



# Implementation of a National Tuberculosis Control Program in Minority Communities

## *Accomplishments and Challenges from Kosovo*

October 2004



Doctors of the World-USA



Tuberculosis Case Study

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The Child Survival Collaborations and Resources Group (**The CORE Group**) is a membership association of more than 35 U.S. nongovernmental organizations working together to promote and improve primary health care programs for women and children and the communities in which they live. The CORE Group's mission is to strengthen local capacity on a global scale to measurably improve the health and well being of children and women in developing countries through collaborative NGO action and learning. Collectively, its member organizations work in over 140 countries, supporting health and development programs.

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# Contents

Acronyms .....	ii
Executive Summary .....	1
Project Context .....	3
Interventions/Activities .....	6
TB Data for Minority/Majority Populations .....	7
Setting Up TB Facilities in Minority Areas .....	8
Training of Minority Doctors and Nurses .....	10
Health Education .....	11
Costs .....	13
Next Steps .....	14
Discussion of Results .....	15
Impact on Stigma .....	17
Monitoring and Evaluation .....	17
Success Factors/Lessons Learned .....	19
Conclusion .....	21
Tables	
Table 1: Incidence and Notification Rates for Minority Areas vs. All Kosovo from 2001–2003 .....	7
Table 2: Treatment Success Rates for Minority Areas vs. All Kosovo from 2002–2003 .....	8

# Acronyms

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ATD	anti-tuberculosis dispensary
DOTS	directly observed treatment, short-course
DOW	Doctors of the World
IDP	internally displaced person
IPH	Institute of Public Health
KAP	Knowledge, Attitudes, Practices Survey
KFOR	Kosovo Force (NATO-led alliance)
MOH	Ministry of Health
NGO	nongovernmental organization
NTP	National Tuberculosis Control Program
REA	Roma, Egyptian and Ashkali
TB	tuberculosis
UNMIK	United Nations Mission in Kosovo
WHO	World Health Organization

# Executive Summary

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In October 2000, Doctors of the World-USA (DOW) initiated a tuberculosis (TB) control project in Kosovo to reduce incidence among minority communities. DOW implemented these activities within the framework of the National TB Control Program (NTP), which was finalized in 1999. DOW recognized the need to work with the Ministry of Health (MOH) and the newly established NTP to integrate outreach and services to minority areas within the formal structure of the NTP. Therefore, DOW introduced a comprehensive and innovative set of interventions to address minority needs, which addressed not only advocacy but also service and communication gaps, as well as training and health education needs. Key partners in the project included the NTP, the Institute of Public Health (IPH), the World Health Organization (WHO) and Health for All, a local minority nongovernmental organization (NGO).

Key project objectives included:

- Supporting the NTP in guaranteeing access to free treatment for 100% of patients, including minorities<sup>1</sup>;
- Strengthening the case detection system through active case finding, quality control for direct smear, and health promotion in minority areas;
- Continuing the implementation, management, and monitoring of a patronage nursing system in majority and minority areas to track the outpatient treatment continuum; and
- Continuing the implementation and monitoring of TB protocol in minority areas (especially North Mitrovica), allowing integration of minority and majority TB control efforts.

Key minority area-focused interventions within the national project included:

- Setting up TB facilities (including Anti-TB Dispensaries, or ATDs) in minority areas;
- Training of minority doctors and nurses in best practices for TB management and control; and
- Health education within minority communities.

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1. Although exact baseline statistics are not available for TB treatment, estimates show that services were virtually non-existent for majorities and minorities, with poor availability of drugs.

Project lessons learned included:

- NGO and majority system providers and staff must build trust with their minority counterparts, particularly those who have been working within their communities, before project activities begin.
- Improving minority access to services requires balancing two strategies: 1) making majority health system services more accessible and 2) establishing minority-focused services in minority communities.
- Utilizing technical experts from outside the region who can provide a more neutral face for training, assessment, and program development helps projects avoid being overwhelmed by local tensions and ethnic differences.
- Because many disparities affecting minority communities are caused by factors beyond the control or scope of NGO- and health-specific activities, political will and support from state actors and structures is essential for gains to be sustainable and less vulnerable to future political upheaval.
- Culturally appropriate health education is important in addressing stigma, avoiding scapegoating of minorities, and improving relationships between providers and patients. Health education can be as effective as provision of quality TB clinical care.

Key informants interviewed for this case study included seven staff from the DOW, MOH and NTP offices. Eleven doctors and nurses, six Serb and five Albanian, were also interviewed. The Serb providers were interviewed in Serb enclaves. Eight patients, including Roma, Egyptian, and Ashkali (REA) (2), Serb (1), Bosniak (2), Turkish (2) and Albanian (1) were also interviewed. Seventy-three additional community members were reached through interviews and focus group discussions. Thirteen of the community members were Serb, and 60 were from REA communities.

# Project Context

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In early 1989, the Yugoslav government abolished autonomy for Kosovo and followed with the dismissal of all Albanians working in areas such as administration, teaching, and health. The health situation of Kosovars worsened considerably at this time and continued to worsen over the next decade due to the departure of qualified Albanian health workers and a general distrust of the Serb-run health system by the Albanian population.

In response, the Albanian community organized an informal, volunteer, parallel health services structure, primarily run from homes, which lacked adequate equipment, drugs, reporting structures and supervision. The health situation, particularly that relating to infectious diseases, was poor. According to the Epidemiology Department at the IPH in Pristina, registered TB cases increased dramatically from 413 in 1990 to 883 in 1997. Kosovo developed one of the highest levels of TB incidence in Europe, at an estimated average rate of 77/100,000,<sup>2</sup> more than four times as high as other areas of Western Europe.

In partnership with the MOH, DOW initiated a response plan, the implementation of which was delayed until after the end of the conflict in June 1999. The conflict and its aftermath exacerbated the already precarious health care situation in Kosovo, as 800,000 refugees living in overcrowded conditions in Macedonia and Albania returned to find badly damaged infrastructure and health care facilities, including ATDs, laboratories, and IPH buildings. In 1999, DOW began implementing the five-year NTP, and after 2000, began to focus on access to services by minorities, primarily Serbs, and REA communities.<sup>3</sup>

After June 1999, the security situation for minorities was desperate, causing up to 240,000 Serbs and Roma to flee the country,<sup>4</sup> while those remaining drew together into isolated mono-ethnic enclaves, often needing protection from Kosovo Force (KFOR) troops. An ongoing returns program, supported by the international community, experienced only modest success, with returns at their peak (prior to the March 2004 violence) estimated at around 3,600.<sup>5</sup> Within Kosovo itself, there are approximately 22,000 internally displaced persons (IDPs), mainly Serbs and Roma displaced from their

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2. Estimated by the World Health Organization (WHO), in 1999.

3. These ethnic identities are, for the most part, self-identified, and describe different parts of the community traditionally known as

'Roma.' The distinctions are based on language, history and social structure.

4. These widely used figures, based on Serbian estimates, are only estimates, and have recently been challenged by the International and Security Network, which suggests a much lower figure of between 100,000 and 65,000. See

The Lausanne Principle: Multiethnicity, Territory and the Future of Kosovo Serbs, June 2004.

5. Interview with ARC Gjilan, July 2004.

homes in Albanian majority areas, but also some Albanians displaced from their homes in the three Serb-dominated provinces in the north.

In the five years since the conflict minority communities have seen some improvements, although most minorities continue to face some forms of discrimination and harassment. Prior to the two days of deadly riots in March 2004, there had been some progress toward gradual integration of minority communities into the Albanian social and political structure. However, the events in March may have a lasting impact on the minority communities in Kosovo. During the riots, 4,100 Serbs and Roma were displaced, and many of their homes and public facilities, such as schools and health houses, were burned or destroyed.<sup>6</sup> Some families have since returned to their homes, but others do not feel safe to do so and remain in enclaves with limited access to health care or outside services.

Generally in Kosovo, both before and since the March violence, TB health facilities and infrastructure in Pristina and the larger provincial towns are quite good; however, rural areas of Kosovo remain extremely poor, with few local facilities, and damaged infrastructure. Rural communities remain isolated, especially during the harsh winters. Access to health care in these rural communities remains a challenge, particularly for rural minority communities.

Access to general health care in minority communities varies considerably, with some communities having relatively easy access to primary, secondary, and tertiary health care with functioning local health houses and access to hospitals, while other enclave communities have almost no regular access to health care and continue to be escorted on special buses to health care facilities far from their homes for the most basic care.

Overall, in terms of access to health care, some communities, such as the Bosniaks,<sup>7</sup> the Turks<sup>8</sup> and, to a lesser extent, the Goranis,<sup>9</sup> have become almost fully integrated in, or have good access to, the Albanian system, while others, such as Serb enclaves, remain isolated.<sup>10</sup> For the isolated groups, access to essential services remains a challenge, due to a lack of security and limits on movement.

The situation for the REA communities is more complicated. Some communities have freedom to access services, while others experience difficulties or discrimination by available providers, and other groups have little or no access to services. The degree of access is linked to the language used by each community (different groups use one or more of three

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6. For further details of the violence, see Amnesty International report: Serbia and Montenegro (Kosovo/Kosova)—The March Violence: KFOR and UNMIK's failure to protect the rights of the minority communities, July 2004

7. Immigrants from Bosnia, Serbo-Croatian speakers, with close ties to Bosnia, and the health care system there.

8. Turkish speaking Kosovars, traditionally based only in the south, and in Pristina.

9. Slavic Muslims living in isolated mountainous communities in the southern-most tip of Kosovo, traditionally with ties to Serbia.

10. Serbs currently live in the three northern most municipalities Mitrovica/ë, Leposavic/q and Zubin Potok, where they are in the majority, and in selected larger enclave communities in Albanian-majority municipalities, notably in Gracanica/Laplje Selo area in central Kosovo, and Strpce in the south, and in smaller more isolated enclaves in municipalities throughout Kosovo, such as in Obiliq, Gjilan, Novo Brdo, and Rahovac among others.

languages: Albanian, Serb, or Roma). The groups most integrated with the Albanian majority speak Albanian, and are identified as Ashkali or Egyptian. Roma communities speaking Serb or Roma appear to have difficulties accessing health care in the majority areas, and in some cases, in the Serb areas as well. On the local level, however, neither Albanian nor Serb communities distinguish between the three REA groups, and all face a certain level of discrimination.

Harassment, fear for personal safety, and intimidation of minorities traveling through and to majority Albanian areas remains a daily occurrence. Discrimination, direct, or indirect, intentional or otherwise, continues to reduce this population's access to health care significantly. The United Nations Mission in Kosovo (UNMIK) and the Kosovar government are in the process of issuing a "Charter of Patient Rights" that would promote equal health care access for all, and promote integration of all minorities into the majority health care system, but as yet, most Serbs and certain Roma communities do not feel secure visiting Albanian health care facilities.

There is an ongoing parallel health care structure in Kosovo, operating under the auspices of medical authorities in Belgrade, Serbia, and serving the Serb enclaves in Kosovo, with hospitals in North Mitrovica and Gracanica. Serbs from other enclaves seek primary medical treatment in small, often inadequately supplied health houses in their communities (if available), and travel to Gracanica and North Mitrovica for secondary and tertiary care. Certain Roma communities are also served by this parallel health care system. Serbs may occasionally seek and receive emergency health care from Albanian hospitals, sometimes on their own, and sometimes with KFOR or international escorts. While they are safe in certain hospitals, others—for example the hospital in Peja—cannot guarantee the safety of patients.

At present, unemployment rates in Kosovo are high, with estimated rates ranging from 47% to 57%<sup>11</sup> for the general population, while estimated unemployment rates for those restricted to enclaves are much higher. While the political fate of Kosovo remains uncertain, employment opportunities in the near future do not look promising. Social assistance is available only for those families without employment or property, and who have children under the age of five, leaving significant numbers of families without visible means of support. Many minorities, however, have trouble accessing even the most meager social assistance available to them.

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11. Riinvest Institute, a think-tank in Pristina, gives estimates of 49%, the Statistics office of Kosovo gives estimates of 57.1%, and UN News Reports give estimates of 47%.

# Interventions/Activities

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Prior to the Kosovar conflict, the majority Albanian population was vulnerable due to limited access to state-run health care. DOW thus saw re-establishing a functioning TB program as a priority. At the same time, the situation for minorities within Kosovo was becoming increasingly precarious, and in 2000, DOW initiated programs for TB health care within minority communities, as an integrated extension of the DOW program in majority areas. Although it is estimated that the minority community of approximately 105,000 represents less than 5% of Kosovo's population of 2.2 million, they accounted for about 6% of TB morbidity, with a case rate of approximately 90/100,000 population.<sup>12</sup>

For security reasons, minority communities did not feel safe accessing the new health care institutions in majority areas. Freedom of movement was severely restricted, and human rights violations (including assault, arson, and murder) occurred regularly. Outside of Serb-dominated Northern Mitrovica, other Serb and some REA communities had no access to inpatient TB treatment.

DOW has been a member of the Kosovo TB Commission since 1999, when the five-year TB Control Action Plan was initiated in response to high rates of TB morbidity and mortality in Kosovo. In 1999, when UNMIK assumed governmental responsibility in 1999, WHO became the coordinating agency for health. To advise on TB and develop an NTP, WHO established a TB Commission, with representatives from the Kosovar TB clinical community, IPH, WHO, and DOW.

DOW took the lead role in strengthening TB control in Kosovo and helping implement the TB Commission's five-year Action Plan. In partnership with the Kosovo NTP, DOW continues to address the needs of current TB patients and to reduce province-wide incidence of TB. During DOW's intervention period, substantial improvements have occurred in the TB situation in Kosovo, with clear positive impacts on treatment and case finding in minority areas.

Providing access to adequate TB treatment for these minority groups became an essential element of the DOW program. DOW introduced a comprehensive and innovative set of interventions, including setting up TB facilities in two minority enclaves, training doctors and nurses in directly-observed treatment (DOTS), and including minority communities in the Kosovo-wide health education program.

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12. This is a rough estimate, as it is suspected that not all cases were being reported.



*Esmerelda, a Roma woman (at left), reported that the DOW Minority Area Coordinator's persistent home visits built the trust and support she needed to complete her treatment and be cured.*

### **TB Data for Minority vs. Majority Populations**

Minority areas included in cohort data reports include Zubin Potok, Strpce, Leposavic, and North Mitrovica. Since the initiation of DOW interventions in minority areas for patients and providers, the TB treatment success rate for minority communities has improved to parallel the success rates in majority areas. At the beginning of the interventions, the minority area treatment success rates were at 62%, as compared to an overall rate in Kosovo of 91%.

By early 2003, minority areas were reporting treatment success rates upwards of 80%. The intervention also stimulated greater case finding and case notification rates, which increased by 16% between 2001 and 2002 (from 92/100,000 to 107/100,000). Table 1 (below) shows the shift in incidence and notification rates, while Table 2 shows the treatment outcome rates over certain quarters.

Data shifts from 2001 to 2002 suggest increased incidence and notification rates due to active case finding by patronage nurses, as well as TB providers trained by DOW. Treatment success rates also improved for minority communities upon project implementation. Treatment outcome data from 2000 were not disaggregated for minorities because data were not collected according to WHO reporting guidelines.

**Table 1: Incidence and Notification Rates for Minority Areas vs. All Kosovo from 2001–2003**

Indicator	2001		2002		2003	
	Minority	Kosovo	Minority	Kosovo	Minority	Kosovo
Population	104,000	2,100,000	104,000	2,100,000	104,000	2,140,000
Absolute number of registered cases	94	1674	112	1443	54	1127
Notification Rate	92	80	107	69	52	53
Absolute number of new cases	75	461	90	402	44	1057
Incidence Rate	72	73	87	63	42	50

**Table 2: Treatment Success Rates for Minority Areas vs. All Kosovo from 2002–2003**

	2002				2003	
	1st	2nd	3rd	4th	1st	2nd
Quarters						
Minority	68%	87%	100%	78%	90%	80%
Kosovo	91%	90%	92%	89%	100%	87%

In Table 2 (above), treatment success for minorities includes both smear-positive and smear-negative patients because the number of patients is low. For Kosovo-wide data, only smear-positive patients are included.

### Setting Up TB Facilities in Minority Areas

The target beneficiaries for this intervention were minorities (mainly Serbs) who were unable to access the majority-Albanian health care system and were isolated from Serbian health care offered in the north of Kosovo. DOW selected two communities in which to set up or rehabilitate TB facilities: Laplje Selo and Strpce. These locations were identified on the basis of degree of isolation, high TB rates, pre-existence of some health care facilities, presence of capable doctors, and size of community. Laplje Selo served approximately 21,800 Serbs and 2,000 Roma from Pristina and Lipjan municipalities,<sup>13</sup> while Strpce served between 9,800 and 12,000 Serbs.<sup>14</sup>

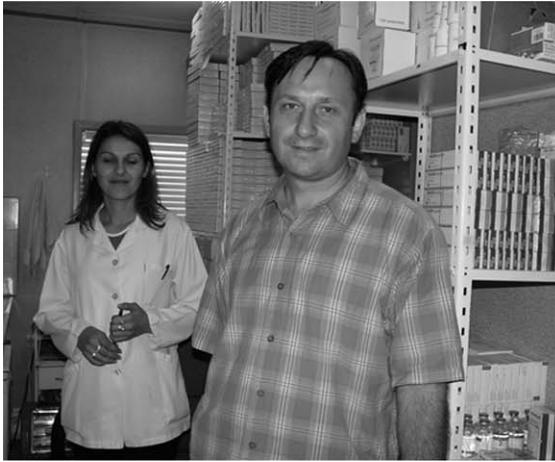
DOW also provided new equipment for the established TB health care facility in North Mitrovica, which served a population of approximately 54,000.<sup>15</sup> Initial contacts with medical staff in the Serb community were made and maintained by the TB Project Director. Contacts were based on relationships that pre-dated the war, and the minority doctors' subsequent moves to minority enclaves from facilities in Pristina. The primary contact was made between the TB Project Director and one pulmonologist, who has since become the coordinator for minority areas.

A key element in establishing functioning TB treatment centers in these areas was the participation of local medical staff. Medical staff from the majority Albanian community could not run the minority area centers, as there is a strict segregation along ethnic lines in the minority areas, so developing or rebuilding working relationships with Serb staff was an essential first step. The parallel health care system in the minority areas was,

13. Population assessment made by OSCE/UNHCR "Situation of Ethnic Minorities in Kosovo" 2001

14. Low estimate from KFOR population assessment in 2001, high estimate from current 2004 Strpce health house estimates.

15. Population figures for the North of Kosovo are highly politicized and it is difficult to ascertain their accuracy. These figures cover the very approximate population figures for Mitrovica, Zubin Potok, Zvecan, and Leposavic.



*The DOW Minority Area Coordinator (right) meets with a dispensary pharmacist in Laplje Selo. Anti-TB dispensaries handle case management including: diagnosis, continuation phase treatment, management of patronage nurses, health education, and data collection and reporting.*

and remains, politicized. In order to work in this environment, a great deal of trust building is required. The initial relationships were personal, but in order to develop a functioning TB facility, an important second step was to expand initial personal relationships into a network of local staff that trusted the DOW model.

Local staff were instrumental in designing the facilities and adapting them to the needs and capacities of their communities, which was an extremely important part of developing trust. In addition, international consultants, who were perceived as being more neutral, carried out technical training. The building of trust has taken years and is an ongoing exercise. The bridges that were built during this program are unusual, and their success is a tribute to the doctors and their staff.

Additional challenges in maintaining and running these facilities include communication difficulties with minority areas, and difficulty in overseeing the implementation of the program from afar. Although fairly frequent meetings between minority clinicians, the TB Director, and other DOW staff were possible, these meetings were not always on-site, and direct monitoring of treatment was not possible. Computers and Internet access have now been provided to two of the three sites, which should facilitate regular communication, but monitoring and oversight remains an ongoing challenge and concern.



*DOW's Albanian TB Project Director (right) confers with a Serb pulmonologist at her home. The DOW Minority TB program is one of only a handful of programs in Kosovo where doctors and medical staff from minority areas are cooperating directly with the majority health care system.*

Doctors in minority areas face further challenges in transporting sputum for testing. At present, they do not feel secure using the labs in the Albanian areas, and need to transport the sputum samples some distance to North Mitrovica for testing. The difficulties in transport have meant that not all patients are given a sputum test prior to receiving treatment, contrary to DOTS recommendations. Efforts to locate an appropriate site for a lab in the minority areas have not yet been successful, and may be partly stymied by a lack of political will on the part of minority health authorities.

One issue yet unaddressed is how to make minority doctors in enclaves throughout central and eastern Kosovo aware of the two TB clinics in central and southern parts of the province, and the availability of these clinics for patient use. At present, knowledge of the two clinics is limited to their immediate surroundings, while their services could be made available to other communities.

TB drugs are now available free of charge throughout Kosovo. However, access to TB drugs remains limited in minority communities. Rather than accessing the drug supply available in Pristina, dispensary staff in minority areas are stocking their supplies with drugs from Serbia. This is a concern because the drugs from Serbia do not conform to standards, and supplies are erratic. Medical staff in minority areas appear to consider access to drug supply as politically weighted, which poses a significant problem to their patients.

### **Training of Minority Doctors and Nurses**

DOW trained doctors and nurses from all over Kosovo in DOT principles. The training, conducted by outside experts such as Dr. G.B. Migliori<sup>16</sup> and Dr. Max Salfinger<sup>17</sup>, included training in standardized treatment regimens of six to eight months for at least all sputum smear-positive cases, with DOT for at least the initial two months. Training also included modules on the *standardized recording and reporting system* that allows assessment of treatment results for each patient and of TB control program performance.

Two Serb doctors practicing in the Laplje Selo and Strpce facilities, and five nurses, practicing in Laplje Selo, Strpce, and North Mitrovica, completed the training course. Minority doctors and nurses who participated in the training are key implementers in the DOW program. However, they also consider themselves to be under the Serbian health system based in Belgrade, and feel they need 'clearance' from Serbian health authorities to attend trainings with other Kosovar health care practitioners. On occasion, this clearance has been denied, and can be considered a statement of the politicization of the health care situation in Kosovo today. While the use of outside (non-Kosovar) experts is more neutral than using local experts, now that Serbia has recently become a DOTS country, it may be possible to use experts from Serbia in training, which might decrease the tension with the Serbian health system authorities.

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16. Dr. G.B. Migliori is a consultant hired by DOW, and is the Director of the WHO Collaborating Center for Tuberculosis and Lung Diseases and Secretary General of the International Union Against Tuberculosis and Lung Disease (IUATLD) European Region.

17. Dr. Max Salfinger is a consultant hired by DOW, and is the TB coordinator for the Fogarty Grant Administration at the New York State Department of Health and Director of Clinical Mycobacteriology Laboratory at the Wadsworth Center, Albany, NY.

The training of nurses to set up and run a patronage nursing system was an essential part of the DOW program. Patronage nurses participate in TB patient contact tracing, treatment monitoring, providing DOTS, and patient health education. Additionally, they make home visits to patients. In the future, patronage nurse responsibilities will be transferred to primary health care/community nurses in an effort to integrate TB into primary health care. The DOW training provided nurses with tools to perform their patronage duties, as well as guidance on how to connect with patients on a personal level and establish trust. Participants evaluated the training positively, and the course's impact was evident in the field: better communication with patients resulted in higher compliance with drug regimens.

During the training, patronage nurses raised the issue of how best to reach rural patients. In Strpce, for example, rural areas reported the highest rates of TB incidence. Rural communities were often not served by public transport, and virtually inaccessible in the winter months. Patronage nurses were only able to access these patients by walking or hitchhiking, often for hours at a time. Additional support for patronage nurse travel is needed for the nurses to continue their work.

Educating nurses and doctors in methods of accurate and consistent reporting was a course priority. DOW provided clinics with detailed reporting instructions and identical reporting cards. Information from all TB facilities, including the three based in minority areas, initially flowed back to the DOW TB program, and now flows back to the National Tuberculosis Program Manager.

Treating patients in minority communities according to best practice guidelines is hindered by the mobility of these populations. Patients tend to travel to Serbia for extended periods, or migrate due to security concerns. Unfortunately, these migrations often lead to the interruption of health treatment. It is difficult for doctors to maintain contact with patients when they move, and because record-keeping and information are not currently shared with Serbian health authorities, doctors sometimes have no way to check if the patient is following the appropriate health care guidelines under another doctor's care in Serbia.

There is no fail-safe method of tracking minority patients' movements in and out of Kosovo; this continues to be a challenge for all three minority clinics, in North Mitrovica, Laplje Selo, and Strpce. Interestingly, tracking is also a concern for the hospital in Gjilan, where Albanian speakers from the Preshevo Valley in Serbia cross the border into Kosovo for TB treatment. In these cases, health authorities in Serbia are not informed, and it is possible that doctors in Serbia experience similar problems tracking their patients.

*"If this program had not been implemented, patients would have had to make their way to the health house themselves. In 1999, only those who could come in were treated—there were no home visits. I'm not sure what would have happened to all the patients if this program wasn't here."*

—Patronage nurse,  
Strpce, Serb minority  
area

### **Health Education**

Based on the results of the Knowledge, Attitudes and Practices (KAP) survey conducted in 1999, and refined by the KAP survey of 2001, DOW staff developed a health education program aimed at reaching three target groups: patients, youth in schools, and the general public. The comparison of results of the first KAP survey (November 1999) and the results of the second KAP survey (August 2002) show that by 2002, patients had a much higher level of knowledge about TB, down from 33.3% of patients who did not know any symptoms of TB to 0% of patients. Results of the first KAP



*A DOW-trained nurse conducts a TB patient education session. The program's education initiative taught patients how to recognize TB symptoms early and emphasized the importance of complying with treatment regimens.*

survey showed shame as a major barrier to treatment, with 12.9% of patients claiming that TB is a shameful disease. The second KAP survey showed shame as less of a barrier to treatment, with only 2% of patients calling TB “shameful.”

The goal in providing health education to TB patients was to educate them about the disease, their treatment, and give them an understanding of their responsibility as patients. In order to target patients, DOW developed videotapes, brochures, and handouts to be used both in the hospital setting and during home visits. Key health education messages focused on increasing TB knowledge among both patients and the general population, regarding early recognition of TB symptoms, treatment regimens, the availability of free drugs, preventive measures, and stigma.

Nurses directly involved in caring for TB patients served as key implementers of the education component. DOW trained minority nurses in TB health education during a course held in Brezovica, in the Strpce minority enclave. Both DOW Albanian staff and Serb staff planned and facilitated the course together. It was the first joint exercise for minority health professionals held in Strpce. Nurse participants returned to their hospitals and were charged with training other nurses involved in patient care.

To reach minority communities, DOW provided Serb nurses with patient materials in Serbian. Nurses used the materials to test patients' knowledge of TB at the end of their stay in hospital. Test results informed further patient education, and refined the nurses' health education methods. Nurses were also trained to target family members at health education sessions in the hospital and in the home. Almost all patients (94%) reported receiving health education information in the hospital, and 100% of patients said education helped them to understand TB.

The intensity of the health education program varied from site to site, with some nurses participating actively, and others less so. Problems that arose concerned resource allocation and nurses' motivation. Nurses in some sites wanted to do additional health education workshops in minority communities, but were restricted by lack of resources. Nurse motivation was connected to the fact that the health education sessions were quite lengthy, and nurses were expected to perform the education duties in addition to all other duties, without additional compensation or consideration of the impact on their other work.

*“I would like to go into schools and health houses, to do health education workshops, but I would need a vehicle, and more brochures to do this. If we had more resources, we would be able to go further with the health education.”*

—Serb Nurse,  
North Mitrovica



*A Serb patient (left) and son meet with a patronage nurse (right). Nurses trained by DOW made regular home visits to ensure compliance with TB drug regimens.*

A second approach to health education was carried out through school-based workshops designed to educate youth about TB. DOW piloted this project in five schools, and continued in regions with high incidences of TB. Teachers, trained at DOW sessions, taught modules in classrooms with the use of brochures, a comic strip, and posters. Schools were chosen based, in part, on the percentages of minority children enrolled. However, schools within Serb minority communities, which follow a parallel education system, were not included in this effort.

To reach the general population, DOW produced informational TV and radio spots, newspaper advertisements, posters for health clinics and other areas, and participated in health education campaigns including International Tuberculosis Day. Key messages included: "Let's Fight TB Together" and "Act Today, Tomorrow is Too Late: Protect Your Family, Treat TB."

Though posters in Serbian were made available to minority TB clinics, efforts were primarily geared toward the majority Albanian population. While the impact of these programs on the general population can be seen in the changes in TB awareness levels (as measured by the KAP survey results from 1999 to 2002), indicators are not yet available for minority communities because minorities have not been included in KAP surveys.

DOW recently started a pilot program with a local NGO, Health For All<sup>18</sup>, targeting the REA community around Pristina. Health For All works on health education programs, through a system of peer education. It is too soon to say what the impact of this program will be on awareness levels of TB in the REA communities, but peer education with local staffers has proven particularly effective in increasing knowledge and influencing behavior within minority communities, as part of DOW's reproductive health project.

*"When I was in hospital, and after, I received some brochures and some information about my lungs. The patronage nurse who comes reads them together with me."*

—Elderly Serb patient, Strpce

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18. Health for All was created by DOW as part of its Minority Health Project, funded by the Open Society Institute. It is the only local NGO operating in Kosovo that works with REA communities.

### **Costs**

The cost of the minority program from October 2000 to September 2004 was approximately \$25,500 per year, for a total of \$102,000, which represents roughly 5% to 11% of the budget for the total TB program per year. These costs include salaries, materials, and training, and are estimates based on separating out minority costs often included within majority programs. It is difficult to disaggregate costs of minority area activities because most of the trainings were integrated. In all, DOW received and invested close to \$1.7 million toward building TB facilities, infrastructure, human resource, and technical capacity in Kosovo between 1999-2004.

### **Next Steps**

DOW's TB program is in the final stages of being subsumed under the NTP within the Ministry of Health based in Pristina. The handover includes parts of the minority program, such as the health education component, but DOW will retain advisory capacity for minority concerns. In the next year, DOW will provide technical assistance in a few key areas that will be handed over to the NTP at year-end. These include: strengthening the case detection system through active case finding, quality control for direct smear and health promotion in minority areas, support to monitor the Pilot DOT sites in Ferizaj, design and implementation of a TB multi-drug resistance survey in collaboration with the NTP and WHO, and support for the NTP to manage these activities. DOW intends to partner with the NTP to implement key activities under the Global Fund to Fight AIDS, TB, and Malaria grant recently awarded to Kosovo.

# Discussion of Results

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The DOW TB program's integration of minority areas in Kosovo led to several successful outcomes, including:

- establishing cooperation between majority and minority health care systems;
- lowering TB incidence rates in certain minority areas;
- improving TB-related treatment seeking behaviors;
- increasing equality of access to TB treatment as measured through improved case finding and successful treatment; and
- lowering the stigmatization of TB amongst the Kosovar population.

The intervention was also followed by a *16% improvement in case notification rates over one year and an 18% increase in treatment success rates for minority areas.*

Overall, after initiation of activities in minority areas, both incidence and notification rates saw an increase and eventually paralleled the rates for all provinces in Kosovo. The drop in incidence and notification could be a result of better treatment success, as well as accessibility to services, to identify the disease and then to treat it. However, not discounting the difficulty of working within minority communities, DOW plans to initiate an active case finding project in minority areas in the next year. Some observations on the nature and context of these successes follow:

*First, the DOW Minority TB program is one of only a handful of programs in Kosovo where doctors and medical staff from minority areas are cooperating directly with the majority health care system. This achievement is significant—trust-building activities, close cooperation, and flexibility were essential in reaching it.*

*Second, the access of minority patients in Strpce, Laplje Selo, and neighboring Gracanica to TB treatment has been much improved by the program. The training of doctors and nurses, as well as implementation of the patronage system, has made it possible for patients to be cared for and cured without strenuous journeys to North Mitrovica or Serbia, some of which patients would not have been able to complete. In a two-year period, 78 cases were seen in Strpce and 81 cases in Laplje Selo, which accounts for almost all the registered cases of TB from minority areas. Many of these cases were older cases, which had not been treated since before the conflict in 1999. In addition, the doctors report a low relapse rate and a low rate of new cases. At present, there are four active cases in Laplje Selo and two new cases in Strpce.*

*“The doctors here in the [dispensary] are different than the other doctors in the surgery—to get therapy or help there, you really have to push, but here they are different. They really want to help, and they have a different message for the patients.”*

—Bosniak Man,  
former TB Patient,  
Prizren

*“The health education of the patients has really helped and had a positive influence—I have new TB cases brought in by former TB patients. That wouldn’t have happened before.”*

—Doctor,  
Peja Hospital

The patronage nursing system in particular had a significant impact in the minority areas. The minority clinician in Laplje Selo reported initial patient resistance to treatment, but patients’ confidence and trust have increased along with the visible success of the program and as a result of health education efforts. The training also appears to have had a positive impact on providers’ relationships with patients.

More could be done, however, in informing minority general practitioners of the TB minority program, to ensure a timely diagnosis and treatment of the patients.

Third, the health education initiative has had a *significant impact on the health and behaviors of patients*. Patients report feeling much more confident in their treatment, and have a better understanding of the importance of the drug regimen. The impact of health education has also made patients more confident in discussing TB with individuals outside the hospital and their immediate family. This is important to note, as the stigma attached to TB patients remains high in Kosovo and contributes to patient concealment of the disease.

Last, the program has *increased equality of access for minorities* in general, but access remains uneven across three minority sub-groups living in different settings. The first group—minorities who have no or a few manageable problems accessing the Albanian health care system<sup>19</sup>—reported no specific complaints about the TB health staff but expressed some feeling of insecurity or discrimination when accessing health care. This discrimination should be a concern for the TB program if it acts as a barrier to minorities seeking TB treatment within the majority health care system.

A second group<sup>20</sup>—composed of minorities living primarily in enclaves who cannot access the Albanian health care system—reported greatly improved access to TB health care as a result of the facilities, doctors, and nurses in the TB clinics in Laplje Selo, Strpce, and North Mitrovica. Members of this group identified care offered by the DOW-trained nurse and the lab technician in North Mitrovica as particularly beneficial.

A third minority group has not yet felt any positive impact from the DOW program. This group includes Serbs living in enclaves in other regions of Kosovo, isolated REA communities, and REA communities living within Serb enclaves who have difficulty accessing health care through the Serb parallel system. For example, the Serbs in the Gjilan region (currently estimated to number approximately 25,000<sup>21</sup>) live in rural communities, and access health care primarily in their own community or in Serbia directly.

In the communities of Silovo and Gornje Kusce, doctors and nurses report not having contact with any TB program within Kosovo, the DOW program in Laplje Selo, or the parallel health structures in North Mitrovica. Patients

19. This group includes groups such as the Bosniaks in the Peja and Prizren regions, the Turks in the Prizren region, and some REA communities, primarily Albanian-speaking Ashkali groups.

20. This group is composed mainly of Serbs and Serbian-speaking Roma communities in Gracanica, Laplje Selo, and Strpce.

21. Taken from Kosovo estimates provided by the Coordination Centre (Government of Serbia), *Principi organizovanja samouprave nacionalnih zajednica na Kosovo i Metohiji*, Belgrade, January 2003.

*“We have TB here, 5 or 6 cases. They are diagnosed in Serbia, in Vryana, but the patients come back here to follow up on their treatment. The number of cases is growing as the economic conditions here decline.”*

—Serb doctor,  
Silovo, Gjilan region

*“I told my neighbors when they came to visit. They asked about my sickness, and I talked to them about my TB. I told them what the doctors and nurses had told me, and my treatment and everything.”*

—Turkish man,  
former TB patient,  
Prizren

are either sent to Vryana, in Serbia, or treated in the small health houses available in the communities themselves. To date, these communities report having received no help, health education or materials. Other enclaves report similar situations. This group also includes Roma communities within the Serb communities, or in isolated enclaves or internally displaced person (IDP) camps, who continue to be severely isolated and have little to no access to adequate health care. While the minority program focused on Serb enclaves in the center of Kosovo, a similar intensive outreach to the REA communities was not attempted.

### **Impact on Stigma**

The impact of the program on the stigmatization of TB is hard to measure. KAP surveys have not yet been conducted in minority communities, and evidence for impact remains anecdotal. The stigmatization of the disease remains a problem in Kosovo in general, and particularly in the minority community. The DOW TB program has tackled this issue through the public awareness campaigns, and health education campaigns in two languages.

For the minorities living within majority communities, there appeared to be a positive impact on how patients thought about themselves and their disease. Some became unofficial educators in their communities, speaking openly about TB and their experience.

Patients in the enclaves were more reluctant to discuss their disease, and in some cases, would not refer to TB by name, but simply mentioned a ‘lung condition.’ This could be due to the fact that public awareness campaigns have had less impact in the minority areas, because the reach of TV, radio, and newspaper ads into these communities is limited.

In general, patients within minority areas seemed to have much higher levels of shame, and indicated that they did not tell their neighbors or speak of their disease openly. This reluctance was related to the perception of the disease in the community at large.

In some communities, notably among the Ashkali, individuals spoke of the stigma of TB being particularly high for young people. To be known to have lung problems within the REA community could have a negative impact on the marriage prospects of young people.

However, by comparison, the stigmatization of TB patients was greatest in minority communities in which the DOW program was not active. In one of these communities, a doctor reported that patients would only speak to one trusted doctor or nurse, and would not even accept medication from any other member of the medical team.

Overall, despite the successes of the program, the implementation of the DOTS strategy in minority areas continues to lag behind majority areas. Inaccurate reporting and non-standardized drug usage are particular areas of concern.

*“The neighbors would come and visit us after I got back from the hospital, but I didn’t get into the disease with them, or other people. With my family, yes, but not with my neighbors—they would go away and stop visiting me.”*

—Roma woman,  
former TB patient,  
Laplje Selo

*“Stigma is very large in this community, even with regard to patient relations with medical staff. Patients will only come to see me for their drugs—if I’m not here, they won’t even say why they’ve come to any other nurse or doctor.”*

—Serb doctor,  
Silovo, Gjilan region

## **Monitoring & Evaluation**

The monitoring and evaluation of the minority program has been a challenge. DOW implementing staff are Albanian, and while they have successful working relationships with the doctors and patronage nurses, they only have partial access to the minority communities themselves. Implementation has been done primarily through minority clinicians, but oversight in the field is less than optimal. The program was assessed by both DOW TB staff and outside consultants and experts through periodic field visits. Consultants included Dr. Lisa Adams<sup>22</sup>, Dr. Migliori and Dr. Salfinger.

The consultants made recommendations for follow-up and specialized trainings for key individuals within the Ministry of Health, the use of survey results as a management tool, consolidation of data and project reports, and guidelines for maintaining and updating the TB data registry. They also recommended a more focused review of data from minority areas, dissemination of WHO guidelines in Russian or Serbian to the minority area coordinator, engagement in health education activities in minority areas, and improvement of monitoring of the transfer of sputum samples from minority areas to Pristina for analysis.

Continuous monitoring and evaluation were also a challenge for the health education program. The DOW health educator implemented a monitoring system for the majority areas that included scheduled and impromptu field visits to oversee the quality of health education sessions. However, access to the areas where minority nurses were working was difficult for DOW Albanian staff, making unscheduled field visits to health education sites impossible and monitoring and evaluation far more limited. Monitoring had to rely on reports written by the nurses themselves, who reported their own progress from the field.

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22. Dr. Lisa Adams is a TB consultant hired by DOW and is an instructor with the Department of Community and Family Medicine, Dartmouth Medical School, Hanover, NH.

# Success Factors/ Lessons Learned

Minority populations often have higher incidences of TB or less access to TB treatment due to exclusion from the health system, and can become scapegoats for the disease in the general community. Strategies must be adapted to specific minority communities to address these concerns within their community and within the larger community as a whole. Access of minority communities to health care always needs to go beyond simply making services available—services need to be available in a manner engendering trust in the minority communities. Furthermore, these services need to be integrated in the main health care system for them to be sustainable, and for the majority community to feel responsible for their success.

From DOW's experience in Kosovo with the Minority TB Program, it is clear that different minority communities can be approached successfully in different ways. Communities can be successfully targeted both through making majority services more inclusive and accessible to certain communities, and by targeting isolated communities with programs specifically for them, located and managed within their communities, but tied to the overall TB network. The DOW TB Minority Program manages both to include certain minorities in the majority health care system and provide TB treatment for those minorities unable, for security reasons, to move beyond enclaves at a trusted local community level, yet integrated in and with oversight from the national level. It is essential to maintain trust between the local and national levels on an ongoing basis, particularly in this period of ethnic uncertainty in Kosovo.

Minority populations often have higher incidences of TB or less access to TB treatment due to exclusion from the health system, and can become scapegoats for the disease in the general community.

*Minority populations often have higher incidences of TB or less access to TB treatment due to exclusion from the health system, and can become scapegoats for the disease in the general community.*

DOW's close working partnership with the Institute of Public Health was key to the successful development and implementation of the program. The personalization of professional relationships can be a bonus when these add to the trust of the program, but may also detract from the program if individuals leave or are unable to maintain that personal level of contact.

In dealing with minority community issues, health programs, regardless of their intent, may become politicized. The DOW TB Minority Program has faced several persistent challenges to smooth operation, such as difficulty in monitoring and evaluation, dual reporting of minority staff to two health structures, stocking of drug supplies through Serbian channels, and limits to minority staff access to majority events and training. Many of these challenges are ultimately political challenges, and their successful resolution may lie beyond the scope of one NGO's programming capabilities.

To fully integrate minority TB clinics into the majority health care system, political will must be present within government ministries in Belgrade and Pristina to harmonize the current disparate health care systems in Kosovo, and provide equal health care for all. This does not imply that creative solutions should not be sought at a local or community level, merely that these efforts must be complemented by progress at a higher, political level.

One key element in the success of the program was *trust-building between the DOW doctors and their minority counterparts*. By approaching the problem of TB treatment in minority communities as a collaborative one to be solved by all parties, rather than by imposing a solution from outside, DOW was able to build a program suitable for the communities and build long-term trust, essential for sustainability. In addition, DOW worked with experts from outside the region who could provide a more neutral face for training, assessment, and program development.

Another element of success was the *emphasis on health education*, particularly with the patients themselves. This element contributed directly to the success of the program by improving patients' awareness levels, compliance levels, and understanding. It also contributed to patient-doctor relationships and nurses' buy-in, as they saw the direct impact of their work.

A final lesson is that although the establishment of TB clinics in certain areas has impact directly in that region, links with other nearby minority communities are not necessarily made without a great deal of conscious effort and deliberate programming. Efforts need to be made at a local level on a community-by-community basis to spread the success of specific regions more widely.

*Major elements of this program could be replicable in other countries and regions.* The model of working with minority communities on a local level—with local staff providing services individually tailored to the community but maintaining international standards and ensuring integration into national health structures—is one that can have impact elsewhere. Further, providing health education in minority communities in specifically tailored programs, designing materials to meet local needs, has an impact on the overall awareness of the community. It is also important to find and provide a neutral ground between minority and majority communities to allow minority programs to concentrate on provision of improved health care, rather than ethnic differences, and to train each community in methods to find neutral ground on their own.

# Conclusion

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Minority communities in Kosovo are particularly vulnerable to TB due to their isolation and corresponding lack of access to health care. Continued ethnic tensions in the region, combined with political pressures from above, have provided very real challenges to the establishment of a TB program for minorities that is integrated into the national TB program but still successfully addresses the needs of its constituents.

The DOW Minority TB Program has tried to emphasize equality of access to health care and minimize political and practical concerns to produce a locally run program to lower TB incidence rates in minority communities. The program has successfully established cooperation between majority and minority health care systems, increased equality of access to TB treatment, improved health related behaviors, and lowered the stigmatization of TB amongst the local population.

Overall in Kosovo and in minority areas, TB case notification and incidence rates have decreased since the project's inception. Although baseline data are not available (data were not recorded due to WHO reporting guidelines), the figures presented in Table 1 and 2 show that providers were successful in identifying TB patients and in treating TB in those who were identified, reporting treatment success rates of 80–100% in the last year of project implementation.

These results, however, are not static, and success will depend on continued efforts to maintain and improve links with minority communities through collaboration, cooperation, and a concerted outreach effort. Further, rigorous efforts to improve standards in operation, reporting, and training, need to be maintained to provide minority communities with the same level of health care enjoyed in majority areas.



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