

Scaling up the development education response to HIV

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The sixteenth International AIDS Conference held in Toronto in August 2006 called ‘time to deliver’ to all those responding to HIV, and the threat it poses to the lives of millions of men, women and children, and the communities they live in. The truths and messages are simple, if the contexts are still complex. Development educators have a key role to play in this mobilisation, especially as clumsy campaigning could leave stigma unchallenged and hinder progress. The chatter and noise are just not out there. I attended the Conference with a team of three journalists from Children’s Express (now Headliners) the young people’s media agency. When we came home from Toronto all fired up with stories, we were met, on the whole, with disinterest. It is still an ‘over there’ problem.

The simple, accepted truth is that AIDS can, in many cases, be stopped. HIV infection can be prevented. Progression from HIV infection to AIDS can be prevented in a majority of cases. The stories to report all have a common theme – injustice and denial of human rights. This is where I feel development educators need to base their response to HIV, firmly in a human rights, and children’s rights, discourse.

HIV is a nasty, complicated, virus that once in the body, cannot be eradicated. There is no drug that can completely destroy it, even on distant horizons. Arguably, the scientific community has met many challenges in the last twenty years and has successfully responded to HIV by producing a range of drug interventions, tools that skilled medical professionals can use to treat their patients. HIV infection is now, for a few, a manageable chronic health condition and AIDS is a word that their doctors rarely use. However, this is possibly the only area where progress has been swift. Legislative systems, for example, have been slow to ensure that the rights of those affected by HIV are protected. States have denied that an HIV response was relevant to them, as HIV prevalence was perceived as ‘low’.

Many countries in Asia, where prevalence was seen as low, are now responding. The first person diagnosed in Pakistan was a man who was deported from the Gulf in 1987, where he had been working and contracted HIV. He faced intense discrimination in Pakistan, and for a long time, HIV was seen as something that came in from outside. Today official prevalence rates are still low at 0.1% in the general population, but infection rates

amongst some groups are high (for example 26% of intravenous drug users are estimated to be infected). Also, it is recognised that there are large groups who are vulnerable to HIV infection because a significant number of their rights are not protected, such as street children, sex workers and so on. National strategies to support prevention programmes are in place, but there is still extremely limited access to treatment.

Often the response to HIV at country level and by agencies, whether international or domestic, is targeted at particular groups of vulnerable people: sex workers, young people, gay men, who are recognised as disproportionately affected. There are very strong arguments for this approach, especially as it is a way to target limited resources. Such a response, however, needs to be carefully communicated so that it does not also reinforce the myths about who HIV ‘targets’ are, and the notion of ‘innocent victims’.

To grab attention for HIV, Save the Children has tried an outraged tone, but that has limited short-term effect and can backfire. A significant number of 16 year olds in Northern Ireland think AIDS is the biggest threat to children’s lives globally (NI Young Life and Times Survey, 2006). It is not; it is still dwarfed by hunger. It is possible to avoid HIV infection, and to live with HIV, even in severely resource limited settings, as Paul Farmer, my current personal hero and the hero of many others, proclaimed in Toronto. Yet these flickers of hope do not shine brightly enough to attract the attention they need to turn into blazing glory.

If one of the functions of development education is to challenge misrepresentations, there are still plenty to challenge. My particular bug bear is the misnomer ‘HIV/AIDS’. Firstly, if a slash indicates ‘or’ then it simply does not make sense. AIDS does not exist without HIV. However, HIV infection only leads to AIDS without medical intervention, so HIV and AIDS are not synonymous. Using the term then leads to other confusing statements like “the prevalence of HIV/AIDS is...”. The prevalence of HIV infection and the numbers of people infected with HIV who then progress to AIDS are different. And, as with all statistics, working out just what the prevalence of HIV infection is, is difficult, and controversial. Determining just when AIDS begins (and ends) I think is also not clear cut.

Too often the tone of communication about HIV still seems to assume that HIV infection = AIDS = Death. What seems to be missing is detailed discussion of all the interventions that can keep a person infected with HIV alive, healthy, economically productive, and most importantly, happy. There seems to be a view that unless we are scared rigid by HIV, then we will not take safe sex seriously.

Instilling fear is still intrinsic to many public awareness campaigns, yet

it is only a brief motivator for behavioural change. The ‘tombstone’ advertisements in the UK in 1986 had a dramatic short-term effect. For about one year infection rates of sexually transmitted infections dropped, but have since risen to an alarming peak, particularly amongst those aged 15 to 24. I think that still, in many workshops and resource materials, the tone is ‘serious’, ‘scary’, and set to create alarm, or at least instil outrage. Ultimately, it is those who are HIV positive who become feared, as the virus is much more difficult to see, and target.

The recent 2006 Northern Ireland Young Life and Times survey seems to include evidence of the impact of such alarm rising. Over 700 16 year olds were asked if they had discussed HIV in school. 84% said they had. Most of this discussion took place in class, mostly in Personal and Social (Health) Education, then in Biology and Geography, and a small percentage in Citizenship. Of this large group, 33% then said they would be bothered if there was a child with HIV in their class compared to 24% of the group who had not discussed HIV when asked the same question.

It seems that there is still a long way to go in challenging the discrimination that many people living with HIV continue to face. Who considers the possibility that one of the adolescents in their group, who are receiving well-intentioned, hard hitting prevention messages, might be HIV positive, and just beginning to negotiate sexual relationships with an inherited sexually transmitted infection?

This also asks the question as to where development education overlaps with sexual health and relationships education, and also how development educators responding to HIV could offer opportunities for greater linking between other ‘educations’.

As well as sexual health education, a reinvigorated response offers a refreshing way to look at media literacy. Young people in Northern Ireland, like those in the UK are most likely to gain their knowledge of global issues via the media (NI Young Life and Times Survey, 2006). How do the media reinforce key messages about HIV? I have used an excellent condom advertisement from South Africa to provoke a discussion on the lack of similar advertisements for young people in the UK. Body and Soul, a London-based HIV charity that works with young people affected by HIV recently produced a viral advertisement which cleverly and comically explodes myths about HIV transmission whilst seeking to fundraise. Responding to HIV could just as easily be an analysis of the pharmaceutical industry, and another slant on Fair Trade. John Le Carré’s novel and the subsequent film, *The Constant Gardener*, is an excellent stimulus for this discussion.

I like the South African advertisements because they use beautiful

actors, are sexy and intergenerational. Just as humour is essential in embedding these messages, success stories are also crucial to motivating people to take action. Recently, Positive Nation, a sexual health magazine in the UK, led with a cover story 'The Kids are Alright' (Positive Nation, 2007). Whilst this was justified in the editorial, with a recognition that globally, the kids are not all right, this positive upbeat story is important because success stories like these motivate those living with HIV, and those who work with them, to talk more freely and confidently, and properly support future parents worried about the possibility of passing on HIV. I believe that one of the most effective motivators for change is the feeling that success is possible.

Finally, how do people living with HIV engage in development education in response to HIV? Often resources use personal stories by those directly affected. This puts the person at the centre of the discussion, vital in a context where large, unconceivable statistics are also frequently cited. However, each and every time, it has to be asked - what is the value of the personal story? Do we still have a desire to 'out' an infected person, or is it because they are the experts, and they have stories we need to hear? How can we do this without promoting the idea that HIV affects certain people (and not others). One of the most important impressions for me from the Conference in Toronto was just how many people, how many *different* people, were hanging out in the lounge set aside for People Living with HIV and AIDS. There were hundreds: grandmothers, teenagers, gay men, straight men, rich, poor, conference veterans and virgins. This is the group of global positive activists. I do not know how you can possibly choose life stories from this group, never mind the rest!

The human rights discourse then includes discussion on realising rights to health, to life, to education, to participation, to information, to privacy, to benefit from scientific advancement and so on. It also involves a child's right not to be separated from its parents, a woman's right to property, and balanced overarching principles such as non-discrimination, diversity and the best interests of the child. It is not about victims, and must not include the phrase, "if only". The discourse must be sensitive, noisy, vibrant and must be omnipresent, until simple truths are universally realised.

References and Bibliography

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