Making Sense of HIV at 30
The achievements and challenges of thirty years of AIDS activism

A Cumberland Lodge residential conference summary report
12th - 14th June 2013

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Registered charity no. 1108677

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Introduction
Participants at this Cumberland Lodge Conference were privileged to hear from those who have led the fight against the illness and stigma associated with HIV/AIDS since HIV was identified thirty years ago. During those thirty years the battle to overcome widespread prejudice and stigma has been fought with passion, energy and commitment by clinicians, scientists, politicians and activists defending the right to treatment and compassionate care for those who are living with HIV. Moving stories were told of those who had lived, worked, and died in the struggle to combat the disease.

The conference showed that HIV/AIDS is a global problem and that its impact in countries which lack the resources for treatment and prevention is particularly devastating. International aid has saved millions of lives, but funding is currently being withdrawn while the need is still enormous. The call was made for more targeted interventions by international aid agencies, to use limited resources more effectively. Similarly, in the UK, there is a need to target for testing those most at risk so more individuals can benefit from treatment. Despite thirty years of activism, which has been successful in many ways, stigma remains and is still sometimes fuelled by emotive media coverage and the damaging application of laws. Yet the need for compassionate care remains as strong as ever: ‘antibody positive or negative – it’s the same for all’.

The miracle of science
Miraculous progress has been made by scientists in the past three decades. Today, anti-retroviral treatment means that those who are diagnosed HIV positive soon after infection can expect to lead otherwise long and healthy lives. Although HIV was identified in 1983, AIDS was first recognised in 1981. In those two years virologists established that HIV is a virus that is not contagious and it can only survive in blood and some other body fluids. In terms of diagnostics, the discovery of HIV through to practical prevention was achieved relatively swiftly. Within a year and a half of its discovery it became possible to determine the presence of antibodies, and screening for all blood donations came in across the industrialised world. That laboratory test saved thousands of lives. The first drug was already sitting on the shelf as a failed cancer drug: AZT was tested on fewer than 500 patients before it was licensed for use; however it did not prove to be highly effective. Treatment took off successfully only in 1996, ten years after the first testing.

Thirty Years of AIDS activism
Over the past thirty years 60 million people have acquired HIV/AIDS and about half of these have died. HIV is particularly devastating for a society because it takes out young adults: those people who are driving the economy. In South Africa scientists and physicians had to confront the disastrous myth which President Thabo Mbeki was promoting: that AIDS was not infectious, that HIV does not exist, or that illness was due to the drugs being used. Mbeki claimed that AIDS was just a way drugs companies could exploit poor people to make a vast profit. The Durban Declaration, signed by five thousand physicians and scientists – but crucially, no one from the drugs industry - stated the truth: HIV causes AIDS. It was only when former President Nelson Mandela ‘came out’ and spoke publically at the 2000 International AIDS conference about both HIV and AIDS that there began to be acceptance of the Durban Declaration.

In the United Kingdom AIDS was not, at first, treated with the seriousness it warranted: it was jokingly described as ‘the gay sniffle’.
Following a BBC Horizon programme ‘Killer in the Village’ a moral majority began to call for the re-medicalisation of homosexuality and the denial of a gay identity. There were headlines such as: ‘March of the Gay Plague’, ‘Monster in our Midst’ and ‘Homo plague’. Politicians were finally propelled to act not because of the spread of AIDS among the gay community but in response to a headline in the Mail on Sunday: ‘Killer blood in British Hospitals’, raising fears of widespread contamination. In 1985 the government gave the first tranche of funding: £1.9 million for HIV testing and combating AIDS, followed soon by another £8.8 million. The first national conference was held; expert groups on AIDS were established; and a national campaign was initiated, with a further £25 million being put towards this and research. A pivotal moment was when Princess Diana opened the first specialist hospital ward and, without a glove, shook the hand of a patient.

Towards the end of the 1980s politicians began to question the parameters of the established AIDS policy. There was anxiety about the level of funding, when spending on medical issues related to alcohol, smoking and drugs was also needed. The AIDS support grant was cut, which impacted on the work of local authorities and organisations such as the Terrence Higgins Trust and Lighthouse. The position of HIV/AIDS being a standalone issue was challenged, and ultimately it was re-instated by Government as a priority, but within an overall sexual health strategy. There are now estimated to be 100,000 people living with HIV in the UK, of which 25 per cent are unaware of their status. Of those who are receiving treatment, complete viral suppression has been achieved for the majority. This is a triumph of good care.

Thirty years of AIDS activism has brought profound changes for everyone in our society. With the growing realisation that the ‘personal is political’, a response to AIDS was devised that challenged everything from health care decisions to civil rights to sexual conduct. In particular, the Denver Principles of 1983 demanded that physicians see their patients as ‘whole people’. Those who were HIV positive demanded that their own opinion on their care should be awarded equal weight. This revolutionary stance predated, by fifteen years, the ‘nothing about me, without me’ policy of the NHS, which is still regarded as an essential operating principle. AIDS activism also challenged approaches to illness, death and dying. New hospices were created, like London Lighthouse, and the importance of living wills was realised. Funerals changed, becoming less ‘funereal’ and more celebrations of life. As more people died, activism became more radical with the founding of ACT UP in New York in 1987: this spearheaded AIDS treatment activism, by challenging the pharmaceutical industry and medical research across the board from how research was prioritised to how clinical trials were designed and results disseminated. Everything changed at the Vancouver AIDS conference in 1996 with the arrival of protease inhibitors. This brought new work for activists, in particular campaigning to ensure equal access for everyone who could benefit from combination therapy. As a health and human rights issue, AIDS has posed a constant demand to resist fear, stigma and prejudice whenever it occurs in our society.

A Global Problem

Less than two decades ago the funding on AIDS was less than US $2 billion internationally. In 2001 Kofi Annan, addressing a UN meeting, said that there needs to be a ‘global fund to fight AIDS, TB and Malaria’. This was founded in 2002. Under George W. Bush’s leadership there was a huge step up in funding by the US government: it made the largest ever donation on a single health issue. Since 2001 US $6 billion have been dispersed each year. This continuous injection of money has saved millions of lives around the world.

The Global Fund has changed the course of the epidemic, but we need to spend money strategically, to work where the risks are in a targeted way, so as to prevent new infections. Studies have shown that focusing on treatment is good not only for keeping people alive but also for preventing the virus from spreading. There is also a need to focus on those most at risk of contracting AIDS, men who have sex with men (MSM), drug users and sex workers. Two years ago the UN launched a laudable plan to eliminate HIV infections among children by 2015,
focusing particularly on children in Africa. It is a disgrace that peri-natal transmission is still a problem, when this is a preventable condition in every part of the world. In addition, it is outrageous that much less is being done to keep mothers alive. Over two decades there has been no real change in the number of women being infected with HIV.

Concern was expressed that there has been a loss of focus, by the UK government and international and national charities, on HIV/AIDS work. Christian Aid, for example, is moving away from ‘community health and HIV’ to ‘integrated community health’, reflecting the fact that globally, HIV has been subsumed under a broader health agenda, particularly a focus on maternal and child health. This means HIV has dropped off the radar, profoundly. In 2005 the UK government committed £1.5 billion to spend on AIDS, and the first ever cross-Whitehall strategy was developed. This was a significant move forward that is thought to have saved 5 million lives. Yet the recent financial crisis means that many international donors are now stepping away, with the UK government being one of these.

A local issue

In the UK public health, including drug, alcohol and sexual health services, has recently been transferred from central to local government. In addition, local government has a new responsibility for the ‘health and wellbeing boards’, which promote integration by bringing together all health and social care. It was argued that local government would be able to deliver public health interventions in a more targeted way. In the past a single public health intervention could be made that improved everyone’s wellbeing, examples being cleaner air, sanitation or decent housing. Today, however, to make a difference millions of interventions are needed at a local level. It is now necessary to give people the information, confidence and advice to help them make their own changes. Having been elected, local governments have stronger links to local people than the Primary Care Trusts were able to achieve, so they should be able to deliver public health interventions in a more targeted way.

With public health moving to local councils, smaller groups can now motivate each other to achieve change about the level of service that should be provided regarding sexual health. It is necessary to lobby health and wellbeing boards to ensure HIV is on their agenda. ‘The Unprotected Nation’ report is an example of effective lobbying on sexual health that made the financial case, not just the human: some people respond better to the argument ‘investment to save’ rather than ‘this is the right thing to do’. In addition, it is worth noting that politicians are sometimes resistant to anecdote, and prefer facts. Yet arguably stories give a sense of the purpose of why we do what we do, and should be presented along with the facts.

Prevention

Despite the fact that the UK has highly trained professionals working in a free and comprehensive health service, the rate of HIV infection in this country has not declined among, for example, younger gay men. Why are we continuing to see, over the last ten years, the same levels of infection, when there are effective tools for addressing this epidemic? In the UK testing for HIV is now done on 50 per cent of the population: this is not enough. We need to scale up testing and make it more targeted on those most at risk: this is the gateway to improved prevention. Investment is needed in HIV treatment literacy: all people need to understand the value of being tested, and to know that treatment is available. Adherence to drug taking is critical and patient or client support and education is needed in this regard. Prevention by using condoms still needs to be promoted. Future success will depend on our ability to implement and bring to scale what works.

In the UK there is still a need to invest in HIV/AIDS awareness and treatment. The lack of money for research is a problem: unlike cancer research, not a single major charity supports research into HIV/AIDS. Even charities which care for people with HIV/AIDS are suffering from
a decline in funding, as the Department of Health has removed its financial support. The Terrence Higgins Trust and many important community-based organisations have had funding reduced and their work is under threat.

There was some debate and difference of opinion as to whether and how Pre-Exposure Prophylaxis (PrEP) should be used to prevent HIV spreading. On the one hand, it was said, there is clear evidence of PrEP efficacy, and that it should be regarded as an effective tool for treating this epidemic. However, another view was that PrEP is a complex technology and it is not just a matter of making it available: social scientists need to research how to make this tool work. If PrEP is used inappropriately resistance might develop. Scientists worry that as the virulence of HIV increases in areas where there is a diverse range of people, it may well develop drug resistance. Is it better to roll out treatment that is not yet fully understood in the interests of saving lives, or should we delay until proper scientific rigour has been applied?

The law and HIV related stigma

It was argued that the extensive use of coercive laws has a negative impact on HIV prevention and contributes to HIV-related stigma. Instead of serving to protect the uninfected from infection these laws feed the ignorance, censure and popular moralism that abound: they should be repealed. There are aspects of the criminalisation of HIV transmission which are harmful and unsafe. First, there is no evidence that it deters risk-taking behaviour: arguments, sometimes advanced, that criminalisation is justified on public health grounds are on shaky foundations. Secondly, criminalisation undermines the message of shared responsibility for sexual health, the need for everyone to practise safe sex. Third, criminalisation may lead people to believe that new partners will explicitly disclose their HIV positive status to avoid liability, leading to a false sense of security and heightened risk taking. Fourth, prosecutions are frequently based on ignorance and unsound science, and may lead to a miscarriage of justice. For example, to sentence someone to an extended period of imprisonment for spitting, when HIV cannot be transmitted this way, is absurd. Finally, criminal cases often lead to lurid, inaccurate and sensationalist reporting in the popular media, and give the impression that people living with the virus are ‘monsters’, ‘murderers’ and ‘assassins’ bent on harming and killing others.

Repealing harmful laws is highly desirable as it will reap benefits, as argued, yet it is always a costly long-term project and is unlikely to be done. However, it is possible to work within existing law to reduce the harms associated with criminalisation of transmission, and to educate police about HIV with the aim of reducing the number of unjustified investigations. It may also be possible to introduce new laws which provide real protection for people living with HIV and for those at heightened risk of infection, such as effective anti-discrimination legislation and guaranteed access to the legal services necessary to ensure its enforcement.

Drug Use and HIV infection

Globally, around ten per cent of new HIV infections result from the shared use of syringes – a figure which is nearer one in three if sub-Saharan Africa is excluded. In some countries, especially those of Eastern Europe and South-East Asia, between 50 – 80 per cent of HIV prevalence is due to transmission through injecting drug use. In addition, there is substantial evidence that the law itself drives up HIV infection among drug users. Laws which criminalise the possession of drugs and drug paraphernalia were thought to create an environment in which users are more likely to share syringes, thus increasing a risk of acquiring HIV and other blood-borne viruses.

Across the world HIV prevalence tends to be higher in prisons than in the general population. It has been estimated, for example, that up to 25 per cent of people in the United States living with HIV have passed through its correctional system, that in many low-and middle-income countries (especially those in Eastern Europe) rates of infection are
significantly higher than average. In South Africa the HIV prevalence in prison has been estimated at 41 per cent, more than double that of the general population. This is due to two factors: first, those with heightened vulnerability to HIV infection, such as sex workers and drug users, have an increased probability of incarceration; second, injecting drug use, along with tattooing and sexual activity is commonplace in carceral settings. It is possible to reduce the harms associated with the spread of HIV via drug use and sex work by working within existing laws. It was suggested that condoms must not be used as evidence of commercial sex work, or syringes as evidence of drug possession and use, and it is necessary to educate and ensure the effective accountability of the police who harass, victimise and make the arrests of drug users and sex workers. Similarly, harm reduction facilities must be made available in custodial settings. Moral opprobrium and zero tolerance may satisfy the righteous, but it is harmful in the fight against HIV.

Those who are HIV positive but have no other risk factors will live a normal life span. However, a recent study found that on average alcoholics will die age 46, and those who are alcoholics and HIV positive will still die on average at 46. Similarly, both drug users and HIV positive drug users will die on average at 43. The reality is HIV has little impact on life span, and only those who have other problems will die early deaths. We need to consider how we work with these difficult groups. Money should be spent on understanding the behaviour of young people, gay men, and drug takers: all those who take risks. Health, rights and responsibilities are rallying cries, but we do not hear much about responsibility. This aspect fell away with the advent of medication in 1996.

is a need to provide mental health and social support for those living with HIV, as much as biomedical interventions: successful outcomes depend on this balance. Social care and peer support remains important for those who are HIV positive.

**Conclusion**

The miracle of science, achieved over the past thirty years, means that people no longer need to die from HIV/AIDS. Yet life-saving drugs cost money: the fact that many poorer countries are not able to offer treatment to those who are HIV positive reveals the continuing need for targeted international aid. We need to see a miracle in social science and care: the right not to be stigmatised on the basis of one’s antibody status. Success in the fight against AIDS depends ultimately on overcoming stigma, in this country and throughout the world. Along with the right to treatment and care comes responsibilities: the need for everyone to recognise their responsibility in the effective prevention or treatment of infection. This global problem needs to be addressed by individuals, at the local level, everywhere.

**The need for social care**

Those who are HIV positive can now expect to live a normal live, without chronic or physical illness. But is preventing death alone a sufficient objective? Over half of people with HIV suffer from mental illness at some point. Depression and other psychological disorders can lead to substance and alcohol abuse, which can contribute to early deaths. There
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Cumberland Lodge orchestrates a variety of events designed to promote the exchange of ideas, initiate fresh debate, influence policy, and foster learning and education at every life stage. From conducting high profile conferences to mentoring university hopefuls, the Lodge works to produce a rich and diverse programme aimed at the betterment of society.
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About Cumberland Lodge
Cumberland Lodge is a house for ideas. It is a former royal residence that has been an independent educational charity since 1947, promoting ethical debate and cross-sector cooperation on a range of matters affecting the development of society. Cumberland Lodge fulfils its mission by designing and facilitating a series of events which enable participants to discuss ethical, moral and spiritual issues.

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