



**ACTIVE FINDING
OF MISSING PEOPLE
WITH TB AMONG RISK
GROUPS IN COUNTRIES
OF THE EECA REGION –
THE CONTRIBUTION
OF CIVIL SOCIETY
ORGANIZATIONS**

**EVALUATION OF THE ROLE OF CIVIL SOCIETY ORGANIZATIONS IN ACTIVE FINDING OF
MISSING PEOPLE WITH TUBERCULOSIS AMONG RISK GROUPS IN THE SITES OF SERVICE
PROVISION AND AMONG CONTACTS**

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INTRODUCTION

In March 2018 TB Europe Coalition carried out documentation of practices of active finding of missing people with TB among risk groups in Ukraine based on the programs of the Way Home foundation in Odessa, one of the most experienced Ukrainian civil society organizations (CSOs).

In September 2019, the report was complemented by a review of the experience gained by the Plus Center Public Foundation working with key populations in the city of Osh in Kyrgyzstan, as well as a description of the cross-border cooperation model involving diaspora organizations for early TB detection among migrants.

The report includes two approaches recommended by the World Health Organization which are implemented among representatives of risk groups in the city of Odessa:

1. Active finding of missing people with tuberculosis among risk groups at the service provision points;
2. Finding missing people with tuberculosis among close contacts of the person infected with TB.

The practice of finding people with TB among homeless people, migrants, internally displaced persons, people who use drugs, and sex workers has been analyzed based on the interviews with the program beneficiaries. Based on this analysis, recommendations for the Eastern Europe and Central Asia (EECA) are given in the current evaluation.

This report is not a complete description of all the existing practices for early TB detection among most-at-risk groups in the EECA region, but only an illustration of some effective approaches recommended by the World Health Organization in relation to key populations.

OBJECTIVES OF THE EVALUATION

- Review the experience associated with active TB detection among most-at-risk groups gained by CSOs;
- Investigate civil society contribution into finding missing people with TB and develop recommendations for the EECA region;
- Provide rationale for the following:
 - development of priorities for national TB programs and state social contracting of civil society organizations working in TB care;
 - conducting additional in-depth operational research among population groups at high risk of TB, as well as among population groups with confirmed multiple barriers to TB treatment;
- Compliment the report on Communities, Rights, and Gender TB Tools Assessments released by Alliance for Public Health in 2018¹ with NGO practices, and cases of program beneficiaries, thus contributing to advocacy of a stronger role of civil society organizations in the national TB programs.

RATIONALE

More than one third of the 10 million people who are infected with TB every year are neither diagnosed nor enrolled into care and consequently do not commence treatment². Many of those who do receive care start their treatment course much later, for the most part due to various barriers in accessing services. Many of those are people from risk groups, including homeless people, drug users, migrant workers, miners, refugees, and people living with HIV³. According to 2015 statistics, approximately 60% of estimated TB cases among people living with HIV worldwide were not covered with treatment. This inability to cover risk groups with diagnostics and treatment causes the further spread of TB.

People and communities facing the greatest risk of TB acquisition often have the most limited access to health care and treatment. This worsens negative consequences from the perspective of epidemiology as well as from the standpoint of financial expenditures for the national economy.

The key populations in terms of HIV and TB are those groups of people who are most at risk of exposure to these two infections, which is compounded by criminalization or limited access to services. A significant proportion of the estimated 4.2 million people with TB who are not identified across the globe are likely to be concentrated in key populations, as they are the last to be detected in routine primary care settings. Due to multiple social, economic, legal, and cultural barriers, key populations living with TB often lack access to health services and social assistance for the general population, therefore benefitting most from targeted civil society programs.

According to the WHO, estimated TB incidence in Ukraine in 2016 was at 87 per 100 000 population⁴ almost three times higher than the target indicator established by the Global Plan "Stop TB". About 22.2% of new TB cases per year are left unattended by the Ukrainian health care system, which causes further spread of the disease among the general population⁵.

¹ Communities, Rights and Gender TB Tools Assessments in Ukraine. Report of the Projects Results. Kyiv, 2018.

² Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations. World Health Organization 2014, reprinted in 2016 with changes. <http://www.who.int/hiv/pub/guidelines/keypopulations/en/>

³ STOP TB Field Guide. TB Case Finding with Key Populations. STOP TB Partnership. 2018. Geneva.

⁴ Global TB Report. 2017 https://www.who.int/tb/publications/global_report/MainText_13Nov2017.pdf

⁵ Global TB Report. 2017 https://www.who.int/tb/publications/global_report/MainText_13Nov2017.pdf

According to the WHO “End TB Strategy”, TB prevalence should be reduced by 95% by 2035⁶. The number of TB deaths should also be reduced by 95% compared with figures from 2015. These objectives will only be achievable if significant efforts are made in terms of finding people with TB among risk groups. In accordance with the above WHO strategy, active TB diagnostics should include drug-susceptibility testing and systematic screening of contacts for risk groups.

Despite the fact that the WHO European Region shows the world's fastest decline in the number of first-time TB diagnoses (-4.7% per year) and deaths from TB (-10.2% per year), the situation with MDR-TB incidence remains alarming (+5.8% per year) while the number of new TB/HIV co-infections continues to grow (+13.8% per year). The countries of the Eastern Europe and Central Asia bear a heavier burden in terms of all key indicators compared to Central and Western Europe. Azerbaijan, Belarus, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Ukraine, and Uzbekistan are among the 30 countries with the highest burden of drug-resistant tuberculosis in the world.

In Kyrgyzstan, the incidence of tuberculosis is the highest in the WHO European Region at 144 cases per 100,000 people.

Due to social and economic reasons, as well as the high mobility of the population in the Odessa region, TB prevalence in this region remains the highest in Ukraine (130.6 per 100,000 people), 1.5 times higher than the average rate in Ukraine (87 per 100,000 people). This level is comparable with TB prevalence in such countries as Vietnam (129 per 100,000 people) and Malawi (131 per 100,000 people)⁷.

After consultations with TB experts, we decided to focus our analysis on the programs of the Way Home charitable foundation in Odessa, Ukraine, and Plus Center Public Foundation in the city of Osh, the Republic of Kyrgyzstan and the pilot project of the International Organization for Migration in Tajikistan and the Russian Federation as examples.

METHODOLOGY

This evaluation is based on the analysis of 17 interviews conducted in March 2019, including six interviews with TB experts and public health experts from three national civil society organizations, six interviews with program coordinators, social workers, medical doctors and a director of health services (all taking part in the program for active finding of missing people with TB carried out by Way Home), and five interviews with the program beneficiaries – representatives of risk groups (two homeless people, one international migrant, one commercial sex-worker, one injecting drug user). The study fieldwork consisted of a two-day observation of outreach activities of social workers participating in the program for active finding of missing people with TB among risk groups. Data received from the interviews and participant observation were analyzed in order to present expertise and opinions of the participants and to develop recommendations for organization of programs aimed at active finding of missing people with TB in EECA countries.

Interviews with the experts from civil society organizations were conducted via Skype in Russian and English. Public health professionals and social workers were interviewed personally in Odessa in Russian. Prior to the beginning of the interviews the participants gave their written consent to voice recording.

⁶WHO the End TB Strategy: objectives and indicators <https://www.who.int/tb/strategy/end-tb/ru/>

⁷Global TB Report. 2017 https://www.who.int/tb/publications/global_report/MainText_13Nov2017.pdf

PROGRAMS FOR ACTIVE FINDING OF MISSING PEOPLE WITH TB AMONG RISK GROUPS

In the Eastern Europe and Central Asia region, the programs for active TB detection among key and most-at-risk populations were originally launched with the support of international donors, such as the Global Fund to Fight AIDS, Tuberculosis and Malaria and the United States Agency for International Development (USAID).

In Ukraine the program for active finding of people with TB among risk groups has been carried out since 2014 by the ICF Alliance for Public Health in 27 regions of the country with the support of the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria. During five years of the program implementation coverage of risk groups with screening interviews was increased 6-7 times which allowed to increase the TB detection rate by 46% among risk groups compared with the baseline from 2014. Out of those detected, 93% have started treatment.

Currently Way Home is implementing this program in the Odessa region among injecting drug users, commercial sex-workers and homeless people. The project team consists of a social worker, doctor, nurse, and a coordinator. The project for active finding of people with TB is carried out with the support of and in cooperation with the Odessa Regional Center of Social Diseases.

«When we started to integrate the services [HIV and TB] all of them [civil society organizations] took up this idea. Practically every CSO carries out at least a small TB project. They [CSOs] skillfully use their expertise. It is extremely difficult to find a really professional organization in TB area. All of them used to be focused on HIV/AIDS and nobody cared about TB but our organizations are flexible and they quickly refocused their activities». Svetlana Esipenko, Director of the Odessa Regional Center of Social Diseases.

1. ACTIVE FINDING OF MISSING PEOPLE WITH TB AMONG HOMELESS PEOPLE AND INTERNALLY DISPLACED PEOPLE IN DIFFICULT LIFE SITUATIONS

(based on the example from program activities of CF The Way Home, Odessa, Ukraine)

Every day a social worker from Way Home conducts outreach in areas where homeless people are known to gather (usually this includes train/bus stations, city markets and other public places). The CSO gained access to the target groups of homeless people due to close cooperation with charities which provide services to homeless people such as provision of food, overnight shelters, etc. The social worker conducts an on-sight screening of homeless people, interviewing them with the help of a standard TB screening questionnaire⁸. If three answers are positive out of eight questions and the client has a "cough" symptom, they will be referred to the Odessa Regional Center of Social Diseases. The client is given a special service ticket. In case of necessity or upon the client's request, they will also be accompanied to health care facilities. If TB is confirmed, the client will be prescribed a free TB treatment course.

Over six months in 2018, 2471 homeless people were screened by means of the aforementioned questionnaire, including 627 people who were referred to TB diagnostics. TB was diagnosed in 41 people and 40 people commenced treatment.

⁸ Early detection of TB among risk groups. International HIV/AIDS Alliance in Ukraine. Kiev 2014, p. 23. http://aph.org.ua/wp-content/uploads/2016/08/modulTB_09_rev_2.pdf

A Way Home multidisciplinary team, consisting of a social worker and a nurse, carries out outreach visits with the purpose of collecting sputum in those clients with a “cough” symptom who were not motivated to be tested. It is an important measure as it brings the TB diagnostic services significantly closer to the beneficiaries, minimizing disruption and resistance. If TB is suspected, the social worker ensures that the client searches options to organize follow-up testing and subsequent treatment.

One of the challenges inherent in this work is the fact that most of homeless people do not have a mobile phone, which complicates communication. They very seldom reach to the Odessa Regional Center of Social Diseases for their test results.

Photo 1: The coordinator of the program for active finding of missing people with TB is preparing a test-tube for sputum samples from representatives of risk groups during an outreach visit to a remote city district of Odessa.



Contribution of the program:

Proactivity.

Places where homeless people can be given food are visited on a regular basis by a social worker wearing a special badge. Now many homeless people recognize this badge, then approach a social worker and ask questions. The service ticket they are given is bright yellow and is thus also easily recognized by homeless people. TB screening and conversations with homeless people are all voluntary. When the screening is over, a social worker accompanies people with positive screening results to the Centre of Social Diseases for testing.

It is free and documents are not required.

Another advantage of this program is the free services provided by civil society organizations, which require neither passport nor housing registration. The services provided by the Odessa Regional Center of Social Diseases are also free of charge and it is very important for the clients is that documents are not required to receive services – it's sufficient to show a referral voucher from a civil society organization. Clients can receive services at the Center of Social Diseases from a CSO or a family doctor. If clients come by themselves, they are assisted by social workers from Way Home who have an small office right in TB clinic.

If a client is diagnosed with TB, they will be hospitalized for intense treatment. If a client refuses hospitalization, they will undergo ambulatory treatment. Service accessing is in compliance with basic WHO recommendations regarding evidence-based access to TB testing and treatment among risk groups. Considering the fact that a significant number of homeless people came to Odessa from other regions of Ukraine and sometimes from other countries, such as Moldova or Transnistria. That is why the lack of requirement to have proper documents and health insurance is a crucial advantage of the program.

Personal story of a male, irregular migrant

Andrey is a construction worker from Russia who came to Odessa 12 years ago. He has neither citizenship of Ukraine nor housing registration in Odessa. He is cohabiting with a woman and he does not have any access to general health care.

"Once I came home after work with high temperature (39°C). I was sweating heavily. This condition lasted for several days. At first, I thought that I had caught a cold at the seaside. I was in bed for several days but I could not get rid of the fever. I was drinking a lot of water, but I could not eat. My female friend brought me here [to the office of Way Home at the Odessa Regional Center of Social Diseases]. I was at the hospital for three months. Now I'm taking a supporting therapy. If I hadn't met those people who explained everything to me and arranged everything, I would have had nobody to ask for help. But they treated me kindheartedly. Probably I would have been dead by now but due to their help I managed to survive".

Direct TB services, avoiding primary care.

Ukraine is currently undergoing health care reform. Within the framework of this reform, the responsibility for finding people suspected to have TB is normally held at primary care level. A family doctor conducts TB screening and if TB is suspected, the patient is referred to the Odessa Regional Center for Social Diseases. However, for representatives of risk groups, this type of referral system is not efficient. According to the long-term experience of social workers whom we interviewed, homeless people practically never visit family doctors as one needs medical insurance that many homeless people do not have. Another important barrier is the level of stigmatization in the primary care towards risk groups. Currently in the framework of the existing health care system CSOs are the only alternative. That is why civil society organizations play an important role in active finding and following up representatives of risk groups to testing services.

Personal story of a homeless man

"I'm homeless. I was born in Odessa region and grew up in an orphanage. After serving in the army I got married. Soon after that I got divorced. I lived in Russia for several years, then I came back to Odessa and a few months later I lost my passport, that is why I ended up in the street. I met some fellows with whom I worked together. We were gathering bottles. Social workers from Way Home found me and brought me here. I was diagnosed with TB. Now I'm taking treatment in the hospital. Had I had my home I would have taken treatment there but I'm homeless. This is a list of medications [to treat side effects] but I have no money at the moment and I do not have any relatives that is why the Foundation is helping me with medications".

A homeless man, 40 y.o.

Integration and Sustainability.

Due to the long-term cooperation between CSOs and the Odessa Regional Center for Social Diseases, an approach based on prioritization of risk groups in testing and linkage to treatment and approaches based on a person's needs have been adopted by the Center as a sustainable standard of performance. The Head of the Center for Social Diseases is promoting the introduction of the program of state social contracting in TB sphere because she appreciates the high work efficiency of CSOs.

"These programs are targeting risk groups which are more susceptible to tuberculosis due to lifestyle and challenges. In their case they have more trust since quite often they do not have the chance to undergo medical examination or to address for help. Quite often they are deprived from access to basic services, and beyond that, they are stigmatized. Or due to life challenges they have other things to do and they would respond only in case of active interaction. Besides that, such clients bring their peers who also need such help".

Anna Muzyka, TB doctor from the Odessa Regional Centre of Social Diseases.

2. ACTIVE FINDING OF MISSING PEOPLE WITH TB AMONG INJECTING DRUG USERS AND COMMERCIAL SEX WORKERS

(based on the example from program activities of CF The Way Home, Odessa, Ukraine)

The program for active TB detection among sex workers is being implemented in partnership with the harm reduction outreach program for preventing HIV among people who inject drugs. The program of active finding of missing people with TB among injecting drug users and commercial sex workers originated from the harm reduction outreach program aimed at HIV prevention. HIV services were complemented with a TB screening program and follow-up in the Odessa Regional Center of Social Diseases. A social bus route was determined in accordance with the location area of the program's clients. From time to time this route is changed depending on the changes of the location area, the details of which were clarified during an interview.

In 2018, Odessa region had 13,649 sex worker and injection drug users who underwent TB screening. During that period, of 289 injecting drug users and commercial sex workers who were given follow up TB tests in the clinic, 29 of them had a confirmed TB diagnosis.

Contribution of the program:

Individual approach and second chances.

Case management, personal attention, and regular contact with the person are all critically important drivers, which are offered by CSOs and which are not always possible in the state health care facilities.

Referrals for further examination after the detection of a positive TB results at screenings often cause problems for social workers working with representatives of risk groups, particularly as it concerns homeless people.

«A large number of people come to us on their own to be screened and to do an HIV test. However, if after screening they need to go through medical examination, I have to accompany them to a dispensary and the client would say: "Well, I'm busy today, let's meet tomorrow". - it's a typical behavior.»

Female social worker from the program for active finding of missing people with TB among injecting drug users and sex worker at the Way Home foundation.

"Due to particular life challenges they believe that nobody cares about them and that their lives are insignificant. It might seem that that or clients have a free life but in fact they have no possibility to find out their doctor's schedule, an address of the clinic and to realize that the services are free that they could address for help. Many of them have low awareness. That's why it is important to have such civil society organizations which bring people for examination".

Anna Muzyka, TB doctor, Odessa Regional Center for Social Diseases.

Attention and care create a responsible attitude to health

When a social worker from a CSO pays regular outreach visits it's possible that a person who at first refused from examination would agree to do it after the second or third meeting with social worker whom he already knows. Having made certain that the value of their health and life is important to someone else, a client might agree to cooperate. In the case of social diseases, especially concerning TB which is an air-borne disease, it's critically important to engage as many people as possible to the continuum of services.

Focus on commercial sex-workers

According to the interviewed female client (she is a client of the prevention program for commercial sex-workers), many female sex-workers do not contact civil society organizations fearing that they will lose their jobs since HIV or TB diagnosis will inevitably cause a job loss.

«It's commonly believed [among female sex-workers] that such organizations are intended for poor people and that only homeless people address them»

- shared a client of the Way Home foundation.

Considering structural barriers and the particular stigmatization of sex-workers, one of the possible solutions could be capacity building on health issues among activists representing the community of sex-workers.

It is necessary to consider engaging the sex-worker community with the aim of creating more favorable conditions for their empowerment and capability enhancement. In case of sustainable support, the community of sex workers might develop services which would consider the needs of beneficiaries to the fullest extent and create prerequisites for overcoming stigma⁹. Community-based service provision for sex-workers is actively practiced in many countries of Central and Western Europe.

Personal story of a female sex-worker

When I contracted tuberculosis, I stopped working in my sphere [sex-work] for some time. I feared that I would transmit this infection to somebody, especially considering that I work with "important people". They might find you at your working place and then nobody will ever remember who you are. It was scary. I have HIV and I always take precautions but in case of TB it is not possible. I probably contracted TB from my husband.

«When he was ill, I would constantly be with him in the hospital ward taking care of him. I was confident that I would most likely get ill as well. And I did get ill. At the moment both of us are taking the second treatment stage [outpatient treatment]. Government only provides the main medications for TB treatment. We're having serious kidney problems that's why we have to buy albumin which costs 1200 Ukrainian Hrivnas [45 USD per month]. We're constantly lacking financial means. "Way Home" used to help us when we could not buy medications ourselves. They used to help us in receiving them.»

Female sex-worker, 25, a mother of 3 children.

3. ACTIVE TB DETECTION AMONG PEOPLE WHO USE DRUGS

(based on the example from program activities of the Plus Center Public Foundation, Osh, Kyrgyzstan)

The Plus Center Public Foundation set up and put in place efforts for early TB detection among people who use drugs through the USAID Dialogue on HIV and Tuberculosis Project. The project lasted from 2011 through 2016 and, although it is no longer active, it has laid the foundation for TB prevention among key populations, particularly among people who inject drugs and people living with HIV. The foundation's staff was trained in TB screening and client support skills during the treatment period. Now that the project has been completed, they are continuing to use their knowledge and skills for training new staff.

The foundation has a high status among the TB service personnel. Its employees are sometimes invited by physicians to attend medical case conferences for individual patients and sharing their expertise on adherence to treatment or medical and social support.

⁹ Sex Worker Implementation Tool (SWIT), Global Network of Sex Workers Projects. 2013. <https://www.nswp.org/resource/sex-worker-implementation-tool-swit>

If program clients presented with TB symptoms, they would be referred to the family medicine center for sputum microscopy, and if a case of TB was suspected, the case manager would refer the client to the City Center for TB and Lung Disease. If the TB is confirmed, the person would be sent to the TB hospital.

Patients were screened for TB by outreach workers making regular walking rounds along the city's designated routes frequented by people who use drugs, as well as in the office of the organization. In accordance with the project objectives, outreach workers were responsible for both performing rapid HIV tests and filling out TB screening questionnaires.

The foundation runs three shelters. Many of the clients were provided with shelter accommodations during their outpatient treatment after checking out of the TB hospital. The foundation's staff was trained in motivational interviewing skills.

Contribution of the program:

Overcoming stigma.

Referrals from the foundation help in addressing stigma and negative attitudes both in general healthcare settings and in the Center for TB and Lung Disease. Now that the TB project has been completed, the use of vouchers stamped with the foundation's seal is continuing as a regular practice.

Free and high-quality treatment based on trust.

The foundation's program has helped in building a trusting relationship with the city's TB center and the members of key populations have been provided with guaranteed access to free government support for tuberculosis. Vouchers stamped with the USAID logo and the foundation's seal ensured a doctor's appointment – the status of the foundation's client was tantamount to quality service. There was a drop in the frequency of informal practices.

Overcoming barriers for undocumented people.

In Kyrgyzstan, there is an algorithm in place that makes sure that the lack of documents, such as a health insurance policy or domicile registration, is not an obstacle that limits access to TB treatment. However, undocumented people may sometimes experience problems when turning to healthcare providers for services, but then the foundation intervenes with help. The foundation can assign a client to a shelter, thus ensuring for them a more reliable treatment trajectory based on the foundation's formal and informal connections. The foundation has Memoranda of Understanding with the TB service in Osh.

High adherence has been ensured through providing shelter opportunities for many of the foundation's clients.

"Treatment adherence was not established somewhere in their homes, where some relatives may find it hard to understand the situation, you take your medication one day and then skip it the next, and drug resistance may develop. But at the shelter there is a person on duty who is responsible for monitoring the course of treatment."

Ravshan Mazhitov, Director of the Plus Center Public Foundation.

A personal story from a man who uses drugs

The man who uses drugs is a citizen of Georgia. Although he is married in Kyrgyzstan and has children, he has not obtained citizenship yet. He works in an auto repair and service shop. A staff member of the foundation once noticed the man had lost weight, asked him to complete a screening questionnaire and gave him a stamped referral slip for TB diagnostic tests, because the man might have encountered difficulties without local ID and other documents. He was in no position to fill out the application for a Kyrgyzstan residence permit because he had lost his passport. The man was diagnosed with drug-resistant tuberculosis, but he was cured of TB through the foundation's intervention and support because he had been admitted to the hospital and reminded of the free treatment algorithm available for everyone, as well as thanks to the foundation looking out for their charges.

4. FINDING PEOPLE WITH TB AMONG CONTACTS

(based on the example from program activities of CF The Way Home, Odessa, Ukraine)

The contact-tracing program is focused on active finding of missing people with TB among the contacts of people with TB from risk groups. A person with TB may volunteer to become an index-case and engage into testing of up to 8 persons with whom he/she had a long-term contact. An index-case receives 8 vouchers with a social worker's contact details and an address for health care facilities. Prior to handing out a ticket to a person from his/her close contacts, an index-case should conduct motivational counseling on the importance of testing. He or she later receives a small remuneration for every person referred for testing. An engaged contact will also receive a motivational remuneration for being tested – a compensation of transportation expenses. The framework of the project also allows for compensation of expensive diagnostics for contact persons as needed.

Contribution of the program:

High efficiency.

A pilot project was launched in July 2018 and in the first six months it demonstrated high efficiency in five regions of Ukraine: 1277 individuals were enrolled into the program of contacts, including 52 individuals with confirmed TB who started treatment. This program has an extremely high level of efficiency.

According to the Coordinator, this program has proven that the “reservoir” of people with TB in Odessa is nowhere near exhausted and there is a long way to go on detecting new people with TB.

A distinctive feature of this program is that it **covers unique clients from hard-to-reach population** who will not get enrolled into other projects carried out by CSOs, for example, HIV-related projects. Another advantage of this program is its engagement of people in the client's surroundings beyond immediate family members.

Continuous presence of the program representative in the health care facility.

A program coordinator works in a specially allocated office in the Odessa Regional Center for Social Diseases. Their continuous presence ensures an important “safety net” for the clients from the contact program, as well as for other clients of the program for active finding of missing people with TB who come to the Center for testing or to receive test results. It's also important in case of extraordinary situations or when support and follow-up are required. Also the project envisages involvement of social workers responsible for enrollment of “index-cases” and clients' follow-up.

“We are dealing with a specific population and there is a large flow of people. Since all the staff of the Center know us they are sympathetic to us – the reception desk personnel as well as doctors.”

Coordinator of the project of active finding of missing people with TB among risk groups, Way Home Foundation.

Social mobility.

This program is also efficient because it can easily cross boundaries between social groups since contacts often provide access to people from their close social circle. Therefore, they provide as a means to target the general population with TB testing.

Challenges and opportunities:

One of the program challenges is related to the fact that many representatives of risk groups with detected TB who could potentially cooperate with the program are not ready to bring their contacts for fear of their diagnosis disclosure. In many cases, in order to enroll on municipal charity programs, clients have to submit a medical certificate proving absence of TB. Stigma also has an impact on enthusiasm to participate in the program.

Recommendations for the program enhancement:

To conduct training sessions on TB infection control for municipal charity organizations in cooperation with the Odessa Regional Center of Social Diseases to ensure unrestricted provision of charity services to all the people who receive outpatient TB treatment because they no longer pose infection threat to the community (according to the WHO Infection Control Recommendations)¹⁰.

Personal story - a homeless volunteer of the program for contact identification

«I was born in Lugansk region and worked in the mines. My mother and father died in 2010. Then I met a pastor and was treated in the rehabilitation center. I used to live in Dnipro. Then five years ago I happened to be in Odessa region where I was living in the Monastery of the Holy Dormition, then in the street. One of my fellows brought me here [to the Center of Social Diseases]. I came here with a medical card. I was lucky to have received medical assistance at the right time. I was hospitalized. Then I started to bring people here. Since other people helped me, I decided to bring people from my surroundings here, mainly homeless people.»

A homeless man from Odessa. He found out about Way Home through the program of contact identification and he became an "index case". In the future he is planning to live and work in a monastery.

5. TB CASE FINDING AMONG MIGRANT WORKERS IN THE HOST COUNTRY

(based on the example of program activities of the International Organization for Migration in Tajikistan and the Russian Federation)

Health issues are not a priority for migrant workers, as they are forced to be focused on doing their work in the host country, postponing treatment until they return home¹¹. Stigma and lack of access to health insurance are also important barriers. For example, in the Russian Federation, which hosts several million migrant workers from Eastern Europe and Central Asia, migrants have guaranteed free access only to emergency medical care in cases of serious health-related situations¹². According to this logic, foreign migrants have access only to treatment for active TB, but cases are sometimes reported when patients are refused hospitalization as well. As soon as a migrant is no longer contagious to others, he or she is discharged from the tuberculosis hospital and advised to immediately seek and continue further treatment in their country of origin. TB is one of the several infections for which it is legislatively prescribed that the residence or stay of foreign citizens with TB in the country is deemed undesirable. In other terms, a migrant with TB may not be granted a permit for work until he is cured, and until then he will remain undocumented. It is not uncommon for migrants with TB, when under threat of deportation, to stay under the radar of healthcare and migration authorities, but not having enough money to arrange their immediate departure to their home country or fearing stigma from family and community members, they often have to stay in Russia for a long time instead. There is no well-established framework in the EECA region for referral and coordination of TB services between receiving and sending countries' of migration. Nor is there, for the time being, any mechanism for the clearing of reciprocal payments in healthcare either. As a result, foreign migrants are becoming one of the most difficult-to-access populations when it comes to TB detection. Neither Russia nor the countries of origin have any accurate data on the actual number of people with TB, nor their place of stay.

¹⁰ WHO guidelines on tuberculosis infection prevention and control 2019 update. WHO 2019.

¹¹ Kennedy, S., J.T. McDonald, and N. Biddle 2006 «The Healthy Immigrant Effect and Immigrant Selection: Evidence from Four Countries», SEDAP Research Paper No. 164.

¹² Demintseva E., and Kashnitsky D. 2016. Contextualizing Migrants' Strategies of Seeking Medical Care in Russia. International Migration 55 (2): 29-42.

In 2017-2018, the International Organization for Migration in Tajikistan implemented a small pilot project entitled «Technical Support and Capacity Building to Improve Cross-Border TB Control and Care of Tajik Migrant Workers», which had four components:

- Training the staff of diaspora organizations and the representative office of the Tajikistan Ministry of Labor in Russia in basic TB knowledge as well as for providing subsequent guidance and advice for migrant workers;
- Providing basic TB information to migrants from Tajikistan in their native language with the support of diaspora organizations;
- Assisting migrants with TB who find themselves in a difficult life situation in returning to their home country;
- Reintegration of migrants upon return to their country of origin (Tajikistan).

A migrant woman with TB from Tajikistan

The woman, a citizen of Tajikistan, came to Russia to work, together with her husband. In order to buy a train ticket to Russia, she had to sell her cow and take a loan from the bank. The job she was hoping to get (working as a nanny) was given to another woman. In order to be able to work legally in Russia, she was advised to apply for a work permit in the Kaluga region. Earlier on, back in Tajikistan, she had been treated for TB and her doctors told her she was cured. But later when she undertook medical tests in Russia, as part of the work permit application process, she was diagnosed with TB again. The doctors told her she needed to immediately go back to her home country, but she had no money at all. Then, in a bid to help her, the local authorities arranged that she be admitted to the Kaluga City Tuberculosis Hospital for a course of free treatment. While she was in the hospital, her children lived with their father. But as he had to go out to work the children were essentially left alone all day. After one month of treatment, the woman had to leave the hospital as she was worried about her children. She took her children and went to the representative office of the Tajik Migration Service. Thanks to the diaspora getting involved, enough money was raised to buy airline tickets for this woman and her children. Besides, she was also linked to the International Organization for Migration in Tajikistan. This organization assisted the woman in accessing outpatient treatment, as well as food aid and drugs mitigating TB treatment side effects through the support of a partner project. A month later, her husband returned to Tajikistan. The IOM assisted him in purchasing a welding machine as part of the reintegration employment program in his home country.

It is critically essential that NGOs and TB services in the host country and the country of origin ensure linkage and interact when sending migrant TB patients back home, thus facilitating the continuity of care.

Photo 2: IOM training for Tajik diaspora at the Moscow-based Steps Foundation, June 2018.



PROGRAM SUSTAINABILITY

Since rotation of regional health management takes place rather regularly, often an incoming director of the health department tries to change priorities in program funding.

«Healthcare management in the region get replaced every six months. I wish I could see their program for strategic development of health sector in the region. Every director brings his/her own program vision and as you can see the issues of TB and HIV/AIDS are of least importance. Oncology is interesting and the issues of the regional clinical hospital are of heightened interest. As far as concerns HIV and TB areas- they will manage themselves... A problem of the project activity is that health administration got accustomed to it and would always rely on their funding. Current thinking of the management is as follows: "They have got lots of projects, let them deal with these areas themselves". But now when funding of the projects is wrapping up everything may get ruined like a house of cards».
Head Doctor of the Odessa Regional Center of Social Diseases.

Photo 2: From left to right:
Stepan Koisa, Coordinator of the program for early TB detection among contacts, Deputy Chief of the Odessa Regional Center of Social Diseases; Daniel Kashitsky, Manager of Communities Capacity Building, TB Europe Coalition; Svetlana Esipenko, Head Doctor of the Odessa Regional Center of Social Diseases



Photos 3, 4: Reception of the TB Unit at the Odessa Regional Center of Social Diseases



RECOMMENDATIONS FOR IMPLEMENTATION OF THE PROGRAM FOR ACTIVE FINDING OF MISSING PEOPLE WITH TB AMONG RISK GROUPS

Programs for active finding of missing people with TB among risk groups have demonstrated their high effectiveness in Ukraine – over five years the TB detection rate increased by 46%¹³. Since these risk groups face stigma, discrimination and other structural barriers in accessing health care services, the implementation of such programs with involvement of civil society organizations is strongly recommended because they have gained specific knowledge and skills which allow organisations to overcome these barriers in an effective way. We recommend sustainable implementation of such programs in all EECA countries if the following recommendations for national managers of public health system are considered:

- Programs for the active finding of missing people with TB among risk groups implemented by CSOs should be integrated into national TB programs and should be recognized by law.

- National operational research focused on the detection of vulnerable groups which face additional TB risks and have structural barriers to accessing health services should be conducted:

- It should be noted that STOP TB Partnership recommends considering the following three risk groups¹⁴:

- people who have increased exposure to TB due to where they live or work (e.g. residents of urban slums, miners, etc.);
- people who have limited access to quality TB services (e.g. migrant workers, homeless people, etc.);
- people at increased risk to TB because of biological or behavioral factors (e.g. people living with HIV, injecting drug users, etc.)

- To extend the list of risk groups considering all the above factors and formalize it in an order from the Ministry of Health to prioritize activities with these groups in the National TB Program.

- Operational research aimed at the assessment of vulnerable groups should be carried out on a regular basis.

- In EECA countries every region should have not only estimated TB incidence data among risk groups but also to be aware of regularly updated and accurate information on access barriers among various risk groups. It is recommended to make assessment using the methodology “Communities, Rights and Gender TB Tools Assessments in Ukraine”¹⁵.

- Lists of high priority groups should define the priorities of programs for active finding of missing people with TB and should be integrated into the municipal health care program.

¹³ Data from the project on early detection of TB, Alliance for Public Health, 2019.

¹⁴ STOP TB Field Guide. TB Case Finding with Key Populations. STOP TB Partnership, 2018. Geneva.

¹⁵ Communities, Rights and Gender TB Tools Assessments in Ukraine. Report of the Projects Results. Kyiv, 2018.

- A program of state social contracting should include grants for civil society organizations implementing programs for active finding of missing people with TB among risk groups.
- It is recommended that regional intersectoral councils on social diseases are organized which should include representatives of the community of TB survivors. This council will play a decisive role in development and approval of the regional HIV/TB program, including funding of CSOs working on active finding of missing people with TB among risk groups.
- Integration of TB and HIV services on the national and local levels will contribute to increasing coverage of risk groups and key populations with services. Participation of key populations and TB survivors in planning, implementation and monitoring of services provision to key populations will add to the success of service coverage.
- To conduct training sessions for primary care providers to enhance their awareness of specificities in working with risk groups;
- For efficient implementation of programs aimed at active finding of missing people with TB among risk groups on the regional level it is necessary to introduce training programs for health care providers, medical students, social workers and decision makers conducted in partnership with civil society organizations. An expert-trainer from the community of TB survivors should be involved into the educational process.
- Partner charity organizations working with risk groups should have accurate information about TB therefore they should be invited to participate in these training sessions as well. People receiving outpatient treatment should have access to charity social and psychological services without fear of being excluded from the program in case of information disclosure about their treatment since they do not pose any infection threat for the surrounding environment¹⁶.
- Programs of active finding of missing people with TB among risk groups should include street work programs as well as programs focused of contact search. Each program has its advantages and potential in finding people with TB and they complement each other.
- Facilitating continued access to TB testing and treatment programs for international migrants. It is necessary to develop cross-border cooperation both at the levels of TB programs and civil society organizations in order to ensure that migrants with TB are linked to services for further treatment back in the home country.
- To consider possibilities for state subsidizing of medications to treat side effects during TB treatment course since risk groups representatives in many cases do not have close relatives able to provide care and purchase necessary additional medications.
- Services for homeless clients should include possibilities for further socialization of the program's clients (psychosocial and legal aid, access to accommodation and employment) within the setting of the same organization which is involved in active finding of missing people with TB or well positioned to refer such clients to partner organizations. Since clients of the program develop trust-based relations with program social workers, they continue addressing them for assistance during their inpatient and outpatient treatment courses.
- To ensure quality follow-up and continuum of services for risk group representatives during their visits to health care facilities for medical appointments, it is important to locate an CSO office close to TB clinics (ensuring social security and infection control to CSO employees).
- Besides active finding of missing people with TB and follow-up, it is important to provide CSOs with the opportunities and necessary resources to satisfy vital needs of risk groups representatives. For example, a service to treat open wounds is highly sought and is important for the program's sustainability and clients' maintenance of health and dignity.
- It's important to have an opportunity to cover clients' transportation costs because representatives of risk groups come to health care facilities for TB testing during their outpatient treatment course by public transport.

¹⁶ WHO guidelines on tuberculosis infection prevention and control 2019 update. WHO 2019.

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