

# **The critical importance of engagement with civil society in national responses to HIV**

**Address by Mark Heywood**

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## **Introduction**

I would like to start my presentation this morning by thanking you for inviting me to this historic occasion, and congratulating you on the bold decision to set up the Red Ribbon Forum. This is a great step forward, but obviously it will be measured and evaluated not only by what you achieve today, but what you achieve over the coming years as a result of this Forum.

I feel fortunate and privileged to be here today. This is my fourth visit to China, and on each occasion I have seen some progress in the recognition and capacity of civil society and in openness from Government to working with civil society. This is not to say that there are not challenges and problems.

I believe that I have been asked to address you on 'The importance of engagement with civil society' because I am a civil society leader from another developing country, South Africa. SA is also a growing political and economic partner of China, so it makes sense that we should also be social partners. I am therefore happy to share with you my views and experience.

I am the Deputy Chairperson of the SA National AIDS Council (SANAC), which is a national forum between 18 civil society sectors and 8 government ministries, whose task is to advise the South African government on HIV/AIDS policy. It embodies the principle of civil society engagement. The chairperson is the Deputy President of our country, Mr Kgalema Motlanthe. I am also the director of an NGO on law and human rights, SECTION27, as well as an executive member of the Treatment Action Campaign (TAC), a social movement of people with HIV and AIDS.

At times in the last decade, I have been a fierce critic of our government – we have taken it to court, demonstrated, been arrested – but ultimately, we achieved meaningful engagement and important results in the fight against HIV. We are also our government's strongest supporter when it does the right thing. This is the first point I want to make: civil society is *independent from government*, but it is not *anti-government*. "Criticism" is not necessarily "opposition".

I hope to convince the government representatives here today that civil society is a critical component to an effective response to HIV. More than this, I want to persuade you not just to pay lip-service to this principle, but also to put it into practice – however challenging this may be in your culture and political environment. But I also want to do this in the context of today's discussion, which centres on human rights and HIV/AIDS, with the hope that this discussion will contribute to the meeting the objectives of the China Human Rights Action Plan (HRAP) on health. This Forum seems fully in keeping with the commitment of the HRAP which reads:

“Democratic and scientific decision-making will be promoted to expand public participation in the decision making process. In principle, public opinions will be solicited when laws, regulations or public policies which are closely related to the interests of the people are formulated. Institution building will be promoted for holding public hearings on the legislation of important laws and regulations, soliciting public opinion for the formulation of major policies and measures, and holding expert consultation or third party verification when making decisions over major issues.”

From the above quotation it is clear that the State Council has recognised that civil society is required for effective governance and accountability in the response to AIDS.

### **Why work with civil society?**

HIV is clearly a major threat to individual and public health, and the type of a major policy question anticipated by the State Council. But why is it one that requires civil society engagement? To answer this question I think we must ask ‘what does HIV/AIDS represent to our society?’ The world is full of viruses, and generally it a rule that it is the poor and weak who suffer the most from preventable disease. However, HIV, more than other virus, exposes and exploits our weaknesses, because the people most vulnerable to HIV are people who are socially disempowered for man-made reasons: because their behaviour is outlawed or stigmatised, or because they are socially or geographically marginalised, or (in some parts of the world) because they are women. Once someone is actually living with HIV, they then experience terrible stigma just because of their health status and the fear and ignorance that surround it.

HIV is like a lithograph that highlights all the fault lines in our society. Some people might think this is deserved punishment for people who deviate from social norms, that the fact that HIV affects the marginalised is all right because that means it does not affect ‘us’. But this argument is unacceptable for two reasons.

Firstly and most importantly, as Justice Michael Kirby has already explained, we live in a world that is committed to equality, non-discrimination and the equal dignity and worth of all people, principles we protect through human rights.

Secondly, the argument is flawed because if HIV is unchecked in *some* people it can end up posing a risk to *all* people. This is what happened in South Africa: HIV began in the most vulnerable populations (sex workers, migrant workers, men who have sex with men), but ended up as a virus that circulates widely within the general population (HIV prevalence in the population has reached nearly 11%). It is true that there are aggravating factors in SA that assisted this to happen and that it is unlikely to happen on the same scale in China, but the principle still stands, and even now the epidemiology of HIV in China is showing an evolution of the characteristics of the HIV epidemic. It is in this way that we see how individual rights and people’s rights are connected: to protect the people you must protect the person.

To prevent this China’s 2006 Regulations on AIDS Prevention and Treatment recognise that it is essential to reach the *currently* at risk populations with information, education, condoms, as well as medical treatment and care when necessary. However, Government cannot reach these at risk populations alone because:

- Government has outlawed or marginalised these people, people are scared of government and do not trust it, and some government officials feel, that if they provide direct services to outlawed people they are also doing something illegal (this does not apply to all in government, but it also points to why government HIV/AIDS education is important).
- There is a point in every society, even China, where government stops and people take over the running of their own lives. It is hard for government to penetrate beyond this line.
- Many people at risk of HIV and many people already living with HIV are in hiding as a result of the severe social stigma that still exists linked to HIV infection in China -- for example, men who have sex with men.

However, whilst government may face barriers, there are organisations who work with those most affected by HIV. These organisations, what we loosely call 'civil society', are either formed by members of these populations themselves (set up for a variety of reasons, sometimes for advocacy, sometimes for information, sometimes to provide care and support), or are organisations - based on human rights principles - that work to advance the interests of groups that are unable to speak for themselves. Fortunately, if you look around this room, some of these groups are represented here.

Another advantage of civil society is that it is able to see things that government cannot. The controversy in November 2009 in Fuyang is an example of this. It was civil society organisations that first complained about discriminating language against MSM. But this was quickly resolved by both the local and national CDC. When NCAIDS spends money on HIV interventions, then it is in the interest of both the government and the people that this money is spent efficient, effectively and in accordance with existing policy. If not, why spend it in the first place? It is in the nature of government officials to report positively about the delivery of services. Few government officials will say "we are delivering bad services"! The recipients of these services are in a much better position to honestly report on the quality of the services. Civil society can therefore be very important for ensuring accountability of government officials and their programmes.

Therefore, in my view, any country that aims to tackle HIV/AIDS effectively requires a compact between civil society and the government.

### **What does working with civil society mean and require?**

Let me speak briefly from my own experience, although the traditions of civil society in South Africa are different from the traditions in China.

In my country civil society played an important part in the liberation struggle from white minority rule. As a result, civil society was very influential in the adoption of a constitution that explicitly recognises that civil society has a role in government and that government must be continually accountable to civil society. As in China, the Constitution is our supreme law, but our constitution goes further by giving people express rights.

Nonetheless, there are similarities between us. We are both developing economies. We are both trying to find ways to express our countries' rights and needs against the old powers. We are both committed to socio-economic rights and to raising the living standards of the millions of poor people in our countries. We face similar legal, environmental, social and health challenges.

## **Five challenges:**

One of the recommendation of the 2009 WHO/UNAIDS Universal Access Mission to China is that civil society participation in joint assessment and UN General Assembly Special Session on AIDS (UNGASS) reviews be strengthened. I believe the Chinese government has accepted these recommendations. But what will this actually require?

In the concluding section of this address, I raise five points that I believe are necessary if the China Red Ribbon Beijing Forum is to result in an effective collaboration (compact) between civil society and government on HIV/AIDS. I realise that some of these points might be considered sensitive, but I raise them for constructive reasons and with respect for the Government of China:

### *1. Space for civil society to operate legally and without interference*

For civil society to be effective, it requires legal recognition that is granted easily and simply for its activities. In South Africa, my organisation is registered under the Companies Act as a non-profit organisation and under the Social Development Act as a public benefit organisation. We are required to comply with ordinary laws, to publish annual financial statements, and to have proper systems for governance. Other than this, we attract no attention from the government.

We conduct extensive human rights education and advocacy amongst the poorest and most vulnerable, but are able to do so without censorship or threat of closure.

Although we are meeting amicably today, I continue to hear reports of the problems some civil society organisations face in China with registration and allegations of harassment in their activities. Organisations that work on human rights like Aizhixing, Dongjen and Yirenping are an asset to China. Individuals like Wan Yanhai, Li Xige, Tian Xi, Zhu Longwei and others are vital for accountability and effectiveness in the AIDS response.

If harassment continues, it will make it difficult to build trust and an effective partnership. Some have already said that this Forum is a sham. It is not sufficient for us to say that they are wrong, I think we should *prove* them wrong. I would appeal to the government in Beijing and the Provinces to continue with positive steps that are being taken to make it easier for BGOs to register and for the Ministry of Health to facilitate NGO registration, funding and scope for operation.

### *2. Space for civil society to engage with government at all levels (national, provincial, county)*

It is a step forward that today you are starting an engagement between government and civil society at a national level. However, when it comes to human rights, often the worst violations take place at a local level by local officials. Further, although we may talk a lot about HIV at a national level, the implementation of HIV programmes takes place at a local level. Therefore it is essential that forums are also created at a local level for discussions on human rights and for measures to be agreed that protect the human rights of vulnerable populations.

### *3. Training within government structures and the health system about the role of civil society & co-ordination and consistency between government departments*

This point relates to the one above. It is not possible to create spaces for dialogue, partnership and action, if government officials resent or are suspicious of civil society. To overcome this requires

engagement with and training of officials at lower levels of government, particularly the police and health care workers.

This challenge is not unique to China. In SA we have very good national structures and almost nothing at a local level. Very often health care workers stigmatise people with HIV. Police harassment of sex workers, who are also illegal in SA, adds to their vulnerability.

*4. Willingness by government to act on civil society's reports and recommendations where warranted*

Engagement with civil society should not mean forming "talking shops" to act as pressure valves to let off steam. Recommendations should be seen to be considered by Government and actually result in positive changes. For example, this year the China Male Tongzhi Health forum, in their contribution to the China 2010 UNGASS report, have called for "more appropriate laws to ease HIV prevention work, better support mechanisms for grass roots organisations, and development of mechanisms for reporting human rights issues." How will these and other recommendations be responded to by Government?

*5. Funding to support independent civil society*

Civil society cannot play its role without funding, as not-for-profit organisations can rarely generate their own funds. This makes them dependent on government, foreign donors and the Global Fund. Almost all NGOs in China express concern about funding. For example, I am aware of the concern of a range of NGOs that the proportion of funding for NGOs from the Rolling Continuation Channel (RCC) is too low, and that the Country Co-ordinating Mechanism (CCM) People Living with HIV (PLHATM) and NGO working committees have assessed that only 12% of the RCC programme budget is for NGOs. This is self-defeating for the RCC and needs to be changed. But I would argue that the Chinese government itself needs to fund, invest in and assist the sustainability of civil society. This is both an HIV prevention and treatment strategy.

I look forward to discussing with members of the Forum and the Interim Steering Committee how to make this Forum – a very significant initiative – into a process where Government and civil society are able to tackle and resolve many of the obstacles that are blocking an effective response to HIV in China.

Thank you.

**ENDS**

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