"Getting to Zero:
Zero new HIV infections,
Zero discrimination,
Zero AIDS related deaths"

It is my great pleasure to be invited onto this panel on World AIDS Day 2012 here at the Commonwealth Institute in London.

I am Margaret Sentamu, a Ugandan by birth, and the President of Mildmay - an International charitable organisation which currently works in East Africa, Zimbabwe and the UK providing HIV Care and Treatment as well as Education and Training.

For many people in the UK, HIV is something they were aware of from the ‘Don’t Die of Ignorance Campaign’ launched by the Government in 1987. The campaign used fear to encourage people into safer sexual practices.

Many people remember the campaign’s image of the falling black gravestone etched with the word AIDS. On the one hand this, the world’s first major government-sponsored national AIDS awareness drive, would be later hailed as the most successful, while on the other there were issues of stigma and discrimination that arose from the very same message.

At the time the campaign was launched there were 43,880 registered cases of HIV/AIDS registered across 91 countries, with a few thousand in the UK.

25 years on there are 34 million people worldwide with living with HIV. Last year it is estimated that there were 2.5 million new infections and £1.7 million deaths globally, including around 6,600 new infections in the UK with 600 deaths.

And to an extent, part of the problem with the battle against the cause and effects of HIV, is that there sometimes seems to be a flip side even to some of the most successful interventions. As in the example above, increasing awareness in an ‘alarming’ way had the flipside of increasing stigma.
When Mildmay first announced that it was making the transition into caring for people with HIV in 1987, bricks were thrown through the windows of our hospital in Shoreditch. It was scary for staff, but even more so for our patients at the time who had paralysis and couldn’t move. And that was during the planning phase!

When we opened for business, ambulance personnel wore protective clothing when bringing patients to Mildmay, and it was difficult to get a haircut in Shoreditch as many barbers refused to serve our staff – just in case!

A turning point for Mildmay was a visit by Princess Diana. She actually came to Mildmay on a number of occasions, but on one she was filmed holding the hand of an HIV + patient. It wasn’t conceived as a publicity stunt, nor as part of a campaign, but it had the effect of taking the public in a direction where stigma reduction began to occur, while at the same time very much keeping HIV/AIDS on the agenda.

In my work with Mildmay I have seen a wide range of interventions.

In Uganda, the Mildmay team currently has 50,000 patients on a large testing and (Anti-retro-viral) ARV treatment programme right across the Kampala region.

As we know, ARVs are truly transformational drugs, producing astonishing results - giving life, very much in all its fullness, to people living with HIV. I can bear witness many times over, to the transformation that testing, treatment, prevention and education can bring to the lives of individuals, both young and old, and communities too.

My feeling now is that the sense of helplessness has disappeared because people perceive that ARVs will sort the problem. All the while there is funding for ARVs and universal access goals then this is a reasonable position to hold. But we know that the situation on the ground can be patchy.

The downgrading of HIV to a long-term chronic illness has, in the UK at least, gone hand in hand with a big fall in awareness.
Pupils at schools are more likely to hear about Chlamydia than HIV, so it’s hardly surprising that the greatest rates of increase in new HIV infection are occurring amongst teenagers, and also the over 50s.

In the UK it is estimated that over a quarter of the 100,000 people currently living with HIV are unaware of their condition. Half of all new infections in the UK are presenting late, and this late diagnosis can lead to very complex issues such as HIV Associated Neurocognitive Disorder—also known as HAND. This is now our UK hospital’s area of expertise. This HIV related type of dementia can be very severe, yet reversible, but the chances of a GP recognising this as HIV-related remains small.

Perhaps it time for Government led a Don’t Live in Ignorance Campaign.

Looking at the 10 Goal’s for 2015 on the UN’s ‘Getting to Zero’ initiative, I can relate how Mildmay is working as a civil society organisation on a number of these fronts.

In Kenya and Tanzania, some of Mildmay’s work takes place in prisons—helping prisoners to come forward for testing, to adhere to their medication, support others and to talk about their illness and prepare for release. A key message for prisoners is about preventing transmission in jail and beyond. Again in Kenya, and along similar lines to our prison work, we are engaging with sex workers and their clients in the fishing communities clustered around Lake Victoria.

Our programme in Uganda has massively scaled up its testing and ARV roll out programme from 20,000 patients 3 years ago to 50,000 patients now. They are also piloting a scheme which is aimed at reducing gender-based violence, and are doing HIV prevention work such as male circumcision for HIV –ve males.

In Zimbabwe and Rwanda, our very small teams are involved in Health System Strengthening projects which have the impact of reaching huge numbers of people and improving health outcomes. In Rwanda, we worked with the Ministry of Health to write the country’s Palliative Care Policy (effectively a holistic approach to HIV management) and the national roll-out plan – this
gives access to care and support for all people living in households affected by HIV.

Through our work in London, we predict that a growing problem will be a continual increase in the number of people suffering with neurocognitive problems caused by HIV and late diagnosis. We believe this will begin to be seen globally, although it not recognised as a problem yet. To this end we will be increasing our capacity from 16 to 26 beds by this time next year, with opportunities for teaching Health professionals.

A marked change in our work in London is the number of deaths we have in the hospital each year. It has fallen from over 50% before the introduction of ARVs to around 1% today.

But I believe that the situation remains varied and patchy. The work I heralded in Uganda, is actually occurring against a backdrop of an increased prevalence rate in the Kampala district. This is in spite of a coordinated effort by CDC and the Ministry of Health working in partnership with a number of implementing civil society organisations on large scale prevention, testing and treatment programmes.

But the reason I am passionate about the Getting to Zero initiative is because I know the devastation that HIV/AIDS can bring.

As a family we have experienced the ghastly effects of HIV/AIDS. I have lost a brother and sister to AIDS and my husband lost a younger brother. As well as dealing with such overwhelming loss, we were also left with the responsibility of caring for 11 orphans and putting them through school, university etc.

All three died at the height of the pandemic in Uganda, some 20 years ago, long before the AVRs came in.

It is very difficult to watch someone you love battle with a disease you hardly understand and then see them lose that battle. The stigma surrounding HIV then made it impossible to talk about it. You simply watched people “waste away” before your very eyes and tried to think of ways of helping them cope with it. That’s why it was called “slim” by the locals.
So for me, it’s the individual suffering of an HIV/AIDS patient, be it through stigma, through not having access to effective drugs, or through the injustice of infection, which can galvanise us to respond, individually, collectively or nationally, as we are doing today.

So there is much to be done and on many fronts, but a unifying vision such as Getting to Zero can align our efforts, and most importantly improve substantially the lives of families living with HIV.