

# Partnering with Grandmothers and Healers to Eliminate the “Disease of Dust” in Senegal

## A Case Study in Community-Based Tuberculosis Control

December 2008



R. Nyberg/USAID



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## CORE Group

Established in 1997, CORE Group is a membership association of international non-governmental organizations whose mission is to improve the health and well-being of children and women in developing countries through collaborative NGO action and learning. Collectively, CORE Group members work in more than 180 countries. CORE Group, Inc. is a 501[c] 3 charitable organization based in Washington, DC.

## Christian Children’s Fund

Christian Children’s Fund (CCF) exists to help: deprived, excluded and vulnerable children who have the capacity to improve their lives and the opportunity to become young adults; parents and leaders who bring lasting and positive change in their communities; and societies whose individuals and institutions participate in valuing, protecting, and promoting the worth and rights of children. CCF has been operating since 1938 and is based in Richmond, Virginia.

## Abstract

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Little has been documented on community-based tuberculosis programming— which includes detection, care, and prevention. Although some non-governmental organizations (NGOs) have offered community level tuberculosis (TB) care and control for years, many organizations are new to this growing component of TB programming. As this approach rapidly expands, community-based TB programmers need to know: What are the key elements? How should progress be measured? What is replicable? What is scalable?

In 2003, Christian Children’s Fund (CCF) Senegal began to offer community-based TB services. This case study documents that effort. It suggests that community health staff and volunteers, with relatively short training, are able to successfully play critical roles within the Ministry of Health’s national tuberculosis program. This success relies on providing the health workers and volunteers with clear knowledge of what they were able to do themselves and when to refer to the health center. Their knowledge and skills are regularly assessed and reinforced through close and supportive supervision. Community participation is the second important piece, indispensable in overcoming powerful stigma.

In 2003, when the project began, only 67 percent of over 1,000 mothers interviewed were able to name at least one danger sign of tuberculosis, such as weight loss or a cough with blood. In 2006, that number had risen to 98 percent. Because this knowledge change was not embedded within a rigorous scientific research design, we cannot claim the project “caused” this change. However, the anecdotal evidence reported in this case study has led us to believe that the project played an important role in the reported knowledge change as well as associated behavior to seek and complete treatment.

A problem more difficult than a lack of TB knowledge threatened to halt progress: entrenched stigma. This stigma was tackled through culturally appropriate mechanisms that were implemented by carefully chosen staff, volunteers, and community representatives. Unfortunately, the scarce use of indicators designed to measure this issue have left us without quantitative data to support the qualitative evidence.

Given the shortage of health professionals in Africa (and throughout the world), this study supports the contention that TB prevention and care (as well as prevention and care of other illnesses) can be successfully delivered at the local level by NGO staff and community members.

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## Getting Started: Government, Donor, NGO

Senegal’s National Programme to Combat Tuberculosis (PNT) faced several problems—tuberculosis (TB) detection and referral rates were low, and TB patients often were not completing their course of treatment. In partnership with the U.S. Agency for International Development (USAID), they asked NGOs in Senegal to help fix the problem.

Drawing on its community health expertise and established presence in Senegal, Christian Children’s Fund (CCF) Senegal proposed an approach. They would reach people with TB in the Mbour Department through their community-based primary health care program, which CCF and partners had begun in 1998 with the revitalization of the “health hut” system. (At the same time as beginning TB services, CCF and partners would also reach out to people with malaria.)

## The Context: Mbour, the Senegal Health System, and Cultural Views of Tuberculosis

### Population

One hundred kilometers to the south of Dakar is the Department of Mbour, the project setting. This department comprises four health districts: Thiadiaye, Joal, Mbour, and Popenguine, which are home to approximately 470,000 people. With the exception of Mbour itself, these districts are predominantly rural. Approximately 80 percent of the population belongs to the ethnic and linguistic group of the Sérères. The Wolof comprise the next largest group, with other ethnic groups forming small minorities. The dominant religion is Islam with some Christian communities. Within both religions, animistic beliefs and practices persist.

<b>Ministry of Health</b> National Programs, including National Programme to Combat Tuberculosis (PNT)	Government oversight and funding
<b>11 Medical Regions</b> <b>58 Health Districts</b> each with one or more Health Center (Supervised by physician)	
<b>Health Post</b> (Supervised by nurse)	
<b>Health Huts</b> Five to 15 health huts supervised by one health post (Each health hut supervised by community health worker)	Community management and funding

## Senegal Health System

The Senegalese public primary health care system is made up of five tiers.

The four health districts in the Department of Mbour have one health center each, with a total of 38 health posts and 88 functioning health huts. Health centers are permanently staffed with physicians, and some are equipped for surgery to enable procedures such as cesarean sections. Health posts are headed by a nurse, who is also responsible for the supervision of health huts and their staff. Health huts are run by a community health worker and—ideally—two traditional birth attendants with training, as well as several community mobilizers (depending upon the service population size). In total, there are eight general practitioners in the four districts (1 per 59,000 people), 41 nurses (one per 11,508 people), and 21 midwives. In addition, there are 119 community health workers, 147 traditional birth attendants with additional training, and 427 community mobilizers.

Like all other health care systems in Africa, the Senegalese system lacks sufficient qualified personnel to fill all posts. Many people also do not have access to government health service sites due to geographic, economic, or cultural barriers. By 2003, when this project began, the revival of health hut sites was helping to broaden access.

However, that progress had not yet reached people with TB. Although there were some adults who sought treatment for TB in the health centers prior to the CCF project, frequently there was a lack of any systematic follow-up, and adherence to treatment was weak. When people started to feel better, they often stopped the treatment. Further, not a single child had received chemoprophylaxis against tuberculosis, although government guidelines provided for it.

## Cultural Interpretations of Disease: TB Stigma

“I did not feel any need to follow regular treatment. The witches had taken me and I was sentenced to death. I lived on my own in a corner, pining with bitterness and loneliness. Sometimes I questioned myself, but I did not know what kind of misconduct I was guilty of to deserve such a fate. I wished my neighbors dead, because I accused them of being the reason for my misfortune. However, with the constant visits of the motivators and the community mobilizers, I came to my senses. I finally accepted treatment, and thank God, I am cured... I honestly regret to have unrightfully accused my neighbors of witchcraft, and I hope that one day they will forgive me”

—Elderly Senegalese man

Even a basic understanding of local stigma makes it clear why so few people sought TB services. Within the local indigenous belief systems, disease—including TB—is not viewed as only a physiological dysfunction. While the community does not deny that bacteria may play a role in the cause of TB, they do not consider that explanation sufficient. Community members often look for cultural reasons to explain TB infection in one person and not another. CCF staff had to develop TB approaches and messages that were credible within this cultural milieu.

### Social Stigma Continues Even After Death

In some villages in Senegal, when a person dies from TB, the family will perform rituals to express a total break with the dead person to symbolically exclude her or him from the family, such as cutting a thick cord. In other villages, families deny a TB victim the right to normal funeral ceremonies, which prevents him or her from entering the place where the spirits of the ancestors live. The belongings of the person, especially clothes, are often burned.

### *Offending the Ancestors*

Local community members in the CCF project area believe that disease is caused by offending the ancestors. Offenses include, but are not limited to, eating things you should not, such as cola (a local stimulant), coffee, pork, or foods that are not well preserved, or drinking too much alcohol, and not praying or not making sacrifices to ancestors. Punishment for these offenses is usually experienced as a “bad wind,” which arrives at dusk. Whatever the cause, a disturbance in the relationship between a person and his or her ancestors is serious, because ancestral spirits, who reside in the invisible part of the world, may punish a person for perceived offenses.

Social stigma of TB was also rampant in the area, with local community members believing that poor personal hygiene also contributed to the illness. They believed sharing things with a person who is sick can lead to TB, and so people with symptoms were shunned by the community.

Such physical exclusion can be life-threatening. As people feel threatened by a person with a communicable disease, especially those whose health is visibly deteriorating, family and community members may avoid and exclude them from social contacts.

If the person sought treatment, they would most likely go first to a traditional healer. If that treatment was not successful, only a few would seek medical treatment—if access was even possible. But all too often, individuals suffering from tuberculosis deny their condition and try to avoid diagnosis, as they were afraid of the social isolation, which would seem to reaffirm that they must have offended the ancestors in some way. Their nutritional status might suffer as well as a result of exclusion, exacerbating the illness as well as the side effects of the medication.

All told, powerful psychosocial forces were at work, which the project needed to overcome if progress was to be made.

### **Some see TB as “Disease of Dust”**

In October 2002, a socio-anthropological baseline study was carried out through focus group studies to help improve community intervention strategies. (Alfred Inis Ndiaye: Rapport de l'étude socio-anthropologique de base du projet CANAH II, Décembre 2002). Although TB was not specifically addressed in the study, the symptoms of the disease, as they were experienced in communities, were discussed. Community members were asked about their interpretation and attitudes with regard to the following symptoms: coughing, respiratory difficulties, fever, and vomiting, among others.

The study revealed that mothers frequently reported respiratory infections among their children. Respiratory diseases were linked to cold climate, climate change, dust (especially important during the Harmattan or West African trade winds), mixture of waters (perspiration and washing), washing during the night, and the lack of appropriate clothing at night. All mothers reported that they treated respiratory infections at home, preparing infusions from different plants, and using massage with shea butter or mentholated products. Some mothers would consider a healer or a health post if home treatments failed, and access to those services was feasible.

## Participatory Processes Set the Stage: Community Steps of Health Hut Revitalization

1. Agree on renovation/new location for health huts.
2. Negotiate partnerships with CCF, leaders, other well-respected persons including religious leaders, local general assembly, local CCF staff, public health authorities.
3. Plan distribution of activities among these stakeholders in health hut start-up, implementation, monitoring and support.
4. Select and train community participants (community health workers, community mobilizers, and traditional birth attendants).
5. Organize community support structure (community health committee, or a group of “resource persons”) responsible for management of health hut administration (such as interpersonal conflicts, budget, and supplies).
6. Construct or rehabilitate, equip, train, and supervise health hut personnel with the support of CCF and according to government standards.

## The Project Building Blocks

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### Reviving Community-Level Health Care

Health huts (based on the Bamako Initiative of 1987) originally were designed to support and extend Senegal’s primary health care system, in which community members could receive basic first aid and treatment for common problems like diarrhea or malnutrition. They were intended to improve the availability, quality, and affordability of community health services with active community oversight and community financial support. However, lack of community participation, poor supervision by health post personnel, and economic constraints led most health huts (over 80 percent, according to health officials) to stop functioning. This left many people with little or no public health care options.

By 1998, when CCF first sought to revitalize the health huts through support from USAID’s Child Survival and Health Grants Program (USCSHGP), most were sorely neglected. Between 2003 and 2006, funds from a second USCSHGP and the launch of the USAID Mission-funded<sup>1</sup> community health project enabled CCF to increase the momentum of reestablishing functional health huts.

At the time the community-based effort began, 95 health huts were thriving, through support from CCF and local partners. An additional 50 health “sites” (which functioned like health huts, but were based in existing MOH health posts) were also operating.

In order to provide basic local health services, as well as expand services (including, eventually, TB services), CCF Senegal worked with local partners to revitalize the system. From 1998 to 2006, CCF and partners systematically expanded the number of functioning health huts through its two USCSHGP projects and actively pursued a revitalization plan. Communities were directly involved in the process and participated in every aspect of the revitalization (see box).

The health hut services and—as importantly—the process of community involvement and management of services and staff combined to lay a foundation of success and trust upon which the difficult topic of TB could be addressed with relative ease

### Project Premise: Each CCF Senegal Effort, Beginning at the Pre-Project Design Phase, is a Community Effort

“This was always our project and not that of CCF. That is what we have understood since a long time. And that is why we shall do everything we can to chase tuberculosis out of our communities.”

— Local Senegal Community Member

From the beginning of the TB project, CCF worked to ensure that community participation was built into all aspects of the project. Before the project proposal was written, a planning workshop was held in which all relevant stakeholders partici-

<sup>1</sup> Projet Santé Communautaire, PSC, 2006 – 2011.

pated, including community representatives, government health authorities, and CCF staff. This gave the project a clear community orientation and ensured that any concerns and needs within the community were addressed upfront.

With community interest and enthusiasm ensured, the health huts would grow to become a natural health service point for TB curative and preventive care at the community level, and a focal point of community organization around TB. Health huts have become a meeting place for community leaders and various community groups. It is here that messages for treatment and prevention of tuberculosis were proposed, discussed, and shaped among health workers, community leaders, and other influential persons, most notably traditional healers.

## Project Structure: Key Components

### *Training and Supervision*

“An important element of the training is that people learn to know the limits of their knowledge and recommended treatments. Primary health care only works with effective referral systems and the knowledge of when to refer patients.”

— Ralph Syring, CCF Africa Region Senior Health Advisor

When the CCF project was approved, tuberculosis became part of the training program for the several groups of volunteers in and around the health huts. During the project period, 1,246 volunteers were trained by project staff and health district staff. This included 945 community mobilizers, 148 community health workers, and 153 traditional birth attendants.

TB training was simple, lasted only one day, and focused on basic elements: danger signs, prevention, management and treatment, and follow up strategies.

CCF considered its use of supportive supervision critical to the success of the project. Supervision was provided by the local health manager of the national TB program, as well as by CCF project staff.

### *Staff and Volunteers*

Mobilizers conducted home visits, provided follow-up for TB treatment, and provided peer education and health promotion activities (including the use of drama groups). Depending on the specific health needs and conditions within the community, community mobilizers also provided education on other health conditions or diseases, such as nutrition, exclusive breast-feeding, malaria, and sexually transmitted diseases.

Community mobilizers, community health workers, and traditional birth attendants were individuals selected by community leaders and assemblies who received short training courses in primary health care components such as integrated management of childhood illnesses, follow-up of childhood illnesses, and tuberculosis and other diseases. The existing government professional supervision system reinforced their performance and identified additional training needs.

### *Community Involvement*

A community-based support system, consisting of different groups of community members, among them cured tuberculosis patients, played an important role in

## DOT Supporters: More than Just Pill Pushers?

"Tuberculosis can be cured. We have had the experience, and we have followed the advice given by the community mobilizers, the motivators, and the health personnel. Today we are accepted without any problem. We have resumed our positions in society and even our professional activities."

—Member of "TB Cell"

There is an interesting cultural aspect linked to community-based DOTS that has been highlighted by at least one author on health in West African societies: "... the principle of DOT, when it leads to the identification of a person in the patient's surrounding who is able to control the effective intake of drugs, makes the intervention ... of caregivers shift from a 'techno-medical' to a real 'social' type of support" (Laurent Vidal: *Ritualités, santé et sida en Afrique*. Paris 2004. P.87/88 – non-authorized translation). Thus, the socialization of the treatment process became part of the wider social acceptance of the patients' suffering from tuberculosis, and played a role in the recognition of the real possibility of successful treatment. The follow-up and support of patients under treatment was an important factor in treatment success, which in turn convinced more patients to come forward and present themselves for treatment at the health centers.

making treatment of tuberculosis credible, available, and affordable to the population. TB support groups helped patients and reinforced the importance of completing treatment.

Project staff created partnerships with the departmental and district health authorities, and with existing community structures including community-based organizations. The latter partnerships fueled the engine of change in the communities, as described later in this paper.

### *Patient Identification and Treatment*

"Once the patient has been identified, we invite him, a member of his family, and his neighborhood community mobilizer, and we explain to him the conditions of good management of the disease and the importance of taking the drugs regularly."

— Member of health center staff

When the project began, CCF project staff and community health workers and mobilizers were informed by the health centers about patients under TB medical treatment and those whose tuberculosis had recently been diagnosed.

Community mobilizers trained by CCF and linked to health huts visited these patients at home and introduced the MOH policy or practice of Directly Observed Treatment (DOT). They also advised patients and their families on hygiene, nutrition, and psychosocial support.

In many cases, the community mobilizer was the one who observed the patient taking his or her drugs, but patients were free to choose another person whom they trusted, including friends, neighbors, and family members, to take on the responsibility of direct observer.

At the beginning, the MOH required that the observer was a nurse or doctor, but over time MOH officials realized that this was not manageable for the many patients who lived far away from a facility. So, in 2004, PNT authorized community members to be designated as observers. Volunteer observers used notebooks to note progress and problems, and informed health center staff of any changes. They ensured that patients completed all medications and followed all clinic guidance. They also supported improvements in the diet, assisted with family disputes or problems, and generally tried to keep the patient in compliance with the treatment plan.

### *Health System Connections*

Intensive follow-up by community mobilizers minimized the risk of patients abandoning treatment. They visited patients who would not go to collect drugs at the health center, and again and again convinced the patients to continue. As a result, drop-out rates for the project largely reflected those patients who left the area and could not be traced. A key element to the success of this approach was the close working relationship between health centers and community volunteers working through health huts. Community health workers and mobilizers tracked patients who appeared at a health center to collect drugs. Health center staff members were informed by community volunteers about any side effects of treatment or suspected cases of treatment failure in order to provide immediate follow up.

Symptoms of TB in the general public and patient side effects of treatment always triggered referral to the health center. If the patient was required to go to the health center for results or follow-up, the mobilizer or volunteer ensured their return.

Volunteers were aware of the symptoms of TB, so they systematically looked for danger signs (coughing more than 15 days, sweating, general fatigue, loss of weight, or blood in mucus). They used a memory aid (T-A-S-S) to remember the signs; in Wolof the word “tass” means “completely beaten down and exhausted.” The letters represented: T for “toux persistante” or persistent cough, A for “asthénie” or asthenia (weakness), S for “sueurs nocturnes” or night sweats, and S for “sang dans les crachats” or blood in mucus.



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### *TB Prevention for Children*

Based on the existing MOH guidelines, if a child under five years of age was in contact with persons who had TB, then the child should receive a six month preventative treatment. Volunteers identified all of the children in their community who were exposed to TB, created a written list (name, age, and weight), and shared it with the project supervisor who passed it on to the health center. As a result, the project ensured that government TB guidelines for children were carried out for the first time ever in the project department.

## Changing Cultural and Social Norms

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### **Back to the Future: Integrating TB Prevention and Treatment Messages into School Curricula**

In order to make children more familiar with the signs of tuberculosis and ways to prevent the disease, a curriculum on tuberculosis was integrated into the sixth grade of the local primary school (children 11 to 12 years of age) through the life and earth science class. This portion of the project was developed in cooperation with CCF and the departmental school inspection authority, Inspection Départementale de l'Éducation Nationale de Mbour.

The curriculum includes sections to be used in French classes and others which can be used in mathematics. It also includes several game elements. Teachers were introduced to the curriculum on a “tuberculosis orientation day,” which was facilitated by CCF project staff and health post nurses.

Children will often take this knowledge back to their family, which serves to re-enforce messages that families receive on different occasions in the community.

### **First Stop: Staff, Volunteers, and Traditional Healers**

In order to adequately address the cultural interpretations and beliefs regarding TB in the community, CCF first had to convince its own staff of the efficacy of the DOT (Directly Observed Treatment) approach, and to present this approach to the larger community using the communications structures created around the health huts.

The strengths and weaknesses of both “modern” and “traditional” views of disease were discussed. Each concept was treated equally by staff, which made sure to build trust among those with traditional views by asking about their worldview with curiosity and tact.

This dialogue took place on different levels: it was integrated into the training of all those who worked in primary health care (in this case health hut workers and community mobilizers); into government health services, where DOT already had been theoretically adopted, but not in practice; and in the community by convincing people that exclusion and isolation did not solve the problem and that better alternatives were available.

Traditional healers expressed their discontent with the existing health structure, in which they did not feel that they were taken seriously, in spite of the existence of a Traditional Medicine Service within the MOH. Project staff made sure that healers felt they were listened to, which made them more open to discussions. Eventually, the “modern” view of disease was accepted by healers, who agreed to refer patients to health centers even as they continued to treat the spiritual causes of the disease. There was a unanimous feeling among project staff and community members that a mutual trust had grown between staff and healers.

### **Going Straight to the Top: The Grandmother Strategy**

In most Senegalese societies grandmothers play an important role within families and in communities. Not all of them are old women, as first pregnancies often occur at an early age. Status as a “grandmother” gives these women an authority role, in which they are expected to give advice to their daughters and daughters-in-law about housekeeping and parenting.

Informal community groups of grandmothers have always existed in Senegal. Building on this already existing network, CCF formalized the grandmother groups and, later, other groups. Most of the groups were organized around a certain age or a specific health condition (like youth groups, groups of pregnant women, or treated

TB patients). These “solidarity circles,” as they are called, serve as useful mechanisms by which peer sharing and support can take place and as a vehicle for information sharing.

Grandmothers held traditional views about TB and most of them would have excluded people suffering from the disease at the start of the project. The “grandmother-strategy” was intended to enhance the knowledge and experience of grandmothers, as well as change some of their beliefs and practices in order to reach younger women and families in the community. CCF and community volunteers contacted local individuals, formed groups, and participated in their meetings, which were public. Community mobilizers were trained to carefully listen to grandmothers’ concerns and opinions, rather than instructing them on “right or wrong behaviors.”

If grandmothers talked about breast feeding or TB, volunteers often would tell the group a story, sing a song, or perform a short drama, instead of lecturing. Afterwards, they would ask for the group’s opinion. The facilitator – the community mobilizer – carefully listened to the opinions of the group and did not necessarily intervene, even if she was convinced that an opinion was harmful. For example, somebody in the group might say that a person with TB needed to be isolated and thrown out of the family, or that the disease was incurable. The facilitator would wait until somebody else disagreed or, possibly with reference to the story told, give a different view. Only at the end would the facilitator tell people her opinion and give advice, and sometimes that would not occur until the next meeting. In these groups, grandmothers learned about danger signs of TB, like persistent cough for two weeks or more, in combination with bloody sputum, fatigue, loss of weight and appetite, night sweats, and chest pain. They were also told that TB could be treated and cured.

The project frequently utilized former TB patients to participate in these group meetings and tell their own stories. (Former patients and other distinguished community members in the communities formed 94 TB solidarity groups, known as TB Cells), and in the district of Thiadiaye, a “TB Association” was formed. These groups adopted the same tasks that were fulfilled by the community activists: they helped to create awareness about the disease and the possibilities of its treatment, they advised people to seek treatment, and they offered support and follow-up to patients. These groups were an expression of increasing ownership of the project by the community.



A. Rives Argeñal/CCF

## Project Data and Outcomes

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### Monitoring and Evaluation

To monitor project progress, a system of documentation and data collection was put in place, consisting of patient registers, documentation booklets, monthly and three-monthly reports, and follow-up cards for people under treatment. Data collected by community volunteers were regularly analyzed and discussed. Motivators (project staff) collected data monthly from the community mobilizers and other community volunteers, and wrote a monthly synthesis that was reviewed with the nurse running the health post. Project supervisors consolidated these documents into quarterly reports and shared them with the project coordinator. Every three months, senior project staff analyzed and discussed these reports during routine meetings. This would permit the team to track project implementation closely and to identify problems that required resolution.

At the community level, monthly meetings were held by project staff and the local health committees where a parallel analysis process took place. Project supervisors were responsible for considering the results of both analysis processes. Finally, a Lot Quality Assurance Sampling (LQAS) survey was used to annually assess implementation with regard to key outcome indicators. A final evaluation was conducted in August 2006. (See below.)

The existing government supervision system complemented project monitoring activities in order to assess staff performance and to identify additional training and other support needs. The community health workers were supervised by the head nurse of a health post, and these were supervised by their superiors at the district health centers. Within CCF, motivators, who were part of the project staff, supervised and supported the community mobilizers. A supervision guidance document was developed and used, and all those who had supervisory tasks as part of their work received training in how to supervise.

### Number of People Treated, Including IPT for Children

From September 2003 to June 2006, approximately 808 tuberculosis patients underwent TB treatment with the support of the CCF project. Among them were 176 children below the age of five years who were living in a household with a diagnosed TB-patient, and who received preventive treatment with Isoniazid for six months, according to the Senegalese MOH protocol. This preventive medication, although a policy of the PNT, as mentioned previously, had never been implemented in Senegal prior to the project.

### Project Data Shows Knowledge of TB Increases

USAID donor reporting requirements of the project included conducting baseline and final evaluation Knowledge, Practices, and Coverage (KPC) surveys.

Some summary process data also were compiled:

- The health huts and volunteers supported by the project resulted in the identification of 1,053 suspected TB cases, which were all successfully referred to health centers for confirmation exams.
- Among the 1,053 cases, 572 were confirmed positive and began treatment.
- 565 cases of recovery were recorded, for an overall case recovery rate of 98.8 percent, and dropout rate of less than 5 percent.
- 808 TB patients were followed up at the community level.
- 45 patients with irregular treatments were sought out in their communities, counseled, and resumed their treatments. This represents 80.35 percent of all patients who stopped their treatment (56) at one time or another.

#### Survey Results of Two TB Questions

Indicator	Baseline	August 2006 (n=324)
Percent of mothers: know at least one TB symptom	67%	98 [97-100]*
Percent of mothers: recommend a referral to health system for TB	57%	97 [94-98]*

\* Confidence Interval (C.I.) = 95 percent

For the baseline survey, over 1,000 women were interviewed in the project area, and during the final evaluation over 300 women responded to the survey.<sup>2</sup>

Knowledge about the causes, risks and treatment of TB in the communities improved. At the start of the project, 67.2 percent of interviewed mothers could name at least one danger sign of tuberculosis. This percentage grew to 98 percent at the end of the project. Looking at different danger signs, 96 percent of interviewed mothers mentioned persistent cough for two weeks or more, 69 percent mentioned cough with progressive loss of weight, and 50 percent mentioned cough together with sputum with traces of blood.

At the beginning of the project, 56 percent of interviewed mothers said that they would take a family member whom they suspected of having TB to a health service point. At the end of the project, this percentage increased to 97 percent. CCF believes that these two results only make a difference in combination. It is important that the knowledge about the disease is supplemented by a strong motivation to make use of health services, which in turn requires confidence in the ability of these services to deal with the problem.

Finally, detection (81 percent) and cure (85 percent) rates, based on district level data, appeared to increase beyond the project's targets, although the authors of this report could not independently verify these results.

These statistics, especially 97 percent of mothers saying that they would take a suspected patient to a health service point, reflect a growing belief in the possibility

<sup>2</sup> During the baseline, four separate 30 cluster samples were used (30 random clusters of 10 interviews each, multiplied by four geographic areas resulted in about 1,200 women interviewed). This was deemed an unnecessarily large sample for the final evaluation, when one 30 cluster sample was conducted of 324 women, of whom 308 responded to the TB questions.



A. Rives Argeñal/CCF

of cure by medical intervention. There is anecdotal evidence that suggests tuberculosis is no longer a hidden issue within communities. For example, former patients have actively participated in a number of public meetings on the subject, and the issue has regularly been raised and discussed in a variety of groups formed around the health hut activities, indicating less fear and more confidence in the possibility of cure.

Like many community-based health projects implemented around the world, the CCF project struggled in its collection of high quality program data on all aspects of the TB intervention. Several issues hindered a more comprehensive M&E approach, including:

1. lack of standardized indicators to measure community-level TB efforts, including those related to advocacy, communication, and social mobilization.
2. use of looseleaf notebooks by community volunteers to record written reminders, which were used for the identification, referral, and management of patients, and which focused more on patient control rather than project record keeping. (Once actions were taken, these data were eventually lost to follow up.)
3. determination by CCF staff that government provided health center statistics were either unavailable for several districts, or were of uncertain quality—ultimately not useful for the final project evaluation. The statistics that did become available covered an area far larger than the project area, and therefore did not provide information on the populations affected.

## Lessons Learned

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- Involving government and community stakeholders from the start, beginning with the project design and proposal developments ensured that TB prevention and control was a true community priority, and linked to the health system from the start. CCF's ongoing community-based health work in this area made this early involvement possible.
- Formative research into the community's interpretation of health and tuberculosis supported a behavioral change strategy that built on and addressed, rather than attacked, current beliefs. This culturally sensitive strategy that integrated modern and traditional views of disease undermined stigma that limited care seeking and treatment for tuberculosis. Again, CCF's established presence allowed this formative research to achieve a depth that outside visitors may not have been able to accomplish.
- Community health workers and mobilizers with relatively short training in tuberculosis control combined with consistent supervision was associated with increased care seeking for tuberculosis and supported treatment continuation and completion.
- The use of several highly visible community mobilization strategies such as revitalization of health huts, working with traditional healers and grandmothers, including TB education within the school curricula, and the formation of solidarity groups enabled social acceptance and understanding of tuberculosis as a disease that could be cured if treated.
- The use of a comprehensive package of community level TB indicators, beginning with the collection of baseline data would have improved monitoring and evaluation efforts greatly. Project evaluation efforts that relied on government data were not fruitful due to gaps in data reporting quality and coverage. The final evaluation author suggested to "...improve the existing information system, [and] create a logical frame for the next project: a clear link must be established in the next interventions between the mobilized means (inputs), the activities to carry out (processes), the immediate expected results (outputs), and the expected levels of coverage (outcomes) and, finally, the expected impacts."
- Building on existing efforts can enable cost-effective interventions that then serve as stepping stones to scale up, replication, and provision of high quality, integrated health services. For example, CCF has used lessons learned from this project to scale up services in multiple regions of the country.<sup>3</sup>



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<sup>3</sup> In 2006, CCF Senegal began managing a USAID-funded five-year community health project (Projet Santé Communautaire, PSC, 2006 – 2011) and World Bank funded integrated health projects (PRN, 2006 – 2008) located in five of 11 national regions. The project is managed by CCF Senegal, and implemented through a partnership with World Vision, Africare, Plan International, Counterpart International, and Catholic Relief Services. Within the partnership, CCF Senegal directly implements programming in three zones, which includes about 50 percent of the country's population; CCF also leads the overall project. More recently, CCF Senegal (with partners Africare, Plan, World Vision, Counterpart International, and CRS) received funding from the President's Malaria Initiative (2007 – 2011) to scale up malaria programming to all 11 regions of the country.

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