



Engaging religious leaders in TB advocacy: experience of the Initiative for Health Foundation in Sofia

Romani communities in Sofia

Roma people constitute one of the largest ethnic minorities in Bulgaria, and have much higher unemployment, death and poverty rates in comparison to the overall population. Since 1989, Romani people have consistently moved towards predominantly Roma neighbourhoods, which have increased marginalisation, segregation and social isolation of Roma community as a whole. As a result, the majority of Roma communities have limited access to health services. Furthermore, as the access to national insurance is directly linked to one's salary contribution, the majority of the community members have no health insurance due to the high levels of unemployment and illegal or seasonal jobs within the community.

This has led to in the majority of the cases, Roma community only engaging with the



national healthcare system in the case of extreme emergencies, when treatment is available for free. In less urgent cases, people tend to rely on the advice of their families and not on the national health system. The overall attitude towards health can also be described as overly focused on predestination, with communities often believing in illness or its cure as an act of God with an aim to punish or redeem

particular individual. Furthermore, due to the precarious financial situation, the individuals remain little motivated to invest in their own healthcare.

In Sofia, the Roma community remains the most affected vulnerable group, when it comes to TB incidence rates, even in comparison to other vulnerable groups such as drug and alcohol users. TB incidence rate can be linked to extreme poverty of Roma communities rather than the risky behaviours such as drug use. The neighbourhoods often have "hot spots", where TB appears and disappears over the years, often in one extended family cluster, for example, grandmother had TB in her youth and 30 years later grandchildren have TB. Despite disease being widespread within the communities, the stigma is still there, with the affected families unwilling to talk about the disease or even hiding it from their neighbours.

Over last thirty years, TB control and prevention has also changed from very top-down and forced process, with TB treatment characterised by forceful treatment and disregard to human rights to the modern healthcare system, where the rights of the



people are respected, but where quality and access to healthcare would often depend on the income level of the person. Thus, the current national TB control and prevention programme, partially funded by the Global Fund, includes continued community testing, carried out by a variety of the NGOs. The approach aims to ensure that healthcare is not top-down, but inclusive and sustainable process, aiming to change of belief system on health within the communities.

Engaging religious and community leaders in TB advocacy

In view of TB situation in Roma communities in Sofia, the Initiative for Health Foundation launched a small-scale community project in the framework of STOP TB Partnership Challenge Facility for Civil Society grant, aiming to engage religious leaders in TB outreach and prevention work in different Roma neighbourhoods. The project lasted for 1 year, with the total cost of \$20 000. In Roma communities, the priests are highly respected and influential, and the Initiative for Health Foundation believed that



their engagement would be essential mean to reach smaller, highly segregated neighbourhoods, which are rarely reached by any official health care interventions.

It was clear that the key to the success of the project is to identify and engage the most motivated priests from various neighbourhoods. The first stage of the project focused on the identification and selection

process of “gatekeepers” or community leaders. The selection process was based both on previous work experience of the outreach workers in various Roma communities and establishing contacts with the most influential priests in the larger Roma communities. After explaining the project activities and aims to the key religious leaders in the larger communities, the NGO asked for suggestions regarding probable leaders in smaller communities. The Initiative also received recommendations on behalf of more influential Church priests, aimed at ensuring the cooperation from the priests in smaller Roma communities. Overall, the NGO approached 28 Roma priests or community leaders in 21 different Roma neighbourhoods in Sofia. The previous work experience and personal referral turned out to be the best way of how to identify the key participants for the project. Although all the priests acknowledged the spread and impact of TB within the community, some of them were not interested to actively participate in the project either because they were not convinced that the project intervention would work or did not consider the issue directly linked to their calling. Out of 28 people approached, 10 were interested and selected as “gatekeepers” for the



next stage of the project. The key criteria for the participation were motivation of the gatekeeper and their readiness to cooperate. In some cases the preference was given to the non-religious community leader rather than a priest.

With interested leaders identified, the second stage focused on one day training to engage them in the project which included training on what TB is by medical professionals and what role each of the leaders could play in helping the community, outlining the timeline and work strategy for each of them. Interestingly some of the “gatekeepers” attended the training together with their wives, as the spouse of the priest is often engaged in various social causes within the community and could contribute to the outreach activities on their own. In order to ensure the longevity of the commitment, the “gatekeepers” were offered food and phone vouchers as a small remuneration. The vouchers were considered a good alternative to direct payment that would have been too complicated to manage due to the financial rules regarding financial contributions to religious institutions, but in the case of phone vouchers also served as a tool to ensure continuous communication. Some priests proceeded to distribute the food vouchers to



the most vulnerable in the community over the religious holidays such as Christmas or the Easter. Furthermore, the engagement of priests often meant that the NGO workers were allowed to use church premises for the outreach work for free. The funding line for the rent was then used to purchase material goods necessary for the local church ranging from coffee machine

to air conditioning unit and heater.

The third stage of the project focused on the actual outreach campaigns within the communities. The NGO carried out 24 sessions in 9 Roma communities, attended by 565 Roma people, out of which 344 were tested for TB. In comparison, the previous year only 240 people were reached tested via outreach activities (most of which were done door to door). The overall number of people tested increased by 64% instead of planned 20%. The priests informed and invited the community members to attend the session to learn about the TB and carry out the testing done by the medical nurse. The sessions were usually divided in two parts: first part focused on the outreach workers and the nurse discussing TB (what it is, how to avoid it, why it is important to treat it etc.), distributing information brochures, answering questions regarding some myths and prejudices, and sometimes even discussing individual cases, and the second part consisted of TB testing (*mantu* testing) in the mobile van. During the first part of the



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session, the NGO also provided fruits and healthy snacks as both an incentive to attend the meeting and encourage healthy eating.

The project was aimed to train and to encourage community leaders to take actions to improve overall health of the community, with specific focus on TB. The project aimed to work within the community settings in order to ensure accessible and understandable information about TB, allowing overcoming stigma and participating in TB testing. The success of the project was further highlighted when priests from other Roma communities learned about the project and contacted the Initiative with requests to get involved. After the end of the project, the Initiative continued to engage with the community leaders and priests, and when organising testing campaigns, they offered their assistance to mobilise the community for both – TB and HIV testing campaigns, with one of the priests providing the church premises for free during the winter months.

Individual story

One of the sessions was attended by a family of eight, with both parents being TB survivors of four years. Although their children tested negative at the time, during the community testing session two of the children – 9 and 11 years old were tested positive and referred to the Sofia TB Dispensary for a follow-up test. After the positive diagnosis, both of them were admitted for in-patient treatment in the children's department of the Lung Diseases Hospital in Sofia. However, the adaptation process to hospital environment did not happen easily, and soon enough both of the children ran away from the hospital back to the community. The outreach worker of the Initiative for Health Foundation was then contacted by the hospital staff, who asked the outreach worker to convince the family to continue with the treatment. After prolonged discussion both family and the hospital agreed to provide treatment at home. The medication and surveillance was provided at home and the outreach worker kept on visiting the family to ensure that there was no problems with the treatment, with both children cured by the end of the treatment. At the moment, the family has grown to have two more children – twins of age of two, and the parents, who are concerned about possible TB infection, have brought the children to the hospital for a testing on their own accord.