

TB ADVOCACY GUIDE

**FOR PEOPLE
WHO USE DRUGS**

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Glossary of terms

ANPUD	Asian Network of People Who Use Drugs
ART	Antiretroviral Therapy
DOTS	Directly Observed Treatment Short Course of TB Treatment
GNP+	Global Network of People Living with HIV
HIV	Human immunodeficiency virus
IEC	Information, education and communication
INPUD	International Network of People Who Use Drugs
IPT	Isoniazid preventive therapy
ITPC	International Treatment Preparedness Coalition
LTB	Latent tuberculosis
MdM	Médecins du Monde
MDR	TB Multi-drug resistant tuberculosis
NSP	Needle and Syringe Programme
OST	Opioid Substitution Therapy
PLHIV	People living with HIV
SMART	Specific, Measurable, Agreed upon, Realistic and Time-based
STI	Sexually transmitted infections
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNODC	United Nations Office on Drugs and Crime
WHO	World Health Organization
XDR TB	Extensively drug-resistant TB

1 INTRODUCTION

This handbook results from collaboration between specialists from the Joint United Nations Programme on HIV/AIDS (UNAIDS), World Health Organisation (WHO), HIT and the International Network of People who Use Drugs (INPUD). It reflects the shared commitment of these organisations to build an effective response to TB among people who use drugs and those living with HIV.

The work of these partner organisations, the partnership between them and the way in which this handbook was developed are described in Appendix 1 and Appendix 2. For the purpose of this handbook we define advocacy as follows:

‘Advocacy is taking action to help drug users and people living with HIV (PLHIV) to say what they want, to secure their rights, to represent their interests and to obtain the services they need. Advocacy is a process by which activists, drug users and PLHIV join together to influence key stakeholders and decision makers to create positive change’.

This handbook has been designed to be a practical tool for activists to support them to assess their local circumstances, identify priorities for advocacy and to design, deliver and review their own TB advocacy campaigns. Each setting and context will throw up different issues and challenges for TB advocacy.

The handbook is designed to support drug user and PLHIV activists who can use their existing skills and expertise to take up the advocacy agenda on behalf of the drug using community. These activists will be described as drug user advocates throughout this handbook but it is hoped that it will be a resource for both drug user and PLHIV activists.

The grassroots advocacy that we hope will follow from the use of this handbook will extend our collective understanding and knowledge of TB advocacy for people who use drugs. This resource provides a platform to further deepen and extend the TB advocacy capacity among drug user advocates.

Most importantly this grassroots practice needs to be held within a collaborative learning model so that good practice evolves and develops. This will allow for the shaping of future advocacy agendas and strategies and require this TB Advocacy Handbook to remain a living and evolving advocacy and learning resource.

TB is a growing threat to people who use drugs, particularly when set against the backdrop of high vulnerability to, and prevalence of, HIV. As such it is important for drug user advocates from drug user organisations and PLHIV groups to help develop a coordinated advocacy response. We hope that this handbook will help this to happen.

**TB IS BOTH
CURABLE
AND PREVENTABLE,
EVEN IN PEOPLE
LIVING WITH HIV.**

2 UNDERSTANDING TB, DRUG USE AND HIV

2.1 What is TB?

- TB, or tuberculosis, is a disease caused by bacteria called *Mycobacterium tuberculosis* (MTB).
- TB is both curable and preventable, even in people living with HIV.
- It is spread when people who have active TB disease expel TB bacteria into the air by coughing, sneezing, or spitting and other people inhale the bacteria.
- In most cases, people who breathe in these bacteria develop latent TB infection, which means that their immune system contains the TB bacteria but they do not have any symptoms.
- About one in ten people with latent TB infection go on to develop active TB disease with symptoms during their lifetime due to a weakened immune system.
- If left untreated, 50% of people will die from the active TB disease.
- The classic symptoms of TB disease are a cough with sputum or phlegm (sometimes blood-tinged), fever, night sweats and weight loss.
- While TB most commonly affects the lungs it can affect any part of the body (extrapulmonary TB) and thus can present in many different ways.
- People living with HIV and children are at greater risk of extrapulmonary TB because of weakened immune function.

Challenges to fighting TB:

Old weapons against a still vigorous adversary

- TB medicines have not changed for decades.
- Basic diagnosis of TB has not changed for more than a century.
- New genetic tests for TB will soon make it possible to rapidly identify everyone who needs TB treatment. A simple quick test, of the sort already available for diseases like HIV and malaria, is needed urgently.
- The only TB vaccine in routine use only protects young children from serious TB disease. It offers no protection to young people and adults.

HIV increases the risk of developing TB and death from TB

- People living with HIV are over 30 times more likely to develop TB than people free of HIV infection.
- TB is the leading cause of death among people living with HIV in Africa, Eastern Europe and central Asia.
- Worldwide, one in four HIV deaths is TB-related.
- Without treatment, the vast majority of people living with HIV who are sick with TB will die within a few months.

Drugs can lose their power

- When people cannot, or do not, take all their treatment TB bacilli can become resistant to medicines and multi-drug-resistant TB (MDR-TB) can develop. MDR-TB takes longer to treat and can only be cured with second-line drugs, which are more expensive and have more side effects.
- Extensively drug-resistant TB (XDR-TB) can develop when people cannot, or do not, take all treatment with these second-line drugs. XDR-TB is difficult, and sometimes impossible, to cure.
- Both MDR-TB and XDR-TB can spread from person to person.

**NEW GENETIC
TESTS FOR TB
WILL SOON MAKE
IT POSSIBLE
TO RAPIDLY
IDENTIFY
EVERYONE
WHO NEEDS TB
TREATMENT**

2.2 **Injecting drug use and HIV**

Injecting drug use is reported in at least 158 countries and territories around the world. The latest available data estimate that 15.9 million (range 11 to 21 million) people inject drugs globally. The largest injecting populations are found in China, the United States and Russia. In 120 countries, there are reports of HIV infection among people who inject drugs. In nine countries – Argentina, Brazil, Estonia, Indonesia, Kenya, Myanmar, Nepal, Thailand and Ukraine – HIV prevalence among people who inject drugs is estimated to be over 20%. Worldwide, approximately three million (range 0.8 to 6.6 million) people who inject drugs are living with HIV.

2.3 **TB and HIV Interaction**

TB and HIV are global emergencies whose deadly interaction affects millions and threatens global public health. HIV infection is a leading risk factor that contributes to people with latent TB infection progressing to active TB disease. HIV also increases the rate at which TB re-occurs. People with HIV may not be properly identified and treated for TB because they have no symptoms. Around two thirds of people with HIV and TB produce smear-negative tests, which can result in delayed diagnosis. In countries where HIV rates are high, TB control targets are often not being met. TB is also a major cause of illness and death among people living with HIV.

2.4 **TB and HIV among people who inject drugs**

Injecting drugs can be linked to a range of factors such as lifestyle issues, homelessness, limited access to healthcare, imprisonment, excessive alcohol use, poor nutrition, poverty, and life with HIV infection, which increase the vulnerability of people being infected with, and developing TB disease. These factors can also cause people who use drugs to have poorer health and treatment outcomes.

TB and HIV among people who use drugs by non-injecting routes of administration

There is limited evidence about why non-injecting drug users are at an increased risk of developing TB. However, patterns of HIV transmission have been identified among people who smoke stimulant drugs, although not to the same extent as people who inject drugs. The routes of HIV transmission with people using stimulant drugs are much less clear than with injecting drug use. While no direct transmission routes exist, the HIV epidemics among people who use stimulant drugs highlight the interwoven nature of social exclusion, poverty, criminalisation and HIV transmission.

Similarly poor living conditions, shared smoking equipment, poor nutrition, and poverty that can be associated with drug use may be factors in increasing TB risk, as well as the immunosuppressive effect of some drugs.

TB, HIV, drugs and prisons – a deadly combination

Prisons have been identified as key vectors of disease and this is particularly worrying given the criminalisation of people who use drugs. Prisons have little positive impact on addressing offending behaviour with drug using offenders. In contrast, prisons have been shown to be extremely effective at creating environments within which HIV, TB - including drug resistant strains - and drug use can all escalate and flourish.

**NSPs AND OST
ARE KEY POINTS
OF ENGAGEMENT
WITH PEOPLE WHO
USE DRUGS AND HAVE TB**

3 TB PREVENTION, DIAGNOSIS, AND TREATMENT

3.1 Isoniazid Preventive Therapy

Isoniazid preventive therapy (IPT) involves the use of a single anti-TB drug for six to nine months to treat latent TB infection and prevent progression to TB disease, especially in people living with HIV. It is important, however, to ensure that active TB disease is ruled out before administering IPT. Although IPT has significant potential to reduce the burden of TB disease among people living with HIV, it is currently not being used widely enough and particularly among people who use drugs. Adults and adolescents living with HIV should be screened for TB and those who do not report any of the symptoms, such as current cough, fever, weight loss or night sweats, are unlikely to have active TB and should be offered IPT.

TB COULD BE
PREVENTED
IN MILLIONS
OF PEOPLE
INFECTED WITH
BOTH HIV AND
TB THROUGH THE
USE OF IPT

A complete medical evaluation for TB should include a medical history, a physical examination, microscopic examination of sputum (if extrapulmonary TB is suspected then some other appropriate sample will be collected), and often a chest X-ray. A more sensitive culture test of sputum may be used to detect TB cases missed by microscopy and/or to determine whether the TB bacteria are drug resistant. Culture tests are more accurate but unlike microscopy, which can provide same day diagnosis, results may take up to six weeks to confirm.

There is a new test, GeneXpert MTB/RIF, which diagnoses TB in less than two hours, simultaneously detects drug resistance and has proved to be more effective at diagnosing smear negative TB which is more common in people living with HIV. This test is being scaled up around the world but it requires a certain level of infrastructure and is very expensive and therefore not available in most health post settings.

Treatment for active TB is difficult and requires at least six months on multiple antibiotics. Contacts are also screened and treated, if necessary. In some countries people receive TB treatment in specialized hospitals, where they are sometimes required to remain for the full duration of the treatment. At times such hospitals can be centres for excellence while at other times they can be outdated centres that are linked to infringements of people's human rights. This is further complicated in situations where opioid substitution therapy, and other drug dependence

treatment, are not provided at all or not in the same facility where people are hospitalized for TB treatment, especially in situations when people actively use drugs and are not allowed to leave the premises. Lack of drug dependence support and treatment in TB hospitals results in treatment interruptions and further complications.

TB treatment requires full adherence, as the resistance of bacteria to available medications develops easily. The emergence of drug-resistant TB is a growing problem. Treatment for multidrug-resistant TB (MDR-TB), which is a form of TB that is resistant to the two most powerful TB drugs, lasts up to two years and requires many pills to be taken daily, sometimes twice a day. Adherence to treatment is important in both preventing onward infection, treating the active disease and avoiding a growth of multi-drug-resistant TB.

A study undertaken by the *Andrey Rylkov Foundation for Health and Social Justice (Moscow)* found that the 'absence of effective drug treatment services at TB hospitals, and in general, is the most serious structural barrier to effective in-patient TB treatment for patients with co-infection. The majority of drug-dependent patients with TB drop out of treatment: *in some cities the level of drop out from in-patient treatment among this group is at 100%*. Inability of the health system to offer adequate drug treatment creates an institutionalized "trap," when drug-dependent patients are excluded from stable TB treatment de-facto'.

A person with Latent TB Infection (LTBI)	A person with active TB disease
Usually has a skin test or blood test result indicating TB infection	Usually has a skin test or blood test result indicating TB infection
Has a normal chest x-ray and a negative sputum test	May have an abnormal chest x-ray, or positive sputum smear or culture
Has TB bacteria in his/her body that are alive, but inactive	Has active TB bacteria in his/her body
Does not feel sick	Usually feels sick and may have symptoms such as coughing, fever, and weight loss
Cannot spread TB bacteria to others	May spread TB bacteria to others
Needs treatment for latent TB infection to prevent TB disease	Needs treatment to treat active TB disease
If exposed and infected by a person with multidrug-resistant TB (MDR-TB) or extensively drug-resistant TB (XDR-TB), preventive treatment may not be an option	If exposed and infected by a person with multidrug-resistant TB (MDR-TB) or extensively drug-resistant TB (XDR-TB) will require prolonged treatment with second line drugs

The WHO's Stop TB Strategy was launched in 2006 and was designed to combat the spread of TB. It has five objectives implemented through six components:

- Achieve universal access to high-quality care for all people with TB.
- Reduce the human suffering and socio-economic burden associated with TB.
- Protect vulnerable populations from TB, TB/HIV and multi-drug-resistant TB.
- Support development of new tools and enable their timely and effective use.
- Protect and promote human rights in TB prevention, care and control.

Two key components of this strategy are to empower both people with TB and communities through partnership and to address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations. The core of the strategy is DOTS, the TB control approach launched by WHO in 1995. Since then 41 million patients have been treated under DOTS-based services. The strategy also responds to access, equity and quality constraints, and adopts evidence-based innovations in engaging with private health-care providers, empowering affected people and communities, to help strengthen health systems and to promote research.

The Six Components of the Stop TB Strategy

- **Pursue high-quality DOTS expansion and enhancement.** This involves the vital elements of political commitment with sustained financing, early case detection and diagnosis, standardised treatment with supervision and patient support, effective drug supply and management, performance and impact monitoring and evaluation.
- **Address TB/HIV, MDR-TB and the needs of poor and vulnerable populations.** This requires much greater action and input than DOTS implementation.
- **Contribute to health system strengthening based on primary health care.** National TB control programmes must contribute to overall strategies to advance financing, planning, management, information and supply systems and innovative service delivery scale-up.
- **Engage all care providers.** TB patients seek care from a wide array of public, private, corporate and voluntary health-care providers. To be able to reach all patients, and ensure that they receive high-quality care, all types of health-care providers need to be engaged.
- **Empower both people with TB and communities through partnership.** Community TB care projects have shown how people and communities can undertake some essential TB control tasks. These networks can mobilise civil societies and also ensure political support and long-term sustainability for TB control programmes.
- **Enable and promote research.** While current tools can control TB, improved practices and elimination will depend on new diagnostics, drugs and vaccines.

Médecins du Monde (Mdm) has been active in Afghanistan for the past 23 years in the implementation of different health programmes. Since 2006, Mdm has focused on prevention, care and treatment for people who inject drugs, the highest risk group regarding HIV in the country.

The aim of the MDM Harm Reduction programme is to build the capacities of people who inject drugs to reduce the risks related to their drug use by making a range of services available. These include:

- information, education and communication (IEC) about blood borne diseases
- HIV/HCV/HBV testing and counselling
- needle and syringe programmes
- prevention and treatment of sexually transmitted infections (STIs),
- antiretroviral therapy (ART)
- Opioid Substitution Therapy (OST)

Key to the service is the use of OST as a starting point for the engagement, assessment and stabilisation of clients. The seven-day a week methadone dispensing service provides a platform for delivering a range of other healthcare interventions including ART and TB treatment. This promotes high levels of treatment engagement and compliance despite the difficult service setting. However, political, funding and policy barriers continue to be a major obstacle to scaling up this pilot service.

Key features of Mdm's service in Kabul, Afghanistan:

- The methadone maintenance service provides a point of engagement with highly vulnerable sections of the local drug using community.
- Professional and peer outreach workers reach out among people who are using drugs and are homeless to engage those at risk.
- All people attending the service are offered TB screening and education about TB.
- TB treatment is integrated alongside the daily dispensing of methadone and provision of ART treatment for people also living with HIV.
- Mdm can send off for advanced TB tests to be analysed in the mainstream health service.
- Clients requiring more advanced treatment are referred to general medical services although stigma and discrimination against people who use drugs still remains a barrier to a fully integrated service.
- Routine monitoring of TB is included in the medical review of clients of the OST service.

**PEOPLE DESERVE
THE RIGHT TO
TREATMENT
WITHOUT
PREJUDICE OR
DISCRIMINATION**

4 ADVOCACY ISSUES, PRINCIPLES AND SETTINGS

4.1 Advocacy issues

4.1.1 Stigma and discrimination

Stigma and discrimination are barriers to both access to, and the completion of, treatment services. The fear of judgement from specialist drug workers, doctors and other health workers is by far the biggest reason why those experiencing problems with drugs choose to stay away from drug treatment.

Arguably when practitioners are not skilled or trained in working with the drug-using community, there may be higher levels of negative attitudes and discriminatory behaviour towards people who use drugs. This may be compounded by staff fears about managing specialist issues like drug overdose, withdrawals or co-morbidities. Concerns about managing the unfamiliar and the unknown can be addressed through sensitivity and skills-building training and this is likely to be of particular value with staff in specialist TB services.

TB itself is also often stigmatised, commonly in relation to its association with poverty or HIV or due to the contagious nature of TB.

Advocacy priorities

- Advocate for training of all health care workers about the needs of people who use drugs.
- Engage with doctors, other health workers and specialist drug workers on issues of judgment and stigma and the effects of discrimination.
- Operate advocacy clinics within, or alongside, drug treatment centres to support individual clients in their engagement with the service.

4.1.2 Criminalisation

Legal barriers and criminalisation can block the empowerment of groups at high risk of HIV infection, such as people who inject drugs, sex workers, men who have sex with men and transgender people. This leads to low levels of service uptake and undermines public health interventions. People who use drugs are criminalised all over the world. In some cases criminalisation is so severe as to create a climate where the risk of being exposed as a drug user outweighs the positive benefits of accessing drugs, HIV or TB services.

In addition to the direct impact of legal barriers and criminalisation on HIV prevention efforts, law enforcers' behaviour also influences the legal environment and access to drug treatment and TB and HIV services. Laws can be enforced in such a way as to infringe the human rights of people who use drugs and this serves as an additional barrier to those seeking to access HIV or TB prevention and treatment services.

In some contexts, the police are involved in high levels of corruption and people who use drugs can be heavily targeted. This may sometimes include drugs being planted on people. This allows poorly paid police to secure bribes from a vulnerable population who are unlikely to formally report corrupt officials. Police may also use health and social care settings as a place to arrest or to harass people who use drugs. Even occasional such actions by police may discourage service access and/or retention.

Advocacy priorities

- Advocate for decriminalisation of drug use.
- Advocate for education and training of police officers.
- Engage with police in designing and implementing harm reduction, and other programmes, for people who use drugs.

Harm reduction and universal access

Harm reduction services are a key point of engagement between health care services and the active drug using community. Needle and syringe programmes (NSPs) and OST are key points of engagement with people who use drugs and have TB.

When harm reduction services are not available reaching out to, and engaging, the active drug using community, and particularly people who inject drugs, becomes far more challenging. This is why advocacy work on TB can be so readily adopted by drug user advocates engaged in more general championing of the rights of people to harm reduction and effective drug treatment services. TB can become another point of advocacy for harm reduction and OST.

Advocacy priorities

- Advocate for harm reduction services in settings without established provision.
- Champion and defend harm reduction services in settings where these are established.
- Advocate for the meaningful participation of people who use drugs in harm reduction services, including OST and drug treatment services.

Access to antiretroviral therapy (ART) treatment

Access to ART treatment is key to the health, quality of life and survival rates of people living with HIV and can significantly reduce their risk of TB disease. However, active drug use and active injecting drug use in particular, can lead to people who use drugs and live with HIV being refused access to ART. Where this occurs, drug user advocates should strongly challenge this practice. Equity of access to treatment is a key agenda for drug user advocates and equal access to ART should be a clear target for advocacy in settings not offering fair access to people who use drugs.

Initiation of ART is critical to reducing the burden of TB among people with HIV. WHO recommends that people with HIV be initiated on ART when their CD4 count is 350 to reduce, among other risks, the risk of developing TB. Likewise all people with HIV who have active TB should be offered ART, regardless of their CD4 count.

Advocacy priorities

- Advocate for ART treatment in settings without established provision.
- Promote treatment literacy for PLHIV within the drug using community.
- Develop peer treatment compliance buddying schemes.
- Advocate for accessible and fairly priced TB and HIV drugs.

4.1.5 Adherence to TB treatment or Isoniazid Preventive Therapy (IPT)

Adherence to TB treatment can be challenging. Failure to complete treatment contributes to the spread of drug resistant forms of TB. TB becomes drug resistant when TB drugs are not given for long enough, regularly enough or not in high enough doses. Drug resistant TB can develop and mutate, making it most likely to survive and go on to multiply and take over. Therefore, supporting people to engage with, and complete, their TB treatment is a key objective and a place where peer buddying has been shown to be very effective, as well as NGO services providing psychosocial support.

Living with an opiate dependency can be time consuming, particularly when people become homeless and/or have to raise funds for drugs through offending. Life becomes harder to forward plan and living day to day and avoiding withdrawal symptoms becomes the primary priority. However, OST provides people who are dependent on opiate drugs, like heroin, the chance to stabilise their lives and create a far firmer platform for TB treatment. This is why advocating for people with TB to get priority access into OST services, and advocating for OST where it does not exist, are both important TB advocacy objectives.

Adherence is critical to ensure maximum impact. With adequate support, injecting drug users have been shown to have similar adherence rates to non-drug users.

Advocacy priorities

- Advocate for access to TB treatment among people who use drugs where this is impeded by local treatment guidelines or practices.
- Promote treatment literacy for people living with TB in the drug using community.
- Advocate for strong links and care pathways between TB and OST drug treatment services.

4.1.6 Service integration

Expecting people to attend different clinics for care and treatment with regard to drug dependency, TB and HIV is often unrealistic. All services dealing with people who use drugs should work together to ensure that everyone in need is able to access comprehensive TB and HIV prevention, treatment and care. As has already been discussed, access to OST and drug treatment is also a key part of this package. These services need to be delivered in a way that meets the client's needs and pays due care to TB infection control. Services built around the client - holistic, person-centred services - will be more effective in maximising treatment access and adherence. Ideally, services should be delivered in a single place (one-stop-shop) and easily accessible for people who use drugs.

Advocacy priorities

- Audit existing levels of service integration and develop an understanding of client perspectives of services.
- Advocate with different stakeholders in the care system to align their care pathways to ensure that services are holistic and person-centred.
- Arrange study tours, or virtual webinars, with services operating an integrated service model.

Prisons have commonly been shown to be environments within which HIV, TB - including drug resistant strains - and drug use can all escalate and flourish.

Advocacy priorities

- A combination of drug treatment and community criminal justice programmes has been shown to have the maximum benefit so lobbying for prison law reform can be an important agenda.
- Challenge prison overcrowding and poor nutrition, and champion access to harm reduction approaches, including drug dependency treatment, TB and HIV infection control and TB and HIV prevention, treatment and care services within prisons.
- Work with prison reform groups and/ or ex-prisoners groups to undertake joint advocacy on TB, HIV and harm reduction.

The employment of people who use drugs with relevant technical skills in specialist drug, HIV or TB services can help sensitise colleagues, and the service as a whole, to the needs of people who use drugs. However, many services operate with requirements for employees to be drug-free and also in some cases to be drug-free for a certain number of years. Such requirements may breach employment law in certain countries, although this may need to be tested and will vary from country to country. More welcoming employment procedures and human resource policies can create environments that allow people to make known their peer status and to share their peer insights and expertise with colleagues. Advocating for fair and effective employment environments for people who use drugs is one of the background advocacy opportunities that helps create the best service environment for people who use drugs and have TB.

Advocacy priorities

- Advocate for explicit policies around the employment of people who use drugs that set out rights, responsibilities and support systems for the drug-using employee.
- Provide technical assistance around the development of employment protocols for people who use drugs within drug services.
- Operate employment support groups to provide a safe space where drug-using employees can discuss their work pressures and challenges and develop and share effective self-management strategies.

WHO's *Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users* is based on four core principles. These principles are important for advocates to follow when developing advocacy work at the policy, service delivery and individual level. They help speak to the spirit of advocacy when working in real situations on the ground.

Equity

The International Standards for Tuberculosis Care and the Patients' Charter for Tuberculosis Care state that people should have the right to treatment without stigma, prejudice or discrimination by healthcare providers or authorities. Therefore people who use drugs should have access to the full range of TB and HIV services without threat of arrest, harassment or abuse.

Ease of access

Services should be based around the person with TB and their needs (person-centred approach). Services need to be delivered from a single location (one-stop-shop), or at least in a coordinated manner, to avoid the need for people to travel between HIV, TB and drug services to access a full package of care and should be close to where most people who use drugs live or congregate. Services should be free of charge.

Health as a public good

Providing TB and HIV prevention, treatment and care services to people who use drugs positively affects their friends and communities. As such, responding to individuals who use drugs effectively has wider public health benefits.

Harm reduction

Harm reduction is a set of policies and programmes which are designed to reduce the negative health, social and economic consequences of all drugs (psychoactive substances) to individual people who use drugs and their families and communities. The WHO, UNODC, UNAIDS Technical Guide, for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users, describes a list of 9 core, agreed harm reduction interventions – see the list below. This list is not exhaustive and innovation is key to the effectiveness of harm reduction. However, interventions on this list have the strongest evidence base and policy endorsement. Harm reduction should be the centrepiece of an effective response to the needs of people who actively use drugs.

Interventions for HIV prevention, treatment and care among people who inject drugs:

- Needle and syringe programmes (NSPs)
- OST and other drug dependence treatment
- HIV testing and counselling (T&C)
- Antiretroviral therapy (ART) Prevention and treatment of sexually transmitted infections (STIs)
- Condom programmes for IDUs and their sexual partners
- Targeted information, education and communication (IEC) for IDUs and their sexual partners
- Vaccination, diagnosis and treatment of viral hepatitis
- Prevention, diagnosis and treatment of TB.

Ref: WHO, UNODC, UNAIDS technical guide for countries to set targets for universal access to HIV prevention, treatment and care for injecting drug users. WHO 2009

The policy setting will include a range of different organisations that may be targeted by drug user advocates wishing to improve the context within which services are delivered to people who use drugs and the environment within which the drug using community interacts. These may include the local, national, regional or global policy bodies that shape guidelines, plan services and/or design strategies that impact on the lives of people who use drugs. With regard to TB, drug user advocates will want to target those policy bodies that make decisions around the guidelines, policy and strategy that relate to the lives of people who use drugs who are at risk from, or infected with, TB. People who inject drugs are the most significant population of people who use drugs affected by TB, although factors like imprisonment, homelessness and poverty can all compound vulnerability to TB among people who inject drugs. A number of different policy forums will have a stake in planning and delivering services for people affected by TB within the drug using community. One of the key advocacy agendas is the need to secure integration between different service providers and joint planning systems. However, in the first instance this may require advocacy to providers of drug, TB and HIV services to encourage a climate of collaboration and to promote effective joint planning. Targeted advocacy interventions should be delivered based on a needs assessment of conditions on the ground. This will help advocates understand where advocacy may best be targeted and which organisations are therefore relevant to achieving the selected advocacy goals and objectives. One of the interventions that may be selected for advocacy is participating in policy making, and lobbying policy makers, to promote enhanced service integration and quality standards, in line with recommended national, regional and global policy guidelines.

Advocacy priorities

- Lobby for service integration and effective care planning between different health programmes and providers.
- Promote the concept of a one-stop-shop approach for people who use drugs, delivered through settings where people can receive drug treatment and HIV and TB services in a single unified setting, whilst paying due attention to TB infection control. This is illustrated by the case study of Médecins du Monde's methadone maintenance clinic in Kabul.
- Defend the right of people who inject, or otherwise actively use drugs to access TB prevention, treatment and care and for active drug use, or continued injecting, not to be used as a barrier for entry into TB services.
- Encourage the provision of OST, such as methadone and buprenorphine for people dependent on opiates, as this provides opportunities to move away from risk behaviour and risk situations, and can support adherence to TB and HIV treatment.
- Highlight barriers to service access whether due to stigma and discrimination, criminalisation, geographic location or transport links.

Health and social care service providers and police and judiciary have a direct impact on the day-to-day lives of people who use drugs. Securing meaningful participation in the design, delivery and review of services delivered to the drug using community, can often provide an effective platform and on-going advocacy relationships. Contributing to the understanding and development of a service creates political capital, which later can be used to raise issues that may be challenging or reflect priorities for the drug using community.

Many drug user advocates have already established working relationships with OST services and sometimes with general medical and HIV services. However, building relationships with TB service providers may be a new venture and investigating the local service model and service strategies can be a useful entry point into the local area. This can enable drug user advocates to identify whether people who use drugs have been identified as a priority group and whether service links exist between TB, HIV and drug services. Depending on working relationships between drug services and local drug user groups, joint approaches may be made to TB services as drug user advocates work with local drug services to help develop a response to the emergence of TB among the drug using community.

The engagement between a service and the drug using community starts with the individual client experience of the service. Therefore, the quality of the practitioner and their ability to engage effectively and non-judgmentally with people who use drugs underpins all other forms of participation within a service. Poor practitioner skills and knowledge will obviously impact on satisfaction with the service. However, fear of judgement remains a substantial barrier for a community that is often multiply disadvantaged, criminalised and stigmatised. A meaningful advocacy intervention can be to offer sensitivity training to staff in local services, allowing them to meet people who use drugs away from the pressures of the clinical setting. This can be particularly useful in health and social care settings new to working with people who use drugs, in this case most commonly, TB services. Given that many drug user groups have very restricted funding, delivering sensitivity or skills training may provide a mechanism for services to acknowledge the contribution of its clients and drug user organisations. This income generation opportunity could provide funding for the core costs of a drug user group or it could fund a social marketing or peer support initiative.

Over time, relationships between service providers and clients can flourish and mechanisms for ongoing participation in service management and clinical meetings can be developed. This can help enhance

the empathic and community literacy of the service, its staff and management. This can lead to the development and delivery of more effectively targeted and focused services that are both more accessible and more able to retain clients, all of which impacts on the clinical effectiveness of the service. Where drug user advocates already have a voice in management or clinical meetings, or other types of interaction with the leadership of a service, these lines of engagement can be used to raise TB advocacy priorities.

The environment in which services are delivered affects the staff and clients of a service, necessitating a collective investment in infection control standards in staff practice, the promotion of good cough hygiene and the proper ventilation of spaces within which people may be congregating. Environment reviews can be used as a tool to audit services and create a dialogue about infection control standards in and around the service setting. Drug user groups should also consider such environmental reviews in their own drop in services, peer meetings or workspaces.

Environmental reviews may be a particular challenge in prisons, which may indicate the need for policy level advocacy to secure the necessary enabling environment and resources to secure structural changes to the building or reduce overcrowding. However, in other cases, simply opening windows and improving ventilation may contribute to a healthier environment.

Advocacy priorities

- Build integration between TB, HIV and drugs services as a key to effective treatment outcomes and treatment compliance.
- Track care pathways and identify referral arrangements between services to help identify if standards have been set and whether these are being monitored and met.
- Test the capacity of drug services to screen, test and refer people who use drugs for TB. This can be easily tested through the review of service protocols, working agreements or Memorandum of Understanding between different services, and individual client experiences of being engaged, or not, around risk and healthcare needs.
- Develop clear referral pathways or integrated service provision around the delivery of Isoniazid preventive therapy (IPT) to those identified as NOT having active TB.
- Promote good cough hygiene among clients and staff and encourage staff actively to employ good clinical hygiene practice.

Stigma and discrimination has been shown to adversely affect service uptake and retention and therefore treatment outcomes. Sensitivity training for staff and individual advocacy when clients are treated judgmentally or discriminated against can be effective tools for challenging stigma and discrimination.

When these approaches are not effective, then drug user advocates may take legal action questioning the denial of a client's right to health or they could take their advocacy agenda to the media and/or the local community. This could be achieved through a campaign built around demonstrations, a petition or a stunt to draw attention to an issue. Examples of such stunts or actions can be found on the Hungarian Civil Liberties Union website.

Advocacy is often initially triggered by individual experiences of services of varying quality and accessibility. This active engagement in services speaks to the merits of engaging active drug user groups, as their members' interaction with service is often a valuable and insightful quality management tool, particularly for the commissioners, planners, and managers of services. Participation and complaints procedures can provide a point of engagement for drug user advocates when they, or one of their peers, have a negative service experience. Advocating around individual client experiences can help drive up quality across a service and help identify poor quality practice and poorly performing practitioners.

HIV activists have promoted a model of treatment literacy among people living with HIV (PLHIV). This model encourages PLHIV to become expert patients, understanding their medications, drug interactions and therefore being better able to manage the self-administration of their medications on a day-to-day basis.

Advocacy priorities

- Support the ability of people who use drugs, and particularly those who actively use or inject drugs, to access TB screening, testing, Isoniazid preventive therapy (IPT).
- Promote appropriate referral and case management between TB, HIV and drug services.
- Challenge judgmental or discriminatory staff behaviour to individual drug users or discriminatory policies and practices within a clinic, which limit equal access to the right to health for people who use drugs.
- Review the quality of services through questionnaires designed with the participation of services but delivered by drug user advocates or drug user groups.
- Foster joint working between services at a policy and management level through flushing out service weaknesses and barriers to access through advocating for individual clients.
- Develop models of peer support around compliance with TB treatment to increase access and retention in treatment. This is a useful focus for the work of drug user groups in partnership with specialist TB services.

HARM REDUCTION SHOULD BE THE CENTREPIECE OF AN

EFFECTIVE RESPONSE

TO THE NEEDS OF PEOPLE WHO ACTIVELY USE DRUGS

5 DEVELOPING EFFECTIVE ADVOCACY RESPONSES

5.1 Using existing expertise

Drug user activists are often already experienced in advocacy, whether around harm reduction, drug treatment - in particular OST, access to HIV services or wider issues of social inclusion and justice or advocacy with criminal justice systems.

Drug user organisations often have established expertise in advocacy with specialist drug treatment services and often with a range of other parts of the health care systems that provide services to people who use drugs.

Networks of people living with HIV often have established experience advocating for quality and participative HIV services and advocating to ensure access to essential medicines.

Using existing skills and expertise can result in efficient and effective advocacy even when TB may be a new focus of work for activists.

It is important that individual advocates and relevant organisations work together to develop advocacy networks. Networks bring a number of benefits including:

- Keeping you up to date about what is going on.
- Providing a readymade audience for your ideas.
- Providing support for your actions.
- Providing access to varied and multiple resources/skills.
- Pooling of limited resources for the common goal.
- The power of numbers and achievement of things that single organisations or individuals cannot achieve.
- Achieving things that single organisations or individuals cannot, through the power of numbers.
- Forming a core group for action and to attract other networks.
- Expanding the base of support.

**USING EXISTING
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This section highlights the practical tasks involved in the advocacy process. They are:

- 5.3.1 Researching and data collection
- 5.3.2 Clarifying advocacy goals/aims
- 5.3.3 Defining objectives
- 5.3.4 Identifying and understanding the target audience
- 5.3.5 Building support
- 5.3.6 Developing clear messages
- 5.3.7 Identifying channels of communication
- 5.3.8 Using social marketing
- 5.3.9 Fundraising
- 5.3.10 Implementing
- 5.3.11 Monitoring and evaluating

The tasks are not listed in a strict chronological order. For example, ‘Research and data collection’ and ‘Monitoring’ are important tasks that need to be conducted throughout the advocacy process and ‘Evaluation’ needs to be planned and to start from the beginning of the advocacy initiative or campaign.

5.3.1 **Researching and data collection**

Drug user advocates need to have a good understanding of the research surrounding TB. This can be achieved through direct reading and partnership working with academic or professional workers who are prepared to communicate on an individual level and open up their development meetings.

Research can help advocates understand and accurately represent the needs, priorities, and interests of their constituencies. Knowing the communities and stakeholders involved means finding out what people think about TB issues and how they are personally and professionally affected by the policies governing the provision of TB services.

Qualitative data collection methods can include surveys, questionnaires, focus groups, interviews and observation. Surveys and questionnaires can also be used to collect quantitative data.

Consulting the community through surveys, consultation events and advocacy surgeries allows advocates to evidence the needs of the community they are representing. Access to data about community needs helps make demands more realistic and representative. Furthermore, grounding advocacy messages in data increases the professional standing and credibility of the advocacy network in the eyes of decision makers and other influential persons.

Types of data collection systems:

Qualitative	Quantitative
Surveys	Surveys
Questionnaires	Questionnaires
Focus Groups	Baseline Studies
Interviews	
Observation	

An advocacy issue is the overall problem or situation that a group or individual seeks to focus on, address and change. In this handbook we have also used the term 'advocacy priorities' in a similar manner. Advocacy 'goals' or 'aims' are general statements about what needs to be achieved and/or changed to effectively address particular issues.

In broad terms, the goal of this Advocacy Handbook is to ensure that plans, funding and responses are put in place that address the needs, concerning TB, of people who use drugs.

Examples of specific advocacy goals/aims include:

- Defending the right of people who inject, or otherwise actively use drugs to access TB prevention, treatment and care and for active drug use or for continued injecting not to be used as a barrier for entry into TB services.
- Encouraging the provision of OST such as methadone and buprenorphine for people dependent on opiates as this provides opportunities to move away from risk behaviour and risk situations, and can support adherence to TB and HIV treatment.
- Integration between TB, HIV and drugs services as a key to effective treatment outcomes and treatment compliance.
- Promotion of good cough hygiene among clients and staff, and staff actively employing good clinical hygiene practice.
- Increasing the ability for people who use drugs, and particularly those who actively use or inject drugs, to access TB screening, testing, Isoniazid preventive therapy (IPT) and second stage treatments
- Fostering joint working between services at a policy and management level by flushing out service weaknesses and barriers to access through advocating for individual clients.
- Developing models of peer support around compliance with TB treatment to increase access and retention in treatment.

**MANY DRUG USER
ADVOCATES
HAVE ALREADY
ESTABLISHED
WORKING
RELATIONSHIPS
WITH MOST
SERVICES**

An advocacy objective is a short-term target - one to two years maximum - that contributes towards achieving a broader, longer-term goal or aim. Objectives are more precise than goals or aims and describe the specific changes that need to happen to achieve goals or aims.

Objectives should be Specific, Measurable, Agreed-upon, Realistic and Time-based (SMART).

Specific

The objective needs to be well defined and clear to anyone who has a basic knowledge of the project or subject.

Measurable

The objective needs to be specific and measurable so that you will know whether and when it has been achieved. What indicators, following from the objective, will show whether or not you have been successful?

Agreed upon

The objective needs to be agreed by all the advocacy partners.

Realistic

The objective needs to be achievable within the available resources, knowledge and timescale.

Time-based

When will the objective be achieved by?
Make sure there is sufficient time to achieve the objective.

Using the SMART approach will help advocacy initiatives to be realistic and effective. Often individual advocates or networks will work on two or more objectives simultaneously in their efforts to achieve a single goal.

Defining clear advocacy issues, goals and objectives, and identifying specific indicators that can be measured, provides the foundation for an effective advocacy campaign. An example is given below. If this is not done, advocacy campaigns will be in danger of losing focus.

Building more effective specialist services:

Advocacy Issues	Goals	Objectives	Indicators
Stigma & discrimination (S&D) from staff.	To reduce levels of S&D among staff and improve consumer experience.	Deliver sensitivity training to staff about working with people who use drugs.	Reduction in complaints. Improved working relationships between staff and clients.
Increase integration between TB, HIV and OST services.	To improve working relationships between services to enhance effectiveness and consumer experience of using multiple related services.	Deploy or develop opportunities for meaningful participation in the planning systems for HIV, TB and OST. Advocate for an integrated service model and promote consumer satisfaction surveys as a means of gathering intelligence from consumer population.	Advocates have places at table of key HIV, TB and OST planning forums. Advocates have points of influence on those engaged in policy forums. Questions are raised about service integration. Consumer satisfaction survey(s) undertaken testing consumer experience of care pathway.
Improve treatment access.	To ensure that people who use drugs have fair and equitable access to the range of treatments promoted in global guidelines and based on availability within any given country.	Advocate where people who inject drugs face barriers to TB or HIV treatment access. Advocate for access to OST services as a core component of effective TB and HIV treatment. Advocate for reasonable access to medicines for OST, HIV and TB without political interference or barriers from pharmaceutical companies.	Number of complaints submitted. Changes in clinical policy following advocacy intervention or interventions. Advocacy activities that bring attention to positive effects of OST on health and wellbeing. OST, HIV and TB drugs accepted as essential medicines in more countries or home country.

Identifying and understanding the target audience

To understand your target audience, it is important to consider both those individuals and groups that support the advocacy initiative and those in opposition. It is also important to be aware of those who are currently neutral on the issue but could be engaged to offer support.

Advocacy campaigns should target both those who are in direct control of a decision – the Primary Target Audience - and those who are able to influence the decision makers – the Secondary Target Audience.

For example, if the Advocacy objective was to get a District Authority to produce a TB strategy for people who use drugs:

- the Primary Target Audience might include the District Authority, the National AIDS Control Programme (NACP) and the local policy committee
- the Secondary Target Audience might include donors, local professional bodies, NGOs, PLHIV and Drug User Organisations, business groups, religious and traditional leaders, the media, family and community groups and academic bodies.

In order to target your audience effectively, you need to get to know them well. This may involve more formal market research and/or networking with friendly members of the target audience or with those who have a long-standing relationship with the target audience.

Building support

The first focus of building support should be among your core constituency. This can be achieved by consulting people directly affected by an issue, through informal peer networking, a survey of peer views and/or a consultation meeting. This helps frame and focus the advocacy strategy while also building the peer network supporting the advocacy campaign.

Further support can be generated by reaching out to other sympathetic networks, which can broaden the base of support and bring additional resources, expertise and contacts to an advocacy campaign. For example, this could involve people who use drugs reaching out to PLHIV and to progressive family and harm reduction networks.

5.3.6 Developing clear messages

Messages will often be specifically framed for different audiences so how you communicate your message to a PLHIV network may often need to be different from how you communicate your message to the Minister of Health. However, all advocacy messages need to be focused, tested and action-orientated.

Importantly, advocacy messages should be evidence-based. This is important to both the credibility and effectiveness of the advocacy message.

Advocacy Messages

Focused

Ideally focus on one advocacy message but if that is not possible then two or three at most. It is better to leave people with a clear idea of one message than to confuse or overwhelm them with too many.

Tested

Messages should always be pre-tested with representatives of the target audience to ensure that the message intended will be the one received.

Action Orientated

Messaging should advocate with clear information and sound logic. It should clearly describe the action the target audience is being asked to take.

5.3.7 Identifying channels of communication

When selecting channels of communication for your advocacy messages, it is essential to know your target audience and to understand how they interact with various media.

When planning how to communicate your advocacy message it is useful to think about the following questions:

- Who are you targeting?
- Why are you targeting these people?
- What do you want them to do or what action do you want them to take?
- Which media do they engage with?
- How can you best engage them?
- When is the best time to engage them?

Answering these questions will help you to select the most appropriate form of communication and the best strategy to reach your target audiences.

Using a combination of community, interpersonal and mass media channels of communication takes advantage of the strengths of each and may provide maximum exposure for your message. Carefully assessing your target audience, your message and your available media will help you decide which channels to choose.

Channels of communication may include:

- Face-to-face meetings
- High level briefings
- Public rallies
- Fact sheets
- Policy forums
- Posters and flyers in public places
- Petitions
- Public debates
- Press releases
- Press conferences
- Contests to design posters, slogans

Using social marketing

Social marketing is a useful framework that involves the adaptation of commercial marketing approaches to support behaviour change programmes among a target audience. The goal is to influence the behaviour of a target audience in order to improve their physical and mental well-being and the community of which they are part.

The process is consumer or peer driven and fits well with peer-based advocacy. By focusing clearly and systematically on a target audience, social marketers are able to identify and tailor responses to meet the needs of the target audience. Social marketing is most successful when it is monitored and evaluated to ensure that the programmes are being reviewed, tailored and adjusted. This process is illustrated in the Social Marketing Wheel below:



Fundraising

The ability to mobilise resources is an important skill for advocacy work. Having access to money and resources opens up and extends the range of advocacy options. This gives members the freedom to try new, creative and sometimes higher-risk activities than would be possible with limited funds. But no matter how much an advocacy campaign benefits from financial resources, it is often possible to launch a successful campaign with the resources and energy of network members alone.

5.3.10 Implementing

Implementation is likely to be more effective if tasks involved are clear, the resources needed are identified, a particular person is made responsible for each task and a timescale is set for the achievement of each task. The table below gives an example.

Advocacy objective:

By (insert year), district authority to put in place a programme to train harm reduction and drug treatment service staff about TB diagnosis and referral

Activity	Needed Resources	Responsible Person	Timeframe
Prepare fact sheet on TB and its impact on people who use drugs	Background documents (e.g. WHO documents)	Policy officer	2 weeks
Liaise with harm reduction and drug treatment agencies	Service resources and policies	Lead drug treatment advocate	4 weeks
Meet with district authority to discuss gap in service	Best practice models of TB service delivery	Chair of drug user group	2 months
Develop TB training for drugs and HIV staff	TB Advocacy Handbook	Training Officer	6 months

5.3.11 Monitoring and evaluating

Sound monitoring and evaluation is important to track progress and successes, build credibility with donors, make adjustments to strategy and motivate members to sustain momentum. If advocacy brings about a desired change, advocates will want to demonstrate a clear connection between their objectives and activities and the outcomes.

Monitoring is the process of routinely gathering information on all aspects of an advocacy campaign and using the information for ongoing decision-making. Monitoring information can help to:

- demonstrate innovative and effective strategies.
- identify difficulties as they emerge so they can be addressed.
- generate financial and political support for advocacy activities.
- market the campaign.

Evaluation involves a systematic review of the performance of the advocacy campaign. Its purpose is to:

- draw lessons from experience in order to improve the quality of advocacy campaigns.
- improve the design of future campaigns.
- demonstrate the campaign's merits to supporters, policymakers, donors, members etc.

We need to monitor activities and evaluate results.

APPENDIX

7

Partner Organisations

The World Health Organization (WHO) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) are working in partnership to combat TB and particularly to address the relationship between TB and HIV.

HIT is an organisation that provides training, consultation and information on drug-related issues. HIT aims to reduce the harm caused by drug use. HIT was commissioned by WHO and UNAIDS to develop, consult on and promote this handbook.

INPUD is a global network of people who use drugs. INPUD promotes the health, and defends the rights, of people actively using drugs around the world. INPUD's role in this partnership has been to facilitate and support the engagement with drug user advocates and organisations and to support the roll out of this handbook through its networks. This will further be achieved through INPUD's partnerships with GNP+ (the Global Network of People Living with HIV) and the International Treatment Preparedness Coalition (ITPC).

Given the prevalence of TB among people who use drugs, WHO and UNAIDS commissioned three TB Advocacy Workshops for people who use drugs. The first of these was run in Bangkok in November 2009 with the Asian Network of People who Use Drugs (ANPUD). A second workshop was run in June 2010 linked to the International Harm Reduction Conference in Liverpool. Finally, a third event was run in Vienna in July 2010, alongside the International AIDS Conference targeted at people from Eastern Europe and Central Asia.

The Liverpool event provided the opportunity for an important discourse between experienced global drug user advocates and staff from WHO and UNAIDS. This event was commissioned through HIT and delivered in partnership with INPUD. One of the calls from the meeting was for an advocacy resource that would make accessible existing technical advice in guidance documents to support drug user advocates so they can bring their advocacy skills and networks to bear upon TB advocacy. The report from this event is one of the source documents for this handbook and informs more specialist issues and strategies recommended in this resource.

In planning and researching this handbook it became clear that the existing WHO TB / HIV advocacy resource 'Networking for Policy Change: TB / HIV Participants Guide' was a valuable source document.

In addition, the recommendations of the WHO's Policy Guidelines for Collaborative TB and HIV Services for Injecting and Other Drug Users underpin the advocacy agenda. Drug user advocates are encouraged to read, or at least have access to, the WHO Policy Guidelines as a reference document.

A consultant was engaged to write this handbook and to manage a participative development process that engaged both experts in TB and HIV from WHO headquarters and the European Regional Office, UNAIDS and drug user, TB and HIV activists. After an initial expert review, a draft of this handbook was subjected to a peer review by drug user activists and specialist professionals during and after a workshop at the International Harm Reduction Conference in Beirut in 2011. This event also tested elements of a capacity building course that can be used to support activists to roll out this handbook. The document was reviewed by experts in TB and HIV from WHO Regional Office for Europe HIV/AIDS, STIs and viral hepatitis programme, WHO HQ Stop TB Department and HIV/AIDS Departments, HIT and INPUD.

This handbook was made possible by financial contributions from the WHO HQ Stop TB Department, WHO Regional Office for Europe HIV/AIDS, STIs and Viral Hepatitis Programme, UNAIDS and the Stop TB Partnership.

Notes
