

Transforming the global tuberculosis response through effective engagement of civil society organizations: the role of the World Health Organization

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Background

Civil society organizations are non-profit organizations that include nongovernmental, faith-based, community-based and patient-based organizations as well as professional associations. They are sometimes referred to as the “third sector”, the government and private-for-profit representing the “first” and “second” sectors respectively. Their health sector-related activities range from care and service provision to research, advocacy, lobbying and activism, and contribution to social welfare and support. Their main drive is usually to protect and empower the most vulnerable and to promote the communities they serve.

The role and influence of civil society organizations in global health has become a subject of great interest due to democratic changes in the political environment of countries and the need for innovation in global health.¹ Strong motivation to respond better to urgent health and humanitarian needs has engendered a debate on how to formalize the significant, at times vital, contribution of civil society organizations in global health governance. Some have suggested establishing a “Committee C” composed of non-state actors at the World Health Assembly of the World Health Organization (WHO).¹ In a report to the 64th World Health Assembly in May 2011, WHO’s Director-General proposed a multi-stakeholders’ global health forum as a means to engage civil society and other key players.²

In this perspective, we argue that governments need to provide civil society organizations with more space and recognition to facilitate a stronger health response with a particular focus on tuberculosis (TB) prevention, care and control. We also argue that WHO and its international partners must play a

brokering and facilitative role to catalyse the process, and we provide a contextual framework about how to do this.

HIV/AIDS response

Although the involvement of nongovernmental organizations in global health was first promoted at the Conference on Primary Health Care in Alma-Ata in 1978,³ there has been a rapid increase in their involvement in the past three decades in the response to HIV/AIDS.^{4,5} This has been due to increased availability of resources from several governmental and philanthropic organizations, as well as new interest in providing funding through civil society organizations rather than traditional government structures.⁶ In many countries, civil society organizations have been responsible for handling the majority of resources to deliver services to individuals and have played a leading role in developing and implementing sustainable strategies to mitigate the impact of HIV/AIDS. The linkage and networking between global and national civil society organizations have also resulted in important national policy and programme changes both for HIV/AIDS and other health issues.^{5,6}

TB response

Every year more than 9 million people are affected by TB and 1.7 million people die as a result. It is a leading cause of preventable morbidity and mortality, particularly among people living with HIV, women and children.⁷ TB is intricately linked with HIV and is also closely related to noncommunicable diseases and determinants of poor health such as diabetes mellitus, smoking, alcoholism and malnutrition.⁸

Due to its complex nature, TB prevention, care and control activities face

numerous challenges. A major problem is that one in three estimated TB cases globally is either not formally reported in the public system or not reached at all by existing services.⁸ TB is rarely recognized as a priority by national political authorities, United Nations agencies, development banks, the pharmaceutical industry and philanthropic organizations. TB is often neglected within development, human rights and social justice agendas. Despite causing more than half a million deaths a year among women and more than 50 000 deaths among children, TB control is rarely acknowledged within maternal and child health initiatives, thus ignoring its intrinsic links to Millennium Development Goals 4, 5 and 6. Furthermore, there is a lack of collaboration on TB control between ministries of health and other ministries (e.g. justice ministries for prison health services, labour ministries for health services in mines). These various challenges require strategic, tactful and innovative ways of dealing with the problem both globally and nationally. Enhanced and effective engagement of civil society organizations will play a critical role in transforming the global and national responses to TB.

Civil society organizations

Civil society organizations have the comparative advantage of a bidirectional influence on community structures as well as governmental institutions; knowledge and understanding of local circumstances; and flexibility and adaptability towards local situations. Their capacity to function in difficult-to-reach, remote areas and conflict zones offers a unique opportunity for increased early TB case detection and treatment adherence through generating demand for services and scaling up of community-based care. If well planned, this will expand TB prevention, care and

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control beyond health facilities and in settings that cannot be easily reached by national programmes.

WHO

In its core role of providing technical support to ministries of health, WHO has the comparative advantage of influencing national policy-making and programme implementation. The core functions of WHO should therefore be fully exploited to promote effective involvement of civil society organizations in global and national responses to most health threats. WHO's facilitative and brokering roles could help develop stronger linkages between ministries of health and civil society organizations. For effective execution of these functions, WHO should further strengthen the competency and rapid adaptability of staff, particularly in countries. Furthermore, while there may be hesitation in engaging civil society organizations, the WHO Constitution clearly spells out in article 2(b) that WHO shall: "...establish and maintain effective collaboration with...professional groups and such other organizations as may be deemed appropriate".⁹

Linkages with government

With the expanded role of civil society organizations in global health, concerns are often expressed about their legitimacy, accountability and representation, especially if their objective is to represent those with poor health.⁶ It is important to avoid fragmentation and duplication of efforts; parallel structures, particularly for monitoring and evaluation; and the provision of poor quality services that are not aligned with national policies and programme practice. To overcome these problems and to function effectively, there is a need for collaboration between governments and these organizations with the main focus on the delivery of quality health services. The first consideration is the diversity of the organizations in terms of size, interest, capacity, scope, geographical coverage and area of work. Second, the political system and governance of the country should be brought into context, particularly for organizations that work in health advocacy and activism. It is also important to recognize that collaboration

with government bodies may be perceived by constituencies as improper allegiances and may pose a challenge of smooth communication and service provision. Effective collaboration often will require additional resources from both the national government and the civil society organizations and will need to include regular evaluation of performance and impact. Better understanding of these factors is essential and will help develop country-specific tailored approaches.

The way forward

Despite some efforts to engage civil society organizations in global TB activities,⁴ in many countries they still lack recognition as legitimate partners at national and local level even in established democracies. Furthermore, there is only a handful of patient-based organizations involved in national responses to TB. This is compounded with a significant lack of financial resources for community and patient-based TB initiatives. There is limited, if any, visibility of TB civil society organizations in the global and national governance of key financial mechanisms such as the Global Fund to Fight AIDS, Tuberculosis and Malaria. TB is not considered a priority for organizations working on development, poverty alleviation, Millennium Development Goals 4 and 5, HIV, human rights or social justice. To make things more complicated, there is also insufficient experience and involvement of staff at WHO and its international partners in brokering the involvement of civil society organizations, especially at country level.

There is an urgent need to overcome these challenges and transform global and national TB responses through effective national partnerships and active involvement of civil society organizations. Action is required at three levels. First, national authorities need to create a favourable and empowering legislative, policy and programme environment that recognizes and promotes the crucial role of civil society organizations. A legal framework that enhances their participation and defines the division of labour, duties and responsibilities of each party has to be established. Second, national authorities need to recognize WHO's unique posi-

tion in facilitating and brokering such a process. As the global coordinator of normative functions, WHO must facilitate and support the creation of effective national partnerships between ministries of health and civil society organizations. WHO should also expand its technical support to these organizations to help build capacity. Third, civil society organizations working on development, poverty alleviation, Millennium Development Goals 4 and 5, HIV, chronic diseases and human rights need to include TB prevention, care and control activities in their core functions. They should also strictly follow evidence-based international and national norms and guidelines. Streamlining monitoring and evaluation systems with recommended indicators is particularly important to prevent duplication, foster linkages with national health systems and monitor their contribution towards improving the health of the populations they are serving.

Conclusion

While we argue for greater and more meaningful involvement of civil society organizations in the response to TB, this concept can be applied to all health programmes. The proper global response to health challenges should start with the principles expressed originally in the Declaration of Alma-Ata in 1978. These affirm the right and duty of people to participate individually and collectively in the planning, organization and implementation of health care making the fullest use of available resources.³ While action of this kind could have appeared ideological 33 years ago, today it is a non-negotiable matter of urgency given the significant role that civil society organizations have since acquired in global health. Missing this new opportunity for a "health for all through all actors" is unforgivable in 2011. ■

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