Engaging civil society and affected communities in the fight against tuberculosis in the WHO European Region

1. Civil society and affected communities

Civil society, as defined by the World Bank, refers to the wide array of nongovernmental, not-for-profit and voluntary organizations that have a presence in public life, expressing the interests and values of members or others based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil society includes nongovernmental organizations (NGOs), community groups, faith-based organizations, foundations, advocacy groups and networks of people living with diseases.

2. Added value of civil society and affected communities in TB care and control

Civil society organizations (CSOs)\(^1\) and affected communities are key players in responding to disease epidemics in countries and at regional and global levels. Being embedded in communities, CSOs are often well placed to take on operational roles in detection and patient support. They can also advocate for the interests of their members or the groups they represent and play an integral role in empowering key populations, helping reduce stigma and discrimination, promoting social and structural changes in the fight against TB and mobilizing resources, advocacy and policy dialogue. Affected communities possess unique knowledge on how their needs can best be addressed.

CSOs have in-depth knowledge of local contexts due to their work with key affected populations. This places them in a strong position to raise awareness of TB among the general population and groups most affected by the disease. For example, CSOs active in TB work can perform educational activities, raise awareness of TB symptoms and the availability of free TB care, and distribute information materials. Greater awareness and understanding of the disease not only contributes to a reduction in TB-related stigma, but also raises the profile of TB as a public health need in the country.

Stigma continues to be an issue in TB, when affected people commonly experiencing disease-associated discrimination or being shunned by their communities. Fear of discrimination can result in delays in seeking treatment and coinfection. CSOs can help combat discrimination by accessing hard-to-reach communities and groups, with community activists who carry out social mobilization activities becoming trusted by patients, communities and vulnerable groups. In Georgia and Tajikistan, for instance, religious and other community leaders are mobilizing to speak out about TB. Thanks to their influential position in society and the number of people they reach, these actors contribute greatly to increasing understanding of TB and facilitating early diagnosis.

Appropriately trained CSOs can also be service providers for vulnerable groups by, for instance, providing directly observed therapy services (DOTS) in ambulatory settings and ensuring treatment adherence by offering social and psychosocial support to TB patients and their families. Some CSOs in Kyrgyzstan actively support TB patients from vulnerable populations by providing outpatient treatment for injecting drug users (IDUs), a group from whom traditional structures

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\(^{1}\) NGO and CSO have very similar meanings. Through custom and practice, NGO tends to refer to larger, possibly international not-for-profit organizations, while CSO usually denotes local and smaller organizations.
typically are not equipped (or ready) to provide services.

As representatives of specific groups, CSOs and affected communities can also be outspoken advocates on TB. CSOs have the potential and moral obligation to demand action to solve problems people face at local and national levels. They have the ability to leverage greater political commitment on given issues and can help mobilize additional financial and technical resources to boost the fight against TB. Affected communities, with their direct experience of people affected by TB and other diseases, are crucial to addressing the human and social dimension of TB. Their understanding of issues such as barriers in accessing TB care and obstacles to completing treatment can lead to better and more patient-friendly TB programmes being developed.

Greater involvement of affected communities and civil society in the design, monitoring and implementation of national TB programmes (NTPs) is essential for the development of comprehensive approaches that involve all actors and which may lead to better treatment solutions. The role of civil society and communities in TB care and control has also been acknowledged in key policy documents, such as the consolidated action plan to prevent and combat multidrug- and extensively drug-resistant TB for 2011–2015, which was launched by the WHO in 2013. It endorsed the WHA post-2015 TB strategy by all 53 countries of the WHO European Region on 15 September 2011.

3. Country examples of how civil society and community involvement have leveraged better results

The degree to which CSOs are officially involved in NTPs varies considerably from country to country. Reasons for variations differ, ranging from legislative challenges to a lack of CSOs working on TB.

Tajikistan is among the 15 high multidrug-resistant TB (MDR-TB) burden countries in the European Region. Thirty-seven CSOs work on TB projects in Tajikistan. Most began operating in the past 5–10 years and provide crucial services to patients and communities in need. Many began operating in the past 5–10 years and provide crucial services to patients and communities in need. Their work is especially important due to Tajikistan’s mountainous terrain, which makes it difficult to reach certain populations, and the fact that 47% of the population live in poverty (2009 figures). Tajik CSOs rely on small numbers of staff and about 3000 volunteers trained in outreach activities around health issues. Volunteers are carefully selected from the community and include teachers, community leaders and inmates. After receiving TB training from the CSOs, they visit households in their communities and raise awareness of TB in schools, mosques and during religious ceremonies, including weddings.

CSOs are being increasingly recognised by the Government of Tajikistan as an indispensable actor in TB care and control and are now involved in discussions with the NTP. Greater local CSO involvement in TB control programmes and social support activities in recent years has contributed to an increase in case detection, ensured higher rates of treatment success and helped catalyse the shift to ambulatory treatment and care. Growing numbers of people are now being treated as outpatients: ambulatory care for MDR–TB patients grew from less than 10% of total TB treatments in 2009 to more than 45% in 2012. The potentially transformative impact of CSOs’ active involvement is further demonstrated in Azerbaijan. Over the past two decades, Azerbaijan has managed to achieve some of the best cure-rates for MDR–TB in prisons not only among former Soviet Union countries, but also worldwide. The Azerbaijani Ministry of Justice and the Main Medical Department have prioritised action to improve prisoners’ health, such as implementing infection control measures, providing a continuous supply of certified medicines and facilitating early detection through rapid diagnostic tools and screening of groups that lack the resources to sustain their TB-related activities.

Also relevant in the Bulgarian health care structure are the home-care nurses who work closely with CSOs. They are attached to local TB hospitals and spend part of their time with CSOs in local communities. The nurses provide a medical backbone to the NGOs’ work: in return, the NGOs ensure the nurses have access to patients and communities (such as Roma and IDUs) who may be sceptical or suspicious about formal health services.

The system has fostered particularly harmonious relationships among CSOs, local TB services and the NTP. CSOs feel they are respected as equal partners in TB care and recognised for providing a service that formal health services cannot. Bulgaria has now achieved a significant drop in TB incidence, almost halving the rate over five years to 32 per 100 000 population in 2012. The NTP and health professionals acknowledge that working with CSOs in a systematic way has been a major contributor to this success.

4. Challenges

Despite the transformative role they can play, CSOs working on TB in the European Region face important challenges. Although country contexts differ, the challenges are often similar.

First, the number of CSOs working on TB remains very limited. Reasons differ across countries, but predominate among them are: lack of domestic and international funding or incentives; legislative constraints, such as the need for special licences to provide health care services; and reluctance of HIV CSOs to expand their work to TB prevention and care due to fear of infection when working with TB patients. Consequently, TB CSOs in the Region are generally younger organizations that lack historical presence. A clear and formalized system to involve them in the work of NTPs needs to be developed in many countries.

Second, a lack of funding, which impacts upon their sustainability, is a major challenge for CSOs. CSOs in many countries are dependent on voluntary work or support from international donors, such as the United States Agency for International Development or the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). External funds are not available, CSOs lack the resources to sustain their TB-related activities and build capacity to collaborate with NTPs. This is the case in Georgia and Ukraine where, despite CSOs being involved in the preparation of NTP strategies, lack of resources to implement plans impedes further collaboration between CSOs and the NTP.

Third, decision-makers in some countries often have a negative view of CSOs. They may see them as disorganised and unreliable work partners and perhaps view them as competitors, rather than allies, in defeating TB. This conception sometimes has its roots in lack of coordination among civil society actors, which represents a major challenge for TB and can hinder effective cooperation with governments and NTPs.


