"This is the moment of happiness when I realized that I was getting better. Before, I couldn't even hold his hand to help him walk. When I threw him in the air, I was thrilled!"

Saleem Ahmed, 27 year-old male, TB patient



GOOD PRACTICE Round 4

Stop TB Partnership Challenge Facility for Civil Society

Financial support to community initiatives for positive change

CHALLENGE FACILITY FOR CIVIL SOCIETY (CFCS)

Supporting communities

CFCS awards grants of up to US\$ 20,000 to grass-roots and community-based civil society organizations that give a voice to people with TB, groups affected by TB and communities that are involved in TB prevention, treatment and care. Proposals are selected by an independent selection committee composed of individuals from communities affected by TB, NGOs, multilateral or technical agencies.



The Challenge Facility has awarded US\$ 1.8 million for 99 grants to CBOs in 37 countries to date.



Challenge Facility objectives

Communities can play a crucial role in improving their own access to health services and in the effective delivery of healthcare in general. Although this role of communities will never replace or match the national delivery of health, it can and does act in synergy with the national systems to improve access for marginalized groups, maintaining contact and referral to health services and ultimately creating a highly effective network of health interventions and community health systems.

In order to deliver on its mission, the CFCS aims to assist community-based civil society organizations by building capabilities of members of local communities, empowering individuals to understand and demand for their rights and assume their responsibilities.

Donors

We would like to thank the donors of the Stop TB Partnership for their generous support of the CFCS. Without the continued financial support of the World Bank, the United States Agency for International Development, the Lilly MDR-TB Partnership, the UN Foundation and the United Kingdom Department for International Development, the programs described in this document would not be possible. The Stop TB Partnership Secretariat is sincerely grateful for their support.



ROUND 4 GRANTS

In its fourth year (2011) the CFCS awarded 21 grants to recipients from all over the world. Grantees used this funding for varied purposes and the essence of the diverse activities can be captured in the following themes:

- mobilizing youth
- establishing and strengthening networks
- policy change and political commitment
- serving high risk groups.

Activities of grantees resulted in:

- increased number of actively involved TB advocates
- involvement of people affected by TB into decision making processes and bodies at different levels



 increased feedback to Stop TB Partnership bodies about the challenges, problems and achievements of TB interventions in the area where they are operating.

COST OF INACTION

Summary of Results from CFCS Round 4

Number of beneficiaries reached in total	82,126
Number of trainings organized	88
Number of community volunteers trained	1,042
Number of TB and ex-TB patients involved in planning and implementing activities	387
Number of meetings held with decision makers	74
Number of people referred for TB testing	18,190
Number of persons that tested positive for TB	1,898
Number of PLWH tested for TB	629
Number of patients in TB treatment	1,190
Number lost to follow-up during treatment	456
Number of people reached through media (not including print media)	665,000

Without dramatic increase in funding for communities





MILLIONS OF CHILDREN will be orphaned



TB is curable but still kills three people every minute

SERVING HIGH RISK GROUPS



Anti-AIDS Voice, Russia

People mobilized by Anti-AIDS Voice reached out to socially closed groups, such as sex workers, prisoners and drug users to disseminate information concerning prevention, diagnostics and treatment of TB. An important result of the grant was the improvement of conditions for vulnerable groups and the provision of social support to them. The project resulted in the establishment of a constructive dialogue between physicians and a task force that helped with the treatment of patients, which led to an overall reduction in the TB epidemic among these vulnerable groups.

Indus hospital, Pakistan

This grant had two major components targeting members of the disadvantaged Korangi community: a photovoice project and a communications campaign. The photovoice project involved TB patients, their family members and TB treatment supporters who were given cameras and asked to take photographs depicting their experiences and challenges. These photographs were then discussed in group sessions with other participants and showcased at a gallery event that was attended by over a 1000 people including policy- makers, community members, practitioners working in the field of TB, the participants and their families.

The communications campaign (TV ads, billboards, flyers, and a street theatre event) raised awareness about TB, helping clarify misconceptions and address stigma surrounding the disease. Moreover, this campaign was very effective in bringing referrals to the Indus Hospital and its partner clinics. In the approximately two months of the campaign, 434 people with symptoms of TB (15% of all TB suspects) surveyed at these sites reported having seen or being told about the billboards or TV ads as their source of referral for treatment.

Centre for Legal Assistance (CELA), Malawi

This project addressed the problem of congestion and the resulting spread of contagious diseases like TB in the Malawian prison community, where separating healthy prisoners from sick prisoners was a challenge. CELA improved the situation by securing funds from The Royal Norwegian Embassy in Malawi to construct two additional blocks as sick bays for TB patients at Maula prison and thus reducing congestion. The CFCS grant enabled CELA to initiate more programmes such as the identification of prisoners to serve as Prison Based Educators (PBEs) in the targeted prisons. The PBEs assist in monitoring, reporting, and raising awareness among other prisoners so that all cases of TB are well attended to, treated and registered. More than 2700 prisoners were screened for TB in seven prisons.

Additionally, the prison officials have also shown interest in being included in TB projects as they realize that they are equally vulnerable and even more exposed to the infection because of their interactions with prisoners with tuberculosis on a daily basis.

Due to CELA's initiative to combat TB in prisons, many stakeholders like national TB officers, faith-based organizations, the media, etc. have joined hands in exposing challenging issues that are affecting prisoners. Nonstate actors have donated food for TB patients and media personnel have also joined awareness raising initiatives. Moreover, the judiciary system now shows a willingness to prioritize cases of TB and terminally ill prisoners when they are brought to their attention.

VOICES FROM PEOPLE AFFECTED BY TB

Saleem Ahmed Solangi, Pakistan

Saleem Ahmed Solangi (picture on cover page) is a 28-year old male from a village near Larkana in the province of Sindh in Pakistan. He was the sole financial supporter of his family but after he got sick in early 2011, he was unable to support his wife and son, send money to his parents in Larkana, or pay for his younger brother's education. So Saleem moved back to his village and visited numerous doctors with complaints of high fever and weakness. He was diagnosed and treated for various ailments such as typhoid and hepatitis but his illness did not get better. After a couple of months, his elder brother brought him and his family to Karachi in search of a cure.

Saleem was taken to the Indus Hospital TB Clinic where he was finally diagnosed with abdominal TB. "I was very afraid of TB. In our village in Interior Sindh, TB patients face many difficulties because people isolate them." However, to his surprise, the doctor who addressed his concerns made him feel more confident in his determination to complete his treatment. While on treatment, Saleem joined the Tasweer-e-Zindagi project, a Photovoice project conducted at the Indus Hospital. Saleem enthusiastically took photographs and enjoyed the group discussions. He explains: "It felt good talking about the difficulties I faced during my illness. With our photographs, we were able to show the world through our eyes, how helpless a TB patient becomes and the problems they encounter." He was touched that there were people out there who felt close to him and were interested in hearing his story.





Jackson Masunga, Tanzania

Jackson Masunga is a 43-year-old truck driver from Marimbe village in Tanzania. Jackson had refused to go to the hospital after seeing a herbal therapist who led him to believe that he had been cured of HIV. He was also told to not take any medicine for another six months and he threw away the medicines he had received from the hospital, including his treatment card. However, his health soon worsened and he developed AIDS, lost weight, cough up blood and developed a fungal infection. During a door-to-door campaign, Sinza Youth Peer Educators met Jackson and motivated him to continue treatment and provided him with counseling, support and encouragement. They also referred him to the hospital for testing where he was diagnosed with TB. Doctors initiated treatment for TB and after two months put him on second line treatment of ART. Jackson's health improved and he testifies that SIYOPE workers helped and strengthened him immensely.

Rwanda Pharmaceutical Students Association (RPSA), Rwanda

This organization promoted education on TB and the effective use of TB drugs in rural communities through a network of trained pharmaceutical students. These volunteers focused on educating and empowering young people in rural areas to create 30 anti-TB youth clubs, with 750 members in total. The clubs promote TB prevention and serve as information points in their respective communities.

RPSA also helped the youth clubs to establish income generating activities, such as rabbit rearing, bee keeping and rice growing, in collaboration with local partners. The skills gained and the financial independence, not only helped the clubs improve their health and living standards, but also developed their social status, and thus their recognition among the community.

The project not only promoted TB know-how but motivated young people to become role models in their own communities, thereby reaching a far wider audience with TB prevention messages and promoting the sustainability of the initiative.

RPSA empowered young people to become catalysts of change within their communities to overcome crucial health barriers including TB.

MOBILIZING YOUTH

4 SUNDAY, JULY 3, 2011



Nagoke Youth HIV/ **AIDS Initiative** (NYAI), Uganda

NYAI worked to strengthen the capacity of young people to advocate for integrated TB/HIV services so as to enable the community to freely access treatment services. By strengthening the relationship between youths in Nagoke and the health service providers, NYAI aimed to fight stigmatization and discrimination of TB patients that were causing patients to drop out from treatment regimens, resulting in development of MDR-TB. NYAI successfully formed partnerships with 30 service providers from six health facilities so as to establish a referral system. They conducted outreach activities through drama groups in schools and communities to sensitize the public. Through public events and outreach this programme was able to reach over 9000 people in 24 communities.

Sinza Youth Peer Educators (SIYOPE), Tanzania

SIYOPE launched its project to educate youth about TB and to reduce myths and misconceptions that contribute to stigmatization and discrimination of people with TB. They facilitated the formation of TB support groups and forums where young people living with disease, treatment providers, leaders and community members met regularly to discuss emerging TB/HIV challenges. These support groups were instrumental in empowering youth to not only understand and advocate for TB/HIV services but also to inform others about the services. SIYOPE mapped the integrated service situation on TB/HIV and shared the report with members, partners, health providers and other stakeholders. Moreover, they were able to develop a community based referral system in collaboration with 20 health service providers.

POLICY CHANGE AND POLITICAL COMMITMENT

Djibouti Treatment Access Movement (DjiTAM), Djibouti

The CFCS grant enabled DjiTAM to build trust between civil society activists and health officials. By encouraging community-driven advocacy and engaging with the ministries, DjiTAM was successful in getting an accessible and decentralized treatment system in Djibouti, including the establishment of an additional DOTS center. This raised the number of DOTS centers in Balbala district to four, alleviating the pressure from the three previously existing centers. Furthermore, this project strengthened community ownership of health care systems by setting in place a treatment guardian system under which new patients nominated one family member to be their treatment guardian for the



duration of the treatment. Involving families in the treatment not only strengthened the support system for patients but also brought about a positive behavioral change among a large portion of residents who used to avoid and segregate TB patients.

Svecha, Russia

Svecha mapped problems in the field of TB/HIV drug abuse co-morbidity by setting up an association against TB among HIV-positive people. One of the important outcomes of the grant was mapping the risk of TB among injection drug users and collection of data on prevention, diagnostics, treatment and post-treatment surveillance available in St Petersburg. Data from the mapping survey indicated that at least 65% of injecting drug users in St Petersburg had at least one symptom of TB. This data was used to advocate for the inclusion of a revised early detection policy of TB in harm reduction programs at the city level. As a result, social work has become a part of the services provided at medical units for patients with TB/HIV co-infection.



OMEGA Project Management Foundation (OPMF), Ghana

OPMF developed a community-based service delivery programme to train community peer workers to serve as treatment supporters. The grant was patient-focused and family-centred to break socio-cultural barriers that were obstructing demand for TB and HIV services. OPMF met the chiefs and elders in the community to address stigmatization and discrimination of TB patients. OPMF also conducted advocacy meetings at the district level to improve the availability of TB diagnostics in laboratories, to increase involvement of civil society organizations in meetings of health committees in the district, and to test and confirm patients as being TB negative before discharge.



OMEGA fostered a strong relationship with the Ghana Health Services to ensure that the integration of TB, HIV and Malaria activities was effectively coordinated through referrals and was sustainable. The programme resulted in increased case detection.

Philip, Ghana

Philip, a young boy of four and a half years, is the only son of a couple in their forties. In fact, he is their only hope for inheritance and support in the future. Philip was always in the company of his mother, a health activist. OPMF project team first set eyes on Philip during the training of selected volunteers by the Ghana Health Service. A week after the training workshop, the mother brought Philip to the facility for sputum examination in an attempt to screen for TB. Everybody was surprised. We all saw him cough during those two days of workshop but little did it occur to anybody that Philip could be a victim of what the training was about: TB. Many confirmation tests were conducted to be certain about the diagnosis as Philip was so young and was otherwise healthy to have TB. The mother of Philip stared at him when she was asked how she felt knowing he is TB positive and tearfully



she proclaimed, "I am so happy I detected it early enough, otherwise I could be losing him".

As part of his treatment, Philip was tested for HIV. To the amazement of the testing officer, Philip was also HIV positive despite both his parents being HIV negative. Counseling proved powerful when the couple smiled and said `all was not lost and that they will not lose him to HIV or TB'. Philip has finished TB treatment successfully and he is in school as the usual happy boy with glad parents watching him grow.

International Community of Women living with HIV/AIDS Eastern Africa (ICWEA), Uganda

ICWEA addressed the urgent challenge of TB/HIV co-infection, focusing its efforts on women in Uganda. The organization trained a core group of 24 women advocates at community level performed services such as conducting health talks, carrying out home visits, referring potential cases to health centres and following up TB patients who had defaulted on treatment.

With the knowledge of TB and TB/HIV policies given, these advocates were able to successfully engage health care service providers and policy-makers to work towards increasing the accessibility and availability of the TB and TB/HIV services for women.

The women advocates were not only able to understand the TB, TB/HIV policy framework that exists at country level, but also carried out a monitoring exercise to identify key challenges and barriers for women's access to TB services and gaps in service



delivery. They were able to document the gaps, challenges and best practices of health facilities and passed these to policy-makers to bring about following changes: nine additional health centers in Mubende district, improved lab services (recruitment of more laboratory staff, provision of reagents and ensuring that every health center has laboratory services) and integration of TB screening at all points of entry into health care at Mubende Referral Hospital.

This grant has enabled ICWEA to ensure that the commitments made by the government to provide quality care to people living with HIV and women are translated into action and implemented through the health service delivery.

ESTABLISHING AND STRENGTHENING NETWORKS



Asociación de Personas Afectadas por Tuberculosis del Perú (ASPAT), Peru

This project achieved the establishment of the "Lima Declaration" for the fight against TB in Latin America and the Caribbean during the First Latin American Forum Against TB that took place on 17 and 18 November 2011. It is the consorted result of technical, academic, economic and human efforts unfolded by the different sectors of society that met at the Forum that aimed to stop the advancement of the epidemic in the region. The event united organizations of people affected by TB and other participants from 6 countries: Bolivia, Brazil, Colombia, Ecuador, Paraguay and Peru. Representative from the national and local government, international cooperation agencies, international organizations of health and development, NGOs, academic institutions, professional associations, social organizations and religious institutions also participated in the event.

Organizations of people affected by the disease were helped to articulate public policy guidelines on prevention and comprehensive health care within a framework of respect for human rights.

Afterwards, Peru elaborated a policy of integral fight against TB called "Law of prevention and control of Tuberculosis" as a follow up to the commitments made by the government at the Forum.

Community Initiative for Tuberculosis, HIV/AIDS & Malaria (CITAM+), Zambia

CITAM+ focused on strengthening partnerships between CSOs, Ministry of Health, medical stores and the District Health Management Team (DHMT) in delivering TB and HIV services. Policy dialogue meetings with parliamentarians helped push the implementation of the National TB Infection Control Guidelines and resulted in the Minister of Health publicly committing to bail out four hospices that provide services to 16,000 people in Lusaka (see case study below). This grant made it possible for CSOs to work in partnership with DHMT and increas civil society engagement in monitoring the supply chain of TB drugs. Additionally, collaboration with the Ministry of Health resulted in civil society receiving two seats on the Joint TB collaborative body that is responsible for forming policies and writing proposals for country TB grants.

Moreover, to intensify case finding in four communities of Lusaka district CITAM+ trained 20 former TB patients as TB treatment supporters who conducted door-todoor outreach activities and community sensitization meetings resulting in over 1,100 people being referred to the health facility for TB screening.

CITAM+ staff, volunteers and other partners took part in a march commemorating the 10th anniversary of the Global Fund to fight AIDS, Tuberculosis and Malaria where they were able to get commitments from the government through the Minister of Health to bail out hospitals facing financial difficulties. The Minister also committed to accelerate the disbursement of funds to civil society organizations through the Churches Health

Association of Zambia (CHAZ) and accountability and transparency by the new government when dealing with health resources.



Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), Zimbabwe

The project facilitated communication among policy-makers, service providers and communities to establish collaboration and feedback mechanisms that were previously lacking.

SAfAIDS held a national policy dialogue where community members, policy-makers, parliamentarians and stakeholders reviewed existing national TB policies and guidelines. As a result, the Zimbabwe National Network for People Living with HIV/AIDS (ZNNP+) included TB initiatives in their advocacy strategy. Also, many community members, including chiefs, headmen, religious leaders and traditional healers, committed to support TB programs by working with communities to reduce stigma, a major hindrance to TB treatment seeking in the region.

Furthermore, SAfAIDS produced a documentary highlighting policy guidelines for TB treatment, and the challenges & experiences of people when accessing services. The DVD served as a useful advocacy tool to mobilize communities to seek early diagnosis and treatment as well as for creating awareness on the importance of completing the treatment course.

The platforms also provided opportunity to review policy implementation around TB as a result of which the National TB Programme committed to speeding up adoption of the WHO guideline on Isoniazid.

Multi-Dimensional Resource Centre (MRC), Nepal

To mobilize and empower the disadvantaged, marginal community in rural remote areas of Makwanpur district in Nepal, MRC aimed to strengthen community networks at grass root level. After conducting a critical assessment of Village Development Committees (VDC), MRC identified deprived areas/locations that had a high risk of TB and targeted case finding to these areas. The demand- based programme garnered a lot of interest and participation from the community. The campaign raised awareness on TB and reached out to communities using different media such as street drama, posters and pamphlets, mass meetings, speeches, regular group meeting, radio, etc.

The project forged partnerships between relevant stakeholders and Anti-TB Groups at district and VDC levels. Development of strong networks and alliances between community leaders and health organizations at various levels in the district contribute to the sustainability of this project.



Resham Bahadur Syangtan, Nepal:

55 year-old Resham Bahadur Syangtan, a resident living in a modest hut in the remote rural area of the Bhainse village development committee, refused consultation and checkup for TB even though his symptoms prevailed. Rather, he relied on traditional practices "Dhami Jhakri" and "Devi Devata". Resham belongs to a disadvantaged ethnic minority and was responsible for maintaining his wife and three young children. After an intensive dialogue session with MRC Nepal motivators and local health volunteers, he could be convinced to seek assistance. After his chest examination and sputum smear test, Resham was found TB positive and started treatment. He gained weight and recovered the energy to do hard work as a laborer and bring income to feed his family.

His wife is now very happy expressing that her husband is recovering well and is a regular patient in the DOTs program. Resham expressed his gratitude to the MRC Nepal staff and Stop TB Partnership/WHO for granting him another chance at a new life with his family.





Initiative for Health Foundation (IHF), Bulgaria

IHF targeted a very hard-to-reach community in Sofia, Bulgaria, by establishing contacts with evangelic priests in segregated Roma communities to carry out the project. The helping priests, who are highly respected and influential in Roma society, facilitated access to the community and helped organize health training sessions. As a result, IHF was able to reach small neighbourhoods which were highly segregated and rarely reached by any health interventions. The priests provided space within churches to carry out health education sessions and encouraged people to participate. After each session, IHF provided TB and HIV testing to participants. They were able to carry out 24 sessions in 9 Roma communities, reaching over 550 Roma people out of which 344 got screend for TB. The success was even greater than expected, priests from other areas who came to know about the benefits of the initiative wanted IHF to expand the project to their communities, too.



TB CAN BE CURED

GOOD PRACTICE R4 Stop TB Partnership Challenge Facility for Civil Society

Financial support to community initiatives for positive change

Stop B Partnership CHALLENGE FACILITY FOR CIVIL SOCIETY

Photo credits

COVER: `Tasweer-e-Zindagi' (Indus Hospital) / P1: `Saleem Ahmed' (Indus Hospital, Pakistan) / P2: `Supporting communities' (Eucharia Help Foundation EHF, Nigeria),
`Street performance' (Multi-Dimensional Resource Center MRC, Nepal), `World TB Day' (ASHA-ODISHA, India), `Screening' (EHF, Nigeria) / P3: `Two people' (WHO/ Vanessa Vick, Uganda), `Testing' (Initiative for Health Foundation IHF, Bulgaria) / P4: `Prevention' (Indus Hospital, Pakistan) / P5: `Saleem Ahmed' (Indus Hospital, Pakistan), 'Jackson Masunga' (SINZA Youth Peer Educators, Tanzania) / P6: `Newspaper' (Health Development Initiative, Rwanda) / P7: `Advocacy' (Djibouti Treatment Access Movement, Djibouti), `Information' (IHF, Bulgaria), `Communities' (OMEGA Project Management Foundation OPMF, Ghana) / P8: `Philip' (OPMF, Ghana), `Women advocacy' (International Community of Women living with HIVAIDS Eastern Africa, Uganda) / P9: `TB 2011' (Asociación de Personas Afectadas por Tuberculosis ASPAT, Peru), `March' (Community Initiative for Tuberculosis, HIVAIDS & Malaria CITAM+, Zambia) / P10: `Street performance' & `new photo' (MRC, Nepal) / P11: `Two patients' (MRC, Nepal), `Roma family' (IHF, Bulgaria), `Resham Bahadur Syangtan' (MRC, Nepal)

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