Lilienfeld Award Acceptance Speech

Abe Lilienfeld was one of my favorite people. This award creates, posthumously, another bond between us. We first met in 1961, but didn't get to know each other well until I was working on the first edition of the *Dictionary of Epidemiology* in the early 1980s; then our friendship grew as Abe began to develop this College. I was, I believe, his principal recruiting agent for epidemiologists in Canada. Abe Lilienfeld was one of the finest people I have ever known, a warmly compassionate human being as well as a scholar, a scientist, and a gentleman.

The last time I saw Abe was in Ottawa in 1984. He came to give a lecture in our annual History of Medicine series, which that year was on the history of epidemiology and public health. I had the pleasure of introducing him. Later we adjourned to my office and looked at some of the letters I had had when I was preparing the first edition of the *Dictionary of Epidemiology*. We chuckled over Michel Thuriaux's erudite notes, the first few of them from some benighted corner of tropical Africa, obviously typed with his own two fingers on an old typewriter with a faded red ribbon, notes spiced with quotations from the lesser-known works of Lewis Carroll. [Michel found some way to quote the last line of *The Hunting of the Snark*, "The Snark was a Boojum" and ever since I've tried to find an epidemiological term I could call a Boojum; I've suggested those un-named figures often used to illustrate meta-analysis].

Abe and I agreed that another file of letters, through me to each other, deserved to be edited and published. This was a polite but acerbic exchange (to use the *New York Review of Books* expression) between a "words-and-concepts" man, and a rising star of the "mathematical-formula-says-it-all" persuasion. We decided we would edit and publish this correspondence; then, alas, Abe died. But I still have the file and one day I will do this. It's in line behind the book

on which I am working now.

This book began in early 1991 as an idea for a monograph on "Ethical issues in epidemiology." I wrote the first draft of most of it as a scholar in residence at the Rockefeller Foundation's Villa Serbelloni, Lake Como, Italy, in November of 1992. I have a contract with Oxford University Press with a delivery date of March 1994. Well, I'm a wee bit late.

The book has been through many revisions and rewrites, has evolved into something quite different from my original concept: it was to have been a straightforward account of common ethical problems in epidemiology, illustrated with case studies. I'm not sure what I'll ultimately call it but my current working title is "Philosophical dimensions of public health."

I broadened the scope from epidemiology to public health because public health is the *raison d'Λtre* of epidemiology. How did the work evolve from ethics to philosophy? This came about because I had to draw on ideas and experiences beyond as well as within the rubric of ethics.

Forty years ago, in 1957, I was a contented, and, I'm told, a competent family doctor in Adelaide, Australia. I had graduated 8 years before, had been well trained and had been established in practice for almost four years. I loved my work, but I was sometimes frustrated by the fact that I saw patients I could not help much. Either we met when it was too late for me to help them, or they had conditions with mysterious causes and no effective treatment.

And there were more than enough other conundrums to provoke any curious observer of the human race.

I was struck by the contrast between objective indicators of health and people's happiness, or lack of it. I was struck by the dramatic differences, apparently related to cultural

origins, in patterns of behaviour, particularly of women during pregnancy, labour and the early child-rearing years. I thought there might be clues here to better understanding of some common diseases of later life, like high blood pressure and arthritis.

I began to count and classify patients and their diseases, an activity then becoming popular among members of the nascent College of General Practitioners. I aimed to go on doing this for many years, maybe my lifetime. When I told our professor of medicine about this, he said, "Aha! So you're getting interested in epidemiology, are you?" That may have been the first time I heard the word; I don't recall hearing it in medical school or hospital residencies. By the way, neither I nor the professor of medicine understood that I needed denominators as well as numerators. That came later.

The professor had one detail wrong: it wasn't epidemiology but a desire to improve health that aroused me. The influenza pandemic of 1958 hit us hard. Some of my patients died, including friends in my own age group. That epidemic led me to convert, like Saul on the Road to Damascus, from trying to cure the sick, to the nobler aim of finding better ways to prevent people from falling ill in the first place.

None of my experiences in the last 40 years have changed my *weltunschauung*. I continue to believe that promoting, preserving and protecting health are the highest aims of medicine. But what do we mean by "health"? I'll come back to this.

I've often wondered how different my life would have been if I had stayed in family practice for the next 40 years. I think I'd probably have been just as happy. But I left a couple of years later to learn more about public health and epidemiology -- including the need for denominators.

Early experiences forced me to confront ethical and moral problems in controlling

epidemics and contagion. Almost before the ink was dry on my medical degree certificate I went off to be an assistant in a small country town. On about my third day, my boss ordered me to give a woman a course of penicillin without telling her why -- it was because her husband, a prominent local citizen, had brought back some gonococci as a souvenir of a business trip. She asked me if it was penicillin I was giving her, and was it because her husband had infected her. I couldn't lie. I told her the truth, to the fury of her husband and his golfing partner, my boss. So I learnt about truth-telling: that although it's the right thing to do, it can be painful.

A few years later I learnt that ethics and law don't always concur. I was chief resident of the infectious disease hospital in Adelaide during the final polio epidemic, a very nasty one with bulbar paralysis and many deaths, mostly young adults in my own age group. One was a young man, married about a year, his wife about half way through her first pregnancy. Quarantine law was explicit and inflexible: she was quarantined at home, and he was going to die all alone in hospital. She wanted to see him one last time. I knew enough to be aware that the quarantine law was an ass, at any rate where polio was concerned. But the law was the law. I defied it. I smuggled her into the hospital disguised as a nurse, for a farewell meeting.

Fast forward to the mid 1980s. My concern about the ethical and moral foundations of public health and epidemiology took on new urgency as the HIV/AIDS epidemic hit us at the same time as increasing societal recognition that discrimination against minorities was harmful and wrong. This is related to our basic problem of protecting privacy, preserving confidentiality, while ensuring access to health-related information in medical records. This has been a smaller problem in North America than in European nations with unhappy memories of their totalitarian past. Particularly in Germany, but all over Europe, this was a highly emotive and hotly contested

political issue until it was resolved in 1995 with European Union Directives (i.e., laws, regulations) to achieve a workable compromise. But it was a close-run thing. In an increasingly intrusive society, people everywhere value their privacy, their right to keep to themselves information about who they are, what they do, what they've done in the past, what illnesses they have had. The Dutch may have taken this to the limits: they haven't even had a census for almost 40 years. On this side of the Atlantic we need to think more about the tension between privacy and confidentiality, and our need for access to information; we must be prepared to encounter the same conflict. Sinister interest groups (and sometimes governments) can be motivated to impede access to epidemiological data, can throw their weight behind that of guardians of privacy, and did so in the European Union. It can and it does happen here... Indeed it is surprising that it hasn't been more common.

There is a fundamental ethical challenge in public health: the human rights of individuals can conflict with the need for protection from threats to collective security, a health-related aspect of a wider dilemma in the body politic.

Threats to the public health require that persons with dangerous infectious diseases must be identified, sometimes isolated. Occasionally contacts who could potentially spread the infection must be quarantined, deprived of their liberty. People with diseases that impair consciousness or vision must be deprived of their right to drive a car. The tension between individual rights and societal needs in communicable disease control dates back to ancient attitudes towards contagion with leprosy and more recently, 19th century attitudes towards syphilis and tuberculosis.

With HIV/AIDS the rules, procedures and societal reactions have been different: the

rights of infected and possibly infected persons have been elevated over the societal need for protection -- even over the health and safety of uninfected sexual partners of HIV positive individuals. An article in the June 1997 *Atlantic Monthly* offered some thoughtful, cogent arguments to challenge this position.

If there is a dominant ethical principle in clinical practice and biomedical research, it is respect for autonomy. In public health, and I believe in epidemiology, we must consider also the ethical principle of justice. This embodies the notion of equity which is a corollary of WHO's "Health for All" policy and strategies. This means fairly sharing societal resources and benefits -- and the costs, risks, and harms, not exposing some, or most people, to unfair risks and harms. We live in a grossly inequitable world. All of us at this meeting live in inequitable nations, where health gaps, like income gaps, between the haves and the have-nots are getting wider and deeper.

Equity, and WHO's "Health for All" policy and strategies mean reducing, ultimately eliminating, these gaps. But in most of the world, the desperate plight of the have-nots is leading, among other things, to grave, perhaps irreparable environmental damage, as well as to regional conflicts, growing numbers of displaced persons and refugees, mounting disease burdens. Virtue-based as well as principle-based medical ethics gives us the same signals and imperatives, through virtues such as compassion and what Michael Ignatieff calls consideration for the needs of strangers.

The balance in the human situation is moving along the continuum in the opposite direction from what we all wish, from health (and happiness) for all to misery for all, all including even those of us in rich and favoured nations like this one. That is why the Union of Concerned Scientists gave poverty a prominent place in its *Warning to Humanity*.

Yet there are awkward questions about health gaps, and about our preoccupation with "preventing death" -- the implicit aim of applying the knowledge we aspire to accumulate in epidemiological studies of causation.

Do you ever wonder what Nikolaus Otto, Karl Benz, Gottlieb Daimler, other pioneers of the internal combustion engine would think of our world? Would they have any misgivings about what they wrought? Cars have changed the world. Cars have become our household gods, turned farmland into supermarket parking lots, tidal marshland into oil refineries, mild-mannered men into armour-plated killers afflicted with road rage, overheated our global greenhouse with huge amounts of carbon emissions...

Just as those pioneers of the internal combustion engine might have doubts about what they did if they were to come back on earth today, sometimes I wonder if a goal like aiming to eliminate all diseases is a wise use of human ingenuity. What are public health sciences doing? Is our world getting better? We live on average twice as long as needed to perpetuate our species by breeding and nurturing the next generation. This has been great for me, but for many people a long life isn't necessarily a happier one, or a more productive and useful one. Indeed for increasing multitudes, life is the opposite of productive and useful. They leave no mark of their presence on earth other than a small contribution to ecosystem deterioration and degradation.

To what end do we aspire to eliminate diseases? Would we be less profligate with the earth's non-renewable resources, less quarrelsome, less violent, if there was no more cancer, no more heart disease? The world remains a nasty, brutish place for untold millions, especially the poor. Tobacco barons argue that addiction to their product at least keeps pension funds solvent because tobacco addicts die nearer retirement than lifelong non-smokers who live on average

five years more.. These are disturbing thoughts. I don't want to upset your digestion of a good meal, so I won't pursue them further.

But I must mention the gravest threat to health that has arisen in my lifetime. This threat will become more oppressive throughout the lifetime of the young people here, unless we all work together to put things right before they get worse. So far, epidemiology has hardly contributed to study and control of this threat. There are challenges aplenty awaiting our response. Few epidemiologists appear even to be aware that the threat exists.

I refer to the health impacts of global change. Global warming and stratospheric ozone depletion have had the most press coverage and have the most obvious health impacts, but depleted fresh water and food resources, reduced biodiversity, loss of sustainability, desertification, emerging and re-emerging pathogens and demographic turbulence also endanger human health. Very few biomedical scientists, even fewer epidemiologists, are studying these problems and searching for solutions.

The health problems associated with global change, and their complex interconnections, force us to reappraise our approach to biomedical science. I share with my friend and fellow-exile from Adelaide, the distinguished epidemiologist Tony McMichael, the view that the reductionist approach to biomedical sciences won't help us solve these problems.

We need innovative, transdisciplinary approaches. A strength of epidemiology is that it is transdisciplinary already, sometimes anyway; so we are quite well placed to lead a paradigm shift in scientific thinking. We would be better able to lead the way if we were more open to ideas from well outside our usual working territory, if we were even more transdisciplinary -- forging coalitions, for instance, with anthropologists and other less quantitatively minded

scientists who also study the human condition, our habitat, our patterns of settlement.

The underlying reasons for the danger from global change, loss of environmental sustainability, and irrecoverable damage to the earth's life support systems, are population pressure and the growth of many kinds of technologies that have transformed life for all of us, especially in the rich industrial nations. Public health has played a role in raising population pressure, through mass immunization programs, environmental sanitation and control of other environmental threats to health. That is another reason why I ask disturbing questions like those I mentioned a moment ago. Will we be confronted by the failures due to our success?

Like those pioneers of the internal combustion engine who might now have misgivings about what they wrought, should we have any misgivings about what we are doing, and aspiring to do? *How do we know we are right?* Medicine has a long and appalling history of disasters due to misguided interpretations, false theories. Even public health isn't blameless. In the first edition of that enormous textbook I've edited through four editions, Rosenau's *Preventive Medicine and Hygiene*, published in 1913, there was a long, eloquent chapter, impressive in the logical force of its argument, advocating eugenics as the best possible solution to many public health problems. Is genetic screening a contemporary variation on that discredited theme?

How do we decide what problems to tackle? How do we assign priorities? We discussed these questions at NIH Epidemiology and Disease Control Study Section meetings over 20 years ago, and at conferences and seminars then and later. But change came slowly. For example, though advocated then, mainly by women on the study section, research on health problems that mainly or only afflict women remained neglected until many years later.

Despite the horror of wars and genocides, we all believe the human condition has

changed for the better in spectacular ways in the 20th century. Another question that bothers me is what we mean by "better" -- and lurking behind this, for how much longer will it be "better"? Will life be as good for my grandchildren, and yours, when they are my age?

There isn't time now to address these questions adequately, indeed at all. They are questions we must all ask ourselves. We can frame them generally or specifically. The general questions go like this: What are we *really* trying to do when we carry out epidemiological research? When we apply disease control programs? We all share Peter Medawar's "very decided preference" for living over dying, but we can't prevent death. So we aim to prevent premature death. But when is a death premature? Is death in the 8th decade, my decade, premature?

Some of us, and I'm one, have applied our epidemiological skills to evaluate health programs. What are the criteria by which we judge the success of a health program? Are we concerned only with the here and now? Will today's successes be regarded differently tomorrow, next year, 10, 20, 50 years from now? How far ahead should we look when we judge success?

I could go on, but I hope I have said enough to provoke and challenge you. Finally let me confess that today is my 71st birthday. I can't think of a better way to celebrate it than by haranguing a cluster, an outbreak, of epidemiologists such as this.

Thank you again for honouring me, and thank you for listening.

John Last

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