The AIDS epidemic begins and ends in the community, with the individuals directly affected by HIV and with those who care for them. Long before the non-governmental organisations (NGOs), governments, donors and multilateral agencies became engaged, those living with HIV, their immediate families and communities worked to support and sustain each other and to champion their right to live free from stigma and with full and equitable access to healthcare. As we wrote in the opening lines of the first Working Paper to accompany this evaluation, “Communities have been at the forefront of movements in support of their own needs” (Rodriguez-García et al., 2011).

The essential contribution of communities is arguably even more important today than 30 years ago, as the number of people living with HIV continues to grow and the world commits steadily less resource to combating AIDS. Today there are some seven million people in need of treatment who are not receiving it. In sub-Saharan Africa, an estimated 90% of the care provided to people living with HIV and AIDS is undertaken in the home by family or community-based caregivers, the vast majority of whom are women and receive no remuneration for their work (Report on the Global AIDS Epidemic: The impact of AIDS on People and Societies, 2004).

The essential contribution of communities has long been recognised by the NGOs and faith-based organisations (FBOs) that constitute civil society, and increasingly by governments and international agencies. The groundbreaking 2011 UNAIDS Strategic Investment Framework calls for the greater involvement of communities as a means of making service delivery more effective, identifying community involvement as being one of the critical enablers in realising the goal of an AIDS-free generation (Schwartländer et al., 2011).

Yet alongside those who have championed the role of communities, there are those who have expressed doubts. To date, they have been encouraged in their view by the lack of rigorous evidence.

That is why this evaluation, led by the World Bank, is so relevant and important as well as so timely. Carried out with an unprecedented degree of rigour and with an equally unprecedented ambition, the evaluation provides a disparate body of evidence about how communities make a difference in specific country contexts. It provides an image of communities not as passive recipients of aid but as active agents engaging in and shaping the HIV response. This in turn provides us, as allies of community actors, with an exceptional opportunity to achieve meaningful changes in the approaches and decision-making of donors and multilateral agencies.

It is this opportunity which best explains the enthusiasm of the UK Consortium on AIDS and International Development (www.aidsconsortium.org.uk) to embrace a partnership with the World Bank. Put simply, in its scale and ambition, this evaluation programme is not something communities, or we in civil society, could have carried out on our own but its findings can help transform our approach to partnering and supporting communities.

As one of our partners reflected at the end of this evaluation process, “Civil society organisations have for some time been struggling to find their rightful space and prove their contribution to the fight against HIV and AIDS. Through the evaluation, CSOs were
able to demonstrate the impact and effectiveness of engaging CSOs in the war against AIDS”.

If the World Bank brought technical skill and funding, what the UK Consortium brought to the partnership was a strong civil society voice rooted in our 25-year history of democratic and inclusive engagement, a healthy enthusiasm and skill for pulling together people from very diverse backgrounds.

We mobilised our membership of over 80 UK international organisations and their international partners. We facilitated a series of meetings which helped shape the research questions and its design. We brokered introductions to civil society organisations and national and regional networks such as the International Community of Women Living with AIDS, KANCO, SAFAIDS and LACASSO. We managed peer review processes for the accompanying Working Papers. And we played an essential role in disseminating the findings of the evaluation through our website, which hosts the main depository of information relating to the evaluation (www.aidsconsortium.org.uk/communityevaluations), and through well-attended seminars organised in London in 2011 and 2012.

I believe our involvement brought three essential benefits.

First, it opened up a line of communication not immediately available to those leading the evaluation, ensuring that the experience and expertise residing within communities and civil society was available to the evaluation leaders.

Secondly, it provided a structure through which the often contradictory voices of civil society could be expressed with confidence and without fear of reprisal, either in the form of the withdrawal of funding or goodwill.

Finally, the participatory nature of the process we helped to establish built civil society’s confidence in the process, thereby increasing the numbers of people and organisations involved. Many of the relationships will outlive the evaluation itself, establishing good habits of collaboration and cooperation for the future.

The cumulative effect of these benefits ensured that we maximised our influence in shaping the evaluation. This in turn maximised the value of the evaluation findings not just for our advocacy with governments and donors but also for our own programmatic work.

As we look to the future, there are four main themes that the UK Consortium will be pursuing.

First, we will be looking to capitalise on how this evaluation has helped rejuvenate a commitment to the role of communities in the response, making the links to the UNAIDS Strategic Investment Framework. As one well-placed employee of a large donor agency remarked shortly before the final seminar (February 2012), “Evaluation results are almost always presented in a meeting such as this and then forgotten. We can’t let that happen in this case. We have to pass the message on to the major donors that community responses to the epidemic can be both programatically effective and cost-effective as well. Thus, donors should consider making the policy change(s) necessary to support more community programming in the areas where it has been proven effective”.

We will reach out directly, and through our membership and partners, to advocate with governments, donors and multilateral agencies for the uptake of these evaluation findings.

Our expectation is that these findings will be used to inform the donor community on priority areas of funding while also serving to build confidence amongst governments to provide a level operational space and support for civil society organisations.

Secondly, we will work to influence the conclusions drawn from the evaluation, especially with regard to the use of volunteers. This is, rightly, a celebrated aspect of the evaluation findings. However, the reliance on volunteers risks perpetuating gender inequalities and exploitative relationships which we believe could put at risk the health and social care provided by communities, and which are so necessary for a sustained response.

To this end, we have already published two policy papers which we will use to engage going forward. The first, *Past Due: The Remuneration and Social Protection of Caregivers* (Greenberg, 2012; http://aidsconsortium.org.uk/resources/), identifies the need to remunerate caregivers, the vast majority of whom currently work as “volunteers”. Our *Girls and Women: Mainstreaming HIV and AIDS into DFID’s Strategic Vision* (Daly, 2012) seeks to address some of the underlying gender inequalities which are driving the HIV epidemic.

Thirdly, we will be using the evaluation findings to help shape our own thinking about how civil society can best contribute to the HIV response. We will encourage civil society, including NGOs and the private sector, to embrace the opportunities provided to improve our work, for example, through our role as hosts of the NGO Code of Good Practice (http://www.hivcode.org/) looking in particular at those aspects of the evaluation which show that community responses do not always have positive impacts: for example, the evidence from Burkina Faso shows civil society had unintended negative impacts on stigmatising HIV-positive men; in Zimbabwe, group membership for men (rather than women), rather than increased responsible behaviours, was associated with an increase in HIV incidence.
Fourthly, we will continue to assert the relevance of the findings to broader health and development responses. At the beginning of this contribution I wrote that the AIDS epidemic begins and ends in the community, with the individuals directly affected by HIV and those who care for them. I might equally have said that there is more to an individual than their HIV status. People living with HIV and the communities of which they are a part enrich our world in ways that go well beyond the HIV response. This evaluation helps capture some of the magical ingredients which we call community. It is invaluable reading for those who want to better understand how we can pull together to improve the health, well-being and rights of us all.

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