



PAN AMERICAN HEALTH ORGANIZATION  
WORLD HEALTH ORGANIZATION



## **42nd DIRECTING COUNCIL**

**52nd SESSION OF THE REGIONAL COMMITTEE**

*Washington, D.C., 25-29 September 2000*

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*Provisional Agenda Item 4.5*

CD42/9 (Eng.)

25 July 2000

ORIGINAL: ENGLISH-SPANISH

### **EVALUATION OF THE REGIONAL PROGRAM ON BIOETHICS**

The Regional Program on Bioethics was established in Santiago, Chile, by Directing Council Resolution CD37.R9 in 1993. Under an agreement among PAHO, the University of Chile, and the Chilean Government, the Program commenced operations in 1994. The resolution requested the Program to evaluate its activities and to communicate the results to the Directing Council in 2000.

This document presents the results of an internal and external evaluation process and includes a brief overview of the background, objectives, activities, and accomplishments of the Program to date. It also includes the report prepared by the external evaluator, Dr. James F. Drane.

The 126th Session of the Executive Committee discussed this item and adopted a resolution (CE126.R6) for the consideration of the Directing Council.

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## 1. Background

Since the 1970s, the developed countries have witnessed a substantial increase in the number of centers, institutes, and educational and research programs devoted to bioethics. Many organizations of this type can be found in the United States and Canada, along with a growing number in the European countries. Many countries, especially the more industrialized ones, have national bioethics commissions. Among the centers specializing in this area, the most influential are the Kennedy Institute of Ethics at Georgetown University (1971), the Hastings Center in New York (1969), and the Master's Degree Program of the Universidad Complutense in Madrid (1987). At the international level, there are other entities for the promotion of bioethics, such as the International Bioethics Committee, created by UNESCO in 1992; the Council for International Organizations of Medical Sciences (CIOMS), the Ad hoc Committee of Experts on Bioethics (CAHBI) of the Council of Europe; and the International Association of Bioethics, in Amsterdam, to which the majority of centers, institutes, and scholars working in bioethics throughout the world belong.

In the academic area, efforts have been under way for some time to encourage the study and teaching of bioethics in Latin America and the Caribbean. Only recently, however, has this discipline been included in the compulsory curriculum of some university degree programs in health. Several countries in the Region have undertaken important educational initiatives in this area. Among these, Argentina, Chile, Colombia, Mexico, and Uruguay are considered pioneers. The work of the following institutions should be acknowledged: in Argentina, the Mainetti Foundation of La Plata, which has an Institute of Medical Humanities, a Center for Bioethics, and a Latin American School of Bioethics; in Colombia, the Center for Medical Ethics of the Colombian Association of Schools of Medicine, as well as the Center for Bioethics of the Universidad Javeriana; in Mexico, the Mexican National Academy of Bioethics. This list is by no means exhaustive, since such initiatives are multiplying at a truly impressive rate. Notable in the clinical area are Cuba, which in 1975 had already authorized the creation of hospital ethics committees to resolve doctor-patient disputes through a special legal mechanism to handle patient complaints, and Mexico, which established CONAMA (the National Commission for Medical Arbitration) for the same purpose.

PAHO's exploration, observation, and recording of bioethical concerns and demands among the countries of the Region dates back to 1985. Consultants from the Organization traveled around the Hemisphere, talked to the principal academic and administrative actors, and proposed concrete measures. Among the formal responses to this concern was the publication of a special issue of the *Boletín de la Oficina Sanitaria Panamericana* (Vol. 108, Nos. 5 and 6, May and June 1990, in Spanish; and the *Bulletin of PAHO*, Vol. 24, No. 4, of 1990, in English; also available as a book, Scientific

Publication No. 527) devoted entirely to issues in bioethics. Prepared by distinguished professionals from around the world, its pressrun of some 11,000 copies sold out, marking an important milestone in the Region. A second printing was issued in 1999. This publication is used as a textbook in many universities and has become essential reading for people entering the field.

Subsequently, during the 109th Session of the Executive Committee and the Working Group of the WHO Regional Committee, PAHO reported on conversations with the Rector of the University of Chile, Dr. Jaime Lavados, about the relationship between scientific and technological advances and the growing importance of bioethics—talks that aroused a mutual interest in establishing an entity in the Region to focus on this emerging area.

The Executive Committee shared that concern and agreed that PAHO should take up this issue so closely related to its mission of pursuing “equitable access to health and well-being for the peoples of its Member States.” The Committee therefore requested that a joint proposal be drafted with the University and the Government of Chile for submission to the Subcommittee on Planning and Programming.

The 19th Session of the Subcommittee on Planning and Programming (December 1992) discussed the possibility of establishing a Pan American Institute of Bioethics. However, heeding the recommendations issued, PAHO opted for a Regional Program on Bioethics, with headquarters in Santiago, Chile. The HBE programming line, Promotion of Bioethics, was therefore added to the Organization’s list of programs.

The 111th Session of the Executive Committee (June 1993) studied the progress of the initiative, concluding with its present formulation as the Regional Program on Bioethics. Finally, the Executive Committee adopted Resolution CE111.R7, recommending the creation of the Regional Program on Bioethics to the Directing Council.

The Program was subsequently placed under the Division of Health and Human Development, alongside the regional programs on Women, Health, and Development; Public Policy and Health; Research Coordination, and the Regional Library of Medicine (BIREME), headquartered in São Paulo, Brazil.

## **2. Mission and Objectives of the Regional Program on Bioethics**

The Regional Program on Bioethics was conceived to meet a critical need in the development of health and to make a direct contribution to the Member States, helping to qualitatively improve the level of health care, respect for people as subjects in health

research, and other ethical dimensions of the relationship between health and society. PAHO, in collaboration with the Government and the University of Chile, established the Regional Program on Bioethics for Latin America and the Caribbean (RPB) in 1993, assigning the following mission to the new program: *to cooperate with the Member States of the Organization and their public and private agencies in the conceptual, regulatory, and applied development of bioethics as it relates to health.*

The functions of the Regional Program on Bioethics have been conceived as technical cooperation. Among them, the following can be distinguished:

- To promote, support, guide, advise, and disseminate information to public and private institutions to develop and raise awareness about bioethics, securing the participation of the PAHO Representative Offices and the governments;
- To report on developments in bioethics in terms of new knowledge, bibliography, and publications, facilitating access to databases and e-mail;
- To relate bioethics with public health to improve, update, and deepen policy-making, with special reference to the concepts of equity and solidarity;
- To promote the formation of bioethics interest groups or centers to encourage the participation of the highest possible number of professionals;
- To encourage and promote the establishment of national mechanisms that promote knowledge about and the development of bioethics (national health councils, national bioethics commissions or councils).
- To promote permanent forums to debate issues in bioethics;
- To promote and support studies and research on priority issues proposed by the ministries, universities, or bioethics centers.
- To cooperate in the education and training of bioethics professionals.

The thematic orientations of the Program are the outcome of consultations with officials at the highest level of PAHO and the chiefs of the technical divisions and are based on the agreements reached at the First Seminar-Workshop, held by the Program in November 1994, "Bioethics in Latin America and the Caribbean."

These orientations, which constitute the main planning areas of the Program, are:

- bioethics in public and international health;
- clinical or medical ethics;
- research ethics;
- training and education in bioethics;
- current or emerging problems stemming from the advances in science and technology and the emergence of new diseases.

The Program has geared its activities essentially to the delivery of technical cooperation through the search for responses to developments in science and technology. However, capacity-building and skills-training are also vitally important for developing specific applications for health programs and activities. In this regard, the Program has opened up opportunities for ongoing dialogue and has created academic programs (Master's degree program and training courses) that have produced an incipient Latin American bibliography of essays and theses that analyze the different aspects of health from a bioethical perspective.

The Program's activities, together with the search for the philosophical underpinnings of the topics of interest, employ methods that have developed into working tools; for example:

- hospital ethics committees;
- research ethics committees;
- expert technical assistance;
- linkage with the legislative health commissions of the countries and with the Latin American Parliament;
- training and specialization programs for health professionals;
- forms of problem analysis;
- publication of documents, research, and guidelines or orientations.

In the research area, the role of the Program is to provide well-founded answers to the wide range of concerns aroused by research areas and methods. Consequently, it should also make an analytical contribution to health programs, whether for treatment or

prevention. The projects implemented, especially in 1998 and 1999, have resulted in a reorientation of institutional work.

The health systems under study or proposed must also be rigorously analyzed from an ethical standpoint to demonstrate that they are really grounded in the principle of respect for justice.

In education, the role of the Program is to improve the training of health professionals so that they can adequately analyze health research topics and programs from an ethical standpoint, which is as necessary as a technical and economic analysis.

In the area of public awareness, the Program has created mass communication tools, such as comic strips that shed light on ethical dilemmas related to specific advances in science and technology. It regularly sponsors colloquia, conferences, and symposia and has become a resource for consultations on certain matters of public concern.

### **3. Context and Development of the Program**

The Regional Program on Bioethics for Latin America and the Caribbean commenced its formal activities on 1 May 1994. During that initial stage, the goal of the activities was to consolidate the institutional capacity of Program headquarters in Santiago, Chile and begin to forge ties with public and private institutions and individuals in the Member States, since in order to design a strategic plan for the development of bioethics in the Region, it was necessary to ascertain the real situation in each of these States. It was also necessary to develop a communications medium to disseminate information on the activities of the Program and bioethics centers in the Region.

A few months into its second year, as an imperative for any future development, the Program established the goal of identifying, promoting, and disseminating information on bioethics activities in Latin America and the Caribbean, offering the Member States and their public or private institutions access to regional and worldwide information on bioethics.

The proposed objectives for 1995 and 1996 therefore included undertaking a situational diagnosis of bioethics in the Member States, improving knowledge in bioethics, providing technical assistance to the countries, and facilitating the creation of a regional bioethics network in the Region, getting the Program's Documentation and Information Center up and running, organizing a bioethics communications and information system, and facilitating the collection of data on bioethics experts and centers. During this period, activities focused on improving knowledge in bioethics, promoting and disseminating information on bioethics activities in Latin America and the

Caribbean through specific programs, improving the knowledge and training of professionals, and giving Member States, professionals, and interested institutions access to regional and global information on bioethics in health with a bibliographic database in Spanish and Portuguese.

During 1997 and 1998 the institutional framework of the Program was consolidated, and new demands surfaced to address emerging issues whose accompanying ethical dilemmas and controversies will require analysis from a bioethical perspective. Moreover, the first Director of the Program, Dr. Julio Montt, retired and a successor was named: Dr. Fernando Lolas Stepke, a psychiatrist and former Vice Rector for Academic Affairs of the University of Chile, a professional widely recognized in the Region as a thinker and educator in the field of humanism and health. In addition to adapting the personnel to Program needs, the new Director redefined the functions of the Program, taking into account the changes that had occurred in the Region since he took office.

Since early 1999 the Program has been characterized by greater selectivity and targeting of the activities. From a stage marked by an attempt to universally respond to all the requests of its various users, the Program is now mature enough to identify its own guidelines and formulate a plan of activities that can be evaluated more precisely. It continues to stress the need to anchor bioethical themes to the specific priorities set by the planners and executives of the Region's health services, which translate into permanent demands on the PAHO Representatives to address areas such as inequities in health care (in access, in resources), the rights of patients, improving the quality of care, and recurrent, unresolved areas: AIDS, aging, gender discrimination, research on human subjects.

The response to this was the formation of a select group of advisers to the Director on bioethical issues, known as the International Advisory Committee on Bioethics, whose members serve for two years and which is committed to periodic meetings on specific topics. The first meeting of this advisory group was held in May 1999 and produced the book *Investigación en Sujetos Humanos: Experiencia Internacional* (Research on Human Subjects: International Experience) which has been widely disseminated both inside and outside the Region.

#### **4. Summary of Program Activities**

Any evaluation of the activities of the Regional Program on Bioethics should be based on the goal assigned to the Program by the Strategic and Programmatic Orientations (SPO) for the quadrennium 1995-1998, which was *to develop bioethics in the Region through the identification, analysis, and promotion of policies and programs linked with this new discipline*. Given this background, the Regional Program on



Bioethics, through its activities, has had a number of significant achievements beyond those outlined for it.

It has become a recognized agency in the field of Latin American and European bioethics, effectively collaborating with the majority of the countries of the Region through the organization and support of numerous courses, workshops, seminars, and working meetings, in addition to providing technical assistance and information to those who need it.

It has created and consolidated a documentation system with a current bibliographic database of 3,500 titles and direct access to world databases for consultation. A joint effort with BIREME has made it possible to send 550 registries on bioethics to bolster the LILACS database, making bibliographic registries available in Spanish, English, and Portuguese. The Virtual Health Library in bioethics is almost in place.

Two periodicals have been created: the bulletin *Bioética informa* (Bioethics Reports) and the *Cuadernos del Programa Regional de Bioética* (Notebooks of the Regional Program on Bioethics). This latter publication, which is more academic in nature, has been reformulated as *Acta Bioethica*, its first issue appearing in the year 2000. Supporting texts on specific topics have been published in the *Serie de documentos del Programa Regional de Bioética* (Document Series from the Regional Program on Bioethics), which is distributed to the different centers and is available to anyone interested in delving further into these matters. There are also research and opinion papers prepared by Program consultants, as well as translations, some of which represent major contributions for the Region. A selection of the gray literature produced in the Hemisphere is being edited in order to publish texts meeting certain quality criteria on CD-ROM. This dissemination of information on bioethics function in the Region can be measured by the number of technical publications in the field, summarized in Table 1.

**Table 1. Publications of the Regional Program on Bioethics, 1994-1999**

Publication	Issues published
Bulletin <i>Bioética informa</i>	19
<i>Cuadernos del Programa Regional de Bioética</i>	7
<i>Serie de documentos del Programa Regional de Bioética</i>	6
Documents presenting the Program	3
Pamphlets presenting the Program	2
Official PAHO Publications	3

A total of 453 centers engaged in activities linked with bioethics and 696 professionals working directly or indirectly in this field have been identified in the Region. All of them are registered in the Program's database, which will make it possible to keep them informed about activities in this area and about other topics of interest. It will also make it possible to obtain information and collaboration from them when necessary. The use of the Internet for electronic mail and, very soon, the addition of a hyperlink to the PAHO Web page will make it possible to construct a regional bioethics network linking all these centers and professionals with each other and the Organization.

Technical assistance has been provided to governments and legislatures through direct participation or supporting documents on topics in bioethics that are currently being debated in public forums and are often the target of legislation. Assisted fertilization, organ transplantation, cloning, the human genome project, euthanasia, and assisted suicide are but a few examples.

Table 2 summarizes the scientific activities in which the Program has participated at the national level, by subregion. Support was provided for 186 scientific meetings on bioethics, the majority of them (111) in Chile. Thirty-four meetings were held in other South American countries; 25 in Mexico, Central America, and the Latin Caribbean; 6 in North America and the English-speaking Caribbean; and 10 in Europe.

**Table 2. Seminars, Workshops, Conferences, Courses, and Congresses Held with the Participation of the Regional Program on Bioethics, 1994-2000 \***

Year	Chile	Other South American countries	Mexico, Central America, and Latin Caribbean	North America and English-speaking Caribbean	Other regions	Total
1994	6	1	2	---	---	9
1995	12	6	7	---	---	25
1996	13	3	2	---	2	20
1997	21	3	4	---	2	30
1998	30	13	7	1	1	52
1999	29	8	3	5	5	50
Total	111	34	25	6	10	186

\* To March 2000

Lines of coordination have been opened with other programs and divisions of the Organization in a process that is almost complete. Especially fruitful has been the work with the Program on Adolescence, the Program on Aging, the Program on Research Coordination, and the Program on Public Policy and Health in the area of health legislation. Joint efforts have been carried out, and there are publications that have been sponsored by more than one Program. All the PAHO Representative Offices in the countries have designated their focal points in bioethics.

An intensive effort has been carried out in academia, with the main objective of convincing universities to include bioethics in the medical, humanities, and social sciences curricula. In this regard, the Program has provided cooperation and technical assistance for working meetings and seminars to discuss methodologies. It has attempted to link these activities with training centers in the United States and Europe, particularly Spain, inasmuch as its historical and cultural affinity appears to be the closest approximation to the bioethical perception that is peculiar to our Latin American character.

This was clearly reflected in one of the main activities of the Regional Program on Bioethics during the period in question: the courses specializing in Basic Bioethics and Clinical Bioethics for a Master's Degree program in Bioethics certified by the University of Chile and headed by Professor Diego Gracia, of the Universidad Complutense in Madrid. The completion of these courses by 80 professionals from different countries in the Region, many of whom have already received their Master's degrees after successfully defending their thesis, is a significant achievement, since these individuals will become multipliers in the teaching of bioethics and will collaborate effectively with the governments and institutions of their respective countries to promote the consideration of bioethical principles in health policies and the day-to-day work in health.

Table 3 details the financial resources with which the Regional Program on Bioethics has carried out its activities during the period 1994-2000. During the period the Program budgeted and spent the equivalent of US\$ 3,843,161, of which PAHO has contributed \$2,017,168, or 70%, of the total. Up to the end of 1999, the Government and the University of Chile had contributed \$717,893, in compliance with the conditions stipulated in the respective Agreement among the parties, equivalent to 25% of the Program resources. The remaining 5% has been mobilized by the Program in the form of contributions from several donors, especially the Ministry of Health and Consumer Affairs of Spain.

## **5. Outlook for the Future**

The Regional Program on Bioethics has carried out an integrating project remarkable for its institutional development activities, promotion and dissemination as a technical cooperation resource, and the fulfillment of its diverse functions.

**Table 3. Financial Resources of the Regional Program on Bioethics by Source, in US Dollars, 1994-1999 \***

Biennium	PAHO Regular Funds	Ministry of Health and Consumer Affairs of Spain	Government and University of Chile	Indirect resources of the University of Chile	Other sources	Total per year
1994-95	578,872		147,961			726,833
1996-97	585,300	72,000 <sup>(1)</sup>	200,000			857,300
1998-99	852,996	55,000 <sup>(1)</sup>	156,362	165,000 <sup>(2)</sup> 20,000 <sup>(4)</sup> 10,570 <sup>(6)</sup> 10,000 <sup>(7)</sup> 8,000 <sup>(8)</sup>	15,000 <sup>(3)</sup> 15,000 <sup>(5)</sup>	1,307,928
Totals	2,017,168	126,980	504,323	213,555	29,987	2,892,061

- (1) Cost of consultants provided by the Government of Spain for the Master's Degree Program in Bioethics.
  - (2) Ford Foundation Subsidy No. 970-0325 to the Interdisciplinary Center for Studies in Bioethics (CIEB).
  - (3) Contribution of the Chilean Safety Association for bioethics courses in Concepción, Chile.
  - (4) Contribution of the National Board of Science and Technology (CONICYT) to the CIEB, for the Comic Strip Project.
  - (5) Contribution of the Ministry of Health of Chile, agreement with the Program on Bioethics.
  - (6) Contribution of the CIEB to the Regional Program on Bioethics (PRB).
  - (7) Contribution of the University of Chile to activities related to the CIEB.
  - (8) Contribution of the Department of Gerontology Studies to the CIEB.
- \* The Government of Chile, through Subsidy No. 064004, should contribute \$100,000 annually. The forthcoming contributions for the period 2000-2001, \$200,000, are not included in this financial summary.

An important task of the international organizations in the field of health is to analyze the facts from an interdisciplinary—that is, social, political, and economic—standpoint, with the obligation to look into the future to anticipate the determinants and consequences of the development of society, in terms of both the health conditions of peoples and all areas that could be affected by this process. This task is especially significant for the Regional Program on Bioethics, which ought to add moral elements to

that vision to make it possible to keep human beings as the ends of actions in health and not just the means.

That strategic orientation defines the Program as a technical and analytical entity that is both collaborative and deliberative—an entity that guides and supports public and private agencies in the Member States in their search for responses to the challenges facing health care, public health, research, and teaching in the health professions. It is perceived as an entity that raises new questions and engages in and supports the debate in search of the necessary consensus in emerging areas that provoke conflict and discord because of religious or political dogma or the special interests of particular groups. Bioethics recurs to moral and philosophical values duly channeled through dialogue as a tool for reaching consensus. The moral and epistemic pluralism of contemporary societies requires principles that are valid for achieving basic agreements, especially when addressing the problems on the “fringes” or “limits” of an issue where the debate requires greater flexibility.

In the next stage, the Regional Program on Bioethics should increase its activities in the following areas:

- Support for the Organization in the face of ethical and bioethical considerations arising from emerging issues that generate conflict and discord, among them the right to health, whatever the socioeconomic group, gender, or race; access and quality of care in the health systems; environment and sustainable development; the terminally ill patient (palliative care, death with dignity), AIDS, genetic engineering (cloning, transgenic products).
- Its relationship with the ministries of health and the governments of the countries, working in close cooperation with the Representative Offices in the countries and technical divisions of PAHO to influence the formulation of health policies and the organization of health systems in a positive manner, in terms of ethics and bioethics. The influence of bioethics should be reflected in guidelines, regulations, standards, and procedures that rethink decision-making and practice in health care to ensure that the basic rights of people are respected and the freedoms and rights of all members of society are protected, especially those of the most vulnerable groups. For this purpose, social participation in public debate on these issues should be encouraged through forums and other entities for interaction, promoted by the bioethics institutions and grassroots social organizations in the countries. PAHO/WHO, through the Regional Program on Bioethics, has an obligation to spearhead this process, which should lead to a change in attitude among citizens and institutions about these sensitive subjects.

- Technical cooperation with institutions and individuals working in bioethics in the Member States. However, this task should gradually be decentralized, since numerous local and subregional initiatives have been generated in the past four years that, in the short term, will not require direct assistance but only occasional collaboration.
- Its link with national and regional legislatures, through their health commissions—also to promote the consideration of bioethical principles when legislating in areas where this is necessary.
- Its consolidation as a source in the field of Latin American and Caribbean bioethics for the industrialized countries of other continents, through the generation of permanent orientation and coordinating entities—especially with Spain, which because of its history, traditions, and culture, can provide ethical and bioethical contents that are closer in their approach to Latin American thinking. The countries of the English-speaking Caribbean, for the same reasons, come closer to Anglo-Saxon thinking.
- Clinical practice and research, through ongoing support (both technical cooperation and institutional support) for hospital ethics committees, research ethics committees and, in broader terms, the national bioethics commissions that are being created in the majority of the countries. Only by launching and sustaining these commissions and committees over time will it be possible to find solutions to the dilemmas that present themselves daily in the relationship between the health team and the patient and to address the frequent violations of people's rights that occur in the field of clinical and population research, while providing ethical and bioethical support for decision-making by health executives in areas that could give rise to conflict or discord.
- Its social visibility and institutional and regional position. The Program should engage in joint actions with the divisions of the Organization. The presence in the Region of a significant group of professionals trained in bioethics, who have the PAHO Program as support and the capacity to influence decision-making in their respective countries and grassroots organizations, can effect a change in the pragmatic thinking that the health processes have come up against up to now.
- The international area. It is important to underscore PAHO's reputation as the first agency of the World Health Organization to have established a permanent program in the field of bioethics. In 1999 a new post for an Adviser in ethics was created in the Evidence-based Health Policies cluster in Geneva; virtually from the outset, the incumbent developed a close working relationship with the

Regional Program of PAHO. In addition, the Fogarty Center of the U.S. National Institutes of Health has also requested the collaboration of the Program to support the development of a regional and global network on ethics in health research with human subjects.

The report prepared by the distinguished U.S. bioethicist, Dr. James F. Drane (see Annex A) presents the results of the external evaluation of the Regional Program on Bioethics, conducted in the first quarter of 2000 with visits to Program headquarters in Santiago, Chile and to several other countries of the Region.

Annex A: Evaluation of the Regional Program on Bioethics  
Annex B: Resolution CE126.R6

## **EVALUATION OF THE REGIONAL PROGRAM ON BIOETHICS\***

### **1. Introduction**

The organization most closely involved with the medicinal enterprise in North and South America and the Caribbean is the Pan American Health Organization. The respect enjoyed by PAHO throughout the Region is a reflection of its important accomplishments and its leadership initiatives. In 1994, PAHO added to a long list of accomplishments and initiatives the establishment of a Regional Program on Bioethics in Chile. Before this, there were a few bioethical activities in Latin America, but they were isolated and regionally uncoordinated.

In the twentieth century medicine became much more powerful, capable of doing both unimagined good and frightening evil. Said differently, contemporary medicine is unthinkable without built in ethical controls. Bioethics functions as a built-in self-criticism system for both scientific research and medical practice.

The role of the Regional Program on Bioethics is to supply this all-important self-critical component in the Region. Before the formal establishment of a bioethics program, PAHO became compromised by research projects that were conducted in Latin America. PAHO had signed as a guarantor that research would be conducted in conformity to international standards. Researchers and physicians promised to conduct trials accordingly but that trust was violated. Following this embarrassment, PAHO took personal responsibility for conformity of medical activities with ethical standards. And yet, even today, research is carried out in Latin America and the Caribbean without review by local committees. This violates international guidelines and is excusable only if serious efforts are underway to educate local committees.

### **2. Why the Regional Program on Bioethics is Needed**

Without attention to ethics, medicine ceases to be a profession. And yet, the ethics that has been linked to medical practice for over 2,500 years in Western culture today is threatened. Economic interests today are like an enormous iceberg against which the medical profession and its traditional ethics may very well crash. Some powerful organization has to enter the dangerous waters to keep this terrible calamity from occurring. The protecting organization must be a respected promoter of scientific medicine and at the same time a respected source of ethical direction. If not PAHO—who

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\* Evaluation carried out by Dr. James F. Drane, the Russell B. Roth Professor of Clinical Bioethics, Edinboro University, Pennsylvania, USA.



will keep ethics and medicine joined and make sure as well that ethics plays its critical role in environmental questions.

Who can protect and advance contemporary medicine? Who can define the problems that must be addressed? Who can promote the institutions necessary to carry out medicine's functions? Who can protect the traditional ethical standards in an increasingly uncaring environment? Who can identify emerging ethical problems associated with high tech practice and scientific research? If not PAHO, who will be responsible for maintaining medicine's professional and ethical standards in Latin America and the Caribbean?

Institutions have always been involved with the profession of medicine: fraternities, guilds, societies, associations, and yet none of the historical medical institutions today can guide the profession through the maze of ethical dangers and possible pitfalls that are endemic to contemporary medicine. None of the historical medical institutions can generate ethical standards that protect vulnerable patients. None of the historical institutions has the credibility to convince an increasingly suspicious populace that its best interests are being pursued. If not PAHO, who will protect the ethical component of scientific research, medical practice, and environmental decisions at a point in history widely recognized as a time of ethical crisis? If not PAHO, who?

### **3. The Evaluation. A First Step**

After more than five years of operation, the Regional Program now has to be evaluated. Has the Regional Program, during this initial period, achieved its stated objectives? Has there been capacity building in the discipline of bioethics? Has the program helped health-care institutions and governments throughout the Region to address the ubiquitous ethical problems in medical research and clinical practice? Is the program involved effectively in advocacy for ethical standards and against ethical failures?

The person writing this evaluation just returned from some weeks in the Caribbean Region where he met with health care officials from many of the independent islands. High quality papers were presented at the meeting. The discussions which followed centered around an analysis of ethical problems associated with clinical and research medicine in the Caribbean and how the ideas presented in the papers could help the officials to make some basic and needed progress. Those of us who gave papers also acted as consultants in meetings on how to develop and then implement basic and needed policies. Some initial steps were taken at the meeting by persons in authority (chief medical officers, secretaries of health, deans of medical schools). These key officials, without exception, expressed appreciation for the Regional Program. If the Regional

Program had not supported and helped to organize this meeting, these all-important first steps would still have not been taken.

Taking advantage of the opportunity, I asked to interview the Caribbean participants at the meeting and received from them an evaluation of the program that reflects many others. They were high in praise for the Regional Program, especially for what had been done from Chile to create a web of communication among colleagues working in the field of bioethics. Graduates of the masters program highly valued the quality of this educational experience and the formation in bioethics that it provided. Following completion of the degree, however, bioethicists needed to keep in contact with colleagues in order to know what was being done in other parts of the Region, and to know what seems to work and what does not.

#### **4. A More Broadly Based and Objective Evaluation**

In order to make this evaluation as broad and as objective as possible, letters were sent to all PAHO Representatives in the Region, members of the International Advisory Board on Bioethics, participants in the Third Congress on Bioethics in Latin America and the Caribbean which was to be held in Panama in May, graduates of the Master's in Bioethics, and persons representing centers of bioethics and regional governments. Each was asked to evaluate the Regional Program from his or her perspective and based on his or her experience with its operation. Responses fill two large spiral binders. What follows are the core evaluations.

Ninety eight per cent of the evaluations made the following points: the great relevance and importance of the Regional Program for their area; praise for the master's degree, its contents and organization, and esteem for Professor Diego García; gratefulness for publications from the Regional Program; and recognition of the work being done through conferences and consultations.

On the negative side, respondents from developing countries tended to feel isolated and wanted greater contact with activities of the Regional Program. A strengthening of the Regional Program's efforts to foster interrelationship and intercommunication among bioethicists was requested. The Regional Program's Documentation Center and the availability of publications were appreciated, but many respondents felt that fewer publications were being distributed by the Regional Program. Respondents from developing countries wanted more publications and more personal contact with fellow practitioners of bioethics. The efforts of the former Director, Dr. Julio Montt, to distribute bioethics journals throughout the Region were recognized.

One respondent complained about what he perceived to be an overly bureaucratic tone to the Regional Program. The same respondent complained about a lack of consideration being given to Brazilian literature. The appointment of Dr. Lolas was seen as a possible solution to the former problem. The present director is perceived as a solidly academic medical humanist. His books and conferences are appreciated. Respondents, however, want him to be present in person at the Regional Program's activities, wherever they are held.

Over and over again respondents called attention to highly publicized controversies around medical ethical issues today. They made the point that scientists, patients, government officials and the public all have to be informed and have available to them intellectual resources for thinking through controversial decisions which cannot be postponed. Several prominent international bioethicists made this point most clearly. They want up-dating newsletters and official document distribution from the Regional Program to deal with the new and old issues and to develop workshops and conferences to teach people how best to handle them.

## **5. The Status of Bioethics in the Region**

Issues in the evaluation cited above can be addressed only if PAHO continues to make bioethics one of its core concerns. In fact, medicine can defend itself as a profession only if traditional and contemporary ethical standards are given serious importance by PAHO. In both North and Latin America and the Caribbean, the historical status of medicine is threatened by forces that could convert the profession into just another commercial enterprise. In both North and Latin America and the Caribbean, medical care is very expensive and corporatization is looked to as a solution for the problem. The linkage of medicine first with science and later with corporate structuralization creates both positive opportunities and dangers to basic and universal human rights. Paradigm institutions like PAHO and the Regional Program have to provide the needed ethical leadership.

Influenced by Catholic theology, medical ethics in Latin America has been dominated by the principle of beneficence: doing what is best for the patient. Historically, medical ethics has been pretty much immune from influence from the principle of autonomy (informed consent requirements, patient rights). Contemporary bioethics in Latin America and the Caribbean continues to reflect certain continuity with objective ethics, and with religious rather than secular background beliefs. Different background assumptions, therefore, and different methodologies from those in Europe and the United States, operate in the region. Points of agreement with North American and European bioethics are real and important, but they have to be placed in context. Without this contextual understanding and familiarity with historical roots, Latin American and

Caribbean bioethics will become an imitation of North American and European ideas. In other words, it will be superficial and imposed from without rather than substantial and generated from within. How will an authentic Latin American and Caribbean bioethics be accomplished without a continuing bioethics presence in the Region, without continuing critical work on background beliefs, and without rigorous attention to contemporary issues in practice and research?

Medical ethics in the Region, until very recently, was synonymous in the mind of most professionals with the professional codes of medical associations. One important challenge faced by PAHO and the Regional Program is to help medical professionals and medical institutions move beyond ethics in the sense of guidelines for professional courtesy and etiquette. The explosion of research and technology in contemporary medicine requires a new, a more rigorous, a more objective, a more patient-oriented, a more internationally respectable medical ethics, now referred to as contemporary bioethics. The new medical ethics has to be promoted, taught, and implemented while overcoming a tradition that creates added problems. What international organization can even imagine working on such a broad and challenging task? If not PAHO, who?

## **6. Specific Continuing Needs**

### **6.1 *Judging Research***

Establishment of the Regional Program was a critical first step in the journey toward an ethically respectable medical system in Latin America and the Caribbean. The research that is taking place in Latin America has to be scientifically defensible in order to be ethical, and only persons well trained both in science and ethics can serve on committees which judge particular research projects. The first steps in training these persons have been taken by the Regional Program's Masters Degree in Bioethics. But much more must be done in each country to identify, train and update research committee members. Again, the first steps have been taken during the first five years of the Regional Program, but many more steps remain to be taken before arriving at the goal of conformity to international policies and local ethical sensitivities.

### **6.2 *Education Programs***

The first steps taken in education have been important ones too and have made a difference. But much more needs to be done. Educational programs have to be encouraged in medical schools. If there is some mention of ethics in a medical school curriculum now, upon closer examination it tends to be a short course or seminar either in legal medicine or deontology in the sense of professional codes of etiquette.

Connected with the goal of professional education is the goal of establishing clinical ethics committees in the health care institutions. Modern medical ethics, or contemporary bioethics, is still not practiced in most of the health care centers. Patients ordinarily are not part of the decision-making process. Patient rights are neither habitually respected nor attended to. Patient-professional disagreements are often handled authoritatively and no recourse is available. Clinical ethics committees are rare. Education at the staff level is an important function of institutional ethics committees and it is not yet getting proper attention.

Education at the sociopolitical level is still for the most part unattended. Bioethics has a legal dimension. Patient rights have to be concretized in local, provincial, and state laws. Legislators at all levels need help in order to understand what is legally feasible and what is not. What bioethical principles, rules, and rights can be legalized, and if so, how? Every good act cannot be legally prescribed. Some good intentioned objectives make disastrous laws. Groups of experts in bioethics law need to be trained and to be made available to legislators in order to provide advice and share the experience of other communities with bioethics legislation.

The Regional Program is not the only bioethics entity in the Region but it is the only one with international contacts, goals and objectives. It is the only one that is looked to by persons in every nation for direction and advice. It publishes the most substantial and widely distributed journal in addition to a newsletter. If bioethics is to grow in the Region, projects taking place in isolated areas have to be provided with start-up help and then be kept in communication with efforts underway elsewhere.

### **6.3 *Quality Publications in Spanish and Portuguese***

The master's degree graduates have to keep in contact because there is a dearth of bioethics publications from Latin American authors. Those working in the field have to keep in contact in order to encourage needed intellectual activity. Latin American and Caribbean perspectives have to be developed and this will happen only if contact and dialogue among themselves and with European and North American colleagues is made possible. Money to travel to Europe and the United States is not available to most. Advancement in bioethics has to be made possible by carefully reviewed and edited journals. But how will this be possible without PAHO's Regional Program?

The Caribbean participants mentioned that most of the intercommunication in bioethics that has taken place up until now, has been made possible by the Regional Program. But continued help is needed to create a communication system for continuing high level meetings and publications. Evaluators from throughout the Region were

grateful to the Program but they wanted more continuity with the newsletter *Bioética informa* and the journal *Cuadernos de bioética*.

## **7. Funding a Bioethics Program: A Rationale Grounded in History**

With all the economic pressure on PAHO's budgets, could the bioethics program be eliminated in favor of other health care objectives? No health organization has the resources to do everything that needs to be done. Health needs, like defense needs, seem impossible to satisfy. Where could a bioethics component be situated in the hierarchy of PAHO projects? At what level should it be funded?

Making judgements about allocation of scarce resources is one of the most demanding tasks faced by PAHO's Directing Council. It is a demanding task no matter where it has to be done. The best decision-makers can do is consider the current medical reality, gather relevant facts, look at history, reflect and then act prudently.

The current medical reality obviously is permeated with ethical questions that demand intense study and sometimes immediate response. The ethical dimensions of contemporary research and clinical care cannot be ignored. Even to think of such a thing would be irresponsible.

The unreasonableness of ignoring or postponing ethical considerations in research and clinical care reaches levels of insanity when we look at modern medicine in historical context. Modern medicine is German medicine. Medicine linked to science began in Germany in the 19th century and reached high levels in Germany in the first half of the 20th century. At that time, German physicians carried out extensive research in ecology, public health, cancer and genetics. They were the first to ban smoking in public places. They began seriously to consider both allopathic and homeopathic approaches to disease. They advocated a diet high in fruits and fiber for cancer prevention and healthy hearts. They restricted pesticide use and forbade pregnant women to smoke.

But, alongside advanced scientific medicine, there were practices in Germany at the time that shocked the world. Most shocking perhaps was the fact that the same medical professionals who were the most scientifically advanced committed the worst atrocities against helpless human beings, many of whom thought they were being treated by a trustworthy physician. Physicians were the most prominent professionals in the Nazi movement that abused and murdered millions of innocent human beings. The most common explanation provided by physicians who were indicted was that they believed that their behavior was justified because it proposed to advance science in medicine.

The very same excuse was offered 25 years later by physicians in the United States who also used innocent and helpless persons in order to advance the same interests of medical science (e.g., the Tuskegee Experiments). Ethics is linked to medicine because the practice of medicine opens opportunities to do great good but also to do terrible evil.

Persons in leadership positions at PAHO enjoy the well-deserved respect of governments and medical professionals throughout the Region. PAHO has always stood for sound science and for the highest ethical standards. Because the PAHO Director and Members of the Directing Council are humanists as well as scientists, they know the history of medicine and especially the troubling questions that have been raised by ethical failures in medical research and clinical practice.

One reflection of the responsible character of present PAHO leadership was the establishment of a separate institute for developing ethical awareness throughout the PAHO Region. The support provided to establish the Regional Program on Bioethics is testimony to the foresight and responsibility of this leadership. A periodic evaluation of this program is another dimension of this responsibility. Besides looking carefully at what has been done by the Regional Program since its foundation, this evaluation has given equal attention to potential ethical vulnerabilities in the Region and better ways to address the ever more complex ethical dimensions of medicine.

## **8. Recommendations for Directing Council Consideration**

After reviewing the Regional Program, I believe that the original goals are being pursued with seriousness and have for the most part been implemented throughout the Region. The development of a Latin American bioethics has been strongly advanced by the master's degree program. This has made possible the creation of bioethics experts within Latin America and Caribbean communities and continued instruction in bioethics by the master's degree graduates in their own countries. Publications from the Regional Program have to contribute to continual development in the discipline of bioethics. The number and quality of books and articles on bioethics have been in steady incline. And yet much remains to be done.

- I recommend a revision of the newsletter that will pull together, for distribution, short columns on current issues and articles from the best newspapers throughout the Region. These will be easy to read, current, and keep medical professionals up to date about the issues. I have provided the staff with copies of the best newsletters that can serve as paradigms for *Bioética informa*.
- I recommend that a team of bioethicists be formed to visit one important medical center and an associated medical school for a two-week period each seminar.

- During the visit, courses and seminars on bioethics will be provided by team members. Efforts will be made to identify members of the local medical community who are interested in bioethics. Arrangements for their continuing education will be made, so that they in turn can provide continuing education for their medical school and hospital communities. If this project is successful, it will be extended (one per semester) to other centers in the Region.
- I recommend that the Director of the Regional Program or his representative make a visit to the major bioethics institutes, centers and programs in the United States. The reasons are many: development of personal relationships with directors and staffs of other programs; discussion of mutual needs and interests; collaboration on international projects. Once a relationship develops and is formalized, an exchange program can be implemented. Scholars from Latin America can be sent to different locations in United States. North American scholars interested in Latin American bioethics can be invited to spend some time at the Regional Program's headquarters in Chile. The United States institutes can be asked to send copies of any bioethics articles, books, and documents to the Regional Program in Chile.
  - I recommend the formation of a team of experts working in collaboration with PAHO's section on law in health care. This team can be made available to groups of legislators in different countries. The objectives would be: to inform legislators about bio-law in other countries; to instruct legislators about distinctions and concepts; to provide examples of how these can best be articulated in law. The overall objective would be first to provide needed help and education to legislators. Secondly, a certain continuity and consistency in bioethics legislation throughout the Region would be pursued.
  - I recommend that a team of experts in academic bioethics be gathered which would be available to major university administrations in order to inform them about different courses that are already being offered at the best universities. Information would also be provided about available faculty who could teach the courses. Finally, ideas about future courses to address upcoming problems and issues would be discussed.

## **9. Needs Yet to be Addressed**

- A more aggressive pursuit of contacts with indigenous peoples in order to address their needs and integrate their values into medical decision-making.
- More attention to ethics in the area of reproduction, especially the need to promote a middle ground between extremists at either end of the spectrum on abortion and contraception.



- Because of the prevalence of AIDS, and all the different ethical issues raised by this disease, special committees are needed to address public policy concerns about confidentiality, informed consent, research priorities, allocation of resources, and access to experimental drugs. Patients in developing countries are oftentimes the subjects of drug research and their access to the drugs being tested is a major ethical concern.
- Despite all the talk about equality and universal access to health care, a large percentage of the population in PAHO's Region receives no medical attention. This gap between "right to health care" talk and the reality of access to health care needs more attention. Specifically, the gap between the resources spent on tertiary care and the little money spent on primary care, immunization, infectious disease has to be exposed.
- Public health crusades for change begin with exposed injustices and this needs to be one of the goals for the next phase of the program. The Regional Program cannot realistically presume to achieve justice, equity, and universal access to health care and yet bioethics in Latin America and the Caribbean cannot ignore these issues. Allocation issues and fair distribution of health services have to be themes for educational and advocacy initiatives. At the very least, a team of experts in these areas needs to be assembled that can then be made available to legislators in different countries who are interested in and prepared to advance health care legislation.

## **10. Further Development Considerations**

- Contact retired distinguished scholars, pioneers in bioethics, and authors of the classical books and articles. Ask them if they would be available to speak or hold seminars or provide short courses in their specialties at different locations throughout the Region. Make a list of those who are available and make it available to medical institutes, universities, alumni of the master's program, and PAHO Representatives.
- Arrange a post-master's degree educational opportunity. I have already contacted the University of Miami (Florida) and it is willing to provide a three or six months post-master's certificate program. It will include classroom experience as well as opportunity for research. All participants will gain practical experience with both clinical and research committee deliberations.

- Videos made by Dr. Lolas could be made available to medical schools throughout the Region.
- A daylong educational seminar might be organized for journalists. The idea is to make them aware of the issues and provide them with the basic conceptual tools to write intelligently about bioethics. One of the respondents to our request for evaluation was the President of the Iberoamerican Association of Journalists. He asked for the same-type contact. In addition he wants literature and a bioethicist from the Regional Program to provide classes at the School of Journalism in Santiago. The time is right.
- A bioethics telephone line or hotline could be considered. The idea would be to make available to hospitals and other health care organizations an information and counseling service. Persons managing the service must be highly trained and have a proven record of prudent judgement.
- A partnering arrangement could be considered with major hospitals, medical schools, and national medical associations. With such an arrangement, the Chile office could serve the different needs of those institutions by providing persons who are qualified to help. In return, these institutions would make a financial contribution to the Regional Program.

## **11. Conclusion**

The Regional Program does for bioethics in the Region what PAHO does in the broader sense for health in general. Since medicine today cannot be disconnected from bioethics, it is appropriate that PAHO supports and oversees bioethics initiatives and activities throughout the Region. If not PAHO, WHO?



PAN AMERICAN HEALTH ORGANIZATION  
WORLD HEALTH ORGANIZATION



## 126th SESSION OF THE EXECUTIVE COMMITTEE

Washington, D.C., 26-30 June 2000

CD42/9 (Eng.)  
Annex B

### ***RESOLUTION***

#### ***CE126.R6***

#### **EVALUATION OF THE REGIONAL PROGRAM ON BIOETHICS**

##### ***THE 126th SESSION OF THE EXECUTIVE COMMITTEE,***

Having reviewed the evaluation of the Regional Program on Bioethics (Document CE126/11), carried out in compliance with Resolution CD37.R9 (1993) by Dr. James F. Drane; and

Convinced that the evaluation demonstrated that the Program has fulfilled its objectives in accordance with the goals set at its establishment and concluded that it should continue to respond to increasing demands in the Region for expertise in the area of ethics and health,

#### ***RESOLVES:***

1. To thank Dr. James F. Drane for carrying out a comprehensive evaluation of the Regional Program on Bioethics.
2. To recommend to the Directing Council the adoption of a resolution along the following lines:

##### ***THE 42nd DIRECTING COUNCIL,***

Having reviewed the evaluation of the Regional Program on Bioethics (Document CD42/\_\_\_\_), carried out in compliance with Resolution CD37.R9 (1993);

Expressing appreciation for the considerable technical and financial support provided by the Government of Chile and the University of Chile toward the establishment and continued operation of the Bioethics Program since its inception, as well as for their commitment to continue support for the Program; and

Emphasizing that bioethical analysis should become an integral part of policy formulation and decision-making in the health sector, particularly in processes involving improving quality of health care and research and increasing equity in access to health care services,

***RESOLVES:***

1. To encourage Member States to incorporate the development of the capacity for bioethical analysis within the normative and stewardship functions of the ministries of health and to formulate public policies in health informed by bioethical principles, particularly with regard to research with human subjects.
2. To request the Director to continue support of the Program, promoting the inclusion of bioethical analysis in technical cooperation activities and stimulating capacity building in bioethics in the Member States.

*(Sixth meeting, 28 June 2000)*