Community involvement in tuberculosis care and prevention

Towards partnerships for health

Guiding principles and recommendations based on a WHO review

World Health Organization

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Please send us feedback on this publication and share your experiences.
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It is anticipated that the recommendations in this guideline will remain valid until 2013. The Stop TB Department at WHO headquarters in Geneva will be responsible for initiating a review of this guideline at that time.

Contents

Abbreviations

AIDS: acquired immunodeficiency syndrome

DOT: directly observed treatment

DOTS strategy: The WHO-recommended strategy for TB control (based on case-finding and cure and comprising five key elements) that forms the precursor to and the basis of the Stop TB Strategy

HIV: human immunodeficiency virus

TB: tuberculosis

WHO: World Health Organization

Acknowledgements

Foreword

Until very recently, the approaches to TB care and control have been focused in most settings on the essential public health and medical interventions with very limited scope to contribution by communities. And yet, the issue of community involvement in public health approaches and in the delivery of health to people is not new. Already 30 years ago, the conclusions of the historical "International Conference on Primary Health Care" in Alma-Ata on 6–12 September 1978 emphasized "the importance of full and organized community participation and ultimate self-reliance with individuals, families, and communities assuming more responsibility for their own health". Indeed, the Declaration of Alma-Ata was very explicit: "The people have the right and duty to participate individually and collectively in the planning and implementation of their health care". In that Declaration, the concept of primary health care as the key to accessing health for all and, thus, fostering societal development was linked for ever to that of social justice. Despite these visionary statements, not much had happened in the delivery of TB care and control with regards to community engagement during the two decades that followed. A few local projects had been started in different regions of the world. However, it was only in the second half of the 1990s that, in the spirit of Alma-Ata and based on the evidence of success emerging from HIV/AIDS community projects, the WHO TB programme embarked on a broader-scale assessment of community participation in the care of TB patients in several African countries. The experience gained reassured the many sceptics that non-medical, often non-governmental staff (in other words, community workers and volunteers) could support national programme efforts effectively with much increased treatment completion and cure rates. Even from an economic viewpoint, community participation in care was assessed as highly cost-effective, with major savings in hospitalization costs and with remarkable benefits to patients and communities affected.

The time had come to explicitly work towards involvement of communities, so that they could become more aware of the huge problem of TB, get engaged in the care of the sick, and contribute in mobilizing energy from the grass roots to demand proper care and investment by their own local and state governments. In 2006, the new 6-pillar WHO Stop TB Strategy included a new component: "Empower people with TB, and communities". This component spelt out the need to promote advocacy, communication and social mobilization in order to influence policy changes and sustain commitment; to facilitate community participation in TB care; and to propagate the "Patients' Charter for TB Care", that is a series of good practice rules based on the sound principles of human rights applied to health.

However, it soon appeared that in too few settings there was a clear comprehension of the concept of community empowerment and its processes. Both civil society organizations as well as national TB programme managers requested WHO to clarify so that the policy and its principles could be translated into practice. At WHO we took this request

seriously, as this component of the Strategy was indeed the one with the least experience internationally and nationally.

An initiative was set up to look at all available evidence in the literature and in a variety of settings in the attempt to produce guidance for national programmes on how to engage effectively their people and communities in the fight against TB. The document we are now ready to disseminate is indeed the result of a fully participatory process right from case studies at country level, up to the creation of a task force with all relevant constituencies represented, a wide internet consultation, and, finally, an inclusive writing committee. The final guidance document focuses on a few essential needs. First, it is essential to build and sustain the motivation of all actors involved: such motivation and rationale for action are rooted in a human right-based approach and principles of social justice. The attempt here is to reverse a widespread approach whereby the issue of motivation is often raised when problems of sustainability occur and not at the very beginning of an initiative. Second, the guidance document addresses the methodological issue of how to initiate and promote community participation and involvement. This methodology is necessarily and substantially based on the same principles of *social justice*, which is the guiding aim of every effort in pursuing better health for all. These principles rely on the universal concept of the *dignity of each person* within which all the others principles rest: that of the common good for which everyone should collaborate; that of *subsidiarity*, through which empowerment and support from higher level institutions are guaranteed to foster development of communities and protect people from abuses; and that of *solidarity*, that incorporates the moral responsibility to share societal needs and the common goods, especially in a world where inter-dependence among people has become widespread. Third, in full respect of the notion of local solutions, the guidance document recognizes that there is no one-size-fits-all in establishing partnerships for health. Thus, a valuable practical guidance document must support country programmes in the design, jointly with communities, of an approach to their involvement that is adequate and specific to local context. "Don't adopt – adapt" should be the guiding principle, to paraphrase WHO's Director General Dr H. Mahler who so stated when addressing the Alma-Ata Conference on 6 September 1978. He added that "self-reliance is as crucial in defining health systems as it is in defining political systems". And, in the end, what is self-reliance if not true empowerment of communities and people?

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Executive summary

This publication provides guiding principles for WHO Member States to promote the involvement of people with tuberculosis (TB) and the community in TB care and prevention. These recommendations are designed to support health policy-makers – and patients' groups and local partners – in including community involvement activities in national strategic plans to control TB. The recommendations also offer advice on how to fund this work and successfully scale up approaches that have worked effectively.

The urgent need to engage and involve people with TB and the community as partners in rolling out the Stop TB Strategy requires clearly understanding the essential terms used in this area and the values and principles that underpin effective and sustainable community-based initiatives.

The terms used in the vast literature on primary health care point to a vision of the involvement of people with TB and the community in health care programmes as a partnership forged with political and health institutions to achieve better health for all and ensure universal access to essential care.

This commitment is an important aspect of social justice, like the values mentioned in the Declaration of Alma-Ata on primary health care. This publication explores the foundation of a rights-based approach building on the Patients' Charter for Tuberculosis Care and on the experiences documented in WHO country reviews (Annex 3). The same principles of social justice should guide the design of community initiatives that sustain the motivation of health staff and members of the community.

The dignity and value of each person is the basis of rights and responsibilities that the society affirms and accepts to make progress towards a common good that 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, as a moral responsibility to share the needs and problems of others and to recognize and defend the dignity of each person, and subsidiarity, whereby higher institutions or governments ensure support to and promote the development of community initiatives.

The recommendations of this publication should guide the actions that public health bodies and civil society can take to plan, implement, scale up and evaluate community initiatives.

The recommendations, based on consensus by the Subgroup on Advocacy, Communication and Social Mobilization at the Country Level of the Stop TB Partnership and endorsed by the WHO Strategic and Technical Advisory Group on Tuberculosis, focus on the essential aspects of community care initiatives. They will also facilitate the identification of the human and financial resources required and, therefore, guide capacity-building and resource mobilization.

The main points for action by national TB programme managers will be based on the process of community involvement summarized in Annex 4:

1. Propose a task force to support initiatives of community involvement inviting all relevant partners. The initiative to propose such a task force may as well be taken by community members and civil society organizations, discussing the proposal with national and local health authorities.

2. Advocate for support from national and local leaders throughout the process and follow it up regularly even after launching the initiative. Establish clear and early communication with communities and with all partners and design with them simple education and promotion material.

3. Conduct a situation analysis (or use a recent one) of TB service delivery and discuss how the community contribution can complement the TB programme capacity.

4. Identify all interested partners on the ground, discuss and define their role (especially the role of community volunteers), plan activities and develop communication and social mobilization material with them. Create synergy with existing community initiatives.

5. Design with partners and community representatives a practical "model" of involvement in TB care and prevention. Issues to be addressed include:

   — clearly defining the roles and functions of all partners;
   — how to ensure regular contact between health services and community through public health workers and community leaders;
   — how to encourage (self-) referral of people with symptoms;
   — how to ensure proper care and adherence to treatment;
   — how to address the issue of community and personal motivation (in particular for community volunteers or treatment supporters);
   — how to adapt the model to rural and urban settings; and
   — how to collect information on community participation through the existing recording and reporting system.

   Agreement among partners on these issues and pretesting of the model in demonstration areas will guide the preparation of national guidelines for community involvement in tuberculosis care and prevention.

6. Build capacity (health staff, partners and communities): identify funds to train facilitators who will promote community involvement at the district level and schedule and conduct workshops and follow them up. Training should be based on task analysis of all people and functions involved and will require preparing and producing training tools based on the national guidelines and on each specific task.

7. Prepare an implementation plan and a scale-up strategy, starting with implementation and fine-tuning in demonstration areas. Budgets should include both start-up and recurrent costs.

8. Public launching of the initiative with the participation of national and local authorities is very helpful to gain public and political support, to share useful information and to create demand for community-based services. Plan periodic local mass-media coverage.

9. Lessons learned in demonstration areas will contribute to improving the initial model to scale up to all regions and administrative health units of the country. An ongoing evaluation of impact and of the quality of care will provide the information necessary to develop and maintain community involvement in TB care and prevention.

The active participation of communities in TB control allows people with TB to be identified and diagnosed more quickly, especially among poor or vulnerable groups who do not normally have access to TB services. Upon diagnosis, people with TB receive better-quality care within their communities, and increased awareness about the disease results in less stigmatization. Treatment outcomes are also improved, and people with TB become empowered by the opportunity to make decisions about the type of care that best suits them and their community.

Introduction

Background

During the World TB Day public events organized on 24 March 2006 around the world, WHO officially launched the new Stop TB Strategy. This builds on the positive experience of the global expansion of the DOTS strategy over the last decade. The Stop TB Strategy aims to address the TB epidemic in today's context, facing challenges that have emerged while implementing the DOTS strategy, due to varying epidemiological contexts and different societal and health system situations throughout the world. The formulation of the Stop TB Strategy was preceded by broad consultation with national TB programme managers, civil society organizations and representatives of people affected by TB/HIV and technical partners of WHO, with extraordinary support and contributions from the working groups of the Stop TB Partnership. WHO Member States should have integrated the elements included in the Stop TB Strategy in their existing TB control policies.

The Stop TB Strategy incorporates important new components such as addressing TB/HIV, managing multidrug-resistant TB, collaborating through public-private partnerships, strengthening health systems, involving people and communities affected by TB and highlighting the need for further research in areas such as diagnostics, drugs and vaccines.

Experience at the country level under very different circumstances confirms that "Empowerment of people with TB, and communities" – component five in the Strategy – has been the object of diverse interpretations. Various national TB programmes, several nongovernmental organizations (such as the Open Society Institute Public Health Watch, PATH, Catholic Relief Services and World Vision) and patients' and activists' groups (such as the World Care Council and Treatment Action Group) have therefore requested the WHO Stop TB Department to provide further clarification on the concept and practice of community involvement to support the efforts of health policy-makers to adapt and include this in strategic plans that countries are preparing for the next decade. This, in turn, would enable them to harness the latent potential of communities to hugely expand the availability and quality of their care.

The Stop TB Partnership has contributed decisively to preparing this publication. During the First Meeting of the Subgroup on Advocacy, Communication and Social Mobilization at the Country Level, held in Mexico City in September 2005, participants requested WHO to better define component five of the new strategy – "Empowering people with TB, and communities" – to provide recommendations and specific guidance to national health authorities.

Process

In 2005 the WHO Stop TB Department, with support from the Stop TB Partnership, started a global review of experience in community-based approaches to TB care and prevention, after a literature review conducted revealed scarce evidence on the motivational aspects in the involvement of communities in TB. It focused on seven countries, in different WHO regions, that had already incorporated this approach in their TB control policy and scaled up their implementation at the national level. It was agreed to conduct this in-country assessment in collaboration with the Advocacy, Communication and Social Mobilization Secretariat of the Stop TB Partnership. The findings would then be discussed with a Task Force on Community Involvement in TB Care and Prevention, involving people affected by TB/HIV, communities committed, national health authorities, international experts and other WHO departments.

The Stop TB Department of WHO established a secretariat to coordinate these activities and support the work of the Task Force to harness all these contributions into one publication that would provide the guiding principles for varying contexts, describe successful engagement of communities and give recommendations on how to promote and sustain this approach to TB care and prevention.

An important milestone to the finalization of this publication was the Task Force meeting that took place in Milan, Italy on 25–27 September 2006. The meeting was preceded by the circulation of a discussion paper among Task Force members to exchange comments and contributions. Following the Task Force meeting, a smaller writing committee prepared draft recommendations and posted them on the WHO Stop TB web site. The e-forum stimulated comments and contributions from a variety of stakeholders. The publication is therefore the result of observations at country level and reflections on these experiences and has benefited from inputs of all the constituencies mentioned above.

The WHO Strategic and Technical Advisory Group on Tuberculosis endorsed this publication and its recommendations in June 2007.

Structure

1. The health policy context within which countries have promoted community-based initiatives, with clarification of essential terms.

2. Discussion of key concepts of social justice that provide the foundation of a rights-based approach to the delivery of health services.

3. Recommendations – addressed to national health authorities and communities striving to take greater responsibility for their own health.

Annex 1 summarizes previous WHO Stop TB research on the community contribution to TB care. Annex 2 summarizes a literature review on community involvement in TB control: how community-based initiatives have been promoted and why they are sustainable, with references. Annex 3 describes some practical experiences – a report on WHO country reviews (Kenya, Malawi, Uganda, Mexico, Bangladesh, Indonesia and the Philippines) with related methods and lessons learned. Annex 4 is a sample flow chart with a generic process to promote national initiatives on empowering people with TB and communities.

I

Community involvement in health care: basic terms

For almost 30 years, since the 1978 Declaration of Alma-Ata, people's participation in and contribution to health systems has been recognized as central for primary health care and accepted as an essential element of many public health interventions. The health reforms of the 1990s have given less attention to community participation and social values, focusing more on technical, economic and management factors in health systems. Initiatives taken up by civil society to address the HIV epidemic have been a remarkable exception to this situation.

The challenges posed by major epidemics, such as HIV, tuberculosis and malaria, and the role civil society has played in helping individuals and families to cope with them, have certainly contributed to making people, including health policy-makers, more aware of some limitations of the health services (public and private), particularly in terms of inequality in coverage and access for people with the lowest income or living in remote areas.

The mere existence of services in a certain administrative area does not prove that they are used or used correctly. Services have to be accessible to be used. This implies organizing a supply of care that is geographically, financially and culturally accessible.

The literature provides abundant evidence about the benefits and possible limitations of greater involvement of communities and civil society organizations in various functions traditionally held by health systems.

More active promotion of the participation of people with TB and the community in aspects of TB control, recommended by WHO and now included in the new Stop TB Strategy, has highlighted opportunities for links to other community-based initiatives, including those promoted by patients' groups and TB activists. But it has also confirmed an urgent need for greater clarity about the terms and definitions used to describe people's contributions to the health system.

For three decades, "community-based health care programmes" have used concepts and terms drawn from the literature on primary health care and health for all, from the United Nations Universal Declaration of Human Rights and from the domain of social justice. Concomitantly, similar civil society organizations that have played a paramount role in supporting people living with HIV and in advocating for their rights have used similar terms, sometimes with different meanings.

A common understanding of terms and issues is, therefore, essential not only to express the richness of experience that immediately becomes apparent in studying the good practices described in this publication but also to encourage collaborative actions with existing initiatives.

WHO defines health as a fundamental human right and a social goal the attainment of which requires a concerted action by the health sector and all the other sectors of society. Health is also a social achievement or goal. Social goals, such as improving the quality of life and health status, are achieved through social means, including com-

munities and individual people accepting greater responsibility for health and actively participating in attaining them.

At the core of the right to health is the dignity of each and every person. The recognition of the dignity of every man and woman provides the most important reason for planning and implementing patient-centred services. Social services (of which health services are an important component) can contribute to safeguarding and promoting human dignity, addressing persistent situations of serious disparity and inequality.

The commitment to ensuring universal access to essential health care is, therefore, not only central to the social and economic development of a community but also an important aspect of social justice; the fundamental principles of social justice (see section 2) should inform how health care is planned and delivered.

The first and fundamental community to which most people naturally belong is the family. Family members, and women in particular, are often the main providers of health care and have a fundamental role in health promotion.

The review of community participation in TB control highlighted that a sphere of close friends and neighbours plays an important role in every person's daily life and acts as an immediate point of reference for help and advice.

A community consists of people living together in some form of social organization and cohesion. Although it may vary significantly in size and socioeconomic profile, its members usually share social, cultural, economic characteristics as well as common interests, including health.

Health can also therefore be defined as part of the common good (see the principles of social justice in Section 2), and all people therefore have the right and duty to participate individually and as a community in the process for improving and maintaining their health. Further, achieving improved health status is linked with and helps the promotion of development in general.

The term "community involvement" is generally preferred to "participation" and points to the idea of partnership and shared responsibility with health services rather than to the notion of using the community to reduce the burden on the health services. For example, involving people with TB and their communities in providing care and then failing to provide high-quality services in terms of diagnosis, drugs and follow-up would damage rather than improve any health initiative. If health services commit to delivering high-quality support but face constraints and if people and families then assume greater responsibility for the community's health, the strain on the health services will be mitigated. Promoting involvement is much more than simply proposing participation in services planned and designed from the outside. People with TB and their communities should be an active part of the entire process from the very start of the intervention design, contributing to defining health problems and needs, to developing solutions and to implementing and evaluating health interventions.

Building an operational partnership with the community, with the goal of improving the health status of the population, is a step beyond participation and involvement. In a partnership, the institution that has the mandate to provide health and social services to address the essential needs of the population intervenes through its normative role and professional expertise to support the community in its own endeavour to achieve better health status. Essential to the creation of a formal or informal partnership is clearly defining the roles and responsibilities of all partners: what each partner can contribute, because of its specificity, to the common goal. Each partner, alone, may not be able to achieve the goal without the synergistic contribution of the other. The establishment of partnerships between the institution and the society requires that people empower themselves to be able to assume such responsibility.

The word "empowerment" has been increasingly used, over the last decade, in international development policy and in strategies for alleviating poverty, but its meaning often lacks clarity. Many different definitions have in common the notion of people who share the opportunities and responsibilities for action in the interest of their own health or of other issues important for their life; supporting such an active role of the society often requires education, adequate information, technical support and ensuring decision-making possibilities. Taking empowerment seriously requires a clear vision, in terms of a social justice approach, and practical strategies. Measuring empowerment in practice is challenging, but local stakeholders can agree on some key indicators, such as the actual involvement in the process of planning and evaluation.

People can undertake health promotion, preventive measures and action to support care in their own homes and communities. Communities, by sharing responsibilities with the health system, may often suggest an approach to these interventions that is more adequate for the local context.

A fundamental principle of primary health care states that everyone in the community should have access to it and everyone should be involved in it. Having access indicates the potential to use a service if it is needed. The proof of access is the use of the service rather than a simple existence of a facility. There may be personal, organizational and/or financial barriers to using the service; such barriers reflect actual or perceived obstacles to access. Adequate communication, social mobilization, access to information and education help communities and civil society organizations to assume responsibility for their health and enhance their ability to address their own health problems.

A society is made up of individual people, families and communities. Families and local communities that are given information about health and have reliable health services will usually act in their best interests. Health initiatives will be most effective and efficient when they connect directly with community structures and consider people's interest and commitment in dealing with problems.

Civil society is usually defined as the social environment that exists between the state or institutional level and the individual person or family. It does not have the coercive and regulatory power of the state but provides the social power or influence of the general population.

All institutions and organizations outside of government can be defined as civil society. In the context of welfare, this includes: consumer organizations, nongovernmental organizations and community-based organizations, faith-based organizations delivering welfare services, patients' and activists' groups, etc.

Individuals and communities may organize themselves to pursue their collective interest and engage in activities of public utility. Civil society organizations may originate from the community, neighbourhood, working environment or any other social context beyond the immediate family, to collectively relate to the state, or lower institution. The role of civil society organizations is increasingly becoming more prominent thanks to a renewed public awareness and concern for the right to participate in policies and processes that affect people's lives. The organization of national and global networks is providing valuable support to local civil society organizations that, nevertheless, remain important collaborators and counterparts of political leaders and administrators since they are rooted in and responsive to the local population they serve rather than to the agencies that may fund them.

A health system consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence the determinants of health as well as direct health-improving activities. A health system is therefore more than a pyramid of publicly owned facilities that deliver personal health

services. It includes parents caring for a sick child at home; private providers; behaviour change programmes; public health campaigns; and health insurance organizations.

The health system is responsible for ensuring high-quality accessible health services, for providing clear information and advice on the benefits of health to the community and for facilitating its early involvement in assessing the situation, defining the problem and managing the action.

A partnership for health between the government or an institution and the community is based on the commitment of both actors to actively collaborate to support the quality of health services or to make public health programmes more effective. This formal or informal collaboration can only be established if political leaders and administrators take on a specific commitment to social development and if the society is ready to assume its responsibility. Political commitment is confirmed by a decision to provide human and financial resources and by the determination to start a dialogue with the society at the level where problems occur. This allows communities to contribute and shape a practical response to their problems and needs. When a partnership is successful, the health services maintain all their technical and professional responsibilities, but they also effectively support what the community, which is directly affected by a health problem, can do through its own efforts. It is a basic shift from a hierarchical relationship to recognizing and respecting the role of communities in health and development.

Health personnel are people who have undergone a formal health or public health training, such as doctors, nurses and public health workers; they are part of and in a continuous dialogue with the community. Their training as health service providers should be complemented with education in essential communication and social mobilization skills to prepare them for dialogue and collaboration with their communities.

The private health sector plays an important role, complementary to public institutions, through the services of private practitioners, pharmacists, traditional healers, etc. Public-private partnerships provide an opportunity to establish and recognize the collaboration of the private health sector with services of public utility and can foster respecting basic standards of service delivery.

Community health workers are generally people with a basic education who are given elementary training to contribute to some specific health activities (short practical training on a specific task). Their profile, role and responsibilities vary greatly between countries and often between communities. Their work, which may take several of their working hours every day, is often supported through incentives in kind or in cash provided by the community they serve or by the health services.

Community volunteers are community members who have been sensitized about a specific and often time-bound service required to benefit their family or wider community and provide their time and energies to render such service without any monetary compensation. Voluntary work is not just a matter of personal generosity but, often, of clearly understanding the benefits that come to one's family or community. Volunteers are usually motivated for being useful to their communities: they recognize the need to do something and are proud of helping others.

The work and services rendered by community health workers and community volunteers actualize their full potential in the presence of effective support from the health system and of the possibility of a two-way referral between health facilities or public health services and the community. Such referral systems require a regular link – often provided by public health workers with community leaders – between the health system and the community, which must be simple, effective and easily accessible to both actors.

Further reading

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2

Partnership with communities and social justice

In 2006 the World Care Council published the Patients' Charter for Tuberculosis Care, which outlines the rights and responsibilities of people with tuberculosis. Initiated and developed by patients around the world, the Charter promotes an idea of a mutually beneficial relationship between people with TB and health providers. The Charter advocates a partnership between people with TB and health services, insisting on implementing the principle of greater involvement of people with TB and suggesting actions "to practice" patients' rights and responsibilities. This important document has been incorporated in the WHO Stop TB Strategy to provide guidance to Member States in formulating new and more patient-centred TB control policies.

Section 1 briefly reviewed the essential terms and concepts of the involvement of people with TB and communities and pointed out that community involvement cannot be the result of a mere reorganization of services or simply the final step of a decentralization process. This section examines the positive implications of a rights-based, patient-centred approach for the relationships between citizens, civil society organizations and the institutions and explores the ethical rationale that should inform how social and health services are planned, delivered and evaluated.

Building a partnership has to do with the relationship between the state – often embodied by local governments – and the society as well as with the relationships between the society and communities. Giving due attention to the principles that should inform and orient these relationships is an ethical and political decision that affects the very possibility to establish such a partnership and its effectiveness and duration.

Considering health service delivery and community involvement from a wider social and ethical perspective is an attempt to better understand the social challenges posed by the TB epidemic and its control. Fundamental principles of ethics and social justice can influence the practical decisions of political leaders, administrators and community members, fostering a favourable environment for the establishment of a partnership for health.

Social justice generally focuses on the social, political and economic aspects of problems and their respective solutions. It refers to organizing society such that the common good, to which all are expected to contribute in proportion to their ability and opportunity, is available to all the members for their use and benefit. Promoting and respecting social justice means contributing to a society in which all members, regardless of their social, political economic and religious background, have basic human rights and equal access to their community's resources.

Applying these fundamental principles is key for promoting greater responsibility for health within a society. The recognition or neglect of these principles will often determine whether work in the social arena will succeed or fail. In each context, the principles need to be translated into an appropriate language and into examples included in

guidelines and transmitted into training material that countries will prepare to carry out effective advocacy, communication and social mobilization.

Individuals, society and the common good

The basis of human rights is the dignity intrinsic to each person. This determines what is fair and just in all areas of interest, including matters associated with the delivery of health care services. Rights and responsibilities in the individual and social dimension are mutually reciprocal: one person's right corresponds to a duty for others. The right to health is a consequence of the natural right to life and to its preservation. Citizens of any country have the right to demand that institutions providing health care do so in such a way that the major health needs of their society are met by the most effective use of available resources.

This is fully consistent with a definition of justice as the condition in which each person is given her or his own due (or right). Justice supposes a society of at least two people between whom there can be some sort of equality, so that each person receives what really belongs to him or her.

Only rational and free members can form a society, since it is a union based on agreement about goals. Members of a society are united in a stable or enduring way and cooperate or work together for attaining some end. This end will be part of a common good that all the members will share and no member could accomplish separately. The moral bond of these ends distinguishes the society from a crowd, makes the individuals committed members and obliges them to their commitment. Society is, therefore, a moral entity made up of a number of relationships; this entity results from the simultaneous free choices of many people to cooperate towards a common end and achieve a common good.

The concept of common good must be properly understood, to avoid extreme interpretations. The common good is not superior to the individual good – the essential rights of an individual person should not be sacrificed to the advantage of the collective. Also, it is not a mere individual good or a sum of all the individual goods. The common good can be realized concretely only among the individuals who make up a society, and they can only achieve the common good through the cooperative interaction of the many. The common good should not just be viewed abstractly. Instead it should be understood as a tangible, specific good – such as basic health care, education, peace, justice, protection of the environment and provision of essential services – that can be quickly achieved in a community through a cooperative effort.

An ethical concern is also the distribution of health (or other essential) services in an equitable manner to all members of society. Equity implies that everyone should have an opportunity to attain his or her full potential for health. Equality compares the ability of different individuals and communities to obtain access to health care. Inequality in health may arise from the level of resources available, inadequate access to health care, inaccessibility of information and variation in the quality of care and outcomes.

Equity requires that everyone share the common good. However, since no common good can ever be perfectly attained and can always be improved, society is never static and the common good is the driving force of social progress and development.

Freedom and responsibility

Experience has repeatedly confirmed that, even though individuals and societies recognize something as a good, they can always choose – or not choose – to commit themselves to attaining that good. Although laws of social relevance bind all citizens, there

are countless examples of actions aimed at fostering a common good that some people decide to pursue and others do not.

This fact prompts a reflection on two different facets of freedom as a condition necessary for individual people and society to pursue and exercise what appears as a good for them.

Freedom in its negative sense means the absence of bonds or restraints or any coercion; this condition is usually and obviously limited by the law that every society should establish to safeguard the true liberty of each of its members.

This kind of freedom (freedom from), however, makes little sense without its positive counterpart, a positive freedom of choice (freedom for) through which people, based on a set of values they choose, commit themselves actively to attaining their end. In a way, "freedom for" is a distinct feature of empowerment, as it enables people to choose to pursue a common good.

Freedom and responsibility are necessary counterparts. We are responsible and accountable to someone for our duties but also, as the word implies, we respond to challenges and opportunities in our individual and collective lives, committing ourselves to a certain line of conduct.

In a profession a person acts responsibly, committing time, knowledge and skills to carry out his or her duties and be remunerated by society. Responsibility is established towards the employer as well as all those who are going to benefit from that particular work.

Responsibility, however, extends beyond this into social life. People freely assume the responsibility to pursue, affirm and defend values or goods they deem important for maintaining, developing or fulfilling their lives and/or the lives of their family or community. The common good involves all members of society; individual citizens and social groups therefore act responsibly whenever they have regard for the rights of others and seek the common good.

Examples of such responsibility may include: seeking care and adhering to a treatment to preserve one's life and protect one's family and community; if occupying a health-related position, placing at the centre of each act and decision the ultimate good of the people being served; and carrying out voluntary work for the community not just out of generosity but because of a commitment to a common good.

Principle of subsidiarity

Families, groups and associations to which people spontaneously give life enable them to grow at a personal and social level. The dignity of a person cannot be promoted without showing concern for all these expressions of social interaction. This network of relationships strengthens the social fabric and constitutes the basis of a society.

The principle of subsidiarity states that assigning to a higher institution or level of the society what a lower form of social organization can do is unjust. All higher-order organizations in a society should attempt to help, support, promote and develop lower-order organizations in that society.

This allows the intermediate social entities or bodies mentioned above to properly perform the functions assigned. Their initiative, freedom and responsibility must not be replaced by "invasive" higher authorities. In other words, a higher institution should give over or delegate to the community what the community can accomplish through its own activity. The process through which government recognizes and supports as part of the public system other actors that institutionally do not belong to the state can be defined in various terms. One term that has increasingly been used in the social and political arena to define this process is "subsidiarity".

Every person, family or intermediate group has something original to offer to the community. Subsidiarity is opposed to extreme forms of centralization and bureaucracy often accompanied by enormous increases in spending. Further, it recognizes the public function of private initiative, such as the government supporting a nongovernmental organization providing public services. This principle clearly builds on respect and promotion of the person and the family and on appreciation of the various existing forms of association and intermediate organizations.

Subsidiarity safeguards human rights and the rights of vulnerable and disadvantaged populations and encourages citizens to be more responsible in actively participating in the social reality of their country. At the highest level, the state is called to step in to supply certain functions, such as technical and professional expertise that is not available or cannot be effectively controlled at the community level.

The participation and involvement of individuals and community are important implications of subsidiarity. They are expressed by activities through which citizens, individually or in collaboration with others, contribute to the social life of the community to which they belong. Participation in activities that contribute to the common good, based on the awareness that such contribution is possible, is a responsibility and a duty for everybody. It is something that the community can propose to and promote among its members with full respect for their specific cultural and social contexts.

Examples of the principle of subsidiarity include: delegating responsibility for support and care to family members, friends and neighbours; recognizing the public utility of private or not-for-profit health care services that contribute to public health; and supporting nongovernmental organizations and faith-based organizations that provide essential health services in remote areas where public services are not accessible.

Principle of solidarity

Solidarity is the moral responsibility to share the needs and problems of others and to recognize and defend the dignity of each individual. Solidarity was the second most frequently reported reason motivating the voluntary work of community members in our reviews. Further, several people mentioned that fostering solidarity reduces stigma and discrimination: stigma and discrimination, conversely, prevent solidarity.

Solidarity highlights in a special way the intrinsic social nature of every person and the equality of all in dignity and rights. The acceleration of interdependence between people and peoples, so evident in today's world, may either further amplify inequality or provide the opportunity for an intense effort on the ethical and social level.

Solidarity is not a feeling of vague compassion for the sufferings of other people. It is a firm determination to commit oneself to the common good, to the good of all and of each individual. Solidarity will often and naturally prompt forms of public expression with the creation of groups and associations for mutual help.

Examples of solidarity in health-related matters are countless and include the voluntary work of thousands of people who take care of sick and disabled people and raise funds for food or transport to access distant health care services. Solidarity is at work whenever somebody is suffering and another person decides to be next to him or her to share the distress and provide help.

Towards a partnership for health

In essence, the Declaration of Alma-Ata also implicitly captured these principles in 1978.

Giving due consideration to these principles in designing health interventions with communities means building more than collaboration with or participation of people in addressing health matters. It means working towards actual and effective empowerment of people and building a partnership between health services and the society.

Partnership has a value that goes beyond the value of its operational returns. It is a kind of social pact that is itself justified because it strengthens both partners and increases the social capital. Solely emphasizing technical, administrative and economic returns would be depreciative, missing out on other type of returns that may have long-term potential.

The progressive expansion of similar social initiatives creates new areas for the direct action of citizens, integrating the functions of the state.

This partnership, even in its less structured forms, is the most effective response to a prevalent mentality of social conflict – it is an opportunity to contribute to a common good based on solidarity and concrete cooperation.

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3

Recommendations for empowering people and communities affected by TB

Introduction

A community consists of individuals and families who live together in some form of social organization and unity. Communities exist in the context of a larger society that should help the personal development of each individual, recognizing that his or her dignity is the fundamental value the society needs to respect and support. Every government has the responsibility to provide essential social services, including education and health services, to all its citizens in order to ensure that every person has a real opportunity for personal growth and development. However, scarce resources, poverty, malnutrition, insecurity, displacement and the global epidemics of HIV, malaria and tuberculosis pose formidable threats to the vast majority of people in the world.

The experiences presented in this publication (Annex 3) show that enhancing the empowerment of people based on increased knowledge and direct involvement in decisions that influence their lives is an effective way of organizing health services. Global initiatives aimed at tackling development, poverty and disease express a renewed effort for global solidarity, but they can be more focused and effective if the people who are more severely affected by these conditions are involved in shaping the answers.

To tackle the threat of TB and of other health problems, some communities have learned how to take care of their health, understand and promote healthy behaviour and take responsibility for providing care and support for sick people. Moreover, by being fully aware that TB is a serious transmissible but curable disease and that diagnostic and treatment services are freely available to all, people can effectively contribute to refer early to the health services every person who may have TB. National health services confronted by the global threat of the TB epidemic should not miss this opportunity. Community involvement in TB care and prevention also provides a chance to communities and civil society organizations, including patients' and activists' groups, to foster their empowerment in matters that strongly affect the common good of a society.

Health services and local communities working together can bring practical solutions that respond to the needs of people where they live. Health services can provide resources, facilities and professional expertise to complement people's efforts to take responsibility for their own health.

Political commitment and community involvement are powerfully sustained by using advocacy, communication and social mobilization. Advocacy ensures political and financial commitment to place TB high on the development agenda and to involve the people affected and their communities. Communication facilitates dialogue and information sharing, helping people to understand and to influence positively their health-related behaviour and helping health services to better understand the personal and social aspects of health problems to provide more adequate answers. Social mobilization refers to promoting the active the involvement of people with TB and communities in health initiatives.

Local communities, people who are directly affected by TB and people who have had TB but have been cured should never be seen as mere passive beneficiaries of health services but as partners who can actively join the fight against the disease. This approach must influence how interventions are designed, planned, implemented and evaluated jointly with people with TB and their communities from the very start.

Country experiences also show that effective involvement does not simply mean decentralizing services into the community or providing suboptimal services for poor people and should not be based on "professional" training and medicalization of lay-people. On the contrary, it means promoting people's responsibility for health through health-related education, identifying problems and establishing a dialogue on possible solutions and how to put them into effect, fostering community self-reliance and ownership of health initiatives.

This publication therefore proposes a vision of partnership based on the fundamental principles of social justice and on the rights-based approach discussed in Section 2. These are overarching principles that provide the foundation for building and sustaining effective collaboration between people, society and institutions.

The following recommendations identify eight specific areas that should be considered to promote and implement the involvement of people with TB and communities in TB care and prevention and to strengthen their empowerment in health interventions:

1. policy guidance, initial implementation and scale-up
2. advocacy and communication
3. capacity-building
4. addressing special challenges in controlling TB
5. ensuring the quality of services provided at the community level
6. budgeting and financing
7. establishing a plan for monitoring, evaluation and supervision
8. operational research.

Each recommendation in this section is divided into principles and recommended actions. The principles are the driving force guiding and orienting the actions that follow. The recommended actions can be expanded, based on the experience acquired and the local context.

Further, some recommendations address needs at a political or normative level and are therefore related to central governments (and national TB programmes), whereas others address local governments and the level of service delivery.

Each recommendation is directed towards one or more stakeholders (national TB programme, civil society organizations and/or communities) specifically responsible for implementation. The term civil society organizations (see Section 1) in this publication refers to a variety of organizations outside the government sector, such as nongovernmental organizations, community-based organizations, faith-based organizations, patients' organizations, activist groups and not-for-profit organizations.

This publication refers to terms, definitions and concepts mentioned in three other publications prepared by partners in the Stop TB Partnership.

- *The Patients' Charter for Tuberculosis Care*[1] and the *International standards for tuberculosis care*[2] provide an overview of the rights and responsibilities of people with

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[1] *Patients' Charter for Tuberculosis Care*. Viols-Laval, World Care Council, 2006 (http://www.worldcarecouncil. org/index.php?nSection=1&module=default&content=34, accessed 30 November 2007).

[2] *International standards for tuberculosis care*. The Hague, Tuberculosis Coalition for Technical Assistance, 2006.

TB and health services in controlling TB and of the standards of diagnosis and care required.

- *Advocacy, communication and social mobilization to fight TB: 10-year framework for action*[1] provides guidance on the use of advocacy, communication and social mobilization in the context of the Stop TB Strategy.

Annex 4 summarizes the generic process with key steps to promote the involvement of people with TB and communities in controlling TB; it is an example of how these areas of work translate into a set of actions that require adaptation to each local context.

1. Policy guidance, initial implementation and scale-up

Develop or revise the national TB programme policy to include component 5 of the Stop TB Strategy.

Principles

- Supporting partnership building and promoting the responsibility of people with TB and community members for their own health is a definite opportunity to translate political commitment into practice, responding to the needs of people, fostering self-reliance, encouraging community life, moving services outwards to where people live and helping bring about behavioural change that will empower communities to enhance their quality of life.

- In the context of a partnership-building process, it must be clearly expressed how active involvement of the community will benefit all its members. An expression of the commitment of the health services and of all stakeholders is crucial to propose and establish a sustainable operational partnership.

- Promoting people's involvement and building the relationship between the health services and the community requires a reasonable amount of time. Involving communities in a project-like manner and pressing for hasty delegation of responsibilities can have serious negative effects on the sense of ownership by the community and on the sustainability of the initiative.

- The national TB control policy should clearly describe a jointly designed process to promote the involvement of people affected by TB and of their organizations and communities and should introduce the use of indicators of such involvement, such as participation in planning, support and evaluation of the intervention, role in improving case detection and treatment adherence, impact on stigma and discrimination, promotion of healthy lifestyles (measured through surveys of knowledge, attitudes and practices) and the quality of care as perceived by the users of health care services and their families.

- A national task force is usually required to steer the process leading to the promotion of involvement among people with TB and communities; its members should include all stakeholders relevant for the setting, such as patients' representatives, leaders of local communities, religious leaders, civil society organization representatives, health staff and health policy-makers.

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[1] Subgroup on Advocacy, Communication and Social Mobilization at Country Level of the Stop TB Partnership. *Advocacy, communication and social mobilization to fight TB: 10-year framework for action*. Geneva, World Health Organization, 2006 (http://www.who.int/tb/publications/2006/en, accessed 30 November 2007).

- Membership of this national multisectoral team should also take into account appropriate personal attitudes, such as interest in and commitment to the task, willingness to learn and to participate and team spirit. Both attitudes and qualifications should be given equal attention.

- The initial situational analysis should identify existing community initiatives, explore possible synergy and describe these interactions in policy documents.

Recommended actions

- To the national TB programme and civil society organizations at the central level: propose and establish a national multisectoral team or task force to work on the national policy, strategy and plan. The team's responsibilities include: analysing the initial situation, identifying all stakeholders, discussing with people with TB and communities to design a "model" for their involvement and providing support for formulating policy by the national TB programme.

- To the national TB programme, civil society organizations and communities at the central level and locally: clearly define and agree on the roles and responsibilities for each of the stakeholders.

- To the national TB programme and national task force, at the central level and locally: plan implementation in demonstration areas and the subsequent scaling up of geographical coverage to serve the whole population with appropriate services; and identify ongoing community initiatives, needs and opportunities for community involvement.

- To the national TB programme, civil society organizations and communities at the central level and locally: start implementation in chosen demonstration areas, learn and share lessons and plan scale-up, ensuring in-field supervision, so that community services can be rapidly extended to all TB units, maintaining optimal quality.

- To the national TB programme, civil society organizations and communities at the central level and locally: highlight the steps towards implementation and also the barriers, constraints and solutions that have surfaced from demonstration areas.

- To the national TB programme and national task force, at the central level: develop national guidelines tailored to the local context, considering both urban and rural settings and experiences initially gathered in demonstration areas, based on schemes designed and implemented in conjunction with local communities.

- To the national TB programme and national task force at the central level and locally: identify advocates and training officers to propose and discuss implementation of the national policy, together with peripheral administrations and local communities.

- To the national TB programme and civil society organizations at the central level and locally: ensure that consistent approaches are implemented across the country during scale-up.

- To the national TB programme locally: when initially approaching a new local community, start by raising awareness about the problems and discuss the possible solutions and opportunities posed by mutual collaboration.

- To the national TB programme, civil society organizations and communities locally: expand community services to all health facilities with TB services within a definite peripheral administrative unit (district or equivalent). Avoiding partial expansion

within administrative units (implementation in a few subdistricts) is key for effectiveness, for sustainability and for monitoring the impact of interventions.

- To the national TB programme, civil society organizations and communities locally: always foster synergy with existing community-based initiatives (such as initiatives and organizations supporting people living with HIV, organizations of people with TB, nongovernmental organizations, community-based organizations and faith-based organizations) rather than creating parallel systems.

2. Advocacy and communication

Principles

- Advocacy is instrumental to influencing authorities and policy-makers: it may initially focus on description of the national or local epidemiological situation of TB, status and performance of the health services available and the advantages associated with the greater involvement of people with TB and communities.

- Communication is an instrument for information and dialogue aimed at encouraging people to promote healthy behaviour and assume greater responsibility for their health. Simple, clear and culturally appropriate messages are needed to inform and create awareness among the general public and people affected by TB: messages will focus on the disease, on available care and on opportunities for people to become actively involved.

- Raising awareness and educating community members about TB is key for changing behaviour. Stigma is often a problem, especially in countries severely affected by HIV. Effective communication starts with personal communication between health workers and the people with TB, their families and local communities and builds a supportive environment for people who feel ill and may have TB.

- The cost of the means of communication varies enormously and usually grows proportionally to the size of the targeted audience. Talks given by community leaders or people who have had TB at schools, churches and/or public gatherings can have great impact and are inexpensive. Printed text and pictures can be included in pamphlets and newspapers. Mass-media campaigns are usually costly and should be carefully tailored to fit the profile of the target audience: they can have a strong positive impact in terms of raising awareness, reducing stigma and increasing demand for TB services.

Recommended actions

- To the national TB programme and civil society organizations at the central level and locally: develop context-specific advocacy and communication strategies based on the national policy, listing activities, tools, indicators and related budget lines.

- To the national TB programme, civil society organizations and communities at the central level and locally: develop advocacy and communication tools adapted to the local context in close collaboration with target audiences (people with TB and local communities) to maximize their effectiveness.

- To the national TB programme and civil society organizations at the central level and locally: with political and health leaders, advocate placing TB high on the political and development agenda and involving people with TB and communities.

- To the national TB programme and civil society organizations at the central level and locally: secure or raise funds for communication tools targeting large audiences: printed materials and mass-media coverage.

- To the national TB programme and civil society organizations at the central level and locally: maintain regular advocacy activities with community leaders and other relevant stakeholders at all levels (such as traditional healers, civil society organizations and patients' organizations).

- To the national TB programme and civil society organizations locally: advocate at the peripheral administrative levels and address, in particular, the challenge of securing funds for primary health care activities at the community level, to facilitate field work and links between health services and the community.

- To the national TB programme and civil society organizations locally: encourage the wide use of communication material, asking people to develop more messages and propose innovative means of disseminating them.

3. Capacity-building

Principles

- Being able to empower and involve communities and people affected by TB, building capacity and trained people involved outside the health sector are essential if all stakeholders are to be able to play an active role at different levels.

- The opportunity posed by the presence and availability of national TB programme partners or, conversely, the constraint of the human resource shortages within the national TB programme may prompt outsourcing to enable planned activities to happen.

- Capacity-building should be based on roles and responsibilities, with related task analysis, agreed on by all partners and clearly presented in national guidelines.

- Partners should recognize and respect the unique capabilities, strengths and weaknesses of each stakeholder. Involvement of people who have or have had TB is of great value to others, given their first-hand experience of the disease.

- Sustainability and the long-term commitment of all stakeholders will require ongoing building of capacity, with recurrent training of health staff and current education of other people who become involved.

- The health ministry and national TB programme need to take a stewardship role in collaboration with other partners to ensure the quality of capacity-building at all levels.

Recommended actions

- To the national TB programme and civil society organizations at the central level and locally: analyse the roles and responsibilities agreed on by the different partners to direct the preparation of the plan to build the capacity of all stakeholders.

- To the national TB programme and civil society organizations at the central level and locally: quantify the shortage of human resources for the support and supervision of all partners involved through workload assessment and carry out gap analysis to prepare a human resource development plan considering the quantity as well as qualifications of staff.

- To the national TB programme and civil society organizations at the central level and locally: an opportunity may arise for establishing a strategic alliance and related partial devolution of responsibility for support and supervision to nongovernmental organizations, faith-based organizations and community-based organizations already operating in hard-to-reach areas or urban settings or other specific situations. This approach may take also the structure of a formal partnership.

- To the national TB programme, civil society organizations and communities at the central level and locally: identify the focal point responsible for coordinating capacity-building activities within the national task force or the national TB programme and, as appropriate, identify focal points at other levels of the health system.

- Develop a capacity-building plan to include:

  — tools for capacity-building for all relevant stakeholders, such as standardized training material and flow charts; consider methods appropriate for adult education (to the national TB programme and civil society organizations at the central level);
  — plan for education activities and related tools addressing also stigma and discrimination (to the national TB programme, civil society organizations and communities at the central level and locally);
  — identify the people responsible for conducting training (to the national TB programme and civil society organizations at the central level and locally); and
  — ensure ongoing training to address staff turnover (to the national TB programme and civil society organizations at the central level and locally).

- To the national TB programme at the central level and locally: identify needs for institutional capacity-building addressed to health managers and local administrators, such as the capacity to adapt the local health budget to include the costs related to component 5 of the Stop TB Strategy.

4. Addressing special challenges such as TB/HIV, multidrug-resistant TB, indigenous populations and ethnic minorities and group settings

Principles

Considering as an example a situation of high prevalence of TB/HIV, countries need to pay attention to the following specific issues.

- Mainstreaming the involvement and partnership of people with TB and HIV and communities can potentially increase the social ownership of any aspect of TB and HIV care and control.

- The involvement of people with TB and communities in TB programmes, building on the experience and collaborating with civil society initiatives on HIV, can provide a strong basis for advocacy for improved TB/HIV services in areas with significant HIV burden.

- Scaling up antiretroviral therapy and improving access to TB services poses a formidable challenge to health services. Community members can complement the efforts of health institutions, providing, with their closeness to the people living with TB and HIV, greater support and care.

- Community involvement should increase the range of treatment support options for people receiving treatment for TB/HIV, including the involvement of family members, people who have had TB, community volunteers and neighbours.

Similarly, the involvement of people with TB and communities can be explored and adapted to address other special challenges such as (but not limited to) refugee settings and internally displaced people, multidrug-resistant tuberculosis, activities in group settings or ethnic minorities that may be harder to reach in terms of geographical or cultural access. For example, the country review for the Philippines provided an interesting illustration of community involvement to sustain the care of people with multidrug-resistant TB and improve the support of people who had previous problems with treatment adherence.

Recommended actions

- To the national TB programme, civil society organizations and communities at the central level: the national task force should analyse the national TB programme policy and implementation strategy with relevant partners to explore opportunities for people with TB and communities to contribute in addressing special challenges to TB control.

- To the national TB programme, national AIDS programme, civil society organizations and communities at the central level and locally: jointly review the TB and HIV programmes and strategies with patients' organizations and communities to identify their possible role in TB/HIV collaborative activities.

- To the national TB programme, national AIDS programme, civil society organizations and communities at the central level and locally: plan, design, implement and evaluate interventions with the participation of people living in or with challenging conditions, such as TB/HIV, multidrug-resistant TB, extensively drug-resistant TB, indigenous populations and ethnic minorities and group settings.

- To the national TB programme, civil society organizations and communities at the central level and locally: identify human resource development needs, training needs, financial needs and resources to enable the participation of people with TB and communities in special settings.

5. Ensuring the quality of services provided at the community level

Principles

- The central level needs to develop standards and a routine supervision system to monitor the quality of services and care provided at the peripheral level. Community members report higher motivation if they are regularly supported.

- The involvement of people with TB and communities should complement high-quality services provided by the formal health services. Health services, therefore, should not neglect their responsibility to provide such services: their commitment is often one of the most powerful motivations for the community to become more involved.

- High-quality services meeting the *International standards for tuberculosis care* should also try to address the needs of people with TB and communities and be tailored to the local culture.

Recommended actions

- To the national TB programme, civil society organizations and communities at the central level and locally: the central level, in dialogue with key stakeholders, should clearly identify the range of services various partners provide at the community level.

- To the national TB programme and civil society organizations locally: identify an effective two-way referral system for people with TB who opt for community-based treatment. This involves identifying people who provide a regular link (interface) between health services and the local leaders or treatment supporters at the community level. Whenever possible, it is advisable to use existing functions, such as a public health worker, and to identify people with the appropriate skills rather than creating new roles, often not sustainable, within the existing services. Ensure sufficient resources (means of transport, per diem payments, etc) to enable such people to carry out their duties.

- To the national TB programme and civil society organizations locally: ensure the availability of appropriate high-quality TB services at all health facilities.

- To the national TB programme, civil society organizations and communities at the central level and locally: prepare the guidelines for community members, monitor, support and supervise patient-centred services in dialogue with the community to ensure high-quality services from both the provider and user perspectives, such as knowledge of the nature of TB (curable, infectious, etc.), symptoms, availability of treatment free of user charges, expectations from the system, waiting times, etc.

- To the national TB programme, civil society organizations and communities at the central level and locally: establish a mechanism of continuous dialogue with communities to ensure that implementation bottlenecks are jointly identified and addressed and that civil society organizations and communities can suggest and contribute to solutions.

6. Budgeting and financing

Principles

- Sustainability and motivation are usually problematic in settings where community members (other than community health workers who devote their whole day to their activity) receive monetary incentives for their involvement. Monetary incentives for a very limited time commitment are often meant to "make things happen faster", skipping the partnership-building process, and they may promote an idea of a project-like approach by the health services, rather than encouraging ownership of the programme by the community and real empowerment. On the contrary, adequate support, including monetary compensation, to community health workers or community members who spend significant working hours providing services to the community should be discussed and regularly provided either from institutional or community resources.

- Health is a developmental issue. Various stakeholders may and should provide resources for health interventions and for initiatives at the community level rather than exclusively from the health ministry budget.

- Opportunities for domestic and international funding sources (such as the Global Fund to Fight AIDS, Tuberculosis and Malaria) should be carefully explored and community-related activities included in funding proposals along with other TB control activities. For many agencies dealing with development assistance, the

commitment of national TB programmes to support partnerships with civil society organizations and local communities is an added value. Preparing funding proposals jointly with all relevant partners is an important part of their empowerment and will assist in preparing accurate and inclusive list of objectives and activities.

- District TB coordinators are members of the district health management team and should actively participate in its activities to counter the prejudice of the verticality of TB control activities and the related consequences on the allocation of funds.

Recommended actions

- To the national TB programme, civil society organizations and communities at the central level and locally: identify a comprehensive list of expenditures relevant to the involvement of various partners (such as training and transport), people with TB and their families, including hidden costs related to care-seeking or loss of income.

- To the national TB programme, civil society organizations and communities at the central level and locally: ensure that national and local budgets for health and funding proposals addressed to development agencies include activities and estimated costs related to the involvement of people with TB and communities.

- To the national TB programme, civil society organizations and communities at the central level and locally: carefully address issues related to remuneration, enablers or incentives for the contribution of involved partners and community members, considering functions and the time spent.

- To the national TB programme and civil society organizations at the central level and locally: identify the resources available from various partners and align resources to ensure the comprehensiveness and non-duplication of budget lines and activities.

7. Establishing a plan for monitoring, evaluation and supervision for component 5 of the Stop TB Strategy

Principles

- Ensure that all relevant partners are involved from the start in creating one monitoring and evaluation plan identifying indicators of the involvement of people with TB and communities, of TB control and of the perceived quality of services.

- Ensure that partners at all levels use standard definitions and indicators to promote more accurate and comparable data collection.

- Ensure the capacity of people with TB and communities to participate in assessing their own contribution and that of the national TB programme and/or health services through adequate capacity-building, when needed.

- Benefit from existing data collection efforts, such as demographic and health surveys, to obtain relevant information on access to health services, etc.

- Ensure the collection only of essential information that is going to be analysed and used for assessing services and the involvement of people with TB and communities, establishing a cost-effective monitoring and evaluation system.

- Periodically analyse qualitative data related to TB knowledge, attitudes and practices at the community level, such as documenting changes over time in attitudes related to stigma.

- Ensure feedback on outcomes and performance to service providers, users and communities.

Recommended actions

- To the national TB programme: decide on and clearly define a set of indicators for the involvement of people with TB and communities. Indicators should:

  — capture the proportion of administrative units (such as districts) implementing community-oriented services at the central level and locally;
  — measure the geographical coverage of community-based services within lower administrative areas (such as the percentage of health facilities with TB services within districts offering community-based services) at the central level and locally; and
  — document the proportion of the national or local budget for TB control and prevention, with specific reference to community interventions, covered by the national or local government, respectively at the central level and locally.

- To the national TB programme and civil society organizations at the central level: document the existence or absence of policy documents and implementation guidelines about component 5 of the Stop TB Strategy.

- To the national TB programme at the central level: include indicators related to component 5 in the existing recording and reporting system.

- To the national TB programme and civil society organizations locally: identify indicators to monitor the involvement of people with TB and communities, reflecting organization, representation, perceived quality of services and viability.

- To the national TB programme at the central level and locally: choose appropriate process, output and outcome indicators for advocacy, communication and social mobilization activities routinely carried out by the programme.

- To the national TB programme and civil society organizations at the central level and locally: document the existence or absence of a communication strategy and related material and its periodic evaluation.

- To the national TB programme, civil society organizations and communities at the central level and locally: measure the satisfaction of people with TB, TB knowledge among the general population and explore stigma through qualitative assessment, such as surveys of knowledge, attitudes and practices. These data should be collected every one or two years.

8. Operational research

Additional operational research may be required to answer general or context-specific operational problems and make the involvement of people with TB and communities more effective.

Principles

- National TB programme–based operational research aims at improving programme performance.

- Both quantitative and qualitative research methods should be considered when assessing the outcome of activities, perceptions and motivation at the community level.

- Although research specialists within the national TB programme (or possibly external consultants) most often design and manage protocols for operational research, health staff, partners and community members should be involved in discussion and decision-making about the objectives of operational research and should participate in implementation and in the final data analysis and interpretation.

Recommended actions

To the national TB programme, (inter)national authorities, civil society organizations at the central level and locally: design operational research:

- to explore the effectiveness of how the people who have or have had TB and communities are contributing (role, comparative advantage, etc.) to health promotion, TB prevention and control;

- to document good practices: quality, acceptability to both users and services providers, motivation and sustainability;

- to link operational research to the establishment of a more accurate monitoring and evaluation system, such as case detection, treatment outcome and the quality of services; and

- to identify relevant operational research themes based on challenges or opportunities (cost and cost-effectiveness of the involvement of people with TB and communities, issues of accessibility related to gender or vulnerable populations, etc.) for the implementation of component 5 of the Stop TB Strategy.

Summary of previous WHO research and reviews

Starting in the late 1990s, WHO has promoted operational research on community contribution to TB care in the African Region (1996–2000) and has conducted reviews of ongoing experiences in South-East Asia and Latin America.

The main research questions addressed by these initiatives were related to:

- the effectiveness of the community-based approach in pilot areas, measured as the impact on treatment outcome indicators and compared with performance in control areas implementing the conventional TB control strategy;

- the cost-effectiveness of community-based initiatives compared with conventional approach in control areas; and

- the acceptability of community involvement to health workers, people with TB and other community members.

The information and evidence gathered through these initiatives have led to the inclusion of community empowerment as an essential element of the new Stop TB Strategy.

This annex summarizes the main findings of these projects, referring to the original publications for in-depth information about methods and results.

Community TB Care in Africa Project

The initial interest in promoting community participation in TB control in the WHO African Region was motivated by the need to address several challenges.

- The limited coverage of public health services has continued to impede accelerated access to TB control services. This has been attributed to several factors: inadequate health services infrastructure, insufficient decentralization of diagnostic and treatment services and inadequate human, material and financial resources.

- Better adherence to TB treatment needs to be encouraged, focusing on support that people with TB can receive from friends, neighbours and their families.

- The direct impact of the HIV epidemic has led to an exponential increase of TB incidence in the Region, increasing pressure on hospital and public health services already stretched by the need to ensure effective delivery of essential packages of primary health care services.

On the other hand, the Region could count on a two-decade-long promising experience in countless community-based public health interventions, which made testing alternative ways to complement public health services in the provision of TB care very reasonable.

The Guidelines for implementing community TB care programmes[1] summarize as

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[1] *Guidelines for implementing community TB care programmes*. Brazzaville, WHO Regional Office for Africa, 2004 (http://www.afro.who.int/tb/res-pub/index.html, accessed 30 November 2007).

follows the main findings from the six countries involved in the Community TB Care in Africa Project.

The Project

Between 1996 and 2000, WHO coordinated a multinational project to evaluate community contribution to TB care in eight sites in six countries in sub-Saharan Africa: Francistown, Botswana; Machakos, Kenya; Lilongwe, Malawi; Guguletu and Hlabisa, South Africa; Kawempe and Kiboga, Uganda; and Ndola, Zambia. The aim of the Project was to evaluate how decentralizing the provision of TB care beyond fixed health facilities to the community level affected the performance of national TB programmes. The main outcomes of interest were effectiveness, acceptability, affordability and cost-effectiveness.

Summary findings from the project

Francistown, Botswana

The Botswana study was designed to determine the cost and cost-effectiveness of home-based care of chronically ill people living with HIV and TB compared with hospital care. The study showed that people with HIV and TB under the conventional hospital-based care scheme stayed in hospital longer than their counterparts, and home-based care was much less expensive than conventional hospital-based care both to the health system and to caregivers. Economic analysis showed that home-based care was 42% more cost-effective than conventional hospital-based care. The investigators concluded that treating chronically ill people living with HIV and TB is more cost-effective at home than in hospital.

Machakos, Kenya

The Machakos study assessed the cost-effectiveness of decentralized and community-based DOTS compared with conventional hospital-based DOTS. All newly registered people with TB were given the option of limited hospital admission followed by either facility-based (hospital inpatient, hospital outpatient and health centre) or community-based care even during the intensive phase of treatment.

For smear-positive people with TB being treated for the first time or re-treated, treatment success rates were similar between the two treatment groups and treatment completion was better in the community-based care group. For people with smear-negative and extrapulmonary TB, treatment completion, default and transfer-out rates were significantly better in the community-based care group compared with the facility-based group. The groups had similar death rates. Finally, both the people with TB and family members preferred home care to hospital care for TB. The study therefore concluded that community TB care was a viable means of implementing DOTS as it served to remarkably decongest the hospital wards, was acceptable to people with TB and family members and was more cost-effective. The main challenges observed were the increased demand for supervision, training of community-based care providers and the need to decentralize and maintain high-quality laboratory services.

Lilongwe, Malawi

The overall objective of the Lilongwe study was to compare treatment outcomes, cost and cost-effectiveness between decentralized TB care services and conventional centralized TB care services. Besides the main TB hospital, 21 new DOTS centres were established at urban health centres where people with TB could choose to receive their

intensive phase of treatment supervised by health centre staff or at home supervised by guardians of their choice. For the economic assessment component of the study, treatment outcomes in the two main hospitals in the study area were compared during and before the study in a before-and-after study design.

The study showed that the overall cure rates were similar between the periods, but the default and transfer-out rates were lower during the period with the community TB care option. The case-fatality rate, however, was higher during the community-based option time (perhaps due to more complete reporting of end-term events due to closer supervision). The acceptability of community involvement was inferred from the willingness of community groups and guardians to participate in providing community-based TB care. Decentralized care was also less costly for people with smear-positive TB but introduced new costs for people with smear-negative TB in the form of directly observed treatment visits and more expensive drug regimens. The investigators concluded that decentralization was more cost-effective for new smear-positive people with TB but less so for new people with smear-negative TB.

Guguletu, South Africa

The Guguletu study was designed to evaluate and compare the programme performance for both new and re-treatment smear-positive people with pulmonary TB supervised at the clinic, in the community and in other supervision options over an 18-month period. Comparison data for economic analysis were collected in neighbouring areas where the community option was not available.

The study showed that the community-based TB care supervision option was more cost-effective than the clinic and other options both for new and re-treatment people with TB. Health system costs and out-of-pocket costs also declined significantly for new smear-positive as well as re-treated people with TB in the community group compared with the clinic-based group. The investigators concluded that community-based care of people with TB was both cost-effective and acceptable.

Hlabisa, South Africa

The objective of the Hlabisa study was to assess the acceptability and effectiveness of traditional healers as supervisors of TB treatment compared with other types of treatment supervisors (clinics, community health workers, shopkeepers and other laypeople). The results showed that traditional healers were another potential group of DOTS supervisors. The traditional healers had case-holding rates similar to those of other types of supervisors, and the people with TB were satisfied with the services they rendered. An earlier detailed economic analysis of the TB control programme in the area that included a costing of the existing community-based DOTS programme showed that community-based DOTS was more cost-effective than hospital care.

Kawempe, Uganda

The study in Kawempe, an urban location in Kampala, was designed to assess the cost-effectiveness and acceptability of community-based management of TB using a non-governmental AIDS support organization, The AIDS Support Organization (TASO). Conventionally, people with TB were admitted for the first 2 months of the intensive phase of anti-TB treatment followed by monthly reporting to health units to collect anti-TB drugs that are taken at home unsupervised. During the intervention, people with TB started treatment in the health unit for the first two weeks and were then given a choice between community and health unit for DOTS supervision.

Intervention uptake and treatment success rates in this study were unexpectedly low even though the treatment success rate for people with new cases of TB was slightly better in the intervention group than in the control group. Community members as well as people with TB had reservations about the community care of people with TB because of issues of stigma (partly because the project was associated with an AIDS support organization), cost and distance to the health unit for those who chose that option. No economic analysis was undertaken. The main conclusion was that successfully implementing a community-based approach for TB care in this urban setting in Kampala had not been possible.

Kiboga, Uganda

The Kiboga study was designed to compare the cost-effectiveness of community care for TB and the conventional approach in which people with TB are admitted for the first two months of treatment. Kiboga served as the intervention population, and Masindi district nearby served as the control population. A before-and-after comparison for Kiboga was also made during the analysis.

The study found that people with TB in the intervention group were twice as likely to be treated successfully as those in the control group. There were also substantial reductions in cost and over 50% improvement in cost-effectiveness in the intervention group. The hospitals have therefore increased the capacity to cope with rising number of people with TB, and community-based DOTS has become highly acceptable to people with TB, health care workers and the community.

Because of the success of this project, community-based DOTS was adopted as the national policy for TB care in Uganda in January 2000. The current major challenge faced by the National Tuberculosis and Leprosy Programme is to allocate adequate resources for successful implementation of the policy.

Ndola, Zambia

The Ndola study was designed to assess the effectiveness of community-based TB care. The project identified Chipulukusu compound, which had an established community-based group serving chronically ill people with symptomatic HIV infection as an intervention site, and Twapia compound, which did not have an established community-based care programme, as a control. In the intervention population, treatment options included community-based DOTS in the initial phase and if necessary in the continuation phase as well; in the control area, staff administered TB treatment to ambulatory people with TB at the health centre daily or weekly.

The results showed that integrating TB care into the home-based care programme in Chipulukusu in which trained and supervised volunteers were used to administer DOT to people with TB is feasible and resulted in high cure and treatment success rates for people with sputum-positive TB compared with the control area. Further, the default rate for all types of people with TB was zero in the intervention compound, which differed significantly from the control area. The approach was also highly acceptable to people with TB, volunteers and the wider community.

Conclusions

The main conclusions and policy recommendations for the WHO African Region included the following.

- Community-based TB care is a feasible, acceptable, effective and cost-effective way to deliver TB DOTS services. However, it must be implemented as an integral component of a national TB control programme.

- Although community-based DOTS is cheaper and more cost-effective than hospital-based care, new resources are often required for implementation. This is mainly for training care providers, strengthening health delivery systems such as laboratory, monitoring and evaluation services and following up the people with TB.

- Successful community contribution to TB care requires close collaboration between the national TB programme and the community to provide technical and other support to the community initiatives and to ensure high-quality services. It should therefore only be pursued if the essential elements of a national control programme are in place (even if the results of programme performance are below targets) and the decentralization of health facility provision of TB services has been maximized.

- Managerial expertise is essential in linking the TB programme, general health services and community care providers. Training of community care providers is essential and should focus on a limited number of activities. Supervision should be regular, frequent and supportive; and community TB care should be designed to complement and extend the capacity of the national TB programme and not to replace it.

- The sustainability of the programme is very important and must be planned for from the start. Good situation analysis is necessary to identify area-specific contexts and to identify appropriate community care providers. Appropriate community providers are more likely to be motivated individuals close to the people with TB or to belong to a well-established and experienced community group or organization as opposed to a recently established and inexperienced group. It is necessary to identify the context-specific motivation of community care providers and ensure ongoing motivation to sustain their activities.

- Effective community contribution to TB care, especially community-based DOTS, requires strong referral, recording and reporting systems, easy access to laboratory services and a secure drug supply. These should therefore be developed as part of general strengthening of the health care system to ensure smooth delivery of services and efficient support for activities at all levels.

Following the successful piloting of the community TB care approach in these six African countries, the WHO Regional Office for Africa included community-based DOTS as one of the approaches to increase population access to DOTS services and improve programme performance.

The WHO publications documenting this project and the *Guidelines for implementing community TB care programmes* provide not only the results of all the studies mentioned above but also valuable guidance for national TB programmes on how to undertake similar initiatives and study their cost-effectiveness.

These publications also point to the need for further operational research in at least three areas:

- All pilot projects focused mainly on the impact of community TB care on treatment outcome indicators: is community involvement going to affect positively, in due course, TB, including the detection of new TB cases?

- What challenges will scaling-up community care to the national level and managing it under routine (rather than "pilot study") conditions pose in these and other countries?

- What will be the long-term sustainability of the community-based approach and, in particular, how can the motivation of community and volunteer care providers be maintained over time?

Since 2000, many more countries in Africa have started introducing community TB care (often jointly with other approaches like TB/HIV collaborative activities and public-private partnerships) in their TB control strategy; the national TB recording and reporting systems are currently being revised to allow proper monitoring and evaluation of the relative impact of these new approaches, and answering the first question is therefore still difficult.

Nevertheless, several of the countries initially involved in the Community TB Care in Africa Project have been committed for several years to implementing it and scaling up; their experience can be valuable for other countries in addressing the second and third questions.

For this reason, Kenya, Malawi and Uganda were included in the WHO review described in Annex 3 of this publication.

Further reading

Community contribution to TB care: practice and policy. Geneva, World Health Organization, 2003 (http://www.who.int/tb/publications/2003/en/index1.html, accessed 30 November 2007).

"Community TB Care in Africa": a collaborative project coordinated by WHO. Report on a "lessons learned" meeting in Harare, Zimbabwe, 27–29 September 2000. Geneva, World Health Organization, 2001 (http://www.who.int/tb/publications/2001/en/index1.html, accessed 30 November 2007).

Community contribution to TB care in Asia

WHO commissioned a review of community contribution to TB care in Asia in 2000, comprising a literature search and visits to selected community TB care projects in Bangladesh (two sites) and India (three sites). Historically, TB control efforts in much of Asia were centred on curative services delivered through a limited number of specialized institutions in urban centres. This approach was associated with limited success, and national TB programmes are now more typically integrated with general health services. However, since even this does not ensure access for the whole population, additional strategies are needed. The potential for community contribution to TB care in Asia is high because of the long history of community involvement generally in primary health care.

The areas of interest investigated during this review included: the type and extent of community involvement, the components of care provided in various programmes by the community, the process of selection of community-based workers, capacity-building for community health workers and their supervision and, finally, the issue of motivation and incentives across programmes.

According to a WHO report published in 2002,[1] the review reported a high level of community involvement in TB care in India and Bangladesh. This seems to be built

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[1] Sharma BV. *Community contribution to TB care: an Asian perspective*. Geneva, World Health Organization, 2002 (http://www.who.int/tb/publications/2002/en/index1.html, accessed 30 November 2007).

on the high levels of direct community involvement in community development and primary health care in these settings. The extension of this activity into TB control is a logical development.

The types of involvement range widely. At one extreme, large nongovernmental organizations provide all TB care (under franchise from the national TB programme) in a large geographical area and for a large population, using a community-based approach for delivering TB care. At the other extreme, there are smaller, innovative projects seeking to establish new ways of delivering TB care in the community. As documented here, several of these programmes are achieving high-quality outcomes.

Following the recommendation from the WHO Regional Office for South-East Asia, the WHO review described in Annex 3 of this publication included two countries in the region, Bangladesh and Indonesia, with the dual aim of describing different models adopted on a large scale in both countries and of looking more in detail into the issue of motivation at the community level.

Community contribution to TB care in Latin America

This review of community contribution to TB care in Latin America in 2001 comprised a literature search and visits to selected community TB care projects in Bolivia and Colombia.

The health care system infrastructure varies substantially across Latin American countries. Many countries have relatively good public health care infrastructure and modern health care technology, at least in major towns and cities, whereas others have a relatively poorly developed system.

In Latin America, the prevalence of HIV is low compared with that of Africa and has not led to an increased TB caseload that multiplies the disease burden and threatens the performance of the national TB programmes.

There is substantial evidence of effective community participation in health care in general in several countries in Latin America, particularly in controlling diseases transmitted by vectors. It seems that such community involvement has been driven both by the need to supplement relatively weak government responses to diseases and by the promotion of community participation within health projects managed by nongovernmental organizations supported from outside the countries.

In Bolivia and Colombia, visits were made to sites selected in consultation with local Pan American Health Organization officials. Only sites where DOTS was introduced and implemented and those known to have a community-based TB care project were considered. Methods used to collect data at the sites visited included observation, interviews with key informants (community project leaders and health officers in charge of TB programmes) using a semistructured interview guide, and review of national TB programme records.

The main findings of the review confirmed the strong foundation of community involvement in primary health care, often through established nongovernmental organizations in parts of Latin America. Community participation in TB programmes includes case-finding, community-based DOTS, contact tracing, social support and lobbying local governments.

There are variable levels of integration with the national TB programme, and the levels of community-based DOTS observed were low. Although evidence of the impact of community contribution on treatment outcomes seemed to be limited, the high level of community participation in civil society in general and in primary health care in particular suggested the potential for substantially enhancing the community contribution to TB care.

In the context of the review described in Annex 3 of this publication, following an invitation by national health authorities as well as a suggestion from the Pan American Health Organization, Mexico was included in this review to document how TB control has been included in a very successful nationwide primary health care programme that promotes extensive participation of the community in managing health-related issues.

Further reading

Jaramillo E. *Community contribution to TB care: a Latin American perspective.* Geneva, World Health Organization, 2002 (http://www.who.int/tb/publications/2002/en/index1.html, accessed 30 November 2007).

Policy recommendations and emerging issues based on the Community TB Care in Africa Project and on the reviews in Asia and Latin America

The following is a summary of the main policy recommendations based on the three reviews published by WHO. Some are followed by a brief mention of issues arising from implementation and reported to WHO by several countries.

1. The first recommendation is about the settings in which community involvement in TB care should be promoted because of its potential contribution to TB control. The decision to adopt a community-based approach has been mostly motivated by the observation of an overwhelming TB case load for health facilities and, on the other hand, by the recognition that existing health services, in many countries, are not accessible enough to the population they have to serve and, in particular, to people living in remote and disadvantaged areas. In terms of access to care and follow-up, a disease such as TB that still requires treatment for 6–8 months poses special challenges to the health system, to the people immediately affected by the disease (people with TB and their families) and to the wider community. The active involvement of people in TB control activities effectively mitigates some of these constraints and makes the treatment more acceptable.

   ### Emerging issue

   Given the proven cost-effectiveness of this approach, is the sole purpose of community empowerment to achieve better TB programme results? Or is it an inherent objective that any health system should actively pursue to fulfil its institutional mandate to serve and improve the health status of the population in which individual people, families and communities remain the most important actors responsible for their own health and development?

2. The political and technical decision to involve directly the community in the management of health issues requires careful preparation and several steps:

   — activities to solicit political commitment and support from local leaders;

   — a clear situation analysis that highlights the burden of disease for the administrative areas as well as community action that could contribute to diminishing that burden and to mitigating the impact of the disease on people with TB and families;

   — identifying all potential relevant partners with specification of the roles and functions of each partner, with special attention to existing community groups and HIV community organizations;

— developing models of involvement with the active contribution of the community from the initial planning phase that should preferably start from a simple redefinition of existing functions within the health system (without planning a parallel system) and the creation of appropriate links (interfaces) between health services and communities (unfortunately, when the responsibility is given to the community without appropriate links back to the formal health services, health services at times abdicate their responsibility); and

— both community members and health staff involved have to go through a capacity-building process aimed at enabling health care and public health personnel to fruitfully interact and collaborate with their community members, who assume specific responsibilities and to play them effectively; the capacity-building process needs to include planning training sessions, preparing adequate (and adapted) tools, identifying the required human and financial resources, conducting training and envisaging means and ways to monitor performance and ensure support.

Emerging issue

Is the community a mere beneficiary of the health intervention being proposed or a partner that needs to be empowered to play its role? The answer to this question determines the method and the content of all activities of advocacy, communication and social mobilization geared towards empowering the community.

3. Community involvement is complementary to and does not replace national TB programme activity and responsibility. The roles of community volunteers need to be defined clearly and carefully. Shared responsibility requires clear terms of reference and adequate empowerment of all partners. Health services and their staff provide (and work towards improving access to) diagnostic and treatment facilities, professional expertise and drugs free of user charges, while community members can share information about TB and help destigmatize the disease, refer people suspected of having TB for sputum examination, support people with TB in ensuring adherence to treatment, refer and/or accompany people with TB for follow-up sputum examinations, help people with TB to keep records of their treatment and give feedback about any complication of treatment to the public health staff, who then refer them to the health facility. If the community is involved from the start in planning activities, it can give valuable suggestions about the responsibilities its members are ready to assume.

Emerging issue

If the community is seen as a partner and as having primary responsibility for its own health, this approach must influence how interventions are designed and decisions taken. The earlier the involvement, promoted with a sound understanding of subsidiarity, the greater the ownership.

In contrast, a community that is merely asked to comply with decisions taken at different levels from where problems occur may or may not accept this responsibility.

Enablers and incentives, agreed on by the community, have to be considered whenever people accept to devote a considerable amount of their time to be trained and to serve their community. This has traditionally applied to community health workers, who may offer a variety of services and spend much of their working time for these.

This level of commitment differs from "volunteer work", freely undertaken, which implies that a person will spend a limited amount of his or her time, without affecting the capacity to earn his or her living, for an activity of public interest, such as providing support to a person with TB, from which the person supported, the wider community and also the volunteer are going to benefit (greater health in the community as a common good).

However, in the absence of clear ownership and advantages for the community, community members will often, and quite reasonably, demand monetary incentives even for a very limited contribution of time and effort.

4. Community-based care often involves significant savings and increased cost-effectiveness compared with facility-based care. However, some regular investment is required to conduct initial training and refreshers for health staff and community members and to ensure proper and regular support and supervision of activities of both health staff and of community treatment supporters.

Emerging issue

Savings and new costs often affect different functional areas of the health system (such as health care versus public health activities). Savings should be redirected to cover new costs, if the same amount of funding can provide better and more accessible services to the population. In view of the overall benefit for the health status of the population, it is typically a government (central or local) duty and responsibility to issue directives to guide financial planning, so that budgets for health reflect the new policy and enable implementation. Regrettably, after benefiting from cost savings, some governments do not reinvest in infrastructure and services but use funds for other pressing causes.

5. The selection of community members who will be trained to carry out specific functions requires collaboration among health staff, people with TB and community leaders that considers such issues as basic requirements (motivation and functional literacy) and acceptability to the people with TB.

Emerging issue

An important debate has arisen, across different contexts, about the role of family members. The family is the community closest to each person with TB. The experience of many HIV organizations, which give proper consideration to issues related to confidentiality and the needs of long-term care, suggests that special attention should be given to the role of family members, provided that they are not left alone assisting their relative but are effectively supported by community members or health staff.

6. Capacity-building, as already mentioned, involves both health care staff and the people who provide support to people with TB. Clear task descriptions will guide the preparation of all training tools.

Emerging issue

The choice of people who provide support at the community level also determines the training required.

— Training of "multi-purpose" community health workers requires more time and resources but may often be more adequate for settings with higher population

density, where they can create networks that cover a given catchment area, maintaining services easily accessible to all.

— Where the population density is lower or people are scattered in distant villages, the on-the-job instruction of a family member or volunteer can ensure closer support to the person with the disease.

— Training community members in advance is not necessarily cost-effective, as they may not have the opportunity to render their service and, therefore, lose motivation and/or forget what they have been taught.

— In contrast, motivation will be higher if a volunteer is trained at the time a person is identified as having TB, since his or her service will be immediately perceived as useful and contributing to the good of the person with TB and the community.

7. Regular contact between the community volunteer and the staff who provide the link with the health services is key for support, motivation, instruction and supervision, to ensure that high-quality care is maintained. The choice of the health staff (in terms of their current function) to provide the link between health services and community is perhaps the most important strategic decision health managers and community leaders have to take at the time they consider involving the community in TB control activities. Public health officers, whose duties over a certain territory ensure regular contact with the community, are the best candidates for this function. If resources are already provided for their routine primary health care activities in the field, TB control activities can be easily integrated into their duties.

8. Regular reporting of results is essential to document the community contribution to TB care and to ensure the quality of home-based care.

Emerging issue

The recording and reporting systems of most national TB programmes that have introduced community TB care do not yet comprise tools to collect information about community contribution. Two basic pieces of information that can easily be incorporated in treatment cards, unit registries and quarterly reports to the Ministry of Health include:

— the role of the community in referring that person to the health facility as a person suspected of having TB; and

— the presence or absence of a community treatment supporter who helps and motivates that person for the duration of treatment.

This allows, whenever required, for easy stratification of people with TB during the cohort analysis and for monitoring of quality of care indicators, determining the contribution of the community to case detection, the proportion of people with TB who opted for community care and their treatment outcomes.

9. Ensuring an effective and secure drug supply system is an essential element of the Stop TB Strategy. The regimens used should be consistent with national guidelines, and drugs that are going to be used at the community level should preferably be supplied as fixed-dose combinations and in calendar blister packs.

Emerging issue

A regular drug supply free of user charges is an important element that builds the community's trust in the health services; it is a specific commitment the government can take in proposing a partnership with communities.

10. The introduction of community empowerment as a new element of the national TB control strategy or its integration into existing community-based health interventions (such as HIV home-based activities) requires the development of plans with estimated costs. Plans including start-up as well as routine implementation costs (and investment required for phased scale-up) should provide all the information required by planners at the central and local government levels to adapt budgets to the new policy.

The recommendations published in 2003 were meant to provide guidance for countries to mainstream community contribution to TB care as part of routine TB control operations. Several new operational research questions were also proposed, considering the challenge of:

- moving from pilot studies in demonstration areas to routine implementation; and

- scaling up this intervention to significantly influence TB control performance.

The technical support provided to the Member States that have incorporated community TB care into their national TB control policy has led to identify the following recurring questions.

How and why does the community contribution to TB care work better in some settings than others? What are the most effective models?

- How can these programmes effectively integrate or collaborate with local HIV, prevention, treatment care and support efforts?

- What is the most effective approach to building the long-term commitment of communities and people who provide social support to their relatives, friends and neighbours affected by TB, HIV and other diseases?

- How can the impact of these initiatives on TB case detection, completion of treatment and reduction of treatment interruption be maximized?

- Are these initiatives sustainable in the long term?

- How does community involvement contribute to combating TB-related stigma? What lessons can be learned from destigmatization efforts in combating HIV?

- Which TB treatment regimens and anti-TB drugs formulations are most practical for use by people with TB and community treatment supporters?

The operational research findings summarized here strongly suggest that the community can contribute very effectively to ensure that people with TB adhere to treatment. This has drawn new attention from the health services. Is it possible to move forward and encourage communities, either as loose partnerships of individuals or as more organized groups, to assume responsibility for other functions that, given their proximity to people with TB, they can carry out more effectively and often more caringly than the health services?

The WHO Stop TB Department and the global Stop TB Partnership have been addressing these issues through country visits and extensive literature reviews. The following section reports the results of a literature review focusing on effective models

and motivating factors in community involvement, complemented by the summary of a specific review commissioned by the Stop TB Partnership on the role played by patients' organizations.

Annex 3 summarizes the main findings of the review of community involvement in TB control carried out by WHO in seven countries from May 2005 to May 2006. The country reviews aimed at describing good practices (effective models) under conditions of "routine" implementation and used qualitative methods to investigate what motivates and sustains commitment of people in community-based TB control initiatives.

The reviews also looked at the role of some community members, such as people who have or have had TB, who play an important role in organizing meetings to share concerns, get information regarding side effects, promote preventive measures and encourage treatment adherence among others.

A literature review on community motivation and involvement in TB control

A literature search with the key words "tuberculosis (OR TB) AND community" was conducted using PubMed between 2000 and the end of 2005. Staff at the WHO Stop TB Department, national TB programme officers and partners were also asked about additional publications and unpublished material. The search returned 628 references, 55 of which were selected as relevant (*1–55*). Table 1 shows the distribution of studies by WHO region and countries by region.

Table 1. Distribution of studies by WHO region and countries by region

WHO region	Number of studies	Number of countries
African Region	32	10
Region of the Americas	3	2
Eastern Mediterranean Region	3	1
South-East Asia Region	8	4
Western Pacific Region	0	0
Other (reviews etc.)	9	
Total	**55**	**17**

The following variables were identified as relevant for the purposes of data extraction:

- author;
- reference;
- publication year;
- country;
- setting within a country;
- WHO region;
- brief description of the focus;
- coverage – population size covered by the study;
- community involvement – formal (such as existing community health workers, volunteers attached to an nongovernmental organization or faith-based organization, religious leaders, etc.) or informal (individuals identified once a person is diagnosed; such as a family member, neighbour, friend, colleague from work, teacher, etc.);
- components of TB control provided;
- effectiveness of the studied intervention; and
- motivation.

Discussion

The aim of this literature search was to identify articles that discuss the model of community involvement, or how the community involvement was operationalized in dif-

ferent settings, and those that discuss the motivation of community members involved in TB control.

However, a vast majority of the publications identified focused on the effectiveness and cost-effectiveness of community involvement in providing TB care (Table 2). Such publications were included only if the author(s) mentioned the model of community involvement or the motivation of community members involved, even if very briefly. Nevertheless, all the papers that compared treatment outcomes according to different types of treatment support provided showed at least comparable outcomes across the different types of treatment support provided.

More than two thirds of the published articles referred to experiences in the WHO African Region. Thirty-two relevant studies were sourced from 10 different countries. Most studies came from South Africa (10), followed by Malawi (5), United Republic of Tanzania (4) and Uganda (3). Twenty papers discussed the effectiveness and/or cost-effectiveness of different types of treatment support. Studies reporting on formal versus informal community involvement were well balanced. In terms of components of TB control provided, 26 studies from the African Region reported on treatment support, 8 on suspect referral, 5 on tracing defaulters, 3 on awareness-raising and 1 on sputum collection. Models of community involvement from the African Region varied greatly and provided valuable information on experiences in different contexts. Four studies from Ethiopia, Malawi and South Africa (*21,23,35,41*) reported on community involvement in components of TB control other than treatment support and referral of suspects: volunteers from nongovernmental organizations and motivated community members effectively traced defaulters in South Africa; tracing people who interrupt their treatment and sputum collection and transport by motivated individuals was successful in one district in Malawi; and an increase in case-finding was reported in a study in Ethiopia in which people with TB were involved in regular awareness-raising activities in their area of residence. The community members involved in TB control ranged from existing community volunteers, motivated individuals, traditional healers, to family members (especially in Malawi), people with TB, neighbours, shopkeepers, farmers, etc. Clarke et al. (*30*) describe some innovative ways of mobilizing the community.

In a South African community where farming is the main source of income, adult farm dwellers have identified suitable peers and sensitized them about TB with the help of health services. They conduct monthly TB screening of all farming families in the area, with adequate supervision by the health services. Case finding and treatment outcomes were higher in intervention than in control areas. In Malawi (*23*), a nongovernmental organization decided to build on prior HIV support groups initiated by church members. In addition to church members, they sensitized influential figures from the community who performed a variety of beneficial tasks in the area. In Kenya (*44*), the national TB programme started designing the intervention by identifying different care groups at the community level and involved them all in treatment support: community-based distributors of contraceptives, community health volunteers, traditional birth attendants, women's development group, religious groups, etc.

Regarding motivation, a study from the United Republic of Tanzania (*6*) reported on the volunteers being motivated by the feeling of prestige related to helping a fellow villager, by good relationships with health workers and refresher training provided. In a site in South Africa (*29*), farm dwellers described how they were motivated not only by altruistic motives but also by the desire to learn relevant things about their personal life and spiritual growth. In some other studies, not enough information was available to understand the situation; for example, Kironde & Neil (*21*) state that discussions

Table 2. Summary of the 55 studies in the literature review

Authors	Reference	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Zafar Ullah et al.	1	2006	National	Bangladesh	Review						Principles of involvement of nongovernmental organizations
Frieden	2	2005	NA	NA	Editorial						Good community argument
Hadley & Maher	3	2000	NA	NA	Review		Formal versus informal involvement				Community lessons from other health care programmes: sustainability, different roles
Elzinga et al.	4	2004	NA	NA	Review						Some text on community care
Macfarlane et al.	5	2000	NA	NA	Review						Government (donor) versus community
Lwilla et al.	6	2003	Kilombero district	United Republic of Tanzania	Different methods for directly observed treatment	522 people with TB	Informal: individuals volunteered	Directly observed treatment	Comparable to facility-based directly observed treatment	Feeling of prestige, helping fellow villager, good relationship with health staff, refresher training, respect from the community	Random facility versus community-based directly observed treatment (good results); directly observed treatment only in intensive phase
Bowyer	7	2004	National	Peru	Health sector reform	3 million					Problems with community participation
Kapiriri et al.	8	2003	Nama sub-county (Mukono district)	Uganda	Decentralization and community participation						Barriers to public participation in Uganda
Khan et al.	9	2002	Three sites: Rawalpindi, Gujranwala and Sehiwal	Pakistan	Different methods for directly observed treatment	500 people with TB	Formal: lady health workers	Directly observed treatment	Self-administered, facility-based and community-based all the same		Self-administered most cost-effective, otherwise just as effective
Farmer et al.	10	2001	National	Haiti	Community involvement in HIV		Formal: community health workers	Directly observed treatment			HIV community involvement based on TB experience; no model or motivation
Bhuyan	11	2004	NA	NA	Review						Good discussion on community approaches
Mullan & Epstein	12	2002	NA	NA	Review						Great for terms and issues around practice
Mumtaz et al.	13	2003	Tehsil Pindi Gheb, District Attock and Punjab	Pakistan	Not TB-specific qualitative analysis	30 interviews at different levels	Formal: lady health workers			Empowerment of women	Good qualitative study (more motivation than model), with not very positive findings

Authors	Reference	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Kironde & Nasolo	14	2002	National	South Africa	Involvement of nongovernmental organizations in community care						Problems with involvement of nongovernmental organizations in TB community care in South Africa
Demissie et al.	15	2003	Este and Adet districts, South Gondar and west Gojam	Ethiopia	TB clubs and case-holding	64 people with TB in the intervention and control groups	Informal: people with TB formed a TB club	Referral of people suspected of having TB	Highly effective in terms of reducing stigma, referring people suspected of having TB and reducing defaulting		Interesting for the involvement of people with TB
Maher	16	2003	NA	NA	Review						Summary and follow-up of the WHO booklet
Green	17	2003	NA	NA	Review						Great article on values in high-income countries versus Africa
Shin et al.	18	2004	Lima	Peru	Community-based multidrug-resistant TB (review)	Lima	Formal: community health workers (and informal: several community members)	Directly observed treatment, referral of people suspected of having TB and contact tracing	Highly effective and wide community involvement		History of community involvement in multidrug-resistant TB care
Singh et al.	19	2004	Gurgaon District, Haryana State	India	Different methods for directly observed treatment	617 people with new cases of smear-positive TB	Informal: shoe-shop owner, priest, traditional doctors, teachers, etc.	Directly observed treatment	Comparable to facility-based directly observed treatment	No incentive	Urban informal community volunteers, effective
Watkins & Plant	20	2004	Bali	Indonesia	Perspectives of people with TB	11 people with or suspected of having TB	Family				Qualitative study on people with TB; need for community education; family directly observed treatment
Kironde & Neil	21	2004	Northern Cape province	South Africa	Involvement of nongovernmental organizations in community care		Informal: random community members; formal: community health workers from nongovernmental organizations	Directly observed treatment, referral of people suspected of having TB and tracing defaulters	Good; challenges and problems identified and discussed too	Hope of eventual remuneration – affected sustainability	Model of involvement of nongovernmental organizations in community care
Chaudhury & Thatte	22	2003	Mumbai	India	Correlation between knowledge and treatment compliance	180 patients					Improving the knowledge of people with TB crucial for treatment compliance

Authors	Reference	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Zachariah et al.	23	2006	Thyolo district	Malawi	Community involvement in HIV and TB		Informal: residents expressing commitment for volunteering	Referral of people suspected of having TB; sputum collection and transport; defaulter tracing (directly observed treatment by guardian)	Good	Various incentives: rain boots, raincoats, seed grain, fertilizer, etc.	Considerable information about the model; good resource
Wandwalo et al.	24	2006	Temeke district, Dar es Salaam	United Republic of Tanzania	Community versus facility-based directly observed treatment	5 major diagnostic centres: 268 people with TB; 103 community treatment supporters	Guardians or people who have had TB	Directly observed treatment	Community-based less costly	Experience of the disease and helping other people with TB (80%); to reduce the burden of TB in the community (20%)	Very useful for involving people with TB
Khan et al.	25	2005	Three sites: Rawalpindi, Gujranwala and Sehiwal	Pakistan	Different methods for directly observed treatment	Different studies with different coverage	Formal: community health workers	Directly observed treatment	Same outcome as self-administered; study of questionable quality		People with TB had the type pf directly observed treatment imposed in the study; low motivation of health staff
Escott & Walley	26	2005	Lubombo region	Swaziland	Qualitative study on experience of people involved in community care	40 interviewees	Guardian or formal: rural health motivators	Directly observed treatment	Overall interviewees' perception: community care an improvement on the previous system	Incentives (doing lots of work for TB) – problem is they are lower than in nongovernmental projects and the inferiority complex is demotivating	Qualitative study on the perception of community care in Swaziland – good
Wandwalo et al.	27	2005	Temeke district, Dar es Salaam	United Republic of Tanzania	Cost effectiveness of community-based directly observed treatment	103 people with TB, 42 treatment supervisors	Guardian	Directly observed treatment	Community-based directly observed treatment US$ 128 per person; facility-based directly observed treatment US$ 203 per person		Cost-effectiveness study – positive outcome
Mohan et al.	28	2005	Nawal Parasi District	Nepal	Impact of community mobilization on utilization of TB services	227 people with TB	Informal: but not enough information	Referral of people suspected of having TB	Reduced diagnostic delay		Some information on empowering people with TB and communities

Authors	Reference	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Daniels et al.	29	2005	Boland district municipality, Western Cape province	South Africa	Involving the community in TB control	50 people with TB	Informal: lay health workers	Referral of people suspected of having TB; directly observed treatment		Altruism, relevance for their personal life and spiritual growth	Very good source of information and evidence
Clarke et al.	30	2005	Boland district municipality, Western Cape province	South Africa	Involving the community in TB control	211 farms	Informal: farmers as lay health workers	Referral of people suspected of having TB; directly observed treatment	Cure rate increased from 79% to 83% in the intervention area	Flexible approach to directly observed treatment (some people with TB prefer self-observation – good outcomes); directly observed treatment providers are farm employees (good sustainability)	Interesting model of community involvement
Watkins & Plant	31	2004	Bali	Indonesia	Staff perceptions of TB treatment delivery	24 staff from 17 clinics					No motivation or model but okay for staff perceptions of community involvement
Sanou et al.	32	2004	Gorom Gorom; Bobo-dioulasso; Pissy	Burkina Faso	Qualitative study on the barriers faced by people with TB and communities	28 in focus group; 68 in-depth interviews	None	NA	NA	NA	First contact – traditional healer; problems of access
Wandwalo et al.	33	2004	Dar es Salaam	United Republic of Tanzania	Community-based versus hospital-based directly observed treatment	587 people with TB	Guardian	Directly observed treatment	Comparable treatment outcomes		Community-based versus hospital-based directly observed treatment; randomized control trial
Barker et al.	34	2002	Sekhukhune-land (four hospitals), Northern Province	South Africa	Community-based versus facility-based directly observed treatment	1104 people with TB	Formal: primary health care nurse; or informal: shopkeeper or family	Directly observed treatment	Continuation phase only: all community directly observed treatment providers comparable		Hospitalization in intensive phase
Kironde & Klaasen	35	2002	Northern Cape province	South Africa	Motivation of lay volunteers; qualitative	3 in a focus group; documentary review of 347 volunteers' records	Lay community volunteers	Directly observed treatment; follow-up of absentees		Altruism, having spare time, need to gain work experience, novelty of community work	Fairly high dropout of volunteers – loss of interest and desire for paid work

Authors	Reference	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Islam et al.	36	2002	National	Bangladesh	Cost-effectiveness of community-based versus facility-based directly observed treatment	371 people with TB	Formal: female community health workers	Directly observed treatment	US$ 64 versus US$ 96 for community-based versus facility-based treatment per person; comparable outcome		Good to argue for community involvement
Mathema et al.	37	2001	Eastern and Central Regions	Nepal	Facility-based versus community-based versus self-observation directly observed treatment	759 people with TB	Formal: community health workers and informal: community or family member	Directly observed treatment	Treatment supervision important		Poor outcomes in self-administration; common to use family members – can be problematic
Nsutebu et al.	38	2001	National	Zambia	Scale-up of community involvement in TB and HIV		Formal: community volunteers (informal too)	Directly observed treatment, referral of people suspected of having TB	Community crucial for access to care in Africa		Good for scaling up and starting community involvement
Pushpananthan et al.	39	2000	Lubombo region	Swaziland	Needs assessment for community care	Rural district hospital (78 people with TB)					Good for designing community participation
Zwarenstein et al.	40	2000	Cape Town suburb	South Africa	Community-based versus facility-based versus self-observation directly observed treatment	156 people with TB	Formal: lay health workers	Directly observed treatment	No statistically significant difference in outcome for the three types of directly observed treatment		Not a crucial paper
Getahun & Maher	41	2000	Estie, South Gonder	Ethiopia	Description of setting up a TB club		People with TB	Referral of people suspected of having TB and awareness-raising	Increase in case-finding		Good involvement of people with TB through TB clubs
Banerjee et al.	42	2000	Ntcheu, Central Region	Malawi	Guardian versus facility versus hospital directly observed treatment	596 people with TB	Guardian	Directly observed treatment	Less effective than hospital- or facility-based		Adherence lower in guardian-based directly observed treatment but interpretation not straightforward
Kahssay & Oakley	43	1999	NA	NA	Review						Great overview of community involvement issues

Authors	Refer-ence	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Kangangi et al.	44	2003	Machakos district	Kenya	Community involvement impact	3244 intervention people with TB; 1141 control people with TB	Formal: community health workers, civil society organizations, faith-based organizations, traditional birth attendants etc.	Directly observed treatment, referral of people suspected of having TB	Very good		Good model, effective, very well described
Nganda et al.	45	2003	Machakos district	Kenya	Cost-effectiveness	209 people with TB	Not clear: community volunteers	Directly observed treatment	Very good		Good for costing argument
Nyirenda et al.	46	2003	Lilongwe	Malawi	Operational research	3224 people with TB	Guardian; formal: HIV community volunteer	Directly observed treatment	Good (decentralization, not only community care)		Piloting guardian-based care (and decentralization) in Lilongwe
Floyd et al.	47	2003	Lilongwe	Malawi	Cost-effectiveness	3224 people with TB	Guardian; formal: HIV community volunteers	Directly observed treatment	Cost borne by the health services declined 54%; out-of-pocket payments declined by 58%		Good for costing argument
Salaniponi et al.	48	2003	Ntcheu, Zomba, Machinga, Salima and Lilongwe	Malawi	Effectiveness of different methods for directly observed treatment; scale-up preparation	5790 people with TB	Guardian	Directly observed treatment	Comparable cure rates; two-month sputum collection and conversion lower in guardian directly observed treatment		Some text on scale-up
Dudley et al.	49	2003	Cape Town	South Africa	Clinic versus community directly observed treatment	2873 people with TB	Formal: community volunteers	Directly observed treatment, awareness-raising and tracing defaulters	Higher cure rate in community directly observed treatment	US$ 4 per month	Process to establish community directly observed treatment; conclusions about community directly observed treatment limited, as the study was mostly descriptive
Sinanovic et al.	50	2003	Cape Town	South Africa	Cost-effectiveness		Formal: community volunteers	Directly observed treatment, awareness-raising and tracing defaulters	Better treatment outcomes with community-based directly observed treatment; more than twice as cost-effective	US$ 4 per month	Good for the costing argument

Authors	Refer-ence	Year	Setting	Country	Focus	Coverage	Community involved	Components of TB control	Effectiveness	Motivation	Comments
Adatu et al.	51	2003	Kiboga	Uganda	Effectiveness of community involvement	990 people with TB	Informal: neighbour	Directly observed treatment	Treatment outcomes after community-based directly observed treatment much better	No monetary incentive; volunteers gained respect from community leaders and members	Community was involved from the inception of project; model description
Okello et al.	52	2003	Kiboga	Uganda	Cost-effectiveness	990 people with TB	Informal: neighbour	Directly observed treatment	Cost per smear-positive person: US$ 911 with hospital care and US$ 391 with community care	No monetary incentive; volunteers gained respect from community leaders and members	Good for the costing argument
Moalosi et al.	53	2003	Francistown	Botswana	Cost-effectiveness and model	633 people with TB	Home-based care (caregiver)	Directly observed treatment	Costs reduced by 44% between hospital-based and home-based treatment		Good for the costing argument; model described
Colvin et al.	54	2003	Hlabisa	South Africa	Traditional healers as directly observed treatment providers	1816 people with TB	Formal: traditional healers, community health workers; informal: shopkeepers	Directly observed treatment	Traditional healers: cure treatment completion rate 88%; all others: 75%		Model, implementation
Miti et al.	55	2003	Chipulukasu and Twapia, Ndola	Zambia	Home-based versus facility-based directly observed treatment	168 people with TB	Formal: home care volunteers	Directly observed treatment	Defaulting with home care 8%, facility care 23%		Good for model and implementation

NA: not applicable.

with volunteers revealed that most of them participated in the hope of eventual remuneration, which in turn affected sustainability. There is no information on how those volunteers were initially approached or what messages were given to them about health in their community. Making judgements about motivation in such cases remains difficult.

Documented initiatives from other regions are more scarce. In the Region of the Americas, three studies came from two different countries: two from Peru and one from Haiti. Two studies reported on treatment support and one on referral of suspects and contact tracing.

One study from Peru (*18*) reported on a cascade system of training and supervision of different community members involved in TB control, common in Latin American cultures, because of the long history and scope of social mobilization. Teams of nurses and health promoters are involved in supporting people with TB and multidrug-resistant TB and supervise additional community treatment-support volunteers. Health promoters are chosen from local community youth groups.

The review identified only three relevant articles from the Eastern Mediterranean Region, all on Pakistan. Two compared the effectiveness of different types of treatment support, and a qualitative study (*13*) was conducted to better understand gender-based constraints among female health workers, whom the government recruited as a response to gender-based constraints on women's access to services. All three studies reported on formal involvement of female community health workers.

In the South-East Asia Region, Bangladesh, India, Indonesia and Nepal each provided two reports. Three studies from the Region discussed the effectiveness of different types of treatment support, and some others provided qualitative information on the perspective of people with TB and staff perceptions on TB treatment delivery. The community involvement reported was equally formal and informal, and the components of TB control provided were restricted to treatment support in three studies and referral of people suspected of having TB in one.

No relevant studies were identified from the Western Pacific Region.

In general, there are two important considerations regarding models of and motivations behind the involvement of community members:

- motivation is a crucial aspect for a sustainable initiative; and

- its modalities vary greatly and make limiting their expression to one scheme difficult and unnecessary.

Non-monetary incentives are more likely to be sustainable, and they can always be identified, such as providing a T-shirt or bicycle, etc.

Important challenges that the published literature has not sufficiently explored include: qualitative research on the motivation of involved community members, good practices in addressing obstacles to scale-up and the roles people with TB and community members can effectively play in TB control and prevention. Such publications would provide further guidance for addressing the difficulty countries are facing in implementing these initiatives.

This literature search also revealed conflicting evidence both for and against the use of family members as treatment supporters. Further research should be conducted to produce clearer understanding of what constitutes good practice in this area.

Empowering and involving people with TB in TB control

In February 2007, the Stop TB Partnership and WHO published the results of a review of published and grey literature on empowering and involving people who have or have had TB in TB control (*56*). It identifies possible trends and conclusions and suggests ways of informing policy-makers and further research.

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Practical experiences: WHO country reviews (2005–2006)

Objectives and method

The objective of this review, which involved seven countries in four WHO regions, was to conduct case studies highlighting different aspects of the involvement of people with TB and communities in controlling TB. The review used a combined qualitative and quantitative research method. The objectives of the review were:

- to define what "community-based initiative" means across different contexts and describe different models and concepts;

- to explore the motivations of community and civil society actors in different settings; and

- to identify examples of best practice to enable the WHO Stop TB Department to better implement component 5 of the Stop TB strategy ("Empower people with tuberculosis, and communities") and provide guidance to countries to include this important component in their national TB control strategy.

Although the success of a health initiative is usually measured by quantitative methods, how and why communities decide to participate in TB control cannot be adequately captured by these methods alone. Motivational aspects are a key factor in sustaining the commitment of communities. As such, these issues need to be subjected to qualitative analysis.

Combining qualitative and quantitative evaluation methods is, therefore, necessary to understand initiatives that aim at bridging the health system and the society. Moreover, as various studies have shown the effectiveness and cost-effectiveness of such interventions, it was important to design and focus on a research tool to adequately explore different approaches to ensuring sustainability and issues around motivation of involved community members. Such realities are understood only by enquiring about their qualitative aspects, so far largely neglected.

The qualitative method in this review focused on how various forms of collaboration between health services and society have been operationalized and on motivation that sustains community participation and the commitment of countless individual people. Each country review was conducted through a series of in-depth semistructured interviews with various stakeholders in TB control, such as: health managers, staff at health facilities, people with TB and civil society or community members.

The countries selected for the review included:

- Kenya, Malawi and Uganda in the WHO African Region;
- Mexico in the WHO Region for the Americas;
- Bangladesh and Indonesia in the WHO South-East Asia Region; and
- the Philippines in the WHO Western Pacific Region.

A team comprising a sociologist and a medical officer from the WHO Stop TB Department conducted site visits in all countries. They were accompanied, whenever possible, by regional WHO staff, local health ministry officials and representatives from local nongovernmental organizations and patients' organizations.

Every country adopting an approach of empowering people with TB and communities has designed and implemented models of collaboration that are specific to the individual context to deal more effectively with public health issues.

Several factors strongly influenced this process, such as the size of the population served, its demographic profile, population density and rural versus urban distribution, socioeconomic profile of more vulnerable groups, local culture and existing traditions of mutual support, existing set-up for the delivery of health services and human and financial resources available.

The summary findings are presented, highlighting four aspects:

- general description of the model(s) adopted;

- general discussion of principles governing the model and factors motivating and sustaining commitment at the community and individual levels;

- aspects of health (and TB control in particular) to which the community is contributing;

- the inherent strengths and weaknesses of the model(s) and opportunities and threats related to the social situation or the set-up of health services.

Kenya

Description of the model for community involvement

The rationale for establishing community TB care included: a vision of public health services based on such principles as accessibility, cost-effectiveness and public participation; the de facto limited coverage of public health services; inadequate health services infrastructure; inadequate resources; increased pressure on existing services due to the HIV epidemic; and the need to alleviate the financial burden on people with TB and their families related to unnecessary hospital admission. Community TB care had the potential to overcome some of these limitations and to increase the acceptance and use of health care services.

The main objective of the Ministry of Health in promoting community TB care was to promote community participation in the provision of TB services beyond health care facilities. Specific objectives included: increasing TB case detection (currently 47%), improving treatment success (currently 80%), reducing default rates (currently 15%) and increasing awareness of TB in the community. All health staff interviewed said that facility-based daily directly observed treatment was very difficult because of the high number of people with TB. People with TB also found it expensive because of the distance they had to travel to the health facilities.

The involvement of the community in TB control was piloted in Machakos District in the late 1990s and found to be feasible and cost effective (see Annex 1).

A standard approach was used in getting communities involved in TB control. The initial step was to hold regional meetings at the provincial level to get the support of all relevant players and then move to advocacy at the district level.

Social bodies that can be described as "a community" are found at more peripheral levels, especially at the location and sublocation levels. Appropriate community groups to work with were therefore more effectively identified at these levels.

Every person newly diagnosed with TB chooses a relative, a friend or a neighbour who will provide support during the treatment. During the intensive phase of treatment, the treatment supporter collects or receives a weekly supply of drugs from a community health worker, provides support and daily directly observed treatment and keeps records on the progress of treatment. During the continuation phase, drugs are collected or supplied monthly.

Community health workers maintain a regular contact between the person with TB and/or the supporter and the health facility. They also inform the community about TB, refer people suspected of having TB to the health centre and convince people with TB who have interrupted their treatment to resume it.

The considerable presence of faith-based organizations and local nongovernmental organizations at the grassroots level provides a huge potential as a channel of communication and social mobilization for health promotion. These groups are committed not only to participation in health interventions but also to various forms of social solidarity, from covering the cost of transport to the health facility for people with TB to providing food to hunger-stricken families.

People with TB and people who have had TB have occasionally been involved during public gatherings to give messages about the disease and the availability of effective treatment free of user charges. In a few districts (Eldoret, Kisumu and Nairobi) they are organized in TB clubs.

In the health facilities visited, all people with TB had been offered counselling and testing for HIV. Most agreed to HIV testing, and on average 60% were diagnosed as HIV positive. Subsidized antiretroviral medicines were available to people with TB at the equivalent of US$ 1.5 per week.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

Treatment supporters, being mostly family members, are strongly motivated to ensure care and help for their relatives.

Community health workers linking people with TB and their supporters with health facilities report being motivated by the desire to serve the good of the community and to avoid the spread of infections.

Faith-based organizations extend their services to all community members in need, regardless of their religious affiliation. Some faith-based organizations have built local dispensaries and work to support people affected by TB, HIV or famine. Strong motivation is found in their internal cohesion and in their desire to help people in need through charitable work.

It is recognized de facto that each level of society – family, nongovernmental organizations, faith-based organizations and health services – can play a specific role in helping people affected by various diseases. Interestingly, this does not seem to be the result of top-down planning but rather of spontaneous organization of the society.

Aspects of TB control to which the community is contributing

The function of the community in TB control is based on joint deliberations between health care staff in peripheral facilities and the community they serve and therefore varies from place to place.

Depending on the situation, the community plays roles in case-finding, case-holding (directly observed treatment through village community health workers) and retrieving sick people who interrupt their treatment.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

The initial community TB care implementation in Machakos was seen as a "project", which raised the false expectation among community health workers that health services would have provided some incentives. Within the health services, community TB care was initially proposed as a form of decentralization rather than a partnership with the community. All places visited reported fatigue and high dropout among community health workers – but these people reported being discouraged more by lack of facilitation (transport and meals) than by the absence of monetary incentives. Successful examples of community TB care suggest that it should be proposed as a partnership with the civil society, with clear terms of reference for each partner.

Lack of clarity about incentives is frequently related to confusion in terms. Guidelines refer to "volunteers", sometimes meaning community health workers and, at other times, treatment supporters. Treatment supporters work voluntarily to assist their relative or friend for the duration of the treatment course. Community health workers are highly motivated to do social work for the community and usually maintain another job outside of this. They cannot afford to avail much of their working time without compensation and to cover the costs of transport and meals. Community health workers and treatment supporters clearly work at different levels and with different functions. Community health workers mostly seem to refer people suspected of having TB and trace people who interrupted treatment but are less involved in routine health promotion work. In community TB care activities, it is advisable for them to visit the person with TB at home from the beginning of the treatment. Involving them at a later stage, when problems like treatment interruption occur, has not proved effective. In recognition of their service, community health workers are given priority when they seek care at a health facility.

The national TB programme recording and reporting system has not been modified so far to identify people with TB receiving community TB care and evaluate the impact of this approach. An ad hoc desk review of cohorts of people with TB receiving community TB care may be periodically desirable to assess the impact of community involvement.

The national TB programme is planning to revise the recommended treatment regimens to introduce rifampicin and isoniazid during the continuation phase and reduce the treatment duration to six months. The need to provide continued support to people with TB and ensure high adherence to treatment can pose a strategic opportunity for a renewed effort to scale up community involvement.

Intensifying health promotion activities at the community level and including TB in a package of messages about priority health problems is the most realistic way to address the problem of a low TB case detection rate.

Advocacy at the provincial and district levels should address in particular the challenge of securing funds for primary health care activities at the community level, to facilitate the work of community health workers. The national TB programme can quantify the shortage of human resources for supporting and supervising health staff by assessing workload. An opportunity to address this problem may be posed by establishing a strategic alliance with major nongovernmental organizations already operating in remote areas. This approach may take also the form of a formal national partnership.

The involvement of people who have had TB and their treatment supporters as TB ambassadors in public gatherings is actively promoted and may play an increasingly important role.

Malawi

Description of the model for community involvement

In the past, all people with TB were hospitalized during the initial two months of treatment. This added to the congestion in hospital wards already congested with people living with HIV.

Most hospitalized people with TB were accompanied by a guardian – an extended family member – throughout the intensive phase of treatment. This resulted in significant costs for the family, as usually two adult members were absent for eight weeks or more.

The national TB programme then decided to propose to the people with TB that their guardian serve as a treatment supporter at home during the initial intensive phase of treatment. During a pilot phase of the intervention, neighbours were also proposed as treatment supporters. In most cases they were not acceptable to the person with TB – possibly due to the strong stigma associated with HIV. Also, culturally and historically, when a person has TB, the relatives are responsible for the care of the person. Some interviewees reported that this is the main reason, rather than the HIV-related stigma, for insisting that the treatment supporter be a family member.

In Malawi, drugs are self-administered during the continuation phase. The people with TB are admitted for the initial two weeks, during which hospital staff can train the guardian how to complete the treatment card and store drugs properly. About three quarters of the people with TB choose their guardian as the directly observed treatment provider. The remaining quarter choose not to have a guardian for one of the following reasons: because the guardian is illiterate, because of problematic relationships in the household or because the person with TB got ill outside of his or her home. In one of these cases, the person with TB can choose between hospitalization or directly observed treatment in a nearby health facility.

In cases when a guardian is the treatment supporter, he or she needs to obtain drugs from a health facility every two weeks and is supposed to accompany the person with TB every other visit so that the health staff can assess possible problems.

In theory, government health surveillance assistants supervise guardians and people with TB. They rotate between working in the community and the health centre and receive eight weeks training on controlling cholera, malaria and TB. In practice, the catchment area of the health surveillance assistants is very large (more than 2000 people), and they pay visits to the homes of guardians or people with TB irregularly. They collect sputum from people suspected of having TB they identify in their areas and take them to a microscopy centre; they follow up guardians and people with TB in cases when guardians do not show up to collect their drugs.

During the continuation phase of treatment, people with TB collect drugs from the health facilities once a month. There are designated days for drug collection, and this facilitates the identification of possible absentees, who are then followed up at home. Problems with following up absentees include an incomplete address in the TB registry or a change of residence. The incidence of people with TB being transferred and interrupted treatment is still less than 6%.

In urban settings, the national TB programme uses the same model. More people with TB opt for facility-based directly observed treatment during the intensive phase as urban areas have more health centres. Problems occur because of the mobility of the urban and lakeshore fishing populations. People with TB who have been transferred are often traced through quarterly meetings of TB district officers, where comparing registries is a standard procedure. Keeping records of the employers of people with TB has also helped in urban settings.

Missionary health facilities deliver 37% of health services in the country. They usually have a trained TB officer in-house, doing the work of the TB district officer. Collaboration between TB district officers and the missionary hospitals is good: missionary hospitals keep their own registries and regularly report to the TB district officer. Such hospitals charge fees for their services, but not for TB, unless a person with TB needs to be admitted. In such cases they charge a small fee for using the hospital bed, and the government partly subsidizes the costs. The national TB programme also provides them with reagents for microscopy, drugs, sputum cups, etc. Some private hospitals charge higher fees for hospitalization. Such hospitals follow national TB programme guidelines as well and have TB officers in house.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

Political commitment is strong at all levels. Volunteers already involved in public health action have implemented all TB activities. Given the scarcity of human and financial resources in public services, the achievements are remarkable.

Treatment adherence in Malawi has always been relatively unproblematic. Nevertheless, introducing guardians as treatment supporters significantly reduced costs for families and eased congestion in hospitals.

Some nongovernmental organizations have trained shopkeepers to recognize symptoms in people suspected of having TB and refer them to health facilities for diagnostic services. Shopkeepers reported increased business and social recognition as a result of their work. Community-based organizations organized health promotion meetings three times a week to discuss malaria and TB issues and publicize the health promotion work of shopkeepers.

The training of shopkeepers and traditional healers and collaboration with existing HIV community-based initiatives have been successful in identifying more TB cases. Nongovernmental organizations are in a better position to carry out such activities due to the limited availability of public sector resources. Some nongovernmental organizations play a role that is complementary to public health services, either providing full TB control services or addressing the needs of the community that cannot be met by public services.

Aspects of TB control to which the community is contributing

In Malawi, guardians mainly contribute by supporting adherence to treatment among people with TB.

In some places, groups of people who have had TB help the people suspected of having TB in seeking attention at health facilities. Shopkeepers also provide advice and refer people suspected of having TB for diagnosis and care.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

Health surveillance assistants support guardians and people with TB, but visits are irregular and adherence to treatment suffers as a result. This is the most important threat to the success of this model. Families can be ideal care supporters, but they cannot do this on their own – they need to rely on a secure link with the health services. Scarcity of public health staff may necessitate the intervention of trained community health workers or qualified volunteers from nongovernmental organizations.

Malawi is shortening its drug treatment regimen to six months and providing a

fixed-dose combination containing rifampicin and isoniazid during the continuation phase. This is more effective for people with both TB and HIV. In such situations, high treatment adherence must be maintained to prevent multidrug-resistant TB. Family guardians are essential to address this challenge, since they can provide support beyond the intensive phase.

Community-based HIV organizations in Malawi organize several awareness-raising activities. Health surveillance assistants, though scarce in number, are possibly under-used in this respect since they could be trained to become more involved in health promotion and awareness-raising.

Uganda

Description of the model for community involvement

People complaining of chronic cough for more than three weeks examined in public or private health facilities are referred for sputum examination to a microscopy centre and, if found to have TB, are admitted for a few days – or asked to stay close to the health centre – to start short-course chemotherapy. Information about each new person with TB is immediately sent to the public health services based in the same administrative area. Public health workers move to the administrative area where the village of the person with TB is located and help the community in choosing a volunteer treatment supporter, who normally lives close to the person with TB. A friend or neighbour is often preferred over a family member to avoid any potential adherence problems.[1] The treatment supporter, who must be acceptable to the person with TB, receives one or two sessions of training by the public health worker on how to store and handle drugs and how to record treatment. The person with TB continues the treatment at home, where the treatment supporter will visit him or her daily for a few minutes to provide adequate support and observe the drug intake. Regular home visits carried out every two weeks by public health workers ensure a regular drug supply and provide an opportunity to assess and report on the progress of treatment.

Home-based care follows a different model, which establishes a scheme of support by a family member. It is a model often preferred in urban settings, because the social context is less communitarian, or whenever greater confidentiality is desired.

TB/HIV collaborative activities have started in many districts, the current focus being on establishing voluntary counselling and testing services: when antiretroviral therapy is available and people living with HIV are eligible for it, the medicines are provided through support by a family member.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

The objective of this model is to improve the treatment adherence of people with TB. There has been a partnership approach from the start. The national TB programme, in the context of integrated primary health care services, assumed full responsibility for training of health professionals, diagnostic services, prescription of treatment, a secure drug supply free of user charges and follow-up visits at health facilities and recognized that the daily support to people with TB could be better provided at the community level.

People with TB and communities are linked regularly to the health facilities through public health workers, who provide new drug supplies and inform them about the

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[1] In Uganda, a younger (or female) family member cannot easily influence an older or male family member in case of difficulty with adherence to treatment.

progress of treatment as required. The existing responsibilities of these health staff were redefined without creating any new or parallel function within the local health services. This was instrumental in mainstreaming community care in the primary health care services.

Encouraging responsibility at the community level is crucial for successful implementation; this is promoted by proposing a partnership between the diagnostic health services and community, whereby the community eventually shares responsibility for its health with the health services. This partnership is therefore effective when the community is sensitized on the seriousness of disease and not when the involvement of people with TB and communities is merely demanded as a new policy. Sensitization of communities also significantly reduces stigma, and people suspected of having TB more easily seek treatment. Whenever funds are available, awareness-raising activities include radio broadcast messages, dramas and flip chart presentations.

Community members have reported being motivated by concern about the spread of TB in the community, concern about increasing drug resistance and the desire to help local people in need.

Some treatment supporters taking up this role in small communities are often labelled the village doctor and are referred to for all future health issues, since community members know that they are in regular contact with health officials. In general, reasons for personal commitment include contributing to the health of the community and social solidarity.

The national TB programme ruled out the introduction of monetary incentives – as all the above motivations in community involvement are internal to that community and therefore sustainable, especially when treatment support usually takes only five minutes per day. Experience with other programmes showed that monetary incentives do not promote a sense of collective responsibility among the community on health issues but give an impression of a short-lived project approach.

There was no dropout of volunteers. Directly observed treatment took 1–5 minutes, and no volunteer said that it conflicted with other daily responsibilities. Some volunteers are people who have had TB, and some have supervised more than one person with TB over time.

People with TB have reported choosing the option of community-based care because it reduces the economic and time burden of seeking treatment at a health centre.

Aspects of TB control to which the community is contributing

Apart from improving adherence to treatment, community volunteers store drugs for the person with TB and record treatment progress. They may refer people with chronic cough for sputum examination and share information about the disease with others to help reduce stigma. They can also remind people with TB about follow-up visits and accompany them to the health facility.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

In districts where the model was properly established it worked well; most of the problems observed related to the quality of implementation. Community-based TB care is generally perceived as useful because it creates awareness in the community; people with TB adhere better to treatment; there is less delay in seeking treatment; stigma is reduced; hospitals are less congested and treatment is decentralized without compromising the quality of care.

The implementation of the model is not consistently adequate. This is mostly related to the autonomy of decentralized districts: support for TB control policies and implementation of the community-based model depends entirely on local government. In some districts, essential elements of the model are being neglected: for example, people with TB are given drugs to take home, without ensuring directly observed treatment.

The most important factor affecting the quality of implementation is how the process for involving people with TB and communities is initiated. Success differs strikingly between districts that did and did not undertake serious advocacy and communication to secure support by political leaders and begin a partnership building process from the start. An advocacy, communication and social mobilization package is needed to address the following issues: the magnitude of the TB epidemic in the area, the major constraints faced by the health services in attaining TB control targets, the barriers to equal access to services and the potential community contribution to effectively controlling TB.

Coordination with other partners – such as local nongovernmental organizations – implementing TB control in some local areas was sometimes challenging because of the scarcity of public health staff to support and supervise them.

Another serious constraint is the late disbursement of funds for primary health care field activities by the district administration – this can delay implementation and compromise its quality.

Other weaknesses included: high turnover of trained staff at the district level, lack of information about community-based TB care, inconsistent and irregular advocacy, complete reliance on external funding and failure to put in place the recommended two-way referral system between health services and the community.

People with TB in urban settings in Uganda preferred to rely on private health services or pharmacies, which in most cases did not follow a sound strategy for stopping TB. The choice seemed related to the belief that using such services meant enjoying a higher social status and concerns about privacy in public services. Stigma in urban settings was reported to be higher than in rural areas.

Mexico

Description of the model for community involvement

TB has been a serious health problem in Mexico for several years. The effort to control the epidemic has focused on creating efficient primary care services and a programme of social mobilization: Mexico's Healthy Communities Program: the White Flag strategy (*Bandera Blanca*).

The main objective of the White Flag strategy under Mexico's Healthy Communities Program is the active participation of community members in primary health care activities in settlements with a population under 2500. Other objectives include active participation in case-finding and ensuring that 100% of TB cases are treated under DOTS.

The responsibility of TB control is shared in partnership between the health authorities and the community. Educational schemes contribute to improving the health of people with TB, enhancing the quality of life and reducing stigma. In 2005, more than 350 000 community volunteers were involved in these initiatives all over Mexico.

The four key messages related to TB control are:

- TB does exist and is an infectious disease;
- its main symptom is productive cough;
- it is curable with six months of treatment; and
- clinical examinations, laboratory examinations and treatment are free of user charges.

Once the community reaches the targets, health staff and community members lift a white flag in a public ceremony. Evaluation surveys are conducted every six months to assess the level of awareness in the population about disease and healthy behaviour. If adequate standards are not maintained, the flag is lowered.

A community becomes "healthy" by progressing through several phases. These phases offer a practical example of a process of community involvement leading to greater empowerment.

- A community is defined as "initiated " when the local health committee has been activated, an analysis has been carried out to highlight the major health problems of the area and a plan of work has been finalized.

- A community is "oriented" when the health committee is active, the work plan is being implemented and the training of health agents and health promoters (see below) has started.

- A community is "active" when people are participating in basic sanitation activities and in action for disease prevention and protection of public health and when it has safe water and sanitation.

- The certification of a "healthy community" takes place when the prevention and control of priority diseases are in place and health agents and health promoters have been trained.

The national TB programme has reported that, if a community does not participate in TB control, it is because it is not informed about the disease. After the community has been informed about relevant health issues, a positive outcome of these initiatives depends on having well-defined projects and clear communication.

In communities not yet involved in the White Flag initiative, numerous events targeted at health promotion still take place, such as festivals and marches where materials are distributed.

Advocacy, communication and social mobilization materials produced by various stakeholders in different locations include comic books, banners, murals, pamphlets and stamps. They deliver effective messages in Spanish and other local languages. Health-related messages are also broadcast from speakers mounted on cars, as well as on television, radio and the Internet. Special attention is always given to exploring inexpensive ways to transmit messages on health promotion. For example, distributing pamphlets in schools is simple and effective as children take the pamphlets home to their parents.

Indicators of effective communication and social mobilization can include any of the following: creation of national TB programme support networks and alliances with partners; activities by social groups and easy integration of new members; production of advocacy, communication and social mobilization material by the community; and mass-media coverage.

Stop TB México at the national level consists of 50 civil society organizations. Stop TB México coordinates work at the state (subnational) level and links health programmes with the community through promotion of social messages: for example, the fight against TB is a social problem. Each state has nominated a Stop TB Ambassador – usually a celebrity – to support TB control by raising awareness among the general public.

The Mexican Network of Tuberculosis Nurses has more than 12 700 members. All nurses are taught about TB and committed to support the White Flag initiative among vulnerable groups, such as prisoners, people living with HIV and indigenous groups. They are trained on technical aspects, human resources development and community

organization. They can enter communities more easily than doctors to look for people suspected of having TB and teach community members about TB symptoms and treatments free of user charges.

Being part of the White Flag initiative provided the following opportunities for the national TB programme: maintaining the sustainability of the programme, intensifying activities with high-risk groups, strengthening the social component through Stop TB México, strengthening the attention focused on the problem of TB/HIV coinfection, maintaining the capacity of health personnel and strengthening the strategic plan of social mobilization.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

The model observed in Mexico is impressive. TB is recognized as a social problem and included in an essential package of interventions at the primary health care level with a very effective approach based on social mobilization.

People are involved in the full range of TB control activities, from early referral of people suspected of having TB to support extended to people with TB to help them adhere to treatment. Health authorities are also committed to social mobilization and ensure that essential services are in place.

The main initiative for committing to the strategy was a clear perception that public health was to everyone's benefit.

People who volunteered to implement the Healthy Community Program received public recognition for their work, and their service appears to have increased social cohesion in their communities.

The attitude of the authorities is that health promotion can be effectively achieved only by involving people with TB and community members and initiating collective behaviour change to enable more effective disease prevention and control. Building partnerships at the national and community levels makes this happen.

Aspects of TB control to which the community is contributing

Health services at the state level form partnerships with different stakeholders, such as Alcoholics Anonymous, student groups and the police. These groups are involved in health promotion in different ways, such as producing materials and identifying people suspected of having TB.

Each municipality implementing the White Flag initiative has a health committee. Committee members identify health priorities in their area and raise funds for activities. They also identify and supervise health promoters who carry out health activities. Health promoters are responsible for the programme at the community level. They contact community leaders and explain the importance of their involvement as partners in TB control. Together, they identify mothers in their community interested in participating in health promotion, who then become health agents. Each agent must be an adult resident in the area regarded by the community as trustworthy and should be interested in serving voluntarily for the welfare of the community. Health agents receive one week of training on the primary health care package and have to organize regular meetings in their sector and give talks on the primary health care package in one of the homes. Their coverage is often so widespread that the ratio of health agents to community population was sometimes 1:10. In terms of TB control, they identify people suspected of having TB and provide daily support to people with TB in remote areas.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

In Mexico, 80% of the population lives in urban areas. This is where most TB cases arise. Access to health facilities is therefore relatively unproblematic for most people with TB. Wherever there is a problem of access, community health agents, civil society representatives and nurses can provide support at the homes of people with TB.

The Ministry of Health is not the sole provide of TB services in Mexico. The Mexican Social Security Institute is another service provider but does not consistently follow protocols based on the Stop TB Strategy. People with TB collect their drugs from a health facility once a week and often take drugs without supervision. Absentees are not consistently followed up.

Bangladesh

Description of models for community involvement

This review focused on the work of two nongovernmental organizations delivering services in TB control: BRAC and the Damien Foundation. BRAC has been treating TB in small areas since 1984 and serves 67% of the population. The Damien Foundation has been treating TB since 1991 and serves 21% of the population. The national TB programme started collaborating with nongovernmental organizations one year after DOTS was introduced based on the following principles: mutual respect and trust; commitment to following national guidelines; pooling resources to maximize the use of partner expertise and to make the programme cost-effective; and periodic review of programme performance.

1. BRAC community-based TB care model

At the core of TB control and other essential primary health care services are female community health volunteers called *shastho shebikas*. They are chosen from village organizations – BRAC female micro-credit schemes containing 40–50 members per village. The village council proposes two or three of the village organization members as possible shastho shebikas, and BRAC selects one after talking to their family members.

Each shastho shebikas is responsible for about 330 households – they visit each household every month to provide primary health care services, including TB control. Shastho shebikas are allowed to sell medicines at an agreed price and are motivated by performance-based incentives. They receive 3–4 days of training and monthly refresher courses to serve as directly observed treatment providers. They usually spend about two hours daily working as health volunteers. A *shastho karmi* supervises every 10 shastho shebikas.

Village leaders know shastho shebikas and refer people suspected of having TB to them. Whenever a new case is diagnosed, the person with TB pays 200 taka (about US$ 3) to the shastho shebika as a pledge. The Global Fund to Fight AIDS, Tuberculosis and Malaria funds pay for the incentives of the shastho shebikas (150 taka) so that the person with TB can get back the entire sum of money upon completion of treatment.

People with TB go daily to the shastho shebika's home to receive directly observed treatment. If a person with TB does not turn up, the shastho shebika is obliged to go to his or her home. If a person with TB still has problems in adhering to treatment, shastho shebikas have to report this to the village authority, which will contact the person with TB to encourage them to continue treatment.

BRAC staff members also visit the homes of people with TB at least monthly during the intensive and continuation phases; the regularity of this exercise depends on the availability of staff in that district.

When a shastho shebika encounters a person suspected of having TB, she provides a sputum container, which is then taken to one of BRAC's smearing centres a few kilometres away. BRAC staff members visit the smearing centres once a week, fixing slides and taking them to a laboratory for sputum smear examination.[1]

If the examination is positive, BRAC contacts the shastho shebikas and provides a weekly dose of medicines for the intensive phase and several months' supply for the continuation phase.

Another body involved in referring people suspected of having TB is the TB club made up of people who have had TB, financed by a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria. TB club members are usually not directly observed treatment providers, but they help to identify people suspected of having TB in their community and workplace. BRAC occasionally holds meetings with TB club members to discuss TB symptoms and how to recognize people suspected of having TB. BRAC management report challenges such as strengthening diagnostic services and lack of funding for awareness-raising activities.

2. The Damien Foundation community-based care model

Unlike BRAC, the Damien Foundation mostly uses the existing function of village doctors as treatment supporters. They usually earn a living by selling medicine, but they do not charge consultancy fees and are often a villager's first contact when they seek care. They are laypeople with six months of government training. One village doctor covers a population of about 5000. One in five village doctors becomes a directly observed treatment provider too, also called a fixed directly observed treatment provider. Fixed directly observed treatment providers identify people suspected of having TB, who are given sputum cups to take to diagnostic centres themselves. Microscopy centres are located at government-run *upazila* (subdistrict) health centres or Damien Foundation clinics. Fixed directly observed treatment providers have responsibility for following up sputum examinations.

Fixed directly observed treatment providers get medicines from the health centres. People with TB are expected to come to the *upazila* health centre every two weeks, where the Damien Foundation staff members ensure that treatment is not interrupted. If a person with TB misses a second visit to the health centre, Damien Foundation staff members visit the person with TB at home, accompanied by the fixed directly observed treatment provider.

People who have had TB are encouraged to join TB clubs. After forming a TB club, members receive annual refresher training. Their responsibility is to refer people suspected of having TB for a sputum check, and they often accompany them. In some cases they may also become directly observed treatment providers.

For management of complicated cases, the Damien Foundation runs hospitals at the district level. Otherwise, all people with TB are on community-based DOTS and are not given the option of being treated at the hospital. The number of women suspected of having TB that go for a sputum check has increased significantly in recent years, but most women still need to ask permission from family members to go to a diagnostic centre.

Both nongovernmental organizations report that stigma has declined significantly with the introduction of community-based care. People are less afraid to seek treatment because they know that the disease is curable and the treatment is free of user charges. The Damien Foundation has reported that approximately 80% of recruited fixed direct-

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[1] In some parts of the country, government staff perform smearing at the *upazila* (subdistrict) health centre. Smearing centres are mostly introduced in places where *upazila* health centres are understaffed.

ly observed treatment providers are very well motivated, 10% need additional encouragement and 10% remain difficult to motivate even with encouragement.

3. TB control in urban settings

In major cities, urban nongovernmental organizations and city corporations have selected diagnostic and treatment centres where staff members are trained by nongovernmental organizations. People suspected of having TB identified in general clinics are referred to TB DOTS centres, where staff administer facility-based directly observed treatment. Treatment interruption rates in these areas are high, as people with TB are more difficult to trace and the population is more mobile. In rural areas, effective TB control relies on community participation. Facility-based treatment is more popular in urban areas where access to health care is better.

Various nongovernmental organizations have started forming partnerships with private pharmacies open after office hours and factories providing some health services to their employees, to facilitate access to care and minimize the loss of working hours.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

Shastho shebikas live within the community and are respected for the services they provide. They have reported being motivated by the following factors: improved social status, serving the poor in their communities, helping their family economy, providing health services to family members, linking the government and their community.

Village doctors operating in the areas supported by the Damien Foundation receive no monetary incentive. The work allows them to gain importance and provide a helpful service in their communities, and they receive regular refresher training from the Damien Foundation. The main challenge of their involvement is maintaining the standard of care and ensuring continuous supervision.

Aspects of TB control to which the community is contributing

The national TB programme and nongovernmental organizations have divided the operational responsibilities as follows.

- **Normative function:** the national TB programme is responsible for overall coordination, and the nongovernmental organizations ensure service coverage of specific geographical areas. However, there are no memoranda of understanding or service-level agreements defining the terms of reference and duration of such commitments.

- **Case-finding and case-holding:** the national TB programme provides equipment, supplies and maintains service facilities. Nongovernmental organizations provide diagnosis, treatment and follow-up services.

- **Training:** the national TB programme has responsibility for the curriculum and training material, technical support, training of trainers and partial funding. The nongovernmental organizations organize training in collaboration with local health authorities.

- **Drug supply:** the national TB programme is responsible for drug procurement, storage and distribution and the nongovernmental organizations for collection, storage and utilization.

- **Monitoring and supervision:** the national TB programme is responsible for policy guidelines for supervision, overall monitoring, supervision and quality control and

the nongovernmental organizations for registration and reporting, local monitoring, supervision and quality control.

- Advocacy, communication and social mobilization: the national TB programme is responsible for national campaigns and nongovernmental organizations for local campaigns in accordance with national TB programme policy.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

One of the most remarkable achievements of the country is the establishment of national partnerships with:

- nongovernmental organizations for DOTS service delivery and civil society involvement;

- academic and research institutions; and

- private practitioners.

Nongovernmental organizations and BRAC in particular are providing health services in the context of a much broader effort to contribute to social development. BRAC-supported areas are an effective example of public-private partnerships. However, given the dominance of the private stakeholder in the partnership, several questions may be raised about:

- the accessibility of such a system to the poorest people;

- the sustainability of the system if the nongovernmental organization withdraws; and

- the creation of a parallel system in BRAC's areas, with concerns about integration and collaboration with government services.

The compensation scheme for shastho shebikas funded by the Global Fund to Fight AIDS, Tuberculosis and Malaria may raise concerns about its long-term sustainability, although BRAC's income-generating activities could bridge the potential financial gap. The Damien Foundation model is definitely more limited in scope and resources but may be more easily replicable in similar settings in South-East Asia.

Indonesia

In Indonesia, five different models of community involvement were reviewed.

1. Community participation in TB in urban setting – Yayasan Syahrullah Afiat in Jakarta

Yayasan Syahrullah Afiat is a nongovernmental organization that runs a health centre in Jakarta. Since 2003, Yayasan Syahrullah Afiat has implemented a TB prevention and control programme using the DOTS strategy. Yayasan Syahrullah Afiat also became a subrecipient of a Global Fund grant in 2006. At the time of the visit, the health centre was treating 105 people for TB and 7 people for TB and with antiretroviral therapy.

The centre had established a partnership with the Ministry of Health, which provided drugs, and with other private clinics that referred people suspected of having TB to them. The health centre had a set of community volunteers attached to it that provided good coverage in their catchment area. Each volunteer supported several primary health care programmes within a 2-km radius of their home. Community volunteers promoted TB control through youth organizations and gave talks at schools and reli-

gious meetings. People with TB received drug supplies in the health centre and usually had two treatment supporters: a family member responsible for daily support and drug collection and a community volunteer who visited each person with TB weekly. Each volunteer could support up to ten people with TB at a time. The health centre had organized quarterly meetings for people with TB, treatment supporters, community volunteers and nurses, where they discussed TB-related issues, and monthly meetings between community volunteers and nurses.

2. Community participation in TB control – TB-aware community group

A TB-aware community group was observed in Lampung Tengah Province. The senior doctor of the local health centre organized a group of individuals who had expressed an interest in fighting TB infection. Each volunteer was responsible for 170 families. They identified people suspected of having TB through door-to-door visits and by attending religious gatherings before referring them to health centres. Volunteers referred more than 90% of the people with TB for treatment. Most people with TB were supported at home throughout their treatment by community volunteers, and due to good volunteer coverage, identification of people suspected of having TB was increasing. The population in the area used to avoid TB treatment before they knew that it was free of user charges.

3. Community participation in TB control – ninik mamah in West Sumatra

Ninik mamah, in West Sumatra Province, are traditional leaders, often responsible for their extended family. One district involves ninik mamah in TB control work through *puskesmas* (health centres). Ninik mamah were initially approached by health centre staff, trained about TB, and encouraged to identify and refer people suspected of having TB to the health centre. They provide support to family members who become treatment supporters to people with TB. Ninik mamah promote free TB treatment at religious gatherings too, and they have reported a change in public perception of the disease. Puskesmas reported an increase in case-finding in the first year of ninik mamah involvement. Previously, the population was not aware of freely available treatment, which resulted in significant diagnostic delays. Lately many more people with TB have referred themselves for treatment.

In most other areas of Indonesia, the treatment registration fee can be waived only for poor people.

4. Community participation in TB control – sub-health centres

In Indonesia, TB diagnostic and curative services are usually provided at puskesmas health centres at the subdistrict level. Smaller facilities, like sub-health centres, usually do not offer TB services. One sub-health centre (Pustu) visited had four community health workers working on TB control. They are trained in primary health care and promote healthy lifestyles in their area of residence. At the time of the visit, they were mostly involved in identifying people suspected of having TB (through door-to-door visits and religious meetings), providing support and referring for sputum testing. People with TB were often supported through family treatment supporters, and either party could come to the sub-health centre for medicine. Community health workers followed up people with TB at home if there was difficulty with treatment adherence. If a person is identified as having TB, the health centre provides the sub-health centre with drugs for that person. People pay about US$ 0.20 in registration fee, which can be waived by the village head if the person cannot afford the amount. The Pustu staff reported a diag-

nostic delay of up to two years in the area and believe that many local people suspected of having TB do not come for sputum testing.

5. Community participation in TB control – Aisyiyah

Aisyiyah is a Muslim nongovernmental organization that has recently entered into a partnership with the national TB programme and is a subrecipient of a grant from the Global Fund to Fight AIDS, Tuberculosis and Malaria. The nongovernmental organization decided to include TB training in the activities of a large number of volunteers already doing community work. At the time of the visit, this initiative had just started. Three volunteers had been trained on identifying people suspected of having TB, on referral and on treatment support. Some people with TB had already been identified through their work. Each volunteer had up to six functions: treatment supporter, treatment supporter supervisor, motivator, promoter, active case-finding volunteer and TB counsellor. Each volunteer was responsible for 50 families in his or her area, and all volunteers are involved in awareness-raising and case-finding activities. TB control basics were also introduced in the curricula of Aisyiyah public health training.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

Yayasan Syahrullah Afiat volunteers reported being motivated by the desire to help others. The Global Fund grant included incentives for Yayasan Syahrullah Afiat community volunteers, who received about US$ 8 for each person with TB who was cured. The population living in northern Jakarta generally has good awareness of TB, but stigma is still reported and is mostly related to fear of transmission of the infection.

Volunteers in the TB-aware community group said they provided their service to protect their communities and families, and few have dropped out over the past three years. They receive no incentive and have expressed a need for refund of transport costs for accompanying people suspected of having TB for a sputum test or people with TB picking up medicine.

In West Sumatra, ninik mamah were initially highly motivated by a desire to support poor people, but later they expressed concern at the transport costs incurred when accompanying people suspected of having TB for sputum testing. They only received reimbursement for transport costs for the regular meetings they attended at the health centre. Ninik mamah were keen to expand their involvement in health-related issues to other diseases.

Aisyiyah is one of the many examples of religious groups promoting health intervention as a part of the overall development of their community.

Aspects of TB control to which the community is contributing

Yayasan Syahrullah Afiat community volunteers teach about TB at schools and religious meetings and through youth organizations and local communities.

Volunteers in the TB-aware community group identified people suspected of having TB through door-to-door visits or during public gatherings before referring them.

Ninik mamah identified people suspected of having TB and accompanied them for sputum testing.

Community health workers at the sub-health centre were mostly involved in identifying people suspected of having TB, support and referral. People with TB were often supported through family treatment supporters. Community health workers followed up people with TB at home if there was difficulty with treatment adherence.

Aisyiyah volunteers informed and educated communities on how to identify and refer people suspected of having TB to the health centre and supported people with TB at the community level.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

The variety of models observed within a highly decentralized health system, often with limited resources, proves that the society in Indonesia is ready to cooperate with the health services in many ways.

The quality of TB control activities was high, and the staff members were highly motivated. There were effective links between communities and the health system.

The involvement of family members as treatment supporters in Indonesia was effective and unproblematic.

Due to political changes in the country, Indonesia is going through a rapid process of social empowerment that is visible in new governance transparency and freedom of the press. This has created a momentum for social participation, community initiatives and ownership. National or provincial government departments are often not involved at the beginning of such initiatives. Government needs to be encouraged to provide adequate support to the communities involved in health initiatives.

Philippines

Description of models for community involvement

1. Community-based TB care model

In rural health facilities where nongovernmental organization support is not available, community health workers are attached to 95% of public health facilities. They are called barangay health workers. They mostly work in their own community, but they also spend time at rural health posts called barangay health stations. Barangay health workers are chosen by village heads or barangay captains, and they are often the wives of community figures.

When a person is diagnosed with TB, a local health official usually chooses a family member as the treatment supporter. The family member then supports the person with TB alongside a barangay health worker acceptable to the person with TB. The family member supports the person with TB daily, and the barangay health worker visits the household occasionally to monitor treatment progress. Either the family member or the barangay health worker can collect medicine from the health post.

People with TB in all DOTS-accredited centres have to sign a contract on diagnosis, agreeing to complete the treatment and to inform the health centre if they move away. There are no penalties for breaching the contract, but staff report that it positively influences treatment.

2. Role of World Vision in community involvement

World Vision is a nongovernmental organization and a national TB programme partner implementing a grant approved by the Global Fund to Fight AIDS, Tuberculosis and Malaria related to social mobilization in the Philippines. World Vision has formed TB task forces attached to each rural health centre. Task force members are responsible for following up people with TB at home daily to support them and the family treatment partner, referring people suspected of having TB for sputum test and tracing absentees. In the areas where they operate, more than half the people with TB are identified through their work. Their strategy is similar to the national TB programme model, but

they receive more training, have more advocacy, communication and social mobilization material, enjoy better coverage in their catchment areas and produce better results. The only incentive they receive is one T-shirt each. TB task force members identify people suspected of having TB by door-to-door visits and promote free treatment and discourage stigma by visiting religious groups and schools. Some central national TB programme sources have raised concerns that task forces are too large for the actual TB burden, especially since barangay health workers are already present.

3. Public-private mix and community involvement

In 2005, the Philippine Coalition against Tuberculosis began forming public- and private-sector partnerships to standardize TB management and increase case detection. Public-initiated units sign an agreement with private physicians who refer people with TB to the DOTS-accredited public health centre. Private-initiated partnerships sometimes charge people with TB a consultation fee of US$ 5.

For example, the private De La Salle University works with a faith-based organization whose field workers have become treatment supporters for people with TB. The organization refers people suspected of having TB and helps trace absentees. People with TB come daily to the University TB Clinic for directly observed treatment in the intensive phase but can be referred to a rural health station if transport is too expensive. A midwife based at the university follows up defaulters at home in areas not covered by the faith-based organization.

The Canossa Health and Social Center Foundation is a faith-based organization and a DOTS-certified health unit serving a population of 65 000 in one of the poorest areas of Manila (Tondo). An agreement was made with private health providers in the area to refer people suspected of having TB to the Foundation. At the time of the visit, 80 adults with TB were being treated. Canossa's nine volunteers provide directly observed treatment at the health unit during the whole duration of treatment – four of them have had TB and been cured. The volunteers get a monthly allowance of about US$ 50. Very sick or homeless people with TB have the option to stay at the facility during the six months of treatment. If a person with TB cannot come to the facility daily, then directly observed treatment is sometimes arranged at their home. The health workers at Canossa saw people who have had TB as an extra resource and encouraged them to become volunteers. The volunteers regularly gave lectures in the community and referred people suspected of having TB for sputum tests. Family members are not used as treatment partners due to the possibility of problematic relationships in some families. However, family members are shown how to support the person with TB and become involved in their care.

4. Multidrug-resistant TB, public-private mix and community-based care

A very interesting and promising example of close collaboration between a major private hospital in Manila, a rural health unit and the community was observed in the Municipality of Atimonan, Quezon Region.

In April 2006, the Atimonan Rural Health Unit was the only health centre outside Manila regularly treating people with multidrug-resistant TB in collaboration with the Tropical Disease Foundation, Inc. The Atimonan Rural Health Unit has a catchment population of more than 60 000 people.

Faith-based organizations in Manila usually house people with multidrug-resistant TB being treated at the Tropical Disease Foundation, Inc. for the six months of the intensive phase of treatment. After the intensive phase of treatment, people with TB from the Municipality of Atimonan are referred to the Atimonan Rural Health Unit

for continuation of treatment. People living nearby go daily to the health centre for directly observed treatment. Those living further away are entrusted to a specially trained barangay health worker, who visits them daily. The treatment partner is always a barangay health worker, not a family member, because of the complexity of treating multidrug-resistant TB.

Some of the barangay health workers are health staff who work with the community outside working hours. All barangay health workers receive a monthly allowance of US$ 6–16.

The local administration promotes several initiatives to raise money from the community to support the poorest people with TB. The only private hospital in the city has offered services free of user charges to the poorest people and has made available a piece of land, cultivated by people with multidrug-resistant TB, which provides enough food for all of them.

All barangay health workers interviewed reported being motivated by the desire to serve and benefit their community.

Discussion of the principles governing the model and the factors motivating and sustaining commitment at the community and individual levels

The community involvement model recognizes the role played by the family of a person with TB. The public service is fully engaged in supporting this model by training and deploying a network of community health workers (barangay health workers) who link people with TB and their families and the health services.

Barangay health workers get a small monthly allowance from the local administration. Some other barangay health workers perform on a purely voluntary basis. All barangay health workers reported being motivated by the desire to contribute to the well-being of their communities.

Several faith-based organization initiatives have been created to respond to especially challenging situations, such as urban slums and care of people with multidrug-resistant TB. They work effectively with the public and private sectors in providing care for people without access to public services, such as homeless people.

At several of the sites visited, health workers played an important role in identifying and encouraging people with TB. Many people who have had TB were motivated to help others and help to reduce stigma as a means of expressing gratitude for having been cured. The people who have had TB were trained as treatment partners and TB advocates. Such empowerment has also led to the formation of organizations of people who have had TB and been cured and people with multidrug-resistant TB, which has provided people with TB with a voice in the society. In developing community approaches to multidrug-resistant TB, people who have had TB and been cured and people with TB who are well along in their treatment represent special added value because of their awareness about the importance of adherence to treatment and of proper care and support.

At all sites visited, health services, nongovernmental organizations, faith-based organizations, patients' organizations and communities collaborated effectively. The model used in the Municipality of Atimonan for controlling multidrug-resistant TB is an impressive example of collaboration between public and private services and communities. It is sustained by the local administration, which takes care of the urgent needs of people with TB, such as transport, accommodation and helping them to find employment once they return to their homes.

Aspects of TB control to which the community is contributing

Barangay health workers act as treatment partners and are also responsible for identifying and referring people suspected of having TB. They trace absentees and promote community awareness of TB symptoms.

World Vision task force members are responsible for following up people with TB at home daily, referring people suspected of having TB and tracing absentees in the intensive phase.

Faith-based organizations take care of all aspects of TB control as well as social support to people and families affected by the disease.

Organizations of people who have had TB help to identify people suspected of having TB in poor areas, share experiences and promote TB services during community meetings and may serve as treatment partners to nearby people with TB.

Inherent strengths and weaknesses of the model and opportunities and threats related to the social situation or the set-up of health services

The observed experiences looked very promising in terms of sustainability in the local context and potential for scaling up in a wider context.

The society offers a huge potential resource for work in partnership with government institutions, local administrations and the private sector.

The contribution to health services by nongovernmental organizations, faith-based organizations and the private sector is recognized, encouraged and supported, providing an example of an effective subsidiary approach to the delivery of social services.

The Atimonan model for the management of multidrug-resistant TB provides an example for scaling up this important component of the Stop TB Strategy in difficult settings.

Lessons from the WHO country reviews

Good practices and strengths observed

The direct involvement of communities in managing health initiatives requires careful preparation. The following section identifies the essential elements of the process of involvement and describes how these elements have been effectively implemented in various countries.

Promoting community participation to traditional and political leaders at provincial, regional and local meetings allows them to realize the burden TB places on local government authorities. Discussions should focus on the problems TB poses for communities and how the impact of the disease can be mitigated. These meetings, along with advocacy at district levels, can help attract political support for people with TB and community involvement. Such initiatives should also focus on potential pools of social capital willing to work in partnership with government and the private sector. Appropriate community groups to work with can be more effectively identified at peripheral levels, where a number of self-help projects usually already exist. Indeed, the participation of people with TB and communities can often be initiated at grassroots levels with or without the knowledge or help of provincial or national government structures.

1. Solicit political commitment and support from local leaders

Creating an efficient infrastructure of primary care services and a programme of social mobilization addressing major public health problems can also be an effective means of combating TB when supported by political leaders. Associated advocacy, communica-

tion and social mobilization activities should emphasize health promotion and include targets of disease control.

Health services should be encouraged to collaborate with communities, and government should be encouraged to explore options and support stakeholders in involving communities in disease control. The contribution by nongovernmental organizations, faith-based organizations and the private sector to health services should be recognized, encouraged and supported.

2. Advocacy, communication and social mobilization

Advocacy, communication and social mobilization activities are at the core of effective strategies to empower people affected by TB and their communities. All country reviews clearly showed that applying advocacy, communication and social mobilization strategies from the political arena to health care settings and to the households is required to involve people with TB and support and treat them effectively with dignity and respect. Further, all those who are most affected by TB are involved in shaping the response.

However, national TB programmes have not given priority to such strategies in recent years. Building capacity for advocacy, communication and social mobilization at the country level and mobilizing political, social and financial resources to eliminate TB is essential to achieve effective community empowerment.

In 2006, WHO and the Stop TB Partnership published *Advocacy, communication and social mobilization to fight TB: 10-year framework for action*,[1] the result of the work of the Partnership's Subgroup on Advocacy, Communication and Social Mobilization at Country Level. This document comprises a call for action, with clarifications on key terms, principles and activities, and a framework for action, including clear components, methods and resources. *Advocacy, communication and social mobilization to fight TB: 10-year framework for action* provides the vision and tools to prepare a country strategy and implement all advocacy, communication and social mobilization activities that have to be undertaken to empower people affected by TB and their communities.

3. Partnership approach

National TB programmes should assume responsibility for training health professionals, diagnostic services, prescription of treatment, a secure drug supply free of user charges and follow-up visits at health facilities. National TB programmes should recognize that the daily social support to people with TB could be better provided at the community level.

At the national level, the Stop TB Partnership may coordinate the work of peripheral-level partnerships or collaborations, designed to link health programmes and the community, by promoting social messages – the main one being that the fight against TB is a social problem. It can also establish agreements with nongovernmental organizations and private practitioners to refer and diagnose people suspected of having TB and support treatment. Partnerships may be implemented to manage more complex challenges such as multidrug-resistant TB. Districts can nominate a celebrity to act as a stop-TB ambassador and raise awareness about TB among the general population.

The role of the community in TB control should be based on joint deliberations between health staff in peripheral facilities and the communities they serve. This partnership was effective in cases where projects were well defined, the various actors com-

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[1] Subgroup on Advocacy, Communication and Social Mobilization at Country Level of the Stop TB Partnership. *Advocacy, communication and social mobilization to fight TB: 10-year framework for action*. Geneva, World Health Organization, 2006 (http://www.who.int/tb/publications/2006/en, accessed 30 November 2007).

municated clearly and the community was sensitized on the seriousness and nature of disease – not when the involvement of people with TB and communities was merely demanded as part of a new national health policy.

The work of community-based organizations in communication and social mobilization around TB expresses how communities organize themselves and become actively involved in answering the challenges they face. Some nongovernmental organizations, too, play a role that complements the function of public health services, either because they provide TB control services or because they address specific needs in the community that are not being met by public services. Collaboration with nongovernmental organizations should be based on the following principles: mutual respect and trust, commitment to follow national TB programme guidelines, pooling of resources to maximize the use of partners' expertise and to make the programme cost-effective and periodic review of programme performance.

Authorities should recognize that health can only be effectively promoted and disease prevented by involving community members, promoting each individual's responsibility towards his or her own health and eliciting collective behaviour change that will enable more efficient control of disease. Partnership building, with each partner assuming its own share of the responsibility, is the approach at the national and community levels that makes this happen.

4. Design of models for community involvement

Community and local leaders were involved from the beginning in discussions aimed at identifying the needs of communities and their possible contributions to controlling TB. This dialogue led to the creation of a successful model of collaboration.

Programmes focused on the promotion of healthy lifestyles, including sharing responsibility for TB control. Communication about TB was based on simple messages about the infectious nature of the disease, symptoms and treatment free of user charges. People were also encouraged to seek treatment early and to adhere to their medication.

The community involvement model should recognize the role the family plays in TB treatment. Public services can support this model by training a network of community health workers who link between people with TB and their families and the health services.

5. Links with existing HIV community initiatives

Some countries had hundreds of local nongovernmental organizations supporting people with HIV, and collaboration with them is key to both TB and HIV care. Models of community involvement in TB care can also act as templates for scaling up antiretroviral therapy.

Community-based organizations organized health promotion meetings to discuss health issues and publicize the work of local shopkeepers providing advice on malaria and TB. Community-based organizations were able to increase awareness and demand for TB services and find more cases by building on existing community-based HIV initiatives. In some areas, people with TB were offered counselling and testing for HIV alongside their TB treatment.

Focusing on high-risk groups – such as homeless people and prisoners – allowed the problem of TB/HIV coinfection to be addressed. Some nongovernmental organizations carrying out HIV work among such groups have trained their members how to identify people suspected of having TB and introduce TB to their skills-building and advocacy activities.

6. The links between poverty and TB

The links between poverty and TB have been documented for many years. In all the countries visited, one of the most important reasons for involving communities in TB control was to make it easier for poor and vulnerable groups to access TB services. Such groups include: those in absolute poverty; those disadvantaged by gender factors; marginalized ethnic groups; people living in remote locations; and urban poor people.

The effective empowerment of communities succeeds in addressing economic, social and cultural barriers and geographical isolation. Involving people with TB and communities in TB control aims to increase awareness about the disease and make diagnosis and treatment more easily accessible and affordable. Implementing this approach is a practical way of reducing poverty.

7. The role of people who have had TB and communities

The main role of community volunteers and groups of people who have had TB was to contribute to detecting new TB cases and to improve adherence to TB treatment. Community volunteers and people who have had TB engage in the following activities: referring people with chronic cough for sputum examination; sharing experiences and serving as advocates during community outreach; promoting DOTS services; serving as treatment partners for people with TB; assisting staff at health centres; giving talks in schools and sharing information about the disease to help reduce stigma and help people to identify TB symptoms; storing drugs for people with TB; keeping records of treatment progress; reminding people with TB about follow-up visits; accompanying people with TB to nearby health facilities; and referring people with TB who experience adverse reactions to drugs.

Health authorities must play their own role by ensuring that essential services are in place to support social mobilization initiatives. Community-based organizations and nongovernmental organizations also conduct social mobilization and health promotion activities, based on the recognition that such diseases as HIV and TB are a social problem. More focus is placed on promoting community health rather than simply controlling disease. This work allows community members, such as shopkeepers, to provide advice and refer people with TB for treatment.

8. Involvement of people in urban settings

In some countries, family members provide treatment support in cities and community volunteers provide support in rural settings. Allowing family members to act as treatment guardians in rural and urban settings simply allows the extended family, rather than the wider community, to establish links with local health services.

Primary health care services can be weaker in cities, as health workers tend to visit less often and people with TB sometimes have to report to health centres in the event of a problem. A positive side of this is that it ensures greater confidentiality and ensures longer-term support, such as for associated antiretroviral therapy.

Adherence to treatment can be particularly problematic in urban areas. Nongovernmental organizations have initiated partnerships between the private health sector and factories, which provide essential health services to their employees to minimize lost working hours.

In some urban settings, private clinics can refer people suspected of having TB to nongovernmental organizations, which use government drugs to provide treatment. Community volunteers in urban areas can support several primary health care programmes at once, giving talks in schools and places of worship to spread awareness of TB and HIV. Some urban people with TB have two treatment supporters: a family

member responsible for daily support and drug collection and a community volunteer who visits each person with TB weekly at their home.

Special faith-based organization initiatives have been created in some urban areas to respond to especially challenging situations, such as urban slums and the long-term care required by people with multidrug-resistant TB. They work effectively with the public and private sectors to provide care for people without access to public services, such as homeless people.

9. Links between health services and communities

Health services in some communities need staff with the skills necessary to promote community involvement in TB control; in many cases, the workload does not allow health care staff enough time to work at the community level. In successful initiatives, public health officers operating in the field visit people with TB and treatment supporters every two weeks, supplying drugs, answering questions, providing support and recording treatment progress. The same public health staff receive information from health facilities about new cases of TB and then attempt to mobilize the community and train volunteers in the area where the person with TB lives.

Community health workers can be identified among members of existing self-help groups, local nongovernmental organizations or faith-based organizations before being trained by health staff. They inform the community about TB, maternal and family health; refer people suspected of having TB for sputum examination; act as a liaison between people with TB and their supporters and the health service; and encourage people with TB who have interrupted their treatment to resume it.

In some countries, laypeople known as village doctors or traditional leaders also act as villagers' first contact for seeking care and work as treatment supporters. They can also provide support to family members who become treatment supporters to people with TB. Evidence shows that family members can work effectively as treatment supporters in some cultures.

10. Capacity-building process

Training requirements vary depending on the choice of volunteers who provide community support or link communities with health services. Where the population density is lower, providing a volunteer with on-the-job instruction can ensure better support for the person with TB.

Health staff and community health workers can be trained on the complex aspects of multidrug-resistant TB management and structured to form a team. The team is responsible for establishing a referral system to and from the community and promoting health messages in support of community volunteers.

Whenever a new person with TB is diagnosed and the community chooses a volunteer, public health staff can train this person on how to store drugs, keep treatment records and refer people suspected of having TB for sputum testing. In some areas, people with TB meet regularly at the health centre to discuss different aspects of their disease, provide support for each other and attend lectures and role-playing organized by volunteers. This results in real empowerment that enables them to extend their support to new people with TB and play an active role in managing the health centre.

The national TB programme should take responsibility for national advocacy, communication and social mobilization campaigns. Nongovernmental organizations can work in pursuit of local campaigns in accordance with national TB programme policy and organize training in collaboration with local health authorities. Systematic educational activities centred on messages about public health can work to empower com-

munities, improve personal health, reduce stigma and minimize many health risks. Community-based organizations, which already work in support of people living with HIV, can also play a crucial role in referring people suspected of having TB for medical examination. TB is often the major health problem of people living with HIV, so spreading knowledge about TB can often facilitate early diagnosis and result in better support of people with TB.

Some nongovernmental organizations were involved in training TB task forces of community health workers, people who have had TB and members of community health committees. Task force members were responsible for following up people with TB at home and supporting them in addition to a family treatment partner, referring people suspected of having TB for a sputum check and tracing absentees in the intensive phase. In the areas where they operate, more than half the people with TB were identified through their community work.

11. Effective and secure drug supply systems

Effective and secure drug supply systems are essential for building trust in the commitment of health services at the community level. This was confirmed across all countries visited. TB treatment regimens and anti-TB drug formulations supplied as fixed-dose combinations and in calendar blister packs are most practical for use by people with TB and community volunteers.

Fulfilling all the elements of the Stop TB Strategy is an effective way of ensuring high-quality services. Health services can promote this strategy when meeting with community leaders and proposing collaboration. The health services do not, and cannot, give up their responsibility. They recognize that some of the needs of the people with TB are better met at the community level and, if people are ready to take up this responsibility, they have a responsibility to support this.

12. Community and personal motivation

Community and personal motivation is the fundamental factor contributing to long-term commitment to health-related activities. Each level of society – families, nongovernmental organizations, faith-based organizations, health services, patients' groups and activists – can play a specific role in promoting and improving health and helping people affected by various diseases. Community members reported being motivated by concern about the spread of TB in the community, concern about the emergence of multidrug-resistant TB and helping friends or community members in need. Community health workers linking people with TB and their supporters with health facilities are motivated by the desire to serve the good of the community and to avoid the spread of infection. Traditional leaders also expressed a desire to support poor people and were keen to expand their involvement to other health-related issues.

Being cooperative in small communities is also a powerful tool for social recognition and results in better social cohesion. For female community health workers, one important additional motivation is the opportunity to secure a supplementary income for their families. The negligible dropout rate among community volunteers is an important indicator of high motivation. Some volunteers expressed a justified concern about the transport costs they incur when accompanying people suspected of having TB for sputum testing.

Motivation can be closely linked with the role of the extended family. Because of their strong bond to the person with TB, family volunteers are motivated to provide even long-term care – very important in case of coexisting HIV infection.

Highly motivated faith-based organizations also extend their services to all commu-

nity members in need, regardless of their religious affiliation. Some now maintain local dispensaries and carry out a range of activities to support people affected by TB or HIV.

13. Involvement of patients' organizations

Groups of people with TB and people who have had TB help spread awareness about TB and treatment free of user charges at public meetings. In some areas, nongovernmental organizations and local TB officials mobilize groups of people who have had TB into TB clubs, sensitizing them in how to raise community awareness and organize TB meetings between people who have had TB and local government representatives. Some people who have had TB act as treatment supporters, referring people suspected of having TB for sputum testing and accompanying them to health centres.

The involvement of people who have had TB and their treatment supporters as TB ambassadors in public gatherings will play an increasingly important role as they have been directly affected by the disease and are therefore often motivated to participate in TB control activities. Their work has had an impact on reducing stigma and providing people with TB with a voice in society.

14. Monitoring and evaluation

The existing recording and reporting system adopted by national TB programmes in most countries does not include information about the role of communities in TB control. WHO has revised this monitoring system to better evaluate individual case management and care delivery.

In most countries visited, it was not possible to measure the contribution of communities to TB control by analysing records at the national or subnational level, yet the treatment cards of people with TB often illustrated the value of community-based support.

Information about the role of the community can easily be introduced to a national recording and reporting system via the following measures.

- A person with chronic respiratory symptoms is advised by a community member to seek health care and is later diagnosed with TB. Health staff can therefore distinguish in their records between people suspected of having TB who are referred by the community and self-referred.

- A person with TB, following diagnosis and prescription of treatment, accepts one of the forms of community-based support ensuring adherence to treatment. Again, this can be recorded on the treatment card of the person with TB as well as in district registries and quarterly reports.

Additional aspects to be recorded include the perception of the person with TB about the quality of care received and the periodic repetition of surveys of knowledge, attitudes and practices to determine the effectiveness of advocacy, communication and social mobilization activities. The national TB programme can monitor indicators of effective communication and social mobilization such as: strategic alliances with partners, participation in activities by social groups and easy integration of new members, production of advocacy, communication and social mobilization material by the community and mass-media coverage.

15. Reduction of TB-related stigma

Levels of stigma varied from country to country. Nongovernmental organizations report that stigma has decreased significantly with the introduction of community-based care. Studies have shown that awareness-raising activities such as radio broadcasts, dramas

and flip chart presentations have significantly reduced stigma in communities, and people suspected of having TB now find it easier to seek treatment. Volunteers and people who have had TB also work effectively in communities to reduce the stigma associated with the disease.

Some health staff report that strong levels of social solidarity resulted in TB being perceived as a social problem rather than a personal curse. This creates a supportive environment for detection of new cases and care.

TB is still associated with malnutrition and poverty. Despite decreasing levels of stigma, some people with TB still expressed shame at contracting TB and were afraid of the risk they posed to others. Stigma in some urban areas prevented people with TB from attending public health facilities.

Weaknesses and threats

The country reviews highlighted several financial and managerial threats to the successful expansion of community TB control. These problems were more prevalent in countries unfamiliar with community-based TB care and in countries in which national health services had displayed a lack of foresight regarding the involvement of people with TB and communities.

In Uganda, regular investment is required to conduct initial training for health staff and community members and to ensure supervision of TB control activities. Unfortunately, political support for community involvement has not reached the level of budgeting for primary health care activities carried out in the field. As primary health care staff are the essential link between health services and community, inadequate funding weakens their support for communities. In more autonomous decentralized districts, local government is responsible for supporting community involvement in controlling TB. If communication and social mobilization are not addressed in these districts, community involvement in controlling TB is not successful.

The high turnover of trained staff and lack of information about community-based care at the district level indicates the need for capacity-building. Cities pose a special challenge in Uganda because of greater stigma in urban settings; because of privacy fears, people prefer to rely on private services, which do not follow sound TB control practices.

In Malawi, community involvement in controlling TB succeeded in reducing costs to people with TB, families and the health system. More intense advocacy, communication and social mobilization activities could facilitate better case detection and help reduce stigma. Because of limited resources in the health system, contacts between health facilities and families are irregular, and this may result in poor adherence to treatment.

In Kenya, public health technicians are based in dispensaries at the district level. They have the potential to act as a liaison between people with TB and the health facility, but they are frequently underutilized because district administrations do not provide adequate funding for their activities.

Community involvement in health services was initially proposed as a form of decentralization rather than of partnership. Dropout among community health workers was reported in all places visited – mainly because per diem payments were not made available. The national TB programme monitoring system has not been used to evaluate the effectiveness of community-based care.

In Bangladesh, the possibly excessive delegation of responsibilities by public services to private stakeholders in the context of public-private partnerships raises a number of questions about the sustainability of this system if nongovernmental organizations or the private sector withdraw from the area in question. It also runs the risk of creating a parallel system that is not integrated into government health services.

Involvement of people with TB and communities: approach to design, implementation, scale-up and evaluation

See the executive summary and recommendations for explanation and details

- Political commitment of national and local leaders
- Partnership building: task force on community involvement
- Community initiatives and demand for community services

- Quantity and quality of TB services available
- Situation analysis
- How can the community contribution complement the capacity of the national TB programme?

- Discuss and define the role of community volunteers
- Specify the roles and functions of all partners
- Patients' groups, activists, civil society organizations, faith-based organizations, nongovernmental organizations, etc.
- Identify all partners and establish mutual communication
- Use synergy: make the most of existing community initiatives (including ones on HIV and AIDS)
- Develop material on advocacy, communication and social mobilization and plan activities jointly with partners

- Verify the effectiveness of the interface between health services and the community to ensure regular contact
- Address issue of community and personal motivation
- Develop the health promotion aspect of the intervention to improve the (self) referral of symptomatic people
- Design a model of community involvement jointly with all partners
- Involve the affected people in shaping intervention
- Consider the differences between rural and urban settings
- Modify the recording system, as necessary, including quality-of-care indicators
- Prepare national guidelines for community involvement

- Prepare and produce training tools
- Training plan for all partners and functions
- Analyse tasks
- Capacity-building
- Identify funds; Train facilitators; Schedule; Plan follow-up
- Facilitate workshops for all stakeholders
- Recurrent training for health staff and other partners
- Ongoing evaluation of the impact and quality of care

- Work plan and strategy for scaling up
- Public launching of initiative
- Mass-media events and plan for periodic coverage

- Budget for start-up costs and recurrent costs
- Scaling up by regions and administrative units
- Implementation and fine-tuning in demonstration areas
- Lessons learned
- Ongoing training for the new community members involved

AREAS OF WORK | Policy guidance | Advocacy, communication | Capacity-building | Special challenges | Quality of care | Budget and finances | Monitoring and evaluation | Operational Research and social mobilization