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INTERNATIONAL ADVISORY BOARD ON BIOETHICS**
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Thank you very much, Dr. Macklin. Let me welcome you all most warmly to this International Advisory Board on Bioethics, which has been planned for a long time. We have great expectations of this Board. Of course this is not the first Board to advise the Pan American Health Organization about bioethics. I remember very well sitting here during that first meeting many years ago, when we discussed what the program should do, and what would be the first directions of the Regional Program.

This Board is taking place at a different time, and the program is much more advanced and much better recognized in the Americas. I have always given credit to those who thought of such a program in PAHO: Dr. Carlyle Guerra de Macedo, the Director of PAHO at that time, people like Hernán Fuenzalida; Professor Jim Drane; Professor Diego Gracia; Susan Connor; and of course Julio Montt, who was the first Director of the Program of Bioethics. I think we owe them a lot and they should feel satisfied and gratified that the Program has come to this particular stage. I think, however, the changes over the years have made it necessary to rethink what we do, to rethink where we are and where we are going in this discipline that has grown so much.

First of all, I would like to make some comments on the role of an Advisory Board and what I expect of you. I wish you to comment on the technical work of the Program and give of your renowned expertise in this field. Your comments will be of inestimable value, but in the final analysis the Advisory Board is advisor to the Director and, obviously, I will take very seriously the advice that you give me and will decide what of that advice is applicable in the context of PAHO today. I will have to consider and weigh your advice in the context of the other demands for technical cooperation, but make no mistake about the importance I place on the advice that you will give. There is of course always some degree of self-interest in an organization with respect to advisory Boards comprised of people of your reputation. Your presence and willingness to advise lend luster to the work of the Organization and I thank you for having agreed to serve on this Board. I say it quite openly that we will use your goodwill and your good names to add weight to our programs and our proposals. I hope that even between the formal meetings of the Board you will at least let us

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steal a portion of your time to comment on matters in which we will ask you to help us. As you will hear, the Regional Program is not large —and that is an understatement— and we are going to need all of the help we can get to cover an area as vast as this.

It would be rash of me, if not arrogant, to try to give any advice in this particular area to a Board that is supposed to advise me or try to enter in any depth into the field with a Board that represents some of the finest minds in the field of bioethics. I confess, however, that having looked last night at what Professor Drane had written, I changed completely the tone of what I was going to say. So, these reflections are more of the nature of personal history that might explain the kinds of decisions I have taken with regard to the Program. For those of you who may question this, let me remind you of one of my favorite aphorisms. Hegel in the "Philosophy of the Right" said, "We do not need to be shoemakers to know if our shoes fit, and just as little have we any need to be professionals to acquire knowledge of matters of universal interest." So if you accuse me of being impudent, I hope you will remember Hegel.

So let me reflect on the growth and development of my own interest in this particular field. I was a practicing academic physician, teaching medical students and spending a considerable portion of my life in research. I taught the principles that I believed in at that time and that I still believe in now. The first principle is *Primum non nocere* and indeed I could never separate my research principles from those I applied in clinical practice. In a sense, every time I treated a patient it was an experiment. So when we discussed protocols in those early days, we never thought of things such as informed consent. Our main concern was that the research was trying to answer some important questions and that there would be a testable hypothesis whose disproof, in a Popperian sense, would advance the cause. At that time we abhorred what we called stamp-collecting research —enquiry just to collect information.

I began to think upon these things more when I came to work in this country in the early sixties and began to review in our group, protocols on some experiments of previous eras that really offended my sensibilities. The issue of dialysis came to the fore in those days and I saw ethical Boards, or so called ethical Boards, making decisions that troubled me —decisions on who would live and decisions on who would die.

Then I became a member of a committee of the Institute of Medicine at the Committee on the Ethics of Investigation in Developing Countries, and I came to face with the philosophical difference between myself and many of my American colleagues, who, to my way of thinking, seemed to adopt the dictum of *caveat emptor*, let the buyer be aware, and the responsibilities lay with the subject. At one of those meetings I had the privilege of speaking to a distinguished physician, Walsh McDermott, who convinced me of the need to broaden the concept of what is in the public's interest, and pointed out that care of the individual was in the public's interest.

I remember going back home from that meeting, and running a trial on an anti-hypertensive drug, and asking a patient for his consent. He berated me soundly and said: "You have been treating me for so many years and you have never asked my consent, why do

you ask for my consent now? Is it that you believe that now you don't trust me, and I don't trust you any longer?" Episodes like that caused me to worry a lot about the ethics of the doctor/patient and the investigator/subject relationships.

I am sure that in my student days, my attention was drawn mainly to the area of the doctor/patient relationship, the ethics of the profession, the ethics with which you treated an individual. I came much later, as I have said, to the ethics of the relationship between the investigator and the subject.

So, at that time, even before coming to PAHO, I was formulating some general principles of my own, and the first was that the most unethical type of research was what my boss at that time, John Waterlow, simply called bad research. John used to categorize bad research as one that posed no hypothesis that would lead to the understanding of a phenomenon that was important in terms of human health. If it was not a hypothesis that would lead to the understanding of a phenomenon that was important in terms of human health, then it was bad research. It was also bad research if it answered no significant question, and if it was so badly designed that it would never produce a valid answer, and the risk was such that we would never expose ourselves or our children to the experiment. That was one of the bottom lines; would you expose yourselves or your children to this experiment? Of course, in the light of modern knowledge we may have erred, but I doubt it.

Last July I went back and visited my old unit —and reminisced on some of the experiments we performed on ourselves and it is a miracle that I am still here. At another time I will tell you some stories about those experiments. At that time I was almost petrified by the power of the technological imperative, and the view that existed in many circles —that if it could be done, then, man would attempt to do it. I was convinced that there would always be persons who would dare the ethical aspects and try simply because it was possible. This technological drive even now fuels man's arrogance to try to change what is conceived as the natural order of things, and this is seen so clearly in the area of terminal care, if you can call it such, that has become so common.

I also came to the conclusion that there is no substitute for cultural appreciation, and many of those who pontificate most loudly about what is right or wrong in terms of the ethics of care or research in the developing world, have never worn the "pajamas" of the people in that part of the world. No fundamental problem related to life and death is contextually neutral in terms of culture, place, and time. Most would agree with me in terms of culture and place, especially since these are so interrelated. I have found very few who are charitable in retrospect with relation to health issues that were played-out in societies in which the cultural dominance and the ingrained notion of "them, being different from us," must have conditioned what are now regarded as being inadmissible. Much of the blame must fall on the cultural norm and not only on the individuals who acted. Both the individual and the system must share the odium.

I have had to reflect a great deal recently, in relation to the principle of autonomy, on the changing role of our States in the Americas. The all beneficent State is no longer with us and we are seeing the growth of the groups and organizations that we call civil society. It is

not only the individual but there are now large numbers of groups that impinge on almost everything we do, and many of the ethical postulations and ethical considerations are now including the fact that we must consult, not only the individual, not only the State, but also those civil society groups.

When I was initially involved in research I struggled with the concept of "rights" in relation to medical ethics and the notion of utility. I read Mill's *On Liberty* as most young persons did in my time, and last night I went back and read that part of it that concerned me. Mill wrote: *I regard utility as the ultimate appeal on all ethical questions.* He went on to say *...but it must be utility in the largest sense grounded on the permanent interest of man as a progressive being.* At that time I agonized over what were those permanent interests in matters related to health, and who would determine such interests.

What does all this personal odyssey of mine have to do with the PAHO Program? I have tried to set out how my background might influence my appreciation of the thinking and the needs of the countries, especially developing countries, for cooperation in the field of ethics. First, I must tell you that the major focus of this Program is one of technical cooperation with the Member States and thus, must respond to the needs of the countries. We may have a deep and abiding interest in many of the issues of the day that fall under the ever-expanding rubric of bioethics, but given our resources we have to concentrate on what relates to technical cooperation. Because of my belief in the contextual relevance to which I referred, our work has to focus on building our capacity in our countries, and I have changed the name from one that referred only to Latin America and the Caribbean to indicate that it is a Regional Program, that is, a Program for the Americas. Not that the Program will dedicate many resources to the more developed countries, but we hope to involve all countries in building local capacity and in many of the reflections we undertake about ethical matters. We wish to "teach how to fish" in our developing countries, I have made it clear that the main areas of concentration will be building capacity in clinical ethics and ethics of research—those have to be our major areas of technical cooperation, because I am convinced that those areas are the weakest in our particular part of the world. My own observations and the guidance of experts have confirmed me in that view. I do not negate the importance of other fields, and I do not take the view that we should not be attuned to other issues.

Last night I read Prof. Wikler's paper on Bioethics and Human Rights and the Renewal of Health for All, and he refers to Callahan's seminal 1980 paper "A call for bioethics to enter a third stage," in which he called for bioethics to enter the field of structure, financing, and regulation of health care professions and health care institutions. Then Professor Wikler went on to call for a fourth stage in which matters of population health would become critical. He envisaged that bioethics will be seeking to explore the determinants of health and the inequities that lay therein and, on reflection, I would imagine this Program, contributing to the debate and to the conceptualization. of this fourth stage. Undoubtedly, you will hear from Dr. Lolas more about the nature of our technical cooperation and what we consider to be its major components, our stress on working with countries, and how we have tried to codify the modalities of that work.

I want you, as you go through today and tomorrow, to think on two planes: how can you advise our Program in terms of its technical cooperation in certain specific areas, and also how can you advise on the kinds of collective collegial thinking that should occur in the Region in important areas which may not necessarily translate into technical cooperation with countries.

You will hear or will have heard that I have tried to emphasize what are the two fundamental values for this Organization, that will guide our thinking for the next four years, if not beyond, they are Equity and the Pan American approach, and both of these have ethical connotations. The notion of equity has concerned philosophers from time immemorial and I still go back and read Aristotle's ethics, which still informs much of my thinking in this particular field. The ethical issue is not that there are inequalities, but which of those inequalities are morally and socially unjust. The American Declaration of the Rights and Duties of Man speaks of the right of every person to have access to those sanitary and social measures that will ensure, protect, and promote his or her health. But Aristotle always pointed out that these have to be seen within the limit of what are the resources available at the level of the State and it is obvious that his line of thinking envisaged there being a preponderant role for a beneficent State. We have adopted a very prosaic approach to this matter of equity and try to identify those gaps that we know can be reduced with the technology and resources available.

Now, after many years, I can resolve some of the internal conflicts I suffered on reading Mill. My thinking now leans more towards the egalitarian rather than towards the utilitarian, although I realize that in this imperfect world there will always be a balance between the utilitarian and the egalitarian positions. It is my leaning towards the egalitarian that has led me to emphasize here in PAHO the development of desegregated data, because in my view the standard descriptions of national averages is essentially utilitarian and in our area of public health, we have to be able to determine where the inequalities lie before speaking of inequities.

The lumping together of groups and populations inhibits us, from being more egalitarian than utilitarian. So when I created a Special Program for Health Analysis, I emphasized my commitment to focus on the information development or the capacity for information development that allows us to discriminate where the inequalities lie. I also did this on the basis of my philosophical thinking that there should be more of the egalitarian than the utilitarian approach to fundamental matters of the public's health.

I was in a regional meeting in Santiago discussing how the United Nations System could work better together, and when we asked various agencies what they thought was the problem that was likely to confront us most acutely in the next century, almost everyone spoke of the inequities that exist in the Region of the Americas. Some saw inequities in terms of economic possibilities, in terms of material resources. Some saw inequity in terms of availability of educational facilities. But, everyone around the table could relate what they did and the problems they would encounter to the issue of equity. I have also come to the view that in this field, perhaps the success lies in the journey and not in the arrival. Although it is not utopian to seek for enhanced equity, it is foolish to think that in our lifetime, in my

lifetime, we will see equity as the elimination of all socially unjust differences. However, our technical programs must be clear about where those differences are, what are the determinants of those differences, and how those differences can be reduced. So in that sense, I am very much in tune with Prof. Wikler's feeling that this fourth stage is one that should occupy much of our thinking in the Americas because, collectively, we have come to the view that there is not much point speaking about inequity in health if one does not look at the inequities in the determinants that contribute to the inequity of health outcomes. It is quite possible and it is highly likely that many of those determinants will fall outside the remit of what is considered traditionally as within the medical profession or within the health sector. But that does not worry me. The fact that some determinants might be considered outside of our normal sphere of interest means that although we do not have the direct responsibility for addressing them, we do have the responsibility for drawing attention to them.

Prof. Wikler has also induced me to look at the relationship between the ethics of care and human rights. I tread very softly in this field because I have become concerned about the prostitution of the notion of rights. I have difficulty in accepting many of the things that are being touted as rights. Jonathan Mann and I, after argument, could come to the conclusion that in our area the rights were those that were pointed out in the American Declaration of the Rights and Duties of Man. There is no right to health as such, but there is a right to those sanitary and social measures necessary to promote and protect health.

I mentioned emphasis on the Pan American approach, but will not try to identify here any major ethical dimension. There is a humanitarian aspect to the countries of the Americas helping one another, but I would point out that panamericanism is not essentially founded on humanitarianism, but it is based on mutual self-interest. I think we are having much more success now in convincing the larger countries of our hemisphere that to support the smaller countries of the hemisphere is not a matter of humanitarianism, but it is a matter of self-interest. The Pan American approach is very important to our work and we can show many examples of countries working together to make a difference to the possibility of achieving some concrete results in health.

I have tried to set out for you what I hope this Board will achieve. I have given perhaps too long a personal odyssey to show how I have reached this particular stage of my thinking. I have set out very briefly the values that we hold dearly in the Organization, and what effect they have on some of our technical cooperation. Let me repeat what I said at the beginning and I thank you very much for your time. I hope you will not think that we are abusing you when we ask for your advice on a continuous basis.

Thank you very much, and let me wish you a productive two days.