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Reflections of a social scientist on doing HIV social research

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Thank HHR initiative especially Daniel Tarantola for giving me the opportunity to speak this evening.

My talk describes **one aspect** of the history of HIV prevention in Australia and places it in the context of current global debates about HIV/AIDS. **I hope the focus I have chosen will illustrate – at least in part – why Australia’s approach to HIV prevention has been and continues to be a success.** My talk includes my reflections on my own research and the research of other social scientists in Australia – with special reference to the National Centre in HIV Social Research (NCHSR) and the people with whom we continue to work – governments, non-government organisations and communities at risk of HIV.

Devising effective HIV prevention, treatment and care programs requires the ability to understand and harness people’s ways of actively striving to deal with HIV in their everyday lives. It involves encouraging and enabling people to transform their sexual lives; it involves treating, caring for and supporting those with HIV and those affected by HIV; and it involves mitigating the impact of HIV – the social, the political and the economic impacts – especially in those regions and countries hardest hit by HIV and AIDS.

Here I am going to talk about the work I know best --- that focused on HIV prevention in Australia. What sort of HIV-prevention education programs work best? What can researchers do to enable people to transform their sexual lives?

In order to address this question I first briefly explore some of the models underlying so called prevention ‘interventions’ and then turn to my own work and that of the

NCHSR to illustrate what I have learnt from 23 years working as an HIV social researcher.

Background

There is no vaccine for preventing HIV and there is no cure. However in 1996 HIV treatments (in the form of antiretroviral therapy, ART, which delay the move from HIV to AIDS to death) were developed. So there is an effective treatment.

There are currently approximately 40,000,000 people living with HIV. Each year the prevalence increases as new infections outstrip the number of deaths. In 2005/6 it was estimated that there were around 4.3 million new infections and around 2.8 million deaths. So last year there were an additional 1.5 million people living with HIV and while the global incidence rate is believed to have peaked – at least in some countries (Laurence 2006) – the absolute number of new HIV infections is growing (UNAIDS 2006).

Part of the problem is that prevention has faltered, it has fallen off the agendas of both governments and donors. One of the reasons for the decline in prevention is the immediacy of the need to treat those with HIV. Anti-retroviral drugs are expensive and many governments are now spending a very, very large portion (if not all) of their AIDS budget on treating those who are ill. So although the HIV budget has increased exponentially since 2001, there are fewer and fewer dollars being spent on prevention – although there has recently been an increase in funding associated with the turn to ‘biomedical’ prevention technologies.

There is a growing and, I believe, an unacknowledged tension between prevention and treatment. Funding is finite. So although there is a great deal of rhetoric about the importance of both prevention and treatment, and some attempts – largely misguided – to link prevention to treatment, prevention has stalled in many countries.

It is not only that the prevention dollar has shrunk ... but coupled with the shrinking prevention dollar is a growing belief in some quarters that prevention (at least what is usually referred to as behavioural prevention) has failed – that it does not work. This

has been coupled in recent times with a move to invest in biomedical prevention technologies – circumcision, pre-exposure prophylaxis, microbicides,....

In other quarters, the belief is not that prevention has failed but rather that governments and donors have failed prevention. I am of the latter view and argue that prevention not only can but has and does work if a ‘social’ public health model is used – as has been the case in Australia – and if prevention programmes are supported and properly resourced.

My argument is that prevention is ‘failing’ because prevention programs and policies are currently informed by a ‘modern’ public health, a public health that is informed by a neo-liberal doctrine – a doctrine focused on notions of agency and individual responsibility and the personal blame, stigma and discrimination that inevitably accompany such a doctrine.

Let me illustrate by describing – at least in part – the HIV response in Australia. What is central to the Australian response is a partnership – between affected communities (gay men, injecting drug users, sex workers, ...), the non-government organisations funded by governments to advocate for, support and educate those communities, governments, researchers, and clinicians and other public health professionals. And the partnership – which is a genuine one in which each partner has a voice – is of a very special sort. I describe here the place / the position of social researchers within that partnership – and what we did and what we continue to do...

Three Public Healths

Public health traditionally was concerned with structures – social and economic structures that are clearly related to and produce the vulnerabilities that make populations susceptible to HIV. So the aims of a ‘*traditional*’ public health are to alleviate poverty, promote gender equality, legislate against discrimination, ... These concerns continue to be central to the eradication of HIV – but to a large extent they continue to be overlooked or reduced to access to health services issues (see Barnett and Whiteside (2006; second edition of *AIDS in the Twenty-First Century: Disease and Globalization*). Structural change is difficult to achieve but as is increasingly apparent, it is essential in any successful response to HIV. Without some move to

gender equality for example, women in many countries will continue to find it difficult if not impossible to protect themselves from HIV.

More recently we have seen a turn to a '*modern*' public health with its concern for and focus on the individual – the neo-liberal rational and autonomous subject – who is positioned as responsible for his or her own health. Within this model of public health the claim is that the needed change is best achieved via providing an individual with the necessary expert information on which to base a rational response.

The HIV prevention response within the modern public health paradigm is educate, advise and counsel the individual to adopt safer practices – condoms, clean needles,... (VCT). Prevention is essentially top down – from the expert to the individual – who is the recipient of advice, and counselling. Risk-taking is positioned as a function of a *misperception* of risk or a lack of information on the part of the individual. Or risk taking is ascribed to psychological factors such as lack of “self-esteem” or “self-confidence” or to other more pejorative factors such as ‘anti-social’ or addictive personalities that compromise the ability of the individual to make “rational” choices, or to act on the information received. The individual is held responsible and blamed if s/he does not act rationally or appropriately. Stigma and discrimination are natural if unintended consequences of this ‘modern’ public health – particularly in the context of the epidemiological naming of ‘risk groups’. Stigma and discrimination are reinforced by the epidemiological categories developed in order to respond effectively to a virus, a virus that is continuing to spread along societies’ fault-lines of race, gender, sexuality and class (Waldby, Kippax and Crawford, 1995, ANZJS, 31, 1-14). . Specialised and precise epidemiological language has been translated into everyday and less precise language, becoming connected to ideas and emotions such as those of blame and stigma (Barnett and Whiteside, p.85).

While the traditional model recognises that epidemic is a *collective* event and is deeply seated in the stresses and strains of a society, a symptom of the ways in which we organise our social and economic relations (Barnett and Whiteside, p.78), both models of public health – the traditional and the modern – are essentially ‘top down’ and change is achieved via the expert, the public health authority.

There is however a third model of public health – a ‘*social*’ public health – one that is informed by sociology and anthropology rather than the more individualistic social science, psychology. It is a model that recognises the collective nature of epidemics and at the same time works with the collective (communities, networks, ...) to transform social relations.

The ‘social’ public health acknowledges that persons/individuals are constituted in the social and recognises that actions/ behaviours are socially produced. Typically this model and its variants are informed by social science notions of practice, social transformation and collective agency. Importantly too, social scientists who developed these theories were inspired (often self consciously) by the collective practices of prevention already at work in various communities, particularly the gay community at the beginning of the epidemic.

These social theorists argue that individual behaviour and “choice” is always mediated and structured by social relationships, which are in turn traversed by important differences of community, social status, class and other structural differences such as gender and age. In other words, individual behaviour is always contextual, always socially embedded.

For these theorists, prevention information is not passively imbibed by individuals but must be actively taken up (appropriated) through talk and collective action within a given social context in order to acquire meaning and become effective (Campbell and MacPhail, 2002), (Kippax and Stephenson, 2005; Stephenson and Kippax, 2006). The model is underpinned by an understanding of people as constantly striving to actively appropriate and transform the material and symbolic conditions of their everyday lives (Haug, 1987). In the social transformation model/s, change in practice is understood as social transformation – and the aim of health promotion or prevention education is to facilitate /enable communities/ peoples to change normative structures and collective practices, e.g. to make ‘safe sex’ normative among gay men.

The prevention interventions are focused on resourcing the communities or groups to educate and skill their constituent members, to change normative understandings and expectations and to act on their behalf to advocate for change. There is support for social movement.

Within this model, success (and failure) lies in the ability of policy makers and researchers to enter the life worlds or take up the positions of members of the communities or populations at risk and understand the world from their point of view, that is, it lies in policy makers' and researchers' ability to be critically reflexive and to build on the understanding and practices of the communities at risk and to harness their collective energies and attempts to respond – in this case to the risk of HIV. In this model failure to respond effectively to the threat of HIV is understood as the inability or unwillingness of government (and civil society) to act – not as the sole failure of the individual.

To summarise : social public health researchers work with community so as to enable community members to change/transform their practice – their sexual behaviour. Much as anthropologists do, researchers come to learn the community's meanings of HIV, of sexual practice, etc., they identify ongoing responses to HIV and build on (or discourage) them to promote strategies that prevent or reduce the likelihood of HIV transmission.

Let me illustrate these characteristics of 'social' public health with reference to the Australian response. I shall concentrate here on two such characteristics:

- (1) working with community (individuals connected one to the other through complex webs of social relations) – not unconnected individuals, that is, understanding cultures and contexts, working with sexual practices not behaviours, dealing with meanings ; and
- (2) working from the bottom up, not top down, that is, not imposing a set of interventions but paying attention to the ways in which community responds to threat and building on those responses.

Illustrations from the Australian Response

Meanings: Practice versus Behaviour

People act with reference to meaning. They do not engage in sexual behaviours – penis-in-vagina, they enact sexual practices – they 'make love' or 'have a one-night-stand'. What turns sexual behaviour into a social practice is meaning. Meaning is not to be confused with cognition – in the sense of meaning residing in the mind of an individual. Meanings are essentially *social* – in the sense that they are formed in the relations *between* people.

So while sexual *behaviour* may be reasonably similar across time and place, sexual practice differs. There are only a small number of sexual behaviours in which two or more people can engage – sexual intercourse (both vaginal and anal), oral-genital sex (fellatio and cunnilingus) and oral-anal sex, a number of more esoteric behaviours, such as sado-masochism, as well as a range of behaviours that involve touching – mutual masturbatory behaviours.

Sexual *practice*, on the other hand, is more fluid: it takes on a number of forms. Sexual practice is a *social* and *cultural* practice produced within a particular historical time and place and embedded in specific locations and formations. Sexual practice is different in Australia from France or Nigeria; it was different in medieval times than now; it changes depending on whether it is enacted within a stable relationship or a casual encounter; whether it is imposed, as in rape, or mutually agreed upon; it is different for men and women; and for heterosexuals and homosexuals.

If research is to inform communities and enable them to act, then research has to engage with these meanings and understand them.

One moment in my early work with gay men illustrates this:

(1) When a member of ACON came to Macquarie University in 1985 requesting help, we formed a steering / advisory committee – comprising gay men from community and academics including political scientists, sociologists and social psychologists. My role was to develop a questionnaire to ‘measure’ the sexual behaviours (practice) of gay men in Sydney but I knew nothing about gay sex. So the committee discussed gay sex – casual and committed, esoteric and ‘vanilla’, sex in bedrooms and saunas and sex clubs, and I was given gay porn to read. These discussions and the pornography helped me develop a questionnaire, a questionnaire that, 21 years later, continues to provide the basis of the cohort and longitudinal studies of gay men’s sexual practice of the NCHSR and the NCHECR. The questionnaire was a **joint** product of researchers and researched: it was informed by gay men who understood their sexual

practice and their sexual lives and by educators from gay community who had some sense of the practices that might be modified to protect gay men.

We worked together – in *partnership*. We worked *with* community, *with* gay men in a manner which recognised their expertise – the expertise of their everyday life. So to illustrate again:

(2) In 1987 the SAPA team (Social Aspects of the Prevention of AIDS) gave our first feedback to the gay community – not to the AIDS Council (we had been doing that throughout our work in 86 and 87) but to Sydney gay men – many of whom had taken part in the SAPA survey. It was my task to deliver the paper describing what we had found in our documentation of gay sexual practice and our early attempts to pinpoint the correlates of safe sex and risk. The proceedings took place at the Albion Street Clinic and the lecture theatre was full. I was extremely nervous. As I rehearsed the paper, I found myself wondering whether I should talk about anal intercourse – receptive and insertive – with or without condoms - with or without ejaculation or whether I should talk about insertive or receptive fucking with or without condoms – with or without cumming; whether I should talk about oral-genital sex or sucking; or oral-anal sex or rimming; or somewhat more ridiculously, brachioproctic eroticism (a term I believe Basil Donovan (1986) coined) or fisting, and so on. In the questionnaires we had used both the more formal and the colloquial terms. As I began my talk I still had not made up my mind – but as I spoke I became certain that I should use the colloquial terms. I was right – using the colloquialisms included them, I was talking with them, not simply about them. It signalled that we, the researchers, acknowledged their lives and their expertise with regard to their lives, their sexual practice – they knew what it was like to be receptive and insertive – to reciprocate – and they knew about relationships between men and how these relationships – be they regular and committed, casual or anonymous – affected the use of condoms. They – the gay audience - realised that I took them and their sexual practice seriously. We jointly recognised that feedback to the community was central to community responsiveness and to community action. Our research was informing their practice and their practice, our research.

‘Bottom Up’ not ‘Top Down’

I use my final illustration to demonstrate the importance of not imposing prevention strategies but building on the responses of community itself.

In response to the threat of HIV, gay men in Australia developed their own strategies. And it was they who decided on condoms – well before public health officials acted. In the main, they did not abstain from sex (sex defines who they are) and they did not adopt monogamy. Although there was some reduction in partner numbers in the very early response to HIV, as condoms became normative, partner numbers went back to where they had been before.

Gay men in Australia (and indeed elsewhere in the developed world) turned their backs (their collective backs) on abstinence and monogamy. They did not reduce their partner numbers but adopted condom use and a range of other strategies – many of which were fashioned on medical knowledge and know-how, for example, serosorting; reliance on undetectable viral load, strategic positioning,.... In other words they actively interpreted the knowledge available to them and fashioned it into strategies to avoid HIV transmission.

Although gay men refused monogamy as a safe prevention strategy (sensibly so) they did develop a strategy of their own – no condoms within regular/primary relationships that were concordant for HIV-seronegativity. We identified this strategy in our data – (fall off of condo use in regular relationships – mainly among the highly educated of the sample) and instead of ringing alarm bells about the increasing number of men dispensing with condoms within their regular relationships, we informed gay community organisations (ACON) and did some more close focus research. On the basis of our work, the AIDS Council came up with TTTT (Talk Test Test Trust): an education campaign to ensure that such a strategy was as safe as possible. This strategy was endorsed by the NSW Health Department (which evaluated the campaigns) and later by other state health departments in Australia and other gay communities in Europe.

There was lots of tension around this move – some gay educators were anxious about a move away from ‘condoms every time’. It was not a decision taken lightly and it was a community decision - and it was done with great flair. TTTT posters and banners hung up and down Oxford Street – on the pylons of the Harbour Bridge, and of course in saunas and sex clubs, gar bars and other places gay men congregate for social and sexual reasons.

Overseas – notably in the U.S. – the researchers and others were not pleased – although they continued to advocate for monogamy (a simple reliance on mutual monogamy – and often (if not most of the time) in the absence of talking and testing). The U.S. researchers discouraged negotiated safety calling it instead negotiated danger. It is now obvious that monogamy is a disastrous strategy; and its endorsement has meant that many thousands of people have become HIV-infected – particularly women – and that negotiated safety is an effective strategy.

So to return to the question I posed at the beginning of this talk.. Good HIV prevention requires the ability to understand and harness people’s ways of actively striving to deal with the problems that emerge in their everyday lives. And this is done by:

- 1: adopting a social health paradigm – as opposed to a ‘modern’ public health paradigm – and working with community – NOT the individual – in designing both survey /surveillance instruments and qualitative research ...
- 2: engaging in reflexive research – seeing from the point of view of the other but at the same time ‘minding the gap’
- 3: working in partnership with government and non-government organisations

Without such engagement and partnership, policy makers/ health care professionals will fail to engage the communities and HIV prevention programmes/interventions are likely to be unsuccessful. In Australia much of the HIV-prevention education is informed by gay community, sex worker cooperatives,... and harm reduction strategies identified in the

community were identified by researchers and built on to render them more effective in reducing harm and protecting community members. While not opposed to the use of top-down interventions and regulation as a means of encouraging risk reduction, the social transformation theorists suggest that the most successful strategies for prevention are likely to be those that are sensitive to the practices and desires of particular communities. Such an approach is in keeping with the actual historical evolution of AIDS prevention practices, since many of the first practices of “safe-sex” were invented and established within urban gay communities well before effective public policy on prevention was put into place. In a recent overview of AIDS prevention strategies, Rosenbrock et al. (2000) conclude that community informed interventions carried out in the EU have proved feasible, effective and efficient and have led to sustainable changes of behavior (2000, 1617). An earlier review by Coates et al, which covers prevention in all developed countries, corroborates these conclusions, stressing that community level interventions lead to significant and sustainable behavior changes (1996).

Conclusions

Effective prevention builds on strategies already developed or being developed by people (collectively) as they actively strive to deal with HIV in their everyday lives: – condom use, strategic positioning, reliance on undetectable viral load, negotiated safety, serosorting, ... Good social public health recognises that people are not only individuals but citizens. It recognises and indeed relies on the fact that people interact (talk, negotiate, have sex,...) *together* and that social relations and their transformation are the bread and butter of social change (Stephenson and Kippax, 2006). So, for example, health promotion initiatives are informed by social research, by biomedical developments and by gay men themselves as they engage with and discuss social and biomedical research with reference to their social and sexual relationships. Some strategies are better than others in terms of reducing harm but if they emerge from within the community, policy makers and health care workers need to be aware of and work with them – to reinforce them or persuade community otherwise.

Effective intervention targets the “glue” between people, the point where meaning is negotiated and changed – not individual behaviour or knowledge. Indeed changing individual’s sexual behaviour is in many ways doomed to fail if societal norms are not

changed at the same time (Kippax, in Stephenson, Imrie and Bonnell). As the world moves to the biomedical prevention – circumcision, pre-exposure prophylaxis, microbicides, and one hopes, vaccines, I urge those in public health to remember that: “An epidemic is *par excellence* a collective event. While individuals do have responsibility for their actions, that responsibility has always to be considered in a context of what individuals (collectively) can do given the structures of inequality and the histories within which they live their lives.” (Barnett and Whiteside, p.79) Unless public health researchers work with these collectives to understand their lives, unless they adopt a critical and reflexive stand, and take up the position of the other (the gay man, the women, the sex worker, and take up these positions in order to see well, they and we will fail.

Prevention can and indeed does work – if carried out with members of the populations affected. These populations are not made up of unconnected individuals but people who have sex with one another – or use drugs together. Harness their energy, resource them, support them and work WITH them and the rewards are enormous.

I certainly have found it rewarding and it’s been a privilege to work with non government organisations such as ACON...just to name one such organisation and with those affected by HIV.