available free of charge if you have health insurance.

**Fact**: In Bulgaria, Finland, Estonia, Latvia, Lithuania and Romania TB screening and treatment is free of charge for all patients irrespective of whether they have health insurance cover.

Myth: Individuals suffering from TB should be hospitalized.

**Fact**: Hospital treatment is usually needed in the intensive phase when patients are infectious. After that most patients can be treated at outpatient sites.

Myth: TB can be fatal.

**Fact**: If a patient follows the complete treatment course, then drug-sensitive TB is fully curable.

#### **EXEMPLARY CASES AND CASE MANAGEMENT**

#### **EXEMPLARY CASE 1**

A young woman, S., arrived at the CBO for the first time and insisted on having a rapid HIV test. She was pale, skinny, and seemed rather nervous. In addition, she said that she had been feeling sick lately; as her partner was an active drug user and was infected with HIV, she thought that she might also have the virus. However, she refused to go to the hospital or a medical centre, because she was afraid of doctors and, in particular, the police. During the HIV test, she had several coughing fits and was breathing heavily.

Describe the steps that you would take if this client arrived at your CBO.

#### **EXEMPLARY CASE MANAGEMENT 1**

- Make sure that the rooms where contact with S. takes place (e.g. HIV testing room) are properly ventilated to reduce the risk of possible TB transmission.
- Create a neutral atmosphere and give pre-test counselling about testing for TB. Speak calmly and explain the basics of TB, the difference between HIV and TB and the need to screen her for TB. If separate questioning is not possible, then try to ask her about TB symptoms and TB risk factors during the conversation.
- Try to keep the client calm. Explain that no one is there to threaten her and that client confidentiality will be assured.
- If necessary, try to persuade the client to go to a TB clinic for further testing. If possible, accompany her to the clinic or try to find alternative ways to do the screening in a safe environment.
- If necessary, consult other CBO personnel or professionals for advice and ideas.

#### **EXEMPLARY CASE 2**

P. is 56 years old and has been a long-term client at the CBO. He was diagnosed with TB about a year ago and was admitted to the regional TB clinic for inpatient treatment. After he had been proven non-infectious, he started to receive DOT at an outpatient setting. A member of the CBO personnel was assigned as his DOT worker and he still has an estimated 6 months of treatment left.

Although initially, he came to the CBO regularly to receive his medication, his attendance became more erratic. Now, he has not shown up for two days. His phone is switched off and, when a designated DOT worker at the CBO went to his given address, it turned out that P. had never lived there, and had given false details.

What else could be done to find P.?

How could this situation have been prevented or the process of finding P. facilitated? In the event that P. is found, what should be done next?

What are the possible consequences when a client does not want to be looked for or to be found?

#### **EXEMPLARY CASE MANAGEMENT 2**

- Contact P.'s social network (e.g. family, friends, neighbors, acquaintances). Ask them about potential places where P. might be found.
- Go to places where the client is likely to be. Contact the client's social network (e.g. family, friends, colleagues). If possible, do outreach work with a partner to find P.
- In all cases, client confidentiality should be protected
- Therefore, remain discreet about the client's TB as not everyone in his circle may be aware of his disease.
- Explore other legal possibilities for exchange of patient-related information and, if possible (taking account of legal obstacles), actively seek information about any people P. has mentioned. Collaboration with NTP and the police can be very helpful in this case.
- If necessary, consult other CBO personnel or professionals for advice and ideas.

#### When P. is found:

- Talk to P. and, if possible, those close to him, about the reasons why treatment was interrupted.
- Try to identify the causes of P.'s problems and look for ways to solve them. Work with P. to identify and address his other needs, so that adherence to therapy can remain a priority.
- Remind P. about the dangers of treatment interruption and the threat
  this poses to his friends, relatives or loved ones. Also tell him how much
  longer he has left until the treatment is finished and how important it is
  not to stop, even when the physical symptoms of TB have improved or
  when the treatment is difficult because of side effects.
- Talk to P. about what could be done to prevent this situation from occurring in the future.
- Try to get a clearer overview of P.'s social network. Ask P. for details of other
  contacts who could have supplied the necessary information about his
  location when he did not report for treatment.

#### **EXEMPLARY CASE 3**

A. is a 30-year-old man who previously worked as a carpenter. After was released from prison (he was convicted for selling drugs), he continued to use drugs, got into debt and lost all his belongings, including his apartment. A. has been diagnosed with HIV, HCV and quite recently with MDR-TB. At the TB hospital, he started to receive both methadone and ART, however, he has been experiencing numerous side-effects due to drug interactions and is therefore reluctant to take all of his medications. Now he has started to receive his treatment at an outpatient site, but the nurses and social workers face constant difficulties with his case, as his social conditions are still complicated – he has no income other than disability benefits, no relatives and no place to live, apart from staying in the homes of his friends, most of whom are still using drugs.

How should case management be conducted in this case? What measures could be used to help A. to finish his TB treatment?

#### **EXEMPLARY CASE MANAGEMENT 3**

- Identify and address A.'s needs and obstacles, such as the lack of a fixed living space, so that adherence to therapy can remain a priority. Try to find solutions to those problems which are a top priority (e.g. find other alternative housing arrangements, offer options for rehabilitation, look for psychological and social counseling. Then, once these have been dealt with, the focus can be shifted to preparatory activities such as training to help A. to enter the job market).
- Find suitable ways of working to strengthen A.'s motivation as well as
  to support his adherence to treatment (e.g. motivational interviewing,
  cognitive and behavioural interventions). If necessary, look for other professionals in the CBO or in the region who could provide those services
  (e.g. therapies, consultations, meetings). Find out what interests A. and
  what could be used to increase his motivation to continue his treatment.
- Look for suitable adherence reminders.
- Encourage A. to inform personnel about his side effects. Help him to understand that side effects and the related discomfort are temporary and go away after the treatment is finished.
- Invite previous TB patients to share their experiences with A.
- If necessary, consult other CBO personnel or professionals for advice and ideas.
- If the patient has problems attending the DOT unit, find out whether other alternatives (e.g. home visits for TB DOT) are available that would be more suitable for A.

