

CHICAGO SPEECH – August 2007

Thank you very much to the organizers of this event for inviting me to speak today.

In honour of National Testing Day, I have chosen to speak about public health and human rights – the great divide. My emphasis will be the problems in public health policy for women's rights, but I am sure that there will be others of you who will see yourselves in these problems.

I will start with a quote I read recently in "The Sun" magazine from a man named Butch Hancock . It is an American quote so I thought you might like it. He said "Life in Lubbock Texas taught me two things : One is that God loves you and you're going to burn in hell. The other is that sex is the most awful, filthy thing on earth and you should save it for someone you love ."

If Butch had worked in AIDS he could have added a third: public health is good for you and you are going to have to give up your human rights to have it. I will use three present day examples to illustrate my point and offer recommendations for good public health in each of these areas. Before that I should give you a working definition of these two terms.

Winslow's Modern Medicine 1920 - hmm, not so modern medicine might be a better title - defines public health as the science and art of preventing

disease, prolonging life and promoting health through the organized efforts and informed choices of society, organizations, public and private communities and individuals.

Human Rights is defined in the UN Declaration of Human Rights as the “right to a standard of living adequate for the health and wellbeing of him/herself, and his /her family including food, clothing, housing and medical care and necessary social services and the right to security in the event of unemployment, illness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his/her control.” Many places in the world have human rights codes of their own. Canada’s protects people from discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, age, marital status, family status or disability.

No other issue more graphically illustrates the problem of the potential irreconcilable dichotomy between these two principles, especially for women, than the great debate between voluntary opt in testing and mandatory opt out testing for HIV. This debate has been raging for some time. The CDC has recently taken a position on this, fortunately not favoured by many States. The World Health Organization has taken a similar position, which we hope will similarly not be followed. I really

would love to see more

Wolfowitz moments in some of those organizations, but I digress. The proponents of mandatory testing argue that it is the only way to ensure that people find out about their HIV status . And we need them to know about their status so that they will protect others from HIV. Sometimes they also add that people can also get treated that way. Well, I certainly agree wholeheartedly that people should be given the opportunity to learn their HIV status . However I would argue that this should be a voluntary decision based on a careful consideration of the pros and cons for the individual of learning this information in this way . If this disease were treated by the medical and legal communities and insurance companies and employers and our own communities and society in general like any other disease , this would be a non issue. But we know only too well that it is not.

The stigma and discrimination practiced in the name of HIV makes this a very different matter. For women the risk is potentially particularly devastating. Legally, there is a requirement for partner notification in most jurisdictions when someone tests positive. So, the woman either tells herself or her partner(s) is told by public health. We know of so many cases of violence against women who have disclosed in this way – even cases of murder. There is also emotional abuse, not just initially but ongoing. In

many cultures, the woman is abused by her relatives and community, loses her job and is left in isolation . She may even be thrown out of her home. If she has children they too suffer with her. She often has been in a monogamous relationship and was infected by her partner although she will have been accused of having infected him (or her).

She also is undoubtedly in no position to negotiate safer sex or intravenous drug use practices within that relationship. So, what great public health service have we done her or anyone else in the community by mandatorily testing her ? Not the prevention service and probably not the treatment service either, since it is often not available or affordable or accessible.

Well Louise, you will say, surely you will concede that this is not the case for pregnant women at least – that they at the very least need mandatory testing. I reply with a categorical and emphatic “No.”

On what do I base this heretical opinion ? Evidence.

In Canada, the provinces (like your States) are evenly divided in policy on this. The province I live in has taken the enlightened view that there must be mandatory offer of testing to all pregnant women with pre and post test counselling by the doctor. Under this regime we have a 92% uptake. We also have anonymous testing so we may well be picking up more that way. The highest province is 98% under mandatory testing but most of the others do

not do as well as we do with a low of 60%.

So, why don't women get out of these terrible relationships you may wonder.

Power and money are the answers to that question. These women and their children are socio-economically dependent on these partners. They are generally not well educated nor trained, have poorly paying jobs with no benefits, have no access to affordable housing , health care, day care, shelters, welfare, community and family support. Many are also subject to other forms of oppression due to their race, culture, religion, sexual orientation, gender. They are trapped.

So what would be good public health policy? First of all, the rule should be mandatory offer of testing with comprehensive pre and post test counselling.

Doctors should also learn the other signs that a woman may be at greater risk for HIV, e.g. her or her partner's drug use, violence in her relationship, and offer her a test too. Even if a woman is negative, use this as an opportunity for education.

There should be anonymous testing sites and adequate numbers of them. We need twenty-first century reproductive health rights and practices – even twentieth century would be good .

We also need to have day care, shelters and affordable housing. And training

programmes , opportunities for education and literacy, jobs.

I would never tell another country what health care policy works for their Country, after all I am one of those polite Canadians. But consider that AIDS is the leading cause of death for African-American women 25-44 years old in the United States. So instead I will just say that you might want to take a look at Michael Moore's new movie Sicko, and draw your own conclusions.

Now for my second example – the infamous ABC policy for prevention.

Abstinence is such a laughable idea on so many levels it is difficult to know where to begin. Let's start with the basic fact that sex is a natural part of a healthy life . Or how about, not all women control the decision to have or not have sex so how can they abstain, even if they wish to do so? I just have to believe

that this idea is made up by straight, white men who are bitter because the Viagra they bought didn't work for them.

Being faithful also falls into a similar category for women. We know that in most of the world being young, married and monogamous are the greatest risks for HIV. It is the partner of the woman who is being unfaithful and bringing HIV home.

Appropriate use of condoms. Well I agree with that. Using them on your

nose is just not appropriate . But seriously, it is with the numbers of new HIV cases soaring it is clear that A and B failed, so let's just skip them, shall we and get to saving lives period, not just on our own terms.

Even condoms are very difficult for women to negotiate for the reasons I discussed when talking about testing. Still, let's get them out there and encourage their use no matter what the policy is. This reminds me of a quote I read by someone named Emo Phillips . He said “ When I was a kid I used to pray every night for a new bicycle . Then I realized that the Lord doesn't work that way, so I stole one and asked for forgiveness .“ Let's use condoms and ask for forgiveness .

What is good public policy in prevention? Obviously condom use, both male and female . In South Africa, women are so happy to get female condoms because if they put them on in the morning and are raped during the day, at least they won't get HIV. We must get HIV education back into the schools. We must integrate anti-violence efforts and reproductive health and rights into our HIV work. We must support research for women – initiated prevention

methods including microbicides and we must support vaccine research.

We must stop all this madness about harm reduction and support needle exchange, safe tattooing in prisons, methadone maintenance programmes,

supervised injection facilities . We need to decriminalize the sex trade and drug possession. Prevention in prisons is not anywhere near acceptable.

Also, we desperately need public education, directed to each population, on an ongoing basis.

In our foreign policy we must stop putting any strings on funding that prohibit reproductive health, family planning, birth control or safe abortions. Instead, we should demand an end to female cutting, child marriages, inability of women to own property, to inherit, to own a business. We should encourage microcredit, education for women by removing school fees, laws to make violence, including spousal violence, illegal.

I must issue a warning here. More bad public policy has been suggested recently by some well known researchers and clinicians. It is to put all HIV + people on antiviral drugs, no matter whether they want or need them for their own health . The theory is that they will thereby have undetectable virus in the blood and be less likely to transmit the virus. This is such bad science that I am hopeful it won't stand a chance but watch for it. Blood and semen and vaginal viral concentrations are not necessarily the same to begin with. And you are risking putting people on these toxic medications for much longer than they need thereby potentially killing off

their vital organs. And as if that isn't bad enough, if they develop resistance they will pass along resistant virus. Otherwise a great idea.

I know that these ideas are so far from what happens right now that you are thinking that I must be mad. But I keep recalling a quote I feel is so apt "Washing one's hands of the conflict between the powerful and the powerless means to side with the powerful." And also "what we need is more sustained outrage...there is far too much unthinking respect given to authority. "

So, these two examples are cases where public health policy has taken active but very counterproductive roles in protecting people's human rights or protecting the health of the public. Now for my last example. I want to move to an area where public health has mostly been missing in the dialogue and where they could make such an important contribution. It is in the area of the criminalization of HIV .

This is becoming ever more prevalent. Many people, both women and men, are being charged with attempted murder, aggravated assault, attempted assault. From the cases we are told about, there is quite a different dynamic going on for the women charged than the men by and large. The men seem to have serious mental health problems and/ or are sexual predators. There is much work needed for this group. Many of the women's

stories have an element that is very disturbing – the attempted blackmail by their partners with whom they have separated, often due to abuse, in order not to go to the police. Many swear that their partners knew about their status and they used condoms or that the partners insisted on unprotected sex nonetheless. Of course, it is one person's word against another and somehow the HIV- man's word seemed to come out as more credible. We even had one case of a Thai woman who spoke no English and didn't understand what had been said to her about her HIV status when she was tested coming into Canada. Her Canadian, non-Asian husband used her credit up and when she left him and refused him any further use of her money, he decided to charge her with assault. Even I found myself in an attempted blackmail situation with one man .Of course it was so laughable I did not react, but it was still unnerving.

These women are too afraid of a trial and the possibility of jail to let the case go to trial. So they plea bargain even if they know they are innocent. It is tragic to hear the stories of these women who are only trying to have some sort of normalcy, some sort of sex life. Some women have become so afraid, they have given up sex altogether.

Others actually negotiate a contract with a counselor present before they get into a sexual relationship with someone. So much for spontaneity.

And where is public health, screaming about the injustice and offering to deal with the situation so that these women can be treated fairly and that HIV + women in general can have sex lives? Nowhere.

This is a place for good public health practices. Public health should be working with police whenever these cases arise and the rule should be to try to avoid charging them if there is a more constructive way of dealing with it. Public health should also be working with HIV + women in general to educate them and organizations working with them how to protect themselves against such situations. Media must also stop portraying all HIV+ people as just waiting to pounce on HIV- people to infect them. So, are these two principles, public health and human rights truly irreconcilable for policy makers ? Absolutely not.

Then why do we choose public health policies that put women and their children at risk and do not really provide good health outcomes for the public in any case? I would argue that it is lazy, unimaginative, poorly advised public policy supported by a number of powerful interests – doctors and the pharmaceutical industry in the case of testing, police in the case of criminalization, religious and cultural leaders as well as their political friends in the case of all three. There are no doubt others I have forgotten.

Public health and the protection of human rights are absolutely not irreconcilable. In fact I would argue that any time they are incompatible the public health policies will fail. People will avoid, evade and ignore them if they recognize them to be in conflict with their own individual rights and principles of social justice. Lazy, unimaginative and poorly informed public health policies and practices do not work even if they appear to be easier and more comfortable for the developers and administrators of these policies.

Involve those at whom the policies are aimed and you will find that they will tell you how to create policies that will be effective and accepted. It may take a little longer in the short run, but it will save a lot of trouble in the long run. We must continue to demand this no matter what.

I will end with a quote from a poem that I have come to like very much. It speaks to me and in my view to the moral imperative we privileged human beings have to protect our own human rights and to support and protect the human rights of others. It is called “Saddam Hussein is Writing Poetry in Solitary Confinement.” It reads in part:

Forget Saddam. Imagine for one moment, all the roughened hands, that have picked your food and sewn your clothes, and kept you alive since day one.

When you die, will there be a reckoning, of what and whom we've used, to

pay for our lives, and how, and will lack of imagination be allowed as an excuse?

I think not. Thank you.