Harm reduction: the advocacy of science and the science of advocacy

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Harm reduction is simple.

People like using psychoactive substances. They like using coffee, tea, nicotine, alcohol, cannabis, and a wide range of other drugs. People use drugs to be convivial, for fun and pleasure, for self-understanding, for mystical experience, for working and playing harder, for self-medicating and for coping. Using drugs can be harmful – though it is usually not. If people use drugs, the public policy question is: what can be done to help them avoid harm to themselves, or to others?

Central to this is an acknowledgement that the human brain appreciates the effects of psychoactive drugs. Therefore societies need to learn to live with drugs: this does not mean acceptance of collateral damage. Harm reduction aims to reduce risks, and to mitigate impact on the individual and the wider society. Harm reduction is good public health and social policy. It should be the underlying principle of all drugs policy.

Tonight I talk from two perspectives. First, as a social scientist.

I came into research over 40 years ago. At the time there was some concern about heroin addiction, but it was only a small issue. There were only 904 opiate dependent patients in treatment in London and about half were being prescribed heroin. The research that I did with Alan Ogborne showed that some were functioning fairly well. They worked, paid their taxes and stayed out of trouble. As I was later to discover, this was harm reduction in practice.

Until the mid 1980s the social science of drug use was insignificant, and divorced from the policy process. Social scientists were outsiders, and enjoyed their critical neutrality. A transformation came with the arrival of HIV/AIDS. Social scientists' skills were now required by policy makers, in order to understand epidemics and what could be done to prevent them. I got caught up in that. I conducted the evaluation of the government pilot needle-exchanges in 1987. I sat on the Advisory Council on the Misuse of Drugs Working Group on AIDS, chaired by Ruth Runciman, which established the principles of HIV-related harm reduction.

From 1990 I led the Centre for Research on Drugs and Health Behaviour at Imperial College, and now, thankfully here at the London School and led by Tim

Rhodes. The Centre helped create a 'public health social science' – and a greater engagement in policy.

I stayed too long in research. In 2004 I became Executive Director of the International Harm Reduction Association. A welcome change. IHRA is an international NGO and focuses efforts on persuading international agencies of the merits of harm reduction. I turned from science to advocacy. So tonight I also talk as a harm reduction advocate.

Harm reduction has a long history. And it is not only for illicit drugs.

Let me give some examples.

A common harm reduction measure concerns product quality and strength. If you drink alcohol in much of Europe you are pretty sure what is in the bottle. Not so in much of the world. Much of alcohol consumed globally is non-commercial alcohol – drink produced for home consumption or limited local trade, unregistered and counterfeit products, and surrogate alcohols such as colognes and industrial alcohols. Some is good quality, but some is toxic, and of unknown strength.

The regulation of bars, clubs and restaurants, can also be used to reduce harm by making places safer for drinking. The bar is the original drug consumption room – but not usually as orderly as drug consumption rooms for people who inject! During the First World War the Defence of the Realm Act' among other things tried to regulate behaviour in pubs – it prohibited 'treating' - the buying of rounds of drinks. We now have a much larger repertoire of interventions to make bars and night life safer for drinkers, drunks and people who are not drinking. We could do better.

Drink driving legislation is also harm reduction. Driving is dangerous, it is made more dangerous by drinking. It is not possible to ban driving or drinking: Drink driving laws aim to separate two risky behaviours.

What of tobacco? Harm reduction has included production of filtered, and light, low tar or low nicotine cigarettes. These were ineffective: people still smoked – which is what the tobacco companies wanted - and inhaled as much toxic material as before due to compensatory smoking. Tobacco Harm reduction requires shifting consumers away from highly dangerous smokable products, to less harmful smokeless tobacco and 'clean' nicotine products such as gum, patches, nicotine lozenges or e-cigarettes.

At the beginning I mentioned the prescribing of heroin to addicts in London. How was this possible? It goes back to 1926, to a committee chaired by Sir Humphrey Rolleston, President of the Royal College of Physicians. It advised that prescribing heroin and morphine could be regarded as legitimate medical treatment for those undergoing cure by gradual withdrawal, or to quote, 'persons for whom after every effort has been made for the cure of addiction, the drug cannot be completely withdrawn because it produces serious symptoms', or the patient, 'while capable of leading a useful and fairly normal life so long as he takes a certain non-progressive quantity, usually small, of the drug of addiction, ceases to be able to do so when the regular allowance is withdrawn'.

This was a medical forerunner of the harm reduction that we know today – acting cautiously to help the patient lead a useful and fairly normal life. That was why those patients in the nineteen sixties got heroin prescriptions. It is far removed from some of today's headlines about people being 'parked on methadone'.

Harm reduction is of course best known in relation to HIV prevention. It came to prominence with the discovery of HIV in the mid-1980s. Russell Newcombe was the first to use the words 'harm reduction' in print in the magazine Druglink in 1987. For people who inject there is a variety of harm reduction interventions including sterile needles and syringes to reduce risk of infections, information on safer drug use, and in the case of people dependent on opioids, effective treatment such as methadone maintenance.

In the Netherlands the Junkie-Bond – the drug user union - started a needle exchange in 1984 response to a hepatitis B epidemic. The first three needle exchanges in the UK started in 1986, and that year grass roots community based needle exchanges started in Australia and many European cities. The first supervised drug consumption room started in Berne in 1986. But there were forerunners – a project I helped establish in Camberwell in 1969 had a 'fixing' room where people could inject – an alternative to injecting on Camberwell Green.

Outreach and peer led projects sprang up, and the ethos was "out of the agency and into the streets". Many countries introduced the medical treatment of addiction using opioid substitution treatment with methadone or buprenorphine, expanded provision, and accepted the idea of maintenance on decent dose levels.

These new harm reduction projects were guided by public health thinking and the 'new' public health model embodied in the World Health Organization's Ottawa Charter for Health Promotion. This made it clear that health promotion requires healthy public policy, the creation of supportive environments,

strengthening of community actions, developing personal skills, and reorienting health services.

As applied to reducing drug related harms the new public health included inter alia engaging populations and communities, and creating the conditions for change. Overall what was evident was a new ethos – one where drug workers and drug users work together to tackle health problems. Drug user organisations were and continue to be an important part of these developments.

A social movement energised around HIV/AIDS prevention and care created a new language of safer sex, and in turn enabled a language about safer drug use.

Conservative party ideologues have rewritten the history of harm reduction. They blame it on Labour. This rewriting of history forgets that Thatcher's government introduced harm reduction into government policy in 1988.

In the UK, HIV-prevention for drug users has been a public health success story. Go onto the Health Protection Agency website and see the low levels of HIV infection that we have. 1.5% of injectors in the UK have HIV. Compare that with Russia, where it is about 60 to 70%. We got it right. We can still get it wrong.

Some good progress with harm reduction.

HIV-related harm reduction interventions now operate in a variety of social, cultural and religious settings for example in Iran, China, Malaysia, Viet Nam,

Morocco, Mauritius and Afghanistan. There are harm reduction programmes in 93 countries - more than half of the 158 countries where people inject drugs.

In the case of alcohol, 82 countries have maximum legal blood alcohol levels for driving.

But tobacco harm reduction is in its infancy. Only two countries have national policies that consider nicotine products as tobacco substitutes.

Let me now turn to the science.

Two and a half decades of research on drugs harm reduction has led to sophisticated methods to assess risks and epidemics to encourage evidence informed policy. There is also a large evidence-base on the effectiveness of harm reduction interventions for preventing the spread of HIV infection. This has been well summarised by the World Health Organization and the US Institute of Medicine.

Harm reduction is feasible in a wide range of national contexts; opioid substitution therapy is effective, a finding replicated in many countries; providing needles and syringes helps people change their behaviour; multicomponent approaches are needed and the higher the dose of harm reduction the more protective it is; and countries and cities with harm reduction can keep HIV prevalence low and turn around epidemics. Harm reduction is a good return on investment – as shown in the Australian studies, and is a good investment even in low prevalence settings – as shown by World Bank in Asia.

But I won't tonight go into details of these studies.

Rather, I will look back over the last two and a half decades and identify important ideas emerging from the science of drug use and harm reduction; at the lessons that should help better formulate policy and develop effective interventions.

What do we know now that we didn't know before? The science moved attention away from the fact of drug use per se: it was not drugs that were the problem but the specific harms that can be associated with drug use. It also showed us that the target population was not only drug users in treatment, but also those who might never contact services. Hence the need to develop methods to research hard-to-reach populations. It led to better methods to rigorously sample hard to reach populations. New technologies helped — saliva tests for HIV and later HCV and HBV meant that non-medical field staff could collect samples in the community.

Most important was the focus on risks. When we conducted the first evaluation of the needle exchange programme in England and Scotland in 1987, there were only five existing studies which reported on needle and syringe sharing. Studies of risk are now commonplace.

The new science of risk behaviour showed that drug users will change their behaviour to protect their own health and others. Implicit – but unremarked - is that the people who consume drugs who are the ones who actually <u>do</u> harm reduction.

Most of us do things that are risky. Ignoring our own failings, we are still amazed at our fellow citizens who eat too much, drink too much, exercise too little, or smoke tobacco. We are puzzled that they ignore the evidence, and

don't follow health experts' advice. So a key insight from science was that being risky is not only a matter of individual inclination - there can be good reasons for – in inverted commas - 'bad' behaviour.

Drug using behaviours are learned. We knew that before AIDS.

Howard Becker's studies of marijuana use in 1950's Chicago showed how people learn from others how to smoke marijuana. Dwight Heath showed the highly structured, time and place specific way in which the Bolivian Camba drink and get drunk. They don't get overly excited or joyful, and are not violent. They have a rather dull time!

The ethnographic literature on drink is superbly analysed by MacAndrew and Edgerton in their book 'Drunken Comportment': they write about the domestication of drunkenness – in other words, people's drunken behaviour is shaped by what they have learned about drinking and drunkenness in their society. Drunkenness is controlled lack of control.

Prior to an awareness of HIV/AIDS, people who injected drugs shared needles and syringes with someone who did not have their own 'works' because it was polite – and functional – to do so. It used to be polite to offer cigarettes to friends. In Georgia there is rarely drinking without toasting – an effective way to get your friends drunk. Drinking intending to get drunk – what has been called 'determined drunkenness' - features in some, but not all groups, cultures or drinking occasions.

Understanding that risk behaviours are shared and reciprocated helps move beyond individual targets: this is something that outreach and public health needs to relearn, the immediate targets might be individuals, but through those individuals, and through their social networks, the aim is social change – this is as applicable to alcohol and tobacco as it is to other drugs.

The 'Good reasons for 'bad' behaviour' are also contextual. Risk does not exist in isolation.

Large numbers of drug users with serious physical, mental and social problems are crowded into the small area of the Vancouver Downtown eastside. In a space of about 5 blocks by 4, with a population of around 9,500, an estimated 4,700 people – 50% of the population - have serious problems with their drug use. The area includes others on the margins - sex workers, people with mental health problems, and the elderly. Many reside in single room occupancy hotels, without private sanitation. People live much of the time on the streets and the back alleys, where they meet friends, hang out, inject drugs, smoke crack, eat, and do other things. This environment encourages unsafe drug use. A confluence of factors brings high risk people into a high risk setting.

There are other examples of risky environments. The rapid de-industrialisation of parts of the UK, and Russia, reduced opportunities for work, and increased opportunities for drug and alcohol use and the illicit economy. The regeneration of inner cities in the UK increased problems with alcohol by concentrating bars and clubs into small areas, with competition for customers leading to unhealthy drinking incentives, over-crowding, lack of places to urinate, concentrations of people leaving at the same time and vying for scarce transport.

Take the legal environment. A consequence of the legal regulation of tobacco and nicotine is that the least harmful products are the hardest to obtain or

most highly regulated. Snus is a Swedish ground tobacco, available loose or in a small pouch, and placed inside the upper lip. Swedish men have the lowest lung cancer mortality in Europe. Epidemiological modelling suggests that health gains from switching to Snus type products are nearly as large as from quitting all tobacco use.

However, the sale of Snus is illegal in Australia, New Zealand, Iceland and throughout the EU except for Sweden. This means that most smokers are unaware of this safer form of nicotine. Perversely, the most dangerous nicotine products – cigarettes – are the most available and most used. Most of you in the audience who smoke have probably not heard of Snus, seen it, or tried it. If you use it you could avoid premature death.

The legal environment for drug users includes laws which prevent the availability of and access to life saving medical supplies. People can't be safer if they can't get needles and syringes or are arrested for carrying them. Police crackdowns prevent access to services. Drug users are needlessly imprisoned. In the Maldives – possession of any drug under 1 gram leads to a mandatory 5 year prison sentence. In some countries drinkers are imprisoned or lashed. In some, drug users suffer insult and abuse. A study forthcoming in the International Journal of Drug Policy is the first to quantify this: in a community sample of drug injectors in Delhi - 88% had suffered physical abuse – they had been beaten by hand or a rod or a stick, kicked, punched, stabbed or shot. 55% had been publicly humiliated – had their head shaved, been chained to a tree, or paraded naked. For many drug users around the world, there is a higher chance of going to prison than getting life saving medical treatment.

I spoke earlier of progress with harm reduction. A sizable number of countries support or tolerate HIV harm reduction. But it's only a partial success. Coverage is poor: as Bradley Mathers and colleagues have shown, globally there are only 2 clean syringes a month for every person who injects; only 8 in a 100 opiate injectors gets treatment, and only 4 in a 100 HIV positive injectors gets Anti-Retroviral Treatment.

This poor coverage is unsurprising. Harm reduction is under-funded. In 2007 funding for harm reduction in low and middle-income countries amounted to about \$160 million dollars for low and middle income countries, about 3 US cents per injector per day. \$160 million is what was spent on President Obama's inauguration events. \$160 million is what one of the candidates spent in the US mid-term elections.

The US, Japan and Russia fight to exclude harm language in international resolutions.

There is mischievous distortion. Prescribing methadone has been portrayed by the some UK media and treatment providers as giving up on 'recovery'. 'Methadone for drug addicts costs the taxpayer £105m in four years' trumpets the Scottish Daily Record adding a comment by a Scottish sociologist who described the bill as "staggering". Or this Monday, in the Sun newspaper – 'Drug Addict Bill could pay for 11,000 nurses'.

Supporting tobacco harm reduction is viewed as reneging on the absolutist's goal of a tobacco free society. Harm reduction for alcohol comes a poor second place because public health experts have put too much emphasis on pricing. Public health scientists who engage with the alcohol and tobacco industry on harm reduction are seen as 'supping with the devil'. As an aside, we should

rather be supporting people in those companies who are trying to sell harm reduction to their Boards.

If evidence were all that is needed – we would be well ahead. We need to advocate for an evidence-informed and evidence-based policy – but that is only a part of the policy process.

Evidence based policy making. It sounds good. Scientists hope that evidence leads to action, that good research leads to good policy. It should, it doesn't, but it helps. The contribution of researchers is only one small part of a 'disorderly set of interconnections' between a large number of players in the policy domain.

Many years back Carol Weiss wrote of various other ways in which research is used: sometimes research is used for problem solving; sometimes research is used after the policy decision has been made to justify a position already taken – what I call the 'policy based evidence making' – this is very common in drugs policy; sometimes it is used tactically – where the government says we know there's a problem and we are funding the research; sometimes it is perhaps a matter of enlightenment - where the impact of science is the insights rather than the data – much as I have suggested in the first part of this talk.

She didn't mention that some policy makers are uninterested in evidence. They persist in doing things despite negative feedback and evidence to the contrary.

The science has told us much about the behaviours of the powerless. We know a lot about people who inject. Although many are impoverished and poorly educated, they do try to change their behaviour when provided with the knowledge and means to do so. In contrast, we know very little about decision makers. To quote Alex Wodak: 'We know most are affluent and well educated.

We know that when provided with abundant, high quality and consistently strong evidence, most will prefer intuitive approaches offering possible short term benefit over strongly evidence based approaches ...'

So, what are the 'good' reasons for the 'bad' behaviour of policy makers'?

There are many. For example, the dominant political ethos takes priority over drugs policy.

Competition policy takes precedence over alcohol policy. Drugs policy had to fit – under Labour - with the idea of 'rights and responsibilities' and of being 'tough on crime and the causes of crime'. Drugs policy has to fit with the current 'big idea'.

This is why recovery gets a good press. Harm reduction is portrayed as part of a Britain broken by Labour, burdened by debt, and over-dependent on the state. David Cameron at the Conservative Party conference: to quote - 'There are 150,000 people in Britain today who get their heroin substitutes on the state, their addictions maintained by the taxpayer'. By this elision - a recovering Britain requires recovering addicts.

Anne Milton, parliamentary under-secretary of state for public health, explained to the DrugScope conference two weeks ago that the government's new drug strategy will, to quote, 'be built on a single word – recovery'. And that the creation of a Public Health Service will help people get off drugs and deal with the wider issues behind their addiction.

But, you can't base a drug strategy on recovery alone. And, a public health service should have wider and more ambitious aims. Options for recovery are necessary, for those who want it and are able to achieve it, with or without medication. But to base a whole strategy on this is nonsense. Recovery is only

relevant to a tiny proportion of drug users. Just for a moment, exchange 'alcohol' for 'drugs' in her statement to see the limited public health vision of the new drugs strategy.

Many treatment providers and the National Treatment agency have however preemptively rewritten their aims to be consistent with the new goal of abstinent recovery. The Government plans to pay agencies by results, which I assume means how many people they get off drugs. This, despite all the evidence of the high rates of morbidity and mortality that follow rushing people into abstinence.

No one challenges this, seemingly happy to follow the way the wind blows. Where are the critics and the critical thinkers? Why are our treatment providers, clinicians and public health experts not sounding warning bells to government about the risks they are taking with the public health? This is damaging domestically. It is damaging internationally. Many countries provide nothing for their drug users. It's difficult to argue the case for methadone in other countries if people back home denigrate it.

We need to know a lot more about how to advocate for harm reduction. The literature on advocacy is very thin, and there are few detailed and analytic case studies of harm reduction advocacy. But there <u>are</u> examples where advocates have helped to change the dominant conception of the way drugs can be dealt with. Where people have risen to the challenge of advocating for change and have been successful. I will give two case studies which illustrate some of teh components of good advocacy. Both aimed to change the policy environment, both provided decision makers with good reasons to change their behaviour.

I earlier mentioned Vancouver Downtown Eastside. If anywhere in the world, this was where a drug consumption room might bring individual and community benefits.

A drug consumption room is a hygienic, controlled and supervised place where people inject. In 2001, it was difficult to find people in authority in Vancouver who would publicly support such a facility. Addiction was seen mainly as a criminal justice issue. The establishment of Insite – what the facility came to be called - was, as Will Small and colleagues argue, a case study of culture change. Crucial was a loose alliance including the peer-run Vancouver Area Network of Drug Users; parents of addicts; community agencies providing housing and health care; some key individuals in law enforcement; lawyers; academics, including at the British Columbia Centre for Excellence in HIV/AIDS; journalists at the Vancouver Sun; local activists; chief medical health officers; coroner Larry Campbell, ex of the Royal Canadian Mounted Police; and a 'product champion' – Don MacPherson – in the city administration.

Three concerns helped: rising overdose deaths, HIV/AIDS, and drug use in public places. As Small puts it, 'the narrative that addicts were deserving of caring and life rather than punishment and death' overtook the 'the conventional narrative supporting law enforcement at all costs.'

One reason for the 'bad' behaviour of policy makers is that 'drugs' are risky for politicians and bureaucrats. They risk being thought to be soft on drugs. Policy makers and bureaucrats allow drug use to be risky because, perversely, bureaucrats and policy makers are risk averse.

Bureaucrats who support unpopular initiatives risk losing their jobs, politicians risk losing voters.

In Vancouver, a number of key individuals took risks to support Insite. In 2001, it was politically hazardous to endorse a safer injecting facility. By the end of 2002 it was politically hazardous not to endorse it. Insite opened in September 2003.

The campaign for Insite helped change the political risk environment, and made it risky for politicians not to support harm reduction.

My second example shows how NGOs helped change the policy risk environment for a UN organisation.

In 2006, there was barely any mention of human rights in international drugs documents; by 2009, it was commonplace. Statements on human rights and drug users now found in UN documents are almost entirely the result of the work of the International Harm Reduction Association and Human Rights Watch. This includes the statements by the recently retired Executive Director of the United Nations Office on Drugs and Crime – 'drugs may kill' he said, 'but we shouldn't kill because of drugs'.

The strategy had a number of components: it included arguing that - under the Convention on Economic Social and Cultural Rights - harm reduction is part of the right to health; it included working with the UN Special Rapportuers on the Right to Health, on Torture, and on Extrajudicial Killings.

It included submitting 'shadow reports' on countries to UN human rights treaty bodies: to the Committee on Economic Social and Cultural Rights, the Committee on the Rights of the Child; and the Committee Against Torture.

But perhaps most successful was using the issue of the death penalty to get leverage for change.

Thirty-two states have laws providing for capital punishment for drug crimes. Executions for drug offences have been carried out in recent years in China, Indonesia, Iran, Kuwait, Malaysia, Pakistan, Saudi Arabia, Singapore, Thailand, Yemen and Viet Nam.

The United Nations Office on Drugs and Crime, the European Commission and individual European governments all fund and or deliver technical assistance, legislative support and financial aid to strengthen domestic drug enforcement in states that retain the death penalty for drug offences.

Specific death sentences and executions can be linked to drug enforcement activities funded by European governments and/or the European Commission and implemented through UNODC.

Donor states, the European Commission and UNODC may therefore be complicit in executions for drug offences in violation of international human rights law and contrary to their own abolitionist policies and UN General Assembly resolutions calling for a moratorium on the death penalty for all offences.

There is a clear contradiction between their activities and the human rights obligations of UN organisations and donors. There is huge potential for personal and organisational embarrassment. IHRA's campaign created a crisis which needed resolution. It changed the organizational risk environment.

There is also potential for organizational and personal gain: a UN agency and its Director can make a play to be a leader on a key issue – hence, 'drugs may kill, but we should not kill because of drugs.'

We need more case studies of advocacy. Advocacy can fail: the Russian Federation is one of the world's most serious injection drug-use epidemics, with up to 2 million people who inject drugs, and 60 to 70% with HIV.

Despite (perhaps because of) huge external investment and technical advice and diplomatic efforts, and despite huge advocacy from the civil society organisations inside and outside Russia, the Russian government is resistant to harm reduction. Methadone and buprenorphine in the treatment of addiction are illegal. It is illegal to advocate for methadone, as this is promoting an illegal drug. According to Tim Rhodes and Anya Sarang, Russian resistance is based on the legacy of the 'narcological' and abstinence oriented approach to addiction; and which sees methadone as one step removed from legalising drug use; and which sees methadone maintenance as an error of western science.

A few final thoughts:

First, advocacy is what the powerless do to persuade the powerful to behave differently. It is about trying to change ideas and get others to spend money and change policies and laws. Civil society organisations are small. Advocacy is generally part-time and unfunded. Advocates rarely have lobbyists, speechwriters, PR people, and media staff. They have few resources, so need to be focussed. They need to work where there is the most leverage and the

least resistance. Advocates can't necessarily make things happen. They move things in the right direction. They set the scene and prepare the ground.

Second, NGOs can change the risk environment in which decision-makers work, so it becomes risky not to change. They have the power of embarrassment. But, it doesn't help to humiliate leaders and politicians. WE have to help them to change their behaviour. Aim for a win-win situation – politicians, bureaucrats, community activists and drug users – in the end - must all gain.

Third, the Vancouver and death penalty examples illustrate the importance of coalitions and networks. Alliances and partnerships came together on a joint issue, not necessarily a permanent partnership. They also hint at the importance of tipping points or crises – overdose, HIV and public drug use in Vancouver – and the potential to create crises – as when challenging an international organisation on human rights issues.

Fourth, there is not a science of advocacy. We know little about what works. We know little about the processes of policy change. There is a small literature on advocacy tools, techniques, models and methods. But we actually know very little about successful and unsuccessful advocacy. We need in-depth case studies of successful and unsuccessful advocacy.

Finally, for too long, public health has focused on the powerless, trying to get drug users, and drinkers and smokers to change their risky behaviour. We tend to ignore the broader risk environment in which people live their lives.

Moreover, there many studies of the knowledge, attitudes and behaviours of drug users, and so few studies of the knowledge, attitudes and behaviours of

policy makers - and it is the behaviours of the latter that are a much more important problem.

At the end of the day, as researchers, public health experts, treatment providers and as advocates, our target should be the real risk takers: the decision makers who put politics above evidence and are prepared to take risks with other people's lives.

END

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