

Right to Enjoy the Benefits of Scientific and Technological Progress

Hearing: Inter-American Commission on Human Rights

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2:00-3:00pm

Testimony of Jessica Wyndham* – check against delivery

Buenos días a todas y a todos. Voy a dar mi intervención en inglés, pero primero quería agradecerle a la Comisión por la invitación a participar en esta audiencia sobre el tema del derecho a gozar de los beneficios del progreso científico y tecnológico. También quiero aplaudir la Comisión por haber tomado la iniciativa de sacar a la luz este derecho tan importante pero también olvidado.

Introduction

Science and technology are integral to every aspect of our lives, from antibiotics to computers, from wells and sanitation systems to high yield grains, from cook stoves to basic numeracy. What is more, science and technology are vital to the realization of human rights, not only the rights to health, food and an adequate standard of living, but to education, freedom of information and expression, and even the right to a fair trial. At the same time, scientific practices and the application of technology have sometimes undermined human rights. Indeed, it was the atrocities that took place during World War II, often undertaken in the name of pseudo-science, that gave rise to the modern human rights movement, the creation of the United Nations and the adoption of the Universal Declaration of Human Rights.¹

The connection between scientific advancement and human rights was first recognized in Article 13(1) of the American Declaration on the Rights and Duties of Man (1948)² which recognizes the right of everyone to “participate in the benefits that result from intellectual progress, especially scientific discoveries.” Article 14 of the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) (1988)³ expands on this right as follows: (1) The States Parties to this Protocol recognize the right of everyone: (a) to take part in the cultural and artistic life of the community; (b) to enjoy the benefits of scientific and technological progress; and (c) to benefit from the protection of moral and material interests deriving from any scientific, literary or artistic production of which he is the

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¹ *Universal Declaration of Human Rights*, GA Res 217(a), UN GAOR, UN Doc A/810 (1948)

² *American Declaration of the Rights and Duties of Man*, (1948) Approved by the Ninth International Conference of American States. Bogota, Colombia, Resolution XXX

³ *Additional Protocol to the American Convention on Economic, Social and Cultural Rights*, OAS TS No. 69 (1989) 28 ILM 156, entered into force 16 November 1999 (San Salvador Protocol)

author.” Article 14 goes on in sub-paragraphs (2), (3) and (4) to set out the responsibilities of states to take steps:

- “for the conservation, development and dissemination of science, culture and art”,
- to “respect the freedom indispensable for scientific research and creative activity”, and
- to “recognize the benefits to be derived from the encouragement and development of international cooperation and relations in the fields of science, arts and culture, and accordingly agree to foster greater international cooperation in these fields.”

These rights are also recognized in the Universal Declaration of Human Rights (1948)⁴ and the International Covenant on Economic, Social and Cultural Rights (1966).⁵ Yet, these rights remain largely unknown to states party, to the human rights community, as well as to the scientific community. That is, until recently. Beginning in 2007, UNESCO initiated a process to define the right to benefit from scientific progress.⁶ The UN Independent Expert on cultural rights is now building on some of that work within the context of her own mandate.⁷

As the UN human rights mechanisms begin to give focus to the right to enjoy the benefits of scientific and technological progress, the Inter-American Commission on Human Rights has a unique role to play. Specifically, the Commission has a role in:

- engaging states party, and civil society, including the scientific community, in defining the right;
- determining the relationship of this right to other human rights;
- addressing barriers to the realization of the right, and
- identifying steps towards the implementation of the right.

Today’s hearing serves as the first and an important step in this process.

Fundamental elements

Turning now to the fundamental characteristics of this right. In our analysis, the right to the benefits of scientific and technological progress, and the other related rights set out in Article 14 of the San Salvador Protocol, contain certain core elements. These are:

- (1) that particular focus be given to the needs of marginalized and vulnerable populations;

⁴ *Universal Declaration of Human Rights*, GA Res 217(a), UN GAOR, UN Doc A/810 (1948), Article 27.

⁵ *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976), Article 15

⁶ Report on the Experts’ Meeting on the Right to Enjoy the Benefits of Scientific Progress and its Applications, Paris: UNESCO, n.d.

⁷ Human Rights Council, *Independent Expert in the Field of Cultural Rights*, A/HRC/RES/10/23, 26 March 2009

- (2) that the right requires the creation of a participatory and enabling environment;
- (3) that realization of the right requires the strengthening of international cooperation and assistance in science;
- (4) inherent in the right is the need to protect against violations of human rights caused by the use or the misuse of science and technology; and
- (5) scientific freedom must be respected as vital to the development of a robust and productive scientific community.

I will now address each of these in some further detail.

(1) Marginalized and vulnerable populations

The right of everyone to enjoy the benefits of scientific progress and its applications is an individual and a collective right. The realization of this right requires states to give particular focus to the needs of marginalized and vulnerable populations. Barriers to the realization of the right experienced by marginalized and vulnerable populations include:

- lack of access to basic technological advances necessary to live with dignity. According to data from the World Health Organization, for example, people living in rural areas in Latin America have access to improved water sources at a rate lower than people living in rural areas in the rest of the world;⁸
- lack of access to an effective basic science education and professional opportunities for entering the science professions are often limited for girls and women, people with disabilities as well as some racial and ethnic minorities. A report recently released by the US Economics and Statistics Administration found, for example, that in the areas of science, technology, engineering and mathematics, non-Hispanic Whites and Asians have much higher college graduation rates than Hispanics, non-Hispanic Blacks and other racial and ethnic groups (including American Indians and Alaska Natives);⁹
- in addition, research funding directed to the specific needs of marginalized and impoverished communities is often lacking. Each year, for example, about 8 million people in the Americas contract chagas and more people die each year from the disease than any other parasite born disease. However, chagas remains a neglected disease, affecting the poor and attracting inadequate research and development funding.

To address these barriers, the realization of the right to enjoy the benefits of scientific and technological progress requires states to give particular focus to the needs of marginalized and vulnerable populations, including with regard to access to basic scientific and technological advances; research funding targeted to the specific needs of

⁸ World Health Organization and United Nations Children's Fund, Joint Measurement Programme (JMP), 2006.

⁹ Economics and Statistics Administration (US), *Education Supports Racial and Ethnic Equality in STEM*, 2011.

marginalized and impoverished communities; and quality science education for all without discrimination.

(2) Participation in decision-making

Dissemination of scientific information is essential to facilitating public participation in decision-making about science, fostering further research and development, and empowering individuals and communities to make informed decisions based on sound scientific evidence. There are concerning trends in the Americas that suggest barriers remain to the dissemination of scientific information and the creation of a scientifically literate society. For example, according to a World Economic Forum survey conducted in 2008, students in Latin America are among the most dissatisfied students in the world with respect to their science and mathematics education.¹⁰ The average birth rate among teenage women is higher in Latin America than in other middle income regions, and higher than the rest of the world, indicating a lack of information about sexual health and reproductive rights.¹¹ Finally, laws declaring homosexuality illegal similarly reflect a lack of scientific understanding.

Underpinning the goal of creating a participatory and enabling environment, is the obligation on states to institute effective science curricula at all levels of the education system; to publicly disseminate scientific information; and to develop mechanisms for engaging the public in decision-making about funding and research priorities, as well as science policy, including as it relates to emerging areas of research and new technological applications.

(3) International cooperation

Strengthening international cooperation and assistance in science and technology is vital to the realization of the right to enjoy the benefits of scientific and technological progress. International cooperation may take the form of direct aid, financial and/or material, as well as the development of international collaborative models of research, development and capacity-building, with a focus on mechanisms aimed to benefit developing countries and their populations. The recent summit on the Millennium Development Goals offers concrete suggestions for the way in which the international community can facilitate scientific progress in developing countries, including by facilitating “the development and dissemination of appropriate, affordable and

¹⁰ World Economic Forum, “Executive Opinion Survey 2008”, 2009. Available at: <http://networkedreadiness.com/gitr/main/analysis/showdatatable.cfm?vno=4.37&viewall=true> (accessed on September 20, 2010).

¹¹ United Nations Population Division, World, 2008. *World Development Indicators & Global Development Finance Database*

sustainable technology, and the transfer of such technologies on mutually agreed terms, in order to strengthen national innovation and research and development capacity.”¹²

UNITAID provides an example of an international cooperative arrangement that has applied an innovative funding model to expand access to essential medicines.¹³ Started as an initiative among Brazil, Chile, France, Norway and the United Kingdom, UNITAID is in essence a drug purchasing facility, the backbone of which is its stable and sustainable funding source – a tax on airfare tickets. The organization aims to use its purchasing power to negotiate lower prices, accelerate the distribution of new and existing medicines, and create incentives for the development of new treatments, with a particular focus on HIV/AIDS, tuberculosis, and malaria. In the area of agriculture, the Consultative Group on International Agricultural Research (CGIAR)¹⁴ provides a different example of a multilateral partnership that unites organizations engaged in research for sustainable development with the funders of the work.

On the other side of the coin, states requiring international assistance have a corresponding obligation. Their obligation is to prioritize requests for assistance and collaborative arrangements that give priority to the needs of marginalized and vulnerable populations, rather than a focus on state-of-the-art technological advances that benefit the few without addressing the basic needs of many.

(4) Protection from human rights violations resulting from science and technology

The right to ensure the benefits of scientific and technological progress includes an obligation to ensure against the use or misuse of science and technology in violation of human rights. Such violations may take place in the process of doing research, and in the application of scientific and technological advances.

For example, a month ago, the US Presidential Commission for the Study of Bioethical Issues, released its report on the historical investigation of a US public health study conducted in Guatemala in the 1940s.¹⁵ The study involved intentionally exposing and infecting vulnerable populations to sexually transmitted diseases without their consent. These populations included prison inmates, psychiatric patients, soldiers, commercial sex workers, orphans and school children. Clearly this research raised serious human

¹² High-level Plenary Meeting of the General Assembly by the General Assembly at its sixty-fourth session, *Keeping the promise: united to achieve the Millennium Development Goals*, adopted by the General Assembly on 17 September 2010, para 78, u.

¹³ See: <http://www.unitaid.eu/>

¹⁴ See: <http://www.cgiar.org/>

¹⁵ Presidential Commission for the Study of Bioethical Issues, *“Ethically Impossible”: STD Research in Guatemala from 1946 to 1948* (September 2011)

rights concerns and could usefully serve as the basis for identifying the connections between human rights and scientific research practices.

Examples of the ways in which the application of scientific and technological advances and knowledge may violate human rights include the use of digital and other surveillance tools to monitor individual actions and correspondence, the arbitrary displacement of communities for the purposes of large-scale infrastructure projects, and the application to civilians of non-lethal weapons designed for military purposes.¹⁶

(5) Scientific freedom

Finally, scientific freedom is vital to the development of a robust and productive scientific community. My colleague, Dr. Jorge Colón has already outlined the basic elements of scientific freedom.

Issues for consideration

In order to fully define the right to enjoy the benefits of scientific and technological progress there are at least four conceptual and legal issues that need to be considered, debated and addressed. These are:

- (1) the meaning of 'scientific responsibility' within the context of Article 14;
- (2) the relationship between the right to benefit from scientific and technological progress as it relates to intellectual property;
- (3) any permissible limitations on the right to benefit from scientific and technological progress as necessary for the purposes of national security; and
- (4) the nature of third party obligations with respect to the right.

(1) Scientific responsibility

Scientific freedom, as recognized in Article 14(3) of the San Salvador Protocol is not absolute. Scientists are expected to conduct their research responsibly in accordance with ethical standards, standards which in practice are often developed and maintained by discipline-specific professional organizations and supported by legal and institutional mechanisms. These standards are rarely based explicitly on human rights standards. For the purposes of conceptualizing the right to benefit from scientific and technological progress, it is vital to determine the meaning of scientific responsibility from a human rights perspective. It is not necessary for me to address this issue in more depth as my colleague, Dr. Colón, has already done so.

¹⁶ Rubenstein, L., 'Human Rights and Non-Lethal Weapons Research', *Professional Ethics Review*, Vol. XXIII, NO. 1, Winter 2010

(2) Right to benefit from science and intellectual property

Clarification of the relationship between intellectual property protections and human rights is evolving. Whereas human rights and intellectual property protections have historically been viewed as being in conflict or, at minimum, reciprocally limiting,¹⁷ creative and effective mechanisms for protecting both the moral and material interests of creators as well as the human rights of individuals and communities are starting to be developed.

A compelling proposal has emerged from the World Health Organization Global strategy and plan of action on public health, innovation and intellectual property.¹⁸ This proposal involves delinking research and development costs from product prices, and creating incentives for researchers and research firms that promote collaboration instead of competition. One mechanism for delinking intellectual property protections and product prices is through innovation inducement prizes.

Another mechanism for increasing access and reducing the costs of research and development is through 'patent pools' whereby two or more patent holders agree to license their patents to third parties with a one-stop licensing mechanism. In October 2010, for example, the US National Institutes of Health (NIH) became the first institution to contribute to the Medicines Patent Pool managed by UNITAID. NIH provided a royalty-free license for patents on the drug 'darunavir', an HIV/AIDS antiretroviral drug.

These are just some examples of the creative mechanisms for protecting both the moral and material interests of creators as well as the human rights of individuals and communities. The conceptualization of the right to enjoy the benefits of scientific and technological progress presents a vital opportunity to contribute further to the identification and promotion of such innovative mechanisms.

(3) Right to benefit from science and national security

In practice, the freedom indispensable for scientific research is frequently restricted on the basis of national security concerns. Export control regulations, travel restrictions, limitations on foreign contacts and information sharing, trade embargoes and sanctions, and similar barriers to international cooperation and research limit the freedom of scientists to conduct their work, and particularly to collaborate internationally and with international partners.

¹⁷ Committee on Economic, Social and Cultural Rights, General Comment 17. The Right of Everyone to Benefit from the Protection of the Moral and Material Interests Resulting from Any Scientific, Literary or Artistic Production of which He is the Author. E.C.12/GC/17 (2005), para. 4

¹⁸ See Resolution WHA 61.21 and Resolution WHA63.28 establishing the Consultative Expert Working Group on Research and Development: Financing and Coordination that is examining some of these proposals (21 May 2010).

A second related issue is that of dual-use research, that is, research that is conducted for one purpose but which can be applied for another, particularly when the principal purpose is benign but the potential applications are dangerous, destructive or in violation of human rights. This was the dilemma with which atomic physicists were faced when it became evident that discoveries regarding nuclear fission and the chain reaction might be used for both beneficial purposes, such as medicine and energy production, as well as harmful purposes, including the production of weapons of mass destruction. One question to be addressed in the context of dual-use research is whether there is a process sufficient, or a higher standard required, by which to determine whether and how such research should proceed, and to monitor its progress.

As connections between scientific advancement, the apparatus of national security, and military and foreign policy objectives continue to exist, Article 14 requires that consideration be given to how human rights inform these connections.

(4) Third party actors and obligations

Finally, in countries where the government's role in identifying priority research areas, undertaking research, and disseminating the products of research has been reduced, the private sector's influence has increased. In this context, determining practical measures for applying the right to enjoy the benefits of scientific and technological progress, and determining how to do so in a way consistent with the general principles of human rights, poses unique challenges. Such measures should address priority-setting for research, dissemination of scientific knowledge and transfer of technology, as well as the conduct of research carried out by private institutions.

These are some of the key conceptual and legal challenges that need to be addressed, and which the Commission may consider as it identifies violations of the right to benefit from scientific and technological progress and determines steps for the implementation of the right.

Going forward

To conclude, I would like to suggest a road map for going forward.

In April 2010, the Board of Directors of the American Association for the Advancement of Science adopted a Statement "On the right to the Benefits of Scientific Progress".¹⁹

¹⁹ AAAS Statement On the human right to the benefits of scientific progress, April 16, 2010. Available at: http://shr.aaas.org/article15/Reference_Materials/Article15_AAASBoardStatement.pdf (accessed on October 20, 2011).

Since then, we have engaged a Coalition of professional societies in determining the meaning of the right to benefit from scientific progress from the perspective of the scientific and engineering community. Our recommendations for going forward have their foundation in the Statement of the AAAS Board of Directors and in our work to date in defining this vital right.

Our recommendations are:

1. That the Commission acknowledge in the course of its activities, including hearings, missions and report development, that realization of the human right to enjoy the benefits of scientific and technological progress is an obligation of states party to the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (1988).
2. That the Commission publish a thematic report on the right to enjoy the benefits of scientific and technological progress and its related rights under Article 14, including an analysis of barriers to its realization in the Americas, practical steps towards its implementation and examples of positive state action in the realization of the right.
3. That the Commission recognize that central tenets of the right include: (1) ensuring equitable access to the benefits of scientific progress, with particular focus on vulnerable and marginalized groups; (2) investing in research and development, and creating incentives for innovation to address forms of suffering experienced by these groups; (3) ensuring the freedom of scientists to engage in scientific inquiry while also conducting their work responsibly; and (4) fostering international cooperation in science.
4. That the Commission bring its perspective to bear on the ongoing international process to define with greater clarity the meaning of the right and to determine how best to implement the right in practice.
5. That the Commission engage the Inter-American Court on Human Rights in the process of defining the meaning and determining steps for the application of the right to enjoy the benefits of scientific and technological progress.
6. Finally, that the Commission collaborate with regional scientific and engineering communities in the process of defining and implementing this right.

Muchas gracias por su atención. We welcome any questions you may have.
