Community approaches for MSM: 25 years on: what have we learned?

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Being active in HIV prevention for 25 years now - and being a gay man all my life - I’ve allowed myself to identify with both sides, from a provider and a member of the community point of view. In doing so, I solved my internal conflict preparing this presentation. The first page was not presented at the conference.

First, a look over our shoulder...

In the 1980’s, prevention was to a very large extent, shaped by gay men themselves. All over the world, using condoms was not the first or only option presented to gay men in the early eighties by public health authorities and medical science. Gay men sometimes were told bluntly not to have anal sex. The concept of ‘safe sex’ was in fact invented by communities most affected by HIV, particularly gay men and, indeed, sex workers. In one of the most impressive and swift sexual behavior changes, condoms were introduced to a public who had never needed them. All over Europe, gay men took the lead.

In Belgium as well, the response to the rising epidemic first came from gay men and health care workers. Gay men, supported by doctors from the Institute of Tropical Medicine, were the initiators of almost every HIV organization in Flanders. This community response was not linked to the gay movement, but originated from small groups of people, set in motion by the spread of AIDS they saw happening around them. The Aidsteam, the Foundation, the HIV-Vereeniging Vlaanderen, the AIDS-telefoon all took on prevention and social support on HIV and AIDS and all were started up or at least co-founded by gay men. When the community was not involved, HIV social marketing often started on the wrong foot, resulting in a fear based approach that has limited impact and kindles stigma. The first – and only – nationwide campaign on HIV ‘open your eyes before AIDS closes them’ was also the last - and only - to use fear as a motivator.

In the beginning, both the ‘altruistic gene’ and an urge to not to stigmatize gay men, led organizations to overstress the medical fact that everyone could be at risk. But after a few years, when it became clear that the much feared general epidemic just didn’t happen, prevention in Flanders focused on the most affected communities, being gay men and heterosexuals from sub-Saharan origin.

Nevertheless, during the nineties and half through the first decade of the 21st century, the gay movement and HIV organizations had little agenda in common. Voluntary participation of gay men in prevention work decreased after the full impact of new and improved HIV-therapy made HIV much more a chronic disease. Ten years after the introduction of highly effective therapy, HIV prevention among gay men seemed to have lost its drive.

Rising numbers of new diagnoses of HIV with gay men and a renewed interest of the gay movement, led Sensoa to initiate a series of Round Tables in 2007 on HIV prevention for gay men with the support of the cabinet of the Flemish minister for Public Health. In an unprecedented way, members of the gay movement, policy makers, scientists and service providers made an analysis of current information and formulated suggestions on activities in different working groups.

Nowadays, ten years after the merger into Sensoa of the smaller original peer led organizations, gay men are still very much at the heart of HIV-prevention work and are represented at every level and collaborate closely with people with HIV. This has some very strong advantages. It prevents us from issuing counterproductive advice: Belgium, contrary to some neighboring countries, has never discouraged testing altogether or called for the abandon of anal sex. We know why condoms are not popular, why gay men have more sexual partners than heterosexual men and why good intentions fall short of actual behavior. We are sensitive to discrimination of any kind.

But this is not enough to say we have sufficiently involved the community. After 25 years, we still have some way to go to connect with our target audience. We need to combine our efforts even more to halt the
rise of new infections. The emerging issues in prevention and HIV care raise questions that are difficult to answer without the genuine involvement of communities. This is the case for example with policies on pre-exposure prophylaxis, treatment as prevention and also for scientific analysis on those populations who are described as being “most at risk” of HIV infection.

Moreover, collaboration between policy makers, researchers, organizations that deliver prevention and care and community stakeholders is a definite motor of innovation: innovation in the questions raised; innovation in methods; and innovation in terms of social utility, by translating new scientific and practice based evidence into practical, real-life field interventions.

So what can we do as health workers and service providers? And what could be a very helpful community contribution?

1 As health workers we can bridge the divide with the gay community if we...

1.1 Adjust our language
In order to communicate effectively with the community, we might have to review our manner of speech. Through the years, even community linked organizations as Sensoa sometimes use a strange language. We need to change this, in order to bridge the divide between health care workers and gay men. ‘Unprotected anal intercourse’ is in fact just sex in it’s most intimate and natural form. ‘Discordant couples’ makes them sound like they are fighting all the time – they are just couples with a different test result. ‘Adherence to medication’ (to the regime that the doctor prescribes) is also ‘good use of medication’ (good for the person). And let us finally stop using the term seropositives – people are not their serostatus, but are living with HIV.

1.2 Take a community perspective on prevention
From a health workers perspective, unsafe sex is a health risk, as are excessive drug use, smoking a lot of cigarettes and driving too hard. But sex without a condom is not an excessive or ‘unnatural’ behavior - it is in fact an act of intimacy and the shared vulnerability that makes the very essence of a sexual experience. Using condoms requires an extra effort and belongs in the category of putting on sunscreen, taking up sport and eating lots of vegetables and fruit. We need to promote it and support it - without condemning those who for some reason don’t live up to our expectations. If we keep treating men who don’t use condoms all of the time with everybody as men who lack responsibility, we don’t have a community approach.

When making assumptions on peoples motives and behavior, these are the best assumptions to make:

- People who are not infected want to stay uninfected
- People who are infected do not want to infect others

Of course, people make mistakes, do not always act responsible (for themselves, or for others), but their intentions are seldom harmful. As health workers and service providers, this should be our starting point.

1.3 Invest in treatment and prevention literacy
The reality of a community living with HIV and AIDS is changing fast. Undetectable viral load, new treatment options, pre-exposure prophylaxis, these rather recent new topics provide the community with new options for dealing with HIV both on the community and the individual level. The first step is however, to disclose this new information both in a comprehensive and understandable way - quite a challenge..
1.4 Create a platform for discussion and interaction

A fruitful discussion between health workers and the affected communities, building consensus resulting in a basis for further action, don't happen out of the blue. We need a specific tool, a (virtual) meeting space, enabling the expressions of many different voices. We might consider organizing round tables again, or start a blog. The suggestion of the Warning to create a group of people living with HIV that acts as an advisory board for action plans seems to me a very good one.

Minister Onkelinx has initiated the process of designing a national aids plan. Community representatives, both from gay men and transgender organizations and gay men living with HIV - and of course community representatives from migrant populations - should be included as advisors from the very beginning of the process. All of this requires an investment of time and means, but without it, progress might be little.

1.5 Review the definition of safe sex

To keep up healthy behavior in the long run, people need options, to reduce risks sometimes without using a condom, at least for a while, or within that special relationship. Some alternatives might offer more protection than others, but this also can be disclosed, drawing up a menu of different harm reduction and prevention strategies that people can read and upon which they can make informed choices. In order to do so, we need to raise the level of knowledge on gay subcultures and on man to man relationships of general practitioners and specialists alike, so the reality of gay life is taken into account when discussing prevention options.

2 We could be more active as a community in different areas to...

HIV in Belgium is primarily a challenge for gay men and the African migrants community. When we accept this reality, we can start to deal with its implications. If 5% of gay men are likely to be infected, this fact will affect our whole community. If one in twenty gay men live with HIV, we all live with HIV.

How can our community involvement help to improve prevention efforts? Let me now a different perspective and formulate some suggestions...

2.1 Support testing as part of our 'gay way of life'

If a friend tells you he got tested, the correct response should be 'good' and not 'why?'.

That should also be the response from our general practitioner. We expect non judgmental counseling and effective advice. And we should be provided us with an HIV and STI test up to international best practice, including taking a look at the genitals and using a swab...

All possibilities to lower the threshold for testing, should be exploited and offered for free.

2.2 Improve the availability of free condoms and lube

Gay men have excellent opportunities for recreational activities of every kind. Belgium has a high reputation when you’re looking for that special party or that kinky venue. Although most owners of gay bars express their willingness to take part in prevention activities, availability of condoms and lube can much be improved. As a community, we can all express our expectation that, when a gay bar or venue provide opportunities for its customers to have sex on the spot, both condoms and lube should be easily available. As a community, we have influence; in the end , we are the customers (and the customer is always right).
2.3 Pay special attention to young men having sex with men

There is a lot of attention in the gay community to young men having sex with men... Young gay men are welcome everywhere. They get a reduction in saunas. They are popular sex partners. Sadly, they are often looked upon as 'fresh meat' in the supermarket of sexual opportunities that gay venues and the internet offer. During coming in (getting acquainted with gay culture), young gay men often have relationships with older gay men. Do we take their view of the world into perspective? Do we reward their trust with taking responsibility? Do we share our experiences?

Also, the sexual education that boys who like boys are getting in schools is currently inadequate. It does not prepare them for a gay culture, thoroughly spiked with sexual opportunities and the reality of man to man relationships that tend to deal with sex in a less exclusive way than man and woman relationship. This should be addressed more accurately. We also have to search for other opportunities outside the school walls to reach out to them and provide them with adequate information.

2.4 Discuss some behavior and specific norms

In our society, the possibility of making individual choices and taking individual responsibility are key values.

This does not mean, that some excess cannot be addressed. Often we hear gay men themselves questioning some aspects of their lifestyle. Do these superficial sexual contacts make us really happy? Has recreational sex become a substitute for intimacy? Is gay culture relationship friendly or does it encourage a lifetime of brief encounters? These are questions that are useful to discuss, but it can only be the community itself that can make a critical evaluation and initiate the debate.

The same thing goes for cultural norms. Sexual etiquette could be promoted to a larger extent as part of gay culture. If you have an active STI infection, you don't have sex. You make an effort to inform sexual partners (your doctor can help). If you're HIV infected, you tell your longtime companion(s). If somebody tells you he has HIV, you don't judge, you listen. If you color outside the drawing, you inform your significant other. These rules that live to a certain extent in our community, can be made more explicit...

2.5 Take care of gay health in a general way

Gay men (and lesbian women, for that matter) face specific health challenges. STI's and HIV are not the only health threats; we have also higher suicide rates and more depression and other stress related psychological problems. These problems affect also the motivation to take care for ones sexual health. We have a lot to gain by addressing these health problems as a gay community. Without adapting the problem, we cannot start solving it.