

A2K4: Access to Knowledge & Human Rights

**A Conference Hosted by the
Yale Information Society Project**



**February 11-13, 2010
Yale Law School**

Conference Program

The worldwide Access to Knowledge (A2K) movement works to promote intellectual property laws, telecommunication policies, technical architectures and social institutions that:

- Encourage broader participation in cultural, civic, and educational affairs;
- Expand the benefits of scientific and technological advancement; and
- Promote innovation, development, and social progress across the globe.

The Information Society Project at Yale Law School has hosted three major conferences on access to knowledge, helping to lay intellectual groundwork for theorizing A2K as a framework for public policy and to consolidate a broad international A2K movement. This year, the Yale ISP again hosts a major A2K conference, but with a more specialized theme: the intersection between access to knowledge and human rights.

The right to take part in cultural life, to share in scientific progress, the rights to education, health care, and food - all are impacted by and impact upon policies and movements around intellectual property and Internet freedom.

This conference seeks to lay the groundwork – conceptual and strategic – to build bridges between the A2K and human rights communities pursuing common goals of promoting greater access to knowledge, culture, technology and tools for innovation worldwide.

The three-day conference features a diverse range of academics and practitioners in panels on topics including Perspectives on Access to Knowledge and

Human Rights, Technologies of Dissent, The Right To Health, Digital Education, Freedom to Innovate, The Right to Science and Culture, Information Ethics, The Right to Development, Accessibility and the Right to Read, and Rights-Based Strategies for Advancing Access to Knowledge.

The conference is being hosted by the Yale Information Society Project, an intellectual center examining the implications of the Internet and new information technologies for law and society. The conference is open to the public but registration is required. For more information, please visit:

<http://www.law.yale.edu/intellecuallyife/a2k4.htm>.

Conference Schedule

Thursday, February 11, 2010

6:30p.m. Film Screening and Panel Discussion

Issue: Gene Patents and the Right to Health (Room 129)

Those arriving Thursday, February 11 are encouraged to attend an evening screening of the documentary film *In the Family* by filmmaker Joanna Rudnick. The screening will be followed by a panel discussion with scientific experts and legal practitioners addressing the implications of gene patents for access to health care. www.inthefamilyfilm.com

Friday, February 12, 2010

- 8:00-9:00 a.m. Breakfast and Registration (Room 122)
- 9:00-9:30 a.m. Welcome and Opening Remarks (Room 127)
- 9:30-11:00 a.m. Panel I. Perspectives on Access to Knowledge and Human Rights
- 11:00-11:30 a.m. Coffee Break and Refreshments
- 11:30-1:00 p.m. Panel II. Technologies of Dissent: Information and Expression in a Digital World
- 1:00-2:00 p.m. Lunch
- 2:00-3:30 p.m. Panel III. The Right to Health: Promoting Innovation and Equity
- 3:30-4:00 p.m. Coffee Break and Refreshments
- 4:00-5:30 p.m. Panel IV. The Right to Education: Realizing the Potential of Digital Tools

(Speakers' Dinner - Heirloom Restaurant at The Study)

Saturday, February 13, 2010

- 8:30-9:30 a.m. Breakfast and Registration (Room 122)
- 9:30-11:00 a.m. Panel V. Freedom to Innovate: Knowledge, Technology, Culture (Room 127)
- 11:00-11:30 a.m. Coffee Break and Refreshments
- 11:30-1:00 p.m. Panel VI. The Right to Science and Culture: Participation and Access
- 1:00-2:00 p.m. Lunch
- 2:00-3:30 p.m. VII. Concurrent Workshops
 - *Identifying Challenges & Opportunities for an African Information Ethics*
 - *The Right to Read: Copyright and Access for Persons with Disabilities*
 - *The Right to Development: Bridging the Gap between Human Rights & IP?*
- 3:30-4:00 p.m. Coffee Break and Refreshments
- 4:00-5:30 p.m. VIII. Rights-Based Strategies for Advancing Access to Knowledge
- 5:30 p.m. Conference ends

Organizing Partners

3D -> Trade, Human Rights, Equitable Economy

AAAS Science and Human Rights Program

*Access to Knowledge for Development (A2K4D) Center, Department of
Economics, School of Business, American University in Cairo*

*A2K Research Program at the Fundação Getúlio Vargas School of Law in Sao
Paulo*

Association for Progressive Communications

The Berkman Center for Internet and Society at Harvard University

*Centre for Technology and Society at the Fundação Getúlio Vargas School of
Law in Rio de Janeiro*

Centro de Estudios Interdisciplinarios de Derecho Industrial and Económico

Consumers International

Electronic Frontier Foundation

Human Rights USA

Institute for Information Law and Policy at New York Law School

Intellectual Property Watch

International Center for Trade and Sustainable Development

IQSensato

Knowledge Ecology International

Orville H. Schell, Jr. Center for International Human Rights at Yale Law School

UCT Intellectual Property Law and Policy Research

University of Wisconsin-Milwaukee School of Information Studies

Thursday, February 11, 2010

Film Screening and Discussion

Thursday 6:30 p.m. in Room 129 at Yale Law School

Sponsored by the *American Civil Liberties Union Women's Rights Project, the American Civil Liberties Union of Connecticut, the Information Society Project at Yale Law School, and the YLS Law and Health Initiative.*

Film description: *In the Family*, www.inthefamilyfilm.com

At 31, filmmaker Joanna Rudnick faces an impossible decision: remove her breasts and ovaries or risk incredible odds of developing cancer.

*Armed with a positive genetic test result that leaves her essentially 'a ticking time bomb', she balances dreams of having her own children with the unnerving reality that she is risking her life by holding on to her fertility. In *The Family* follows Joanna as she takes us on a journey through the unpredictable world of predictive genetic testing.*

Turning the camera on herself, Joanna bares her conflicting emotions about preventative surgery and the potential consequences. Turning the camera on her new relationship, she and her partner capture a young couple falling in love in the shadow of the mutation. Turning the camera on the company that owns the patents to the BRCA genes, she questions their control over access to the test. Along the way, she looks to other women and families dealing with the same unbelievable information.

*Intensely personal and timely, *In The Family* is a groundbreaking investigation that attempts to answer the question: How much do you sacrifice to survive?*

The screening will be followed by a panel discussion addressing the implications of gene patents for access to health care. Refreshments will be served.

*Christopher Mason, Weill Cornell Medical College of Cornell University
Ellen Matloff, Genetic counselor and plaintiff in BRCA-1 gene patent lawsuit
Sandra Park, ACLU Women's Rights Project Attorney
Rahul Rajkumar, Brigham and Women's Hospital & Harvard Medical School*

This event is a collaboration with P.O.V., PBS' award-winning nonfiction film series; more information available at <http://www.pbs.org/pov/>.

Friday, February 12, 2010

Welcome and Opening Remarks

Friday 9:00-9:30 a.m. in Room 127 at Yale Law School

Jack Balkin, Yale Information Society Project

Lea Shaver, Yale Information Society Project

Panel I: Perspectives on Access to Knowledge and Human Rights

Friday 9:30-11:00 a.m. in Room 127 at Yale Law School

Ahmed Abdel Latif, International Centre for Trade and Sustainable Development

Laurence Helfer, Duke Law School

Molly Beutz Land, New York Law School

Natasha Primo, Association for Progressive Communications

Commentator: Jeremy Malcolm, Consumers International

To date, the intersection between intellectual property and human rights has been analyzed from several perspectives. Some claim that intellectual property is a human right; others object that IP protection conflicts with efforts to realize the rights to health, food, education, or free expression. A consensus perspective on how to view the intersection of IP and human rights is far from achieved.

Access to knowledge, however, is broader than IP alone. It is concerned with the myriad ways in which government and private action either enable knowledge to be shared widely and improved upon, or cause it to be tightly controlled and restricted, and the ultimate impacts of these decisions on human well-being and justice. Adopting this concept as the starting point of a human rights inquiry suggests new perspectives that may enliven the IP-human rights debate, but also poses new conceptual and strategic challenges.

Some of the questions to be pursued by this panel include:

- What is the relevance of A2K and human rights to each other? Which substantive aspects of human rights – for example, health, education, food, freedom of expression, and cultural rights – are implicated by A2K issues and how? Which methodological and institutional approaches hold relevance?

- Do the A2K and human rights approaches fit together easily or in tension? What unique insights can each offer the other? What would it mean to theorize A2K as a human right? Is access to knowledge better understood as a negative liberty or a positive entitlement?
- Is the human rights framework – norms, institutions, and methodologies of advocacy – a useful one for advancing A2K goals? What are the risks, challenges, and opportunities involved in theorizing A2K as a human right? What venues, tools, allies and enemies might be acquired by this framing?

Panel II: Technologies of Dissent: Information and Expression in a Digital World

Friday 11:30 a.m. - 1:00 p.m. in Room 127 at Yale Law School

Anupam Chander, UC Davis School of Law
Laura DeNardis, Yale Information Society Project
Theresa Harris, Human Rights USA
Eddan Katz, Electronic Frontier Foundation

Moderator: Nabiha Syed, Yale Information Society Project

This panel explores A2K issues relevant to classic civil and political rights, particularly freedom of expression.

Political expression and dissent are increasingly exercised online, through technologies ranging from social networking tools, blogs, email, and cell phones to more concealed and complex technical approaches such as the use of distributed denial of service attacks to disrupt government servers. Some governments have responded to new forms of digital dissent with new forms of technological repression.

The same technologies that expand opportunities to engage in legitimate political protest have created unprecedented privacy concerns; of particular concern is the practice of deep packet inspection allowing scrutiny by governments, often through private industry, of the details of users' text messages, web searches, and emails.

Some of the questions to be pursued by this panel include:

- What are examples of online technology and expression that may be empowered or made vulnerable? How are governments responding to these new forms of dissent? Is there anything truly new about these forms of protest versus more traditional forms?
- What is the nature of the technical architecture that enables these new types of democratic expression and protest? In what ways can the same

- technologies be used to violate human rights? Is there a human right to any particular form of technology, or rights *vis a vis* technology?
- What is the role of corporate social responsibility in relationship to Internet freedom? To what extent should we be concerned about private control over new forms of dissent and speech, as well as government control?
 - What is the role of government investment in telecommunications, universal access and closing the digital divide, and infrastructure design as human rights issues? Does freedom of expression require positive government efforts to extend technological access and what would these look like?

Panel III: The Right to Health: Promoting Innovation and Equity

Friday 2:00-3:30 p.m. in Room 127 at Yale Law School

Christopher Mason, Weill Cornell Medical College of Cornell University

Thana Cristina de Campos, Fundação Getúlio Vargas Law School - Sao Paulo

Amy Kapczynski, UC Berkeley School of Law

Talha Syed, UC Berkeley School of Law

Moderator: Lisa Larrimore Ouellette, Yale Information Society Project

International human rights treaties, as well as domestic constitutions in many countries, recognize a universal right to the highest attainable standard of health, which includes a claim to effective and equitable access to health care. Realization of this right guarantee, however, has been complicated by the high costs of health care, in the context of limited available resources. These questions of access, affordability, and quality in health care are in turn intricately tied to issues of efficiency and equity in health care innovation, among other factors. Recent expansions of patent coverage have dramatically raised the cost of medicines in many parts of the world, and also introduced new questions of upstream innovation controls through gene patents. Technological innovations in eHealth hold great promise for improving access to healthcare and health information for the poor and underprivileged. Unfortunately, obstacles to effective eHealth include lack of open and interoperable standards, closed digital repositories and inaccessible scholarship, and technical infrastructure barriers. How will these developments impact access to health care in the years to come?

Some of the questions to be pursued by this panel include:

- In light of the increasing trend toward personalized medicine, what are the implications of genetic patenting for the right to health care?

- How has TRIPS implementation impacted access to medicines in developing countries? What implications does this have for constitutional treatment of the right to health in those countries affected?
- What solutions are promising for easing the tradeoffs currently experienced between innovation systems and access to health care? How can the tensions be resolved between conceptions of health and knowledge as public goods, and efforts to create markets for the supply of health innovations?
- What other ingredients of access to effective and equitable health care should an A2K framework be concerned with; for example, eHealth innovation, access to health information, technical infrastructures, training of personnel, etc.?

Panel IV: The Right to Education: Realizing the Potential of Digital Tools

Friday 4:00-5:30 p.m. in Room 127 at Yale Law School

Neeru Paharia, Harvard Business School & Peer 2 Peer University

Shai Reshef, University of the People

Luis Villarroel, Corporación Innovarte

Esther Wojcicki, Creative Commons/Palo Alto High School

Moderator: Carolina Rossini, Berkman Center for Internet and Society

International human rights instruments recognize a right to education. Within this concept, primary education should be “universal, free and compulsory.” Opportunities for secondary and higher education, however, are recognized to be contingent upon the resources available to states. This panel explores how the power of digital technologies, social networking and peer production may be leveraged to reduce the costs and improve the quality of traditional educational models, so as to expand enjoyment of the right. New social media and processes of globalization have profoundly shaped the world of education in the last decade. Digital education involves more than moving existing educational practices into online spheres: it holds the potential to constitute a fundamentally new type of education. The role of this panel is to examine the key issues around the construction process of this 'new' education.

Some of the questions to be pursued by this panel include:

- Does the greater cost-effectiveness of online venues strengthen the argument to recognize a more universal human right to higher education? Alternatively, could the availability of free online resources become an undesirable substitute for public efforts to promote traditional education?

- Is digital education more democratic than previous forms of education? How can we ensure that preexisting social inequities – of gender, race, class, and linguistic background - are not replicated or reinforced in ways that violate the right to equal educational opportunities?
- What are roadblocks to digital education in areas such as telecommunication policies, broadband infrastructures and access, and accreditation. What are the new business models or institutional forms that can support the expansion of digital education? What is the necessary role of the state and of companies that may not self-consciously see themselves as providing digital education, although their tools and services may be essential to this end?
- To what extent are copyright and market concentrations in software and Internet applications a barrier to the effective implementation of digital education? How significant are these barriers in comparison to other ones, such as minimum levels of technological access and literacy, linguistic barriers, cultural barriers, etc.?

Saturday, February 13, 2010

Panel V: Freedom to Innovate: Knowledge, Technology, Culture

Saturday 9:30-11:00 a.m. in Room 127 at Yale Law School

Edward Felten, Princeton University Center for Information Technology Policy
Ronaldo Lemos, Center for Technology & Society, FGV-Rio
Katherine Strandburg, New York University School of Law

Commentator: Nagla Rizk, Access to Knowledge for Development (A2K4D) Center at the American University in Cairo

We live in an age of decentralized innovation in which civil liberties and cultural freedom depend on the freedom to innovate and share innovations with others.

Increasingly, cultural freedom, access to knowledge, and freedom of expression depend on the ability of entrepreneurs to create new tools for sharing, producing, and distributing content. Increasingly, new ideas and new designs come from open source entrepreneurship communities in which loosely affiliated groups of individuals produce new knowledge and new technological tools. Innovation in software and hardware is inextricably connected to cultural innovation and the dissemination of knowledge.

For these reasons, we can no longer protect civil liberties without paying attention to innovation policy and particularly to the individual freedoms to create, modify,

distribute, and share advancements in information production and information technology. This freedom to innovate requires an open information infrastructure in which telecommunications policy, intellectual property laws, and technological architectures leave individuals free to build new things out of old, to remix, create, tinker, and repurpose.

Some of the questions to be pursued by this panel include:

- What policy areas (e.g. spectrum policies, open access) are the critical topics of study to address the freedom to innovate? To what extent is a human rights framing for these issues helpful or desirable?
- What are the technological and legal architectures that are necessary to give individuals the space and the opportunity to innovate? How do these structures rely on, enhance or inhibit the enjoyment of rights? Whose rights are counted in this story?
- Where will new content and information technologies come from and how we can empower as many different individuals as possible to maximize innovation? What is the role of civil and political liberties themselves in creating the conditions that facilitate innovation?

Panel VI: The Right to Science and Culture: Ensuring Access and Participation

Saturday 11:30 a.m. -1:00 p.m. in Room 127 at Yale Law School

Yvonne Donders, Faculty of Law of the Universiteit van Amsterdam

Eve Gray & Andrew Rens, University of Cape Town

Lea Shaver, Information Society Project at Yale Law School

Jessica Wyndham, AAAS Science and Human Rights Program

Moderator: William New, Intellectual Property Watch

Article 27 of the Universal Declaration of Human Rights recognizes the right of everyone to take part in cultural life, and to share in the benefits of scientific progress. This “right to science and culture” has great relevance for access to knowledge issues, but is still in the early stages of development.

This panel will explore the multiple faces and possible dimensions of the right to science and culture, examine the challenges and tensions inherent in conceiving of these goals as human rights, and identify ways for human rights and A2K advocates to utilize international human rights norms and fora, as well as national rights frameworks, to support related goals.

Particular attention will be paid to the Committee on Economic, Social and Cultural Rights' recently elaborated General Comment on the right to take part in cultural life, and the forthcoming process on the right to share in the benefits of scientific and technological progress.

Some of the questions to be pursued by this panel include:

- What are the most important current developments surrounding the right to science and culture? How do these relate to the discussions surrounding human rights and intellectual property?
- Should access to knowledge be understood as part of the right to science and culture? What would be the opportunities and risks of defining the right in this way? What conceptual problems would need to be solved?
- What are the possible alternative futures for the right to science and culture, as interpreted and applied in international human rights law? What impact could this evolving norm have on access to cultural and technological goods, and control of indigenous knowledge?

VII. Concurrent Workshops

Saturday 2:00-3:30 p.m. at Yale Law School

Workshop A: Identifying Challenges and Opportunities for an African Information Ethics

Saturday 2:00-3:30 p.m. in Room 121 at Yale Law School

Organized by the UW-Milwaukee School of Information Studies

Johannes Britz, School of Information Studies, UW-Milwaukee

Rafael Capurro, International Center for Information Ethics

Dennis Ocholla, University of Zululand

Moderator: Michael Zimmer, School of Information Studies, UW-Milwaukee

As our contemporary information society continues to take hold on the African continent, there is a pressing need to recognize and formalize an "African information ethics", that is, understanding and applying principles of information ethics (access to knowledge, intellectual property, information literacy, intellectual freedom, privacy) within the unique context of the African information and knowledge society. This breakout workshop will explore the challenges and opportunities for the establishment of an African information ethics, discussing issues ranging from the incorporation of African philosophy into Western ethical

frameworks, the development of information ethics curricula in African universities, and strategies for focusing attention on how the dilemmas triggered by the growing information and knowledge society within Africa impact the continent's economic, social, and political development.

Workshop B: The Right to Read: Copyright and Access for Persons with Disabilities

Saturday 2:00-3:30 p.m. in Room 124 at Yale Law School

Organized by Knowledge Ecology International (KEI)

Eric Bridges, American Council of the Blind
Daniel Gervais, Vanderbilt Law School
Marc Maurer, National Federation of the Blind
Luis Villarroel, Corporación Innovarte
David Hammerstein, Transatlantic Consumer Dialogue

Moderator: Manon Röss, Knowledge Ecology International

Persons who are blind, have limited vision, have dyslexia, or other disabilities face considerable challenges in access to books and other documents. New information technologies have provided expanded opportunities for presenting information in formats that are much more accessible, such as refreshable Braille, large type, synthetic speech, or in other formats that expand access. Many countries provide some exceptions to copyright, so that protected works can be published in accessible formats, without permissions from copyright owners. WIPO is considering a new treaty that would set global minimum standards for such limitations and exceptions, and provide for the cross-border import and export of formats of works created under such exceptions. This panel will discuss the proposal for a WIPO treaty for disabilities, as well as other topics concerning the right to read for persons with disabilities.

Workshop C: The Right to Development and the WIPO Development Agenda: Bridging the Gap between Human Rights and IP?

Saturday 2:00-3:30 p.m. in Room 128 at Yale Law School

Organized by the International Centre for Trade and Sustainable Development

Ahmed Abdel Latif, International Centre for Trade and Sustainable Development

James Love, Knowledge Ecology International
Stephen Marks, Harvard School of Public Health (invited)
Violette Ruppanner, 3D -> Trade, Human Rights, Equitable Economy

Moderator: Kaitlin Mara, Intellectual Property Watch

The right to development (RTD), proclaimed in 1986, is "an inalienable human right by virtue of which every human person and all peoples are entitled to participate in, contribute to, and enjoy economic, social, cultural and political development, in which all human rights and fundamental freedoms can be fully realized." It requires the international community to promote fair development policies and effective international cooperation. The WIPO Development Agenda (DA), adopted in 2007, is a landmark initiative to ensure that IP rights are addressed within the broader context of economic, social development and the public interest. From this perspective, the implementation of the WIPO DA has enormous potential for advancing the implementation of the right to development. At the same time, a human rights based approach, exemplified by the right to development, can also positively contribute to the effective implementation of the WIPO DA. However, this interconnection remains relatively unknown. The WIPO DA implementation process is not closely followed by the human rights community and the relevance of the RTD framework is often not well understood in the IP community. How can this gap be bridged? The aim of the panel is to examine possible linkages and synergies between the WIPO Development Agenda implementation process and the Right to Development in the context of the wider nexus between intellectual property and human rights. Achieving greater coherence between the two requires a sustained effort of dialogue, information and policy analysis and research. The review by the High Level Task Force on the RTD of the WIPO DA within the framework of its work plan for 2008-2010 could provide a valuable opportunity for this purpose.

Panel VIII: Rights-Based Strategies for Promoting Access to Knowledge

Saturday 4:00-5:30 p.m. in Room 127 at Yale Law School

Shyam Balganesh, Penn Law School
Audrey Chapman, University of Connecticut Medical School
James Love, Knowledge Ecology International
Alice Miller, UC Berkeley School of Law

Moderator: Violette Ruppanner, 3D -> Trade, Human Rights, Equitable Economy

Much of the conference has focused on synergies between access to knowledge and human rights goals in specific subject areas. The concluding panel will discuss more

generally the broader challenges and opportunities implicated by attempts to promote A2K goals through a human rights framework.

Some of the questions to be pursued by this panel include:

- What are the different forms that human rights advocacy takes today, and what are the different fora to which public interest advocates should be attentive? How influential are these strategies and tactics, or is human rights law ineffectual in comparison to trade and other international legal frameworks?
- Where are there gains, gaps, contradictions or retrenchment in rights? What are the fault lines in human rights frameworks and how would or should A2K 'take sides' in rights fights?
- Is an increasing judicial role in the design of intellectual property regulation appropriate or desirable? How would this likely differ from the current system, which is dominated by legislative regulation and, especially in the increasing realm of treaty negotiations, executive leadership?
- How does the less well developed and more controversial nature of economic, social and cultural rights claims impact the prospects for advancing access to knowledge as a human right? To what extent can these goals be achieved through a more traditional, liberties-centered approach, or do they necessarily rely on being able to advance positive rights claims?