***“We need to move beyond the old approach of sitting in the clinic waiting for sick patients to come to us.”***

In 2018, Doctors Without Borders (MSF) launched a pilot programme in Khayelitsha, in South Africa's Western Cape province, which set out to identify older children and adolescents who were sick with drug-resistant tuberculosis TB (DR-TB). Finding these children early in the course of their disease, gives them a much better chance of being cured. We chose to focus on this group because only eight per cent of the estimated 25,000 children and adolescents who become sick with DR-TB each year are diagnosed and started on treatment. Older children and adolescents are a generally neglected group, often lumped together with adults in many healthcare policies.

Reaching this group initially proved to be an extremely difficult task, in particular getting them to visit one of the area’s government-run clinics. To better understand the reasons for this, we conducted a community assessment, where we asked questions about the barriers to clinic access. We heard that clinic opening times (usually Monday to Friday, from 8:30 am to 3:30 pm) were part of the problem, as children are at school and parents and guardians are at work on weekday mornings, and in Khayelitsha if you do not arrive at the clinics in the morning you will not be seen – they are that busy.

We also heard that there were problems in the clinics, too, , including long waiting times and people being told they had to go to a different facility for a chest x-ray on another day, meaning a further day out of school and away from work.

It is very difficult to ask a parent or guardian to jump through these hoops when their child or adolescent is not yet feeling sick. They have a point because they are being asked to sit and wait among people who are definitely sick, and of course, children being children, they don't keep their masks on for more than two minutes.

At this time our programme was only able to enrol 10 per cent of eligible participants, and probably the key issue was that we did not offer preventative therapy. We only offered symptom screenings, chest x-rays and physical examinations to look for DR-TB. Screening for active DR-TB without offering preventative therapy to household contacts is not going to get you good results. We needed to come up with a different approach.

In the meantime, TB treatment for children and adolescents in South Africa took some overdue steps forward, with child-friendly formulations of new and better TB medicines becoming locally available. South Africa also introduced a progressive new policy that expanded the eligibility criteria for preventative therapy to include all DR-TB contacts considered to be at high risk of developing TB, including all children and adolescents, not just those aged under five.

So what did we do? To address barriers at the clinic level, we identified specific TB champions – clinic doctors with a passion for TB treatment – who were more than happy for us to refer individuals to them for preventative therapy, using flexible clinic schedules. We also took a home-based approach, with MSF teams conducting clinical assessments of exposed children in their homes. This allowed us to see families at times that worked best for them, and did not require them to spend money to get to the clinics or lose work time while waiting there.

Then came COVID-19 and a hard lockdown across South Africa, which gave rise to huge concerns among our team. Families were told to shelter in place at the same time as fewer people were being diagnosed and started on DR-TB treatment, which is the most effective infection control measure we have. This increased the risk of TB infections spreading through families. However, this period also gave us some important insights and opportunities because a greater number of older children and adolescents were now at home, as were their parents and guardians. This made it much easier to implement the new DR-TB guidelines of the National Department of Health, issued in 2020, in an innovative way.

All of these factors – including home-based care, clinic flexibility and a family-friendly focus – contributed to the programme being successful as a way to diagnose DR-TB among household contacts, possibly preventing more than 90 vulnerable children and adolescents in Khayelitsha from falling ill with DR-TB.

One of the great successes for me was that eight children were identified as having DR-TB and started on treatment. Thanks to the home-based screening, we managed to find them earlier than would have been the case, before they became sick, so they didn't have to be treated in hospital or be separated from their families. And, because of the new treatment options we have access to, our doctors reckon the children can be easily cured.

Following the arrival of COVID-19, we also took a decision to provide home-based care to those individuals with DR-TB who were very sick, and, since our team was visiting homes anyway, they started screening household contacts as well. This was when the benefits of a home-based approach really hit home for me because, when you visit homes, you find a completely different story to the one that gets presented at the clinic. For example, one patient told us during a clinic visit that he had two children at home, but when I visited the home I found six children there, two biological children and four cousins. Our home-based approach enabled us to identify all of these contacts, screen them and begin them on preventative therapy.

The home visits have really confirmed for me that TB is a family disease. You hear that a particular family member had TB in 2014, and today there is still someone in that house with TB. It shows you the current approach of telling people to open windows at home, which is the advice often given to families by public health programmes, is not working, especially in high density areas like Khayelitsha or Mumbai, where many people live together in small houses.

The other major benefit of the home-based approach in areas, such as Khayelitsha or Mumbai, which have large and increasing numbers of people living in unplanned settlements, is the potential for minimising the number of patients who are lost after their initial visit. Often when you try and call the cellphone number a person gives when they register at a clinic it no longer works, and when you visit their home you hear they are living elsewhere, and so you lose this patient. Whereas if you follow a home-based approach, screening and starting the whole family on preventative therapy, you have many contacts and many ways of reaching your patients.

If we are really serious about ending TB we need to move beyond the old approach of sitting in the clinic waiting for sick patients to come to us. I'm telling you; we are fighting a losing battle if we only do that. With the home-based approach, we not only protect exposed individuals through preventative therapy, you also identify the social issues affecting them and their family. You know who is using drugs in the house, and who is working and providing food, rather than knowing just the one patient who was carried out of the house because they were sick. We need to move away from this focus of just giving a pill, without knowing the rest of the story.