Partnering with Communities :

an approach to planning and implementation

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COMMUNITY INVOLVEMENT IN TUBERCULOSIS CARE AND PREVENTION

Community involvement in tuberculosis care and prevention

Towards partnerships for health

Guiding principles and recommendations
based on a WHO review

WHO

World Health Organization

Overview

- WHO Stop TB Strategy

- Component Five: Empower people with TB, and communities through partnership

- Characteristics of effective models

- Promising practices from the field

WHO Stop TB Strategy

1. Pursue high-quality DOTS expansion and enhancement
   a. Secure political commitment, with adequate and sustained financing
   b. Ensure early case detection, and diagnosis through quality-assured bacteriology
   c. Provide standardized treatment with supervision, and patient support
   d. Ensure effective drug supply and management
   e. Monitor and evaluate performance and impact

2. Address TB-HIV, MDR-TB, and the needs of poor and vulnerable populations
   a. Scale-up collaborative TB/HIV activities
   b. Scale-up prevention and management of multidrug-resistant TB (MDR-TB)
   c. Address the needs of TB contacts, and of poor and vulnerable populations, including women, children, prisoners, refugees, migrants and ethnic minorities

3. Contribute to health system strengthening based on primary health care
   a. Help improve health policies, human resource development, financing, supplies, service delivery and information
   b. Strengthen infection control in health services, other congregate settings and households
   c. Upgrade laboratory networks, and implement the Practical Approach to Lung Health (PAL)
   d. Adapt successful approaches from other fields and sectors, and foster action on the social determinants of health

4. Engage all care providers
   a. Involve all public, voluntary, corporate and private providers through Public-Private Mix (PPM) approaches
   b. Promote use of the International Standards for TB Care (ISTC)

5. Empower people with TB, and communities through partnership
   a. Pursue advocacy, communication and social mobilization
   b. Foster community participation in TB care
   c. Promote use of the Patients' Charter for TB Care

6. Enable and promote research
   a. Conduct programme-based operational research, and introduce new tools into practice
   b. Advocate for and participate in research to develop new diagnostics, drugs and vaccines

- Community involvement values:

- **The dignity** of each **person** at the centre.

- At the origin of **rights** and **responsibilities**

- A **common good** which will benefit all its members.

- The **empowerment** of people who recognize their rights and assume responsibility for their own health has at least two fundamental **dimensions**: solidarity and subsidiarity.

Characteristics of effective models

- Patients and communities **involved from the outset** in planning, implementation and evaluation of TB control efforts - including joint periodic reviews.

- National and local health services worked to establish a **partnership** with the society.

- Clear definition of **roles and responsibilities** of all partners involved.

- Issues of **communication and social mobilization** addressed

- There was a **commitment by all partners** to pool resources, follow guidelines and ensure improved awareness and quality of care.

- **Motivation** has often been solidly rooted in **personal and community values**.

Promising practices

- The ACSM Sub Group (ACSM SG), currently under the DOTS Expansion Working Group of the Stop TB Partnership, was established in 2005 to foster the development of more effective ACSM programming and implementation within countries

- 14 ACSM best practices studies from a total of 13 countries with two case studies accepted from the Philippines.

- Were reviewed and selected by the ACSM SG to represent a range of partnerships and interventions in different locations and epidemiological conditions

Notable characteristics of TB-ACSM programming

- Engagement of diverse stakeholders in TB

- Direct outreach to communities and vulnerable populations;

- An emphasis on effective IEC strategies and appropriate materials;

- Patient-centered approaches in service delivery;

- Impact: ACSM approaches improved early case detection and treatment adherence, combat stigma and discrimination against TB patients, empower people affected by TB and mobilize political commitment and resources to address TB.

Project PACS (Programa de Agentes Comunitários de Saúde) Brazil

Situation:

- Rocinha has an incidence rate of more than 500/100,000 habitants

- There is only one primary care health center

- All TB suspects are referred to this facility for diagnosis and TB patients for treatment and follow-up.

- PACS project began as a community based DOTS project in 2003, as a partnership between the TB program of Rio de Janeiro, John Hopkins University/USAID, the local Catholic Church and the Rocinha favela

ACSM Intervention

- Intensive training and engagement of community health agents (CHA) to provide TB services directly in the community and build social support networks for patients and families.

  - The first step was a mapping exercise of all homes and families in Rocinha
  - The neighborhood was divided into 15 zones with 2-3 CHAs living and working in each zone
  - The second step was the identification of health risk factors, such as access to clean water and sanitation as well as vulnerable socio-economical groups
  - The third step was to set up a Social Support Network, mapping all local civil society organizations, schools, community leaders, and commercial enterprises that could provide any type of support to the population.

Comprehensive package of community DOTS

- Collection and storage of sputum samples (diagnostic and follow-up)

- Safe transport to the lab located outside Rocinha, and feedback of results to patient

- Contact tracing within household and community (friends, work, bar, school,etc.)

- Prophylaxis for contacts < 5 years old and those who are HIV positive

- Follow-up with patients

- Provision of DOT at the homes of patients unable to go to the HC

- Updating patient treatment cards

- All other care as needed to ensure adherence of treatment

Treatment outcomes PACS Rocinha, 2004-2007

YEAR	% CURED	% DEFAULTERS
2004	90	4.4
2005	88	6.3
2006	80	7
2007	86	3.9

Overcoming stigma by engaging traditional community leaders- Ghana

Situation:

- TB epidemic in Ghana in fueled by high rates of HIV infection.

- Many people are reluctant to seek medical care because they believe that TB is a spiritual disease, often referred to as a "ghost" disease.

- TB case fatality rates increased from 3.4% in 1996 to 8.6% in 2004 (NTP)

- Stop TB Ghana Partnership started in 2005 and was officially launched in 2007 . It is co-hosted by Afro Global Alliance (GH) and the Ghana Society for Prevention of Tuberculosis (GSPT). The Partnership has over 120 organizational partners

ACSM Intervention

Engage traditional community leaders with high status in society, so called Kings and Queens, who can influence traditional belief systems about TB and HIV aiming to diminish TB fear and stigma and pursuing adequate health seeking behavior.

ACSM Intervention

- Sensitization of traditional community leaders (Two lead Chiefs/The House of Chiefs)
- Definition of roles of traditional leaders and community based volunteers
- Community sensitisation meetings (CBHV)
- Training in case detection and Case management
- Provide training on community Treatment Supporters
- Produce and distribute IEC materials

Treatment outcomes Central Region- Ghana 2006-2008

YEAR	CURED %	DEFAULTERS %
2006	62.8	19.6
2007	74	9.2
2008	81.8	2.9

Increase in access to microscopy in a conflict setting- Philippines

Situation:

- Maguindanao Province has achieved case detection and treatment success rates that are close to the national average.

- Some of the barriers :
  - Outdated technical competency
  - Irregular supervision and monitoring
  - Poor access due to the ongoing conflict, lack of health personnel and geographic terrain and
  - Limited community knowledge on the cause and transmission of the disease and stigma related to TB

- The Maguindanao Tuberculosis Control Project a four-year project CRS in partnership with Integrated Provincial Health Office (IPHO)-Maguindanao,

ACSM Intervention

The ACSM strategy is aimed to focus on key behaviors at different levels to improve the quality of TB preventive and curative services

- Behavior change communication for health staff,
- Development of an ACSM plan:
- Reactivation of 11 local health boards to plan and solicit for greater political support for TB, and
- Quick Disaster Response Team, health personnel were dispatched on site to assess, and respond to the emergency situation brought about by the escalation of armed conflict.
- Community based TB care services were especially useful for those who could not travel due to security risks.

Innovation one: Improving access with Barangay Health Workers role

Training in DOTS, and sputum collection & smearing

- DOTS: 2-day
- Sputum Collection & smearing: 5-day training (didactic 2 days; practicum 3 days)
- Monthly monitoring

Major roles:

1. Collecting & smearing
- Transport slides
- Recording
2. As treatment partner

Innovation two:
Microscopists on Wheels

Private transport group (mostly single motorcycle) plying at remotest area volunteered to provide services for TB control & prevention.

– Free or discounted fare for TB patients & symptomatic
– Free transport of slides or specimen

– Promote TB awareness & free services of RHU

Process used:

– RHU recommended transport group from their area
– Gen. orientation & core group formation at provincial level and follow-up at RHU level.

Innovation three
TB Club

Serves as a peer-support group to ensure patient's treatment compliance & reduce stigma.

- Activities:
    - sharing and encouragement among members to motivate adherence to treatment regimen
    - cured patients as peers
    - contact tracing
    - case referral
- Membership: voluntary
- Structure: flexible, formally

loose-group.

Innovation four:
Networking with Muslim Religious Leaders (MRLs)

- 135 Muslim Religious Leaders (MRL) pledged to take part in the fight against TB in their respective Mosque before a formal worship takes place.
- Giving TB information to the Muslim Ummah (community)

Process:
- Reactivate the Local Health Boards (LHBs) in most municipalities
- The RHU team initiated advocacy conferences and meetings with Local Chief Executives (LCEs to increase awareness)
- The LHBs are expected to solicit support from LCEs in the form of ordinances and resolutions in order to strengthen the TB program.

Treatment outcomes- IPHO Integrated Provincial Health Office 2004-2007

Year	% Cured	% Defaulters
2004	72	6
2005	70	5
2006	78	4
2007	79	5

Stigma indicators

Indicator	Baseline (%) 2006	Final (%) 2009
% of people who thinks that avoiding a person with TB symptoms is correct	58	44
% of people who sympathize with a person sick with TB	18	51
% of people who said that a person sick with TB is treated like any normal person	32	69

CAN YOU IMAGINE A WORLD WITHOUT TB?
WE CAN

WHO Guidelines on
Community involvement in TB care and prevention
are available for downloading at:

whqlibdoc.who.int/publications/2008/9789241596404_eng.pdf