Main ethical issues and challenges in bioethics from the gender perspective in Education: the work of the UNESCO Chair in Bioethics at the University of Barcelona

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Abstract: This chapter will outline the contributions made by the UNESCO Chair in Bioethics at the University of Barcelona at “UNESCO Conference on Gender and Bioethics” held in Kazan on 21 and 22 November 2011, at the request of UNESCO. Mention is made of the function of the UNESCO Chair in Bioethics at the University of Barcelona under the auspices of the Bioethics and Law Observatory Research Centre a the University of Barcelona, which has introduced the perspective of gender into its various lines of work based on a concept of bioethics linked to international recognised human rights. Thus the actions carried out on bioethics connected to gender in the fields of research, teaching and transfer of knowledge will be analysed herein. Lastly, special mention is made of the research project funded by the Spanish Agency of Cooperation for Development (AECID) to empower women in the field: “Gender & Bioethics: Women’s Autonomy in Health Care” which has been carried out by the Chair focused on education and capacity building in bioethics integrating the gender perspective.

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1. The function of the UNESCO Chair in Bioethics at the University of Barcelona: a brief introduction
The UNESCO Chair in Bioethics at the University of Barcelona was established in 2007 under the auspices of the Bioethics and Law Observatory Research Centre (OBD) at the University of Barcelona (UB) to disseminate a multidisciplinary, global and flexible concept of bioethics linked to internationally recognized human rights. The aim is to extend the work done at OBD in the fields of research, teaching, and knowledge transfer to other countries, specifically Latin American countries. In this sense, it is oriented to facilitate collaboration between highly qualified researchers and distinguished professors from universities and higher education institutions in Spain, Europe, America and Latin America and the Caribbean in addition to other areas in the world. Sharing methodologies and developing training activities that can be consolidated and long-lasting through the creation of international networks which focus on research and teaching in bioethics, has been one of the main goals and now it can be said it is one of the achievements.

The Bioethics and Law Observatory at UB was created in 1995 linked to the Masters Degree in Bioethics and Law at the UB. It is focused on analyzing the ethical, legal and social implications of biotechnology and biomedicine from a secular point of view. The aim is to provide reliable information and arguments to encourage social debate and independent decision-making, thus contributing towards a more transparent and democratic society. Scholars from various Spanish, European and international universities, and also several professionals form part of the OBD conducting research, teaching and spreading a concept of bioethics along the lines laid down by UNESCO’s Universal Declaration on Bioethics and Human Rights.

As pointed out by UNESCO, the UNESCO Chair in Bioethics at the University of Barcelona is part of the UNITWIN network of UNESCO Chairs whose aim is to facilitate regional cooperation among universities and also UNESCO in the field of higher education and awareness of bioethics. Today of the 715 UNESCO Chairs that exist in the world, 8 are specialized in Bioethics, and the University of Barcelona’s UNESCO Chair in Bioethics is the only one of its kind in Spain. As regards setting up networks and promoting contact among the UNESCO Chairs in Bioethics, UNESCO has made an effort from the former Bioethics section (now work group) headed by Dafna Feinholz to link the Chairs and project their work onto UNESCO and internationally. The Kazan Conference is one such example.

2. Research, teaching and knowledge transfer actions in Gender & Bioethics

The Bioethics and Law Observatory -UNESCO Chair in Bioethics at the University of Barcelona accomplishes its functions through research, teaching and knowledge transfer activities in the field of Bioethics and Human Rights. This part illustrates the activity carried out focused on introducing the gender perspective in bioethics and the projects recently set up with a view to the future. As a prelude it should be noted that part of the work conducted has had a great impact on society not only by promoting debate on bioethics but also on scientific associations involved depending on the topic treated such as assisted reproduction or women and science. Finally, as a basic contribution of this interdisciplinary research group in bioethics, the work of the Observatory of Bioethics and Law - UNESCO Chair in Bioethics has had an impact on changing regulations in laws. Lawmakers have taken into account the research and proposals made by the OBD Chair when reviewing the regulations to adapt it to social reality social

a) Research

Research financed solely with regional, national and international public funds, in which the projects are assessed by peers, represents the cornerstone of the activities carried out by the OBD-UNESCO Chair in Bioethics at UB. A body of knowledge is created which needs to be transferred to society based on interdisciplinary work.
At the heart of the OBD-UNESCO Chair in Bioethics at UB a “Bioethics, Law and Society” research group has been set up and is recognized by the Government of Catalonia. It has worked on such items as the legal and social implications of ethics as regards Alzheimer and assisted human reproduction which was financed by the former ministry of education and included donating oocytes or stem-cell research. Both when analyzing Alzheimer and assisted human reproduction, bioethical subsequent analysis required introducing a gender perspective bearing in mind considerations based not only on feminism but also on the social constructions of the meaning of gender and economic determinants. In Spain, for instance, it is true that women live longer, but they are also the ones burdened with dependent persons and thus become completely indispensable minders in a system that presently cannot provide social care due to the economic crisis. Women must thus give up their life plans to care for relatives.

In the field of assisted human reproduction, the gender perspective takes on a fundamental role both for those who defend these techniques and for those who criticize them for turning women into an ovule container for reproduction without bearing in mind the physical and psychological strain involved in undergoing these processes. The donation of oocytes is another instance, and also surrogate mothers. The situation of vulnerability, discrimination and even exploitation which women may have to face is part of the bioethical analysis from the gender perspective.

Another project carried out with funding from Spain’s Ministry of Science and Innovation involved analyzing the legal and social ethical implications of nanotechnologies. Under the acronym of NANOBIOLAW one of the fields of work carried out in the project was to analyze to what extent nanotechnology can contribute to achieving at least some of the objectives of the Millennium Development proposed by United Nations. Again from the viewpoint of bioethics, gender takes on a leading role. For instance the principle of social responsibility and health included in the Universal Declaration on Bioethics and Human rights points out that the breakthroughs in science and technology should promote issues such as the access to quality medical care and medicine that is essential for women and children. We should not forget that the objectives of the Millennium Development include, in addition to gender equality, improving the health of mothers and their babies and reducing poverty and illiteracy, issues which directly affect women. Recently, the OBD-UNESCO Chair in Bioethics at UB developed a project financed by the AECID on giving more powers to women in health care by promoting their autonomy. Since this is the latest initiative and specifically addresses the training and education in bioethics and gender, it will be discussed in the last section of this chapter. On its own initiative the OBD-UNESCO Chair in Bioethics at UB Chair has addressed sexual and reproductive health in adolescence and the voluntary interruption of pregnancies, examining the legal status in Spain and carrying out an analysis of comparative law which has enabled the publication of the Opinion Group’s findings to address the dialogue between universities and society.

Another line opened by the OBD-UNESCO Chair in Bioethics at UB is research and teaching in bioethics by building networks. This can be witnessed from the project funded by the EU’s Alfa Programme, whose good practices are based on building networks to teach bioethics as a comprehensive subject in universities involving many specialities subsequently received a special mention. European and Latin American universities have taken part in this project and, as regards gender, among other issues, it has enabled us to show that the most relevant voices in bioethics are mostly female academics and professionals. Regarding the above, also proposed by OBD-UNESCO Chair in Bioethics at UB, at the beginning of 2000, it was deemed necessary to begin research on the status of female academics. The findings were published by the Opinion Group at the Observatory of Bioethics and Law. Thus, by using research it carries out, the work of the OBD-UNESCO Chair in Bioethics at UB has gradually focused on gender, and also the
field of education and training in this subject. As may be seen in the following pages, as regards training there has been a move from teaching bioethics towards bioethics and gender.

The projects now underway and those left for future research are themes such as integrating gender into research following the programmes established by the EU. As pointed out by the European Union, the projects that are assessed to obtain funding from the European Union’s Framework Programmes are examined from the viewpoint of gender and the research team that receives these European funds must include gender in their proposal for research, which is highly appraised. For this line of work, the Toolkit developed by the EU is used and allows one to see how the issues of gender are addressed and thus contribute to excellence in research, including equal opportunities for men and women. This line of research has a priority within the already published work group on women and science. One of the objectives is to promote good practices which can be included when preparing research proposals, not only in Europe but also for international, national and regional applications for aid.

The participation of women in research on bioethics is now being studied. Again the viewpoint of gender brings together the issue or better said layer of vulnerability and exploitation and for instance the lack of specific findings on the effects of medication on women since the tests have been carried out only on men. Spain’s regulations regarding biomedical research have begun to address these issues since 2007, that is, to establish specific regulations on the participation of women, pregnant women and those who breastfeed in research projects. These changes together with in-depth bioethical issues will be addressed in future research. Another project underway is to analyze the issue of the participation of women in ethics committees both as members and researchers, especially when Spain’s laws regulating the conditions of setting up and accrediting committees establishes parity in this sense. Thus the participation of women in national or international ethics or bioethics committees is important.

It is not difficult to see why these lines of work are prized above others by the OBD-UNESCO Chair in Bioethics at UB. Several members of the group are also members of bioethics committees and commissions who carry out their work in various areas such as Spain’s Committee of Bioethics, the Bioethics Committee of Catalonia, the Committee of Care Ethics and the Ethics Committee of Research at Hospital Clinic in Barcelona or the University of Barcelona’s Bioethics Committee. Thus, besides detecting possible problems and loopholes where more research is required, the findings obtained have some impact on the various authorities and fields through the Group’s members.

The findings of the research carried out have been published in various monographic works by highly reputed publishers both in Spain and also internationally. Worthy of mention is the Chair’s active participation in the publishing of the collection “Issues in Bioethics” published by Civitas Thomson Reuters in hard cover and e-book (www.bioeticayderecho.ub.es/publicaciones). Among the works published, worthy of mention as regards Bioethics in and from Latin America coordinated by Prof. Maria Casado, chairholder and Prof. Florencia Luna (FLACSO, Buenos Aires Argentina) or On Bioethics and Gender in Health, coordinated by the former which is due to appear in late 2012.

Since 2004 the Bioethics and Law Observatory has published an electronic quarterly open journal –Journal of Bioethics and Law: www.bioeticayderecho.ub.es/revista- directed by Prof, Maria Jesús Buxó and Prof. Maria Casado. The Journal serves as a platform for publishing the findings of research published by the group, professors invited in exchange programmes and also manuscripts sent by scholars and professionals which analyze a range of issues from the viewpoint of bioethics. At the moment the magazine has several already consolidated sections which have been successful among readers such as the section of animal bioethics or the section
of Bioethics and Cinema under the direction of Prof. Ricardo García Manrique from the University of Barcelona in which commercial cinema is analyzed from a bioethical viewpoint. Films of worthy of analysis from the gender viewpoint such as Vera Drake or The Cider House Rules are discussed openly. The Journal is indexed for instance in main repositories in Spanish language such as Scielo, Redalyc and also in DOAJ.

b) Teaching & capacity building for members of ethics committees

The members of the OBD-UNESCO Chair in Bioethics at UB carry out tasks of teaching at the various levels of degree courses, Postgraduate courses, Doctorates and Masters in both the UB and also other Spanish and foreign universities. From the outset of the Alfa Project has aimed and due to students of different editions of the Master in Bioethics and Law at UB coming from different backgrounds and who, on finishing their studies, joined the networks built up by the OBD, it may be said that introducing bioethics into the syllabuses in various universities is still an active work line from the perspective of teaching.

In 2008 the line of research into bioethics and law was begun as part of the University of Barcelona’s PhD programme in law and political sciences, adapted to the Bologna programme and headed by Prof. María Casado. To date two women have read their doctoral theses and another two are about to read their theses, and these deal with issues such as assisted reproduction techniques and conscientious objection in the health, both integrating a conception of bioethics with a gender perspective.

Recently, following the publication of the core curriculum in bioethics by UNESCO the members of the group have introduced it as part of their teaching objectives in the various degree and post-degree courses. This is the case of the University of Barcelona’s Master in Bioethics and Law at the University of Barcelona organized by the OBD-UNESCO Chair in Bioethics at UB headed by Prof. María Casado, a pioneer in establishing and promoting the relationship between bioethics and human rights in Spain.

The Masters Degree in Bioethics and Law is a post-graduate study course offered by the University of Barcelona associated with UNESCO’s Ethics Education Programme. It is a two-year course and represents 90 ECTS credits; it may be undertaken entirely by distance-learning through the virtual campus, which includes the opportunity to attend teaching sessions every January.

The Master’s Degree is orientated towards the education and training in bioethics of healthcare professionals, members of ethics committees, legal practitioners and in general of individuals who are interested in obtaining an overall, flexible and integrated picture of bioethics set against a background of respect for recognised human rights, and in acquiring interdisciplinary training to facilitate rational decision-making in the face of problems stemming from scientific progress.

The teaching staff on the course is made up of professionals and academics of recognised standing. The methodology is adaptable to the needs of individual students from different professional and geographical areas.

At the OBD-UNESCO Chair in Bioethics at UB personalized training is provided and courses are held providing a la carte training in bioethics to prepare members of ethics committees which include attendance or research and are also held at a university level. For these training courses, which attempt to address the demands of each institution and person who request them, not only the UNESCO Core CV in bioethics is used but also the guidelines published by UNESCO on ethics committees as part of the Assisting Bioethics Committees Programme.
c) Knowledge Transfer

The OBD-UNESCO Chair in Bioethics at UB Opinion Group, as mentioned above, have published opinion documents on issues which are part of the contents of bioethics and which worry and even divide society. With the intention of taking part in the dialogue between university and society, the Opinion Group was set up in 1996 to analyze the social, legal and ethical implications of the latest technologies and biomedical problems from an interdisciplinary viewpoint based on scientific evidence. The aim is to promote debate and awareness in bioethics by transmitting scientific-technical knowledge and the necessary arguments for citizens to be able to make informed decisions. In this dialogue between the university and society the media are especially important due to the impact they have to create public opinion, but also to improve the quality of information. The group’s announcements following publication of its research include recommendations for the scientific associations involved and for public authorities with the aim of promoting change in legislation for example or drafting regulations and policies in line with social awareness.

Assisted human reproduction and related issues have been discussed by the OBD’s opinion group in the last decade. The change in the law on assisted human reproduction techniques which was passed in 2006 and the enactment of the law on biomedical research in 2007 in Spain considered recommendations issued by the group such as the donation of oocytes and stem cell research. This was highlighted by analyzing several regulations in the document published in 2008 to show its impact on the law. Sexual and reproductive health in adolescence and voluntary interruption of pregnancy were issues discussed in documents published in 2003 and 2008 respectively, and which also had a notable impact. As pointed out earlier, they not only had a social impact but also lawmakers used them to address and change the law concerning issues which surround public health and the recommendations issued by the Group also directly affect women. All the Group’s documents are published openly in Catalan, Spanish and English (www.bioeticayderecho.ub.es).

The work carried out by the OBD regarding the role of women in the teaching world has already been pointed out. The Document on Women and Science published in 2004 studied the academic and professional presence of women in science. A number of shortcomings were detected and thus there was a need to adopt gender policies to overcome discrimination against women in public and private research and teaching. Solving underrepresentation demands informed social debate to determine actions to be taken and the necessary legislative changes.

c.1) Networks

The transfer of knowledge created at the OBD-UNESCO Chair in Bioethics at UB is projected through the international networks of teaching and research coordinated by the research centre and this has been continued in the wake of the aforementioned Alfa Project and funded by several contests held by the AECID. The experience and methodology of the Observatory of Bioethics and Law at UB have been transferred to several universities and countries through networking, especially its expertise in training in bioethics and to create and implement bioethics committees in universities, hospitals and other institutions in the member countries.

Below special mention is made of the IberoAmericanNetwork, which belongs to the International Association of Bioethics and has taken up the challenge of spreading the tasks carried out through networks in all Latin American countries. Firstly, this network is worthy of mention because it is coordinated by relevant female scholars and researchers in bioethics who
have dealt with the issue of gender such as Florencia Luna, Debora Diniz and Maria Casado. Also these three head bioethics research and teaching centres such as the Observatory of Bioethics in Argentina (FLACSO), which coincidentally used the University of Barcelona’s Observatory of Bioethics and Law as a model; the Instituto ANIS, in Brasilia and the Bioethics and Law Observatory - UNESCO Chair in Bioethics at the University of Barcelona. Secondly, because the network has considered it fit to choose as the main theme of the special session of the IAB at the 2012 Congress in Rotterdam issues surrounding “reproductive health: Women’s Autonomy in Health Care”, and thirdly because the network aims to analyze from the perspective of bioethics specific problems in each region by promoting intercultural activities. One of the aims of this network is to foster the value of free, open, and reasoned discussion in order to reach thoughtful and reasoned positions regarding many of the bioethical problems faced by Latin America or that may be of interest to the people of this region. As an anecdote, it is worth mentioning that the number of women attending the session in Rotterdam and those taking part in it outnumber the men. The participation in this network is open to anyone who is interested and who complies with the established requirements and is authorized by the IAB of which IberoAmericanNetwork is a member.

c.2) International Seminar on UNESCO’s Universal Declaration on Bioethics and Human Rights

The OBD-UNESCO Chair in Bioethics at UB also contributes to raising the awareness and encouraging public debate of Bioethics, as advocated by UNESCO, by organizing an annual international seminar at the University of Barcelona open to the university community, professionals and the general public, and dedicated to disseminating and analyzing the principles of bioethics and human rights included in the Declaration. From the outset these seminars have addressed issues such as social responsibility and health linked to justice and the concept of risk, autonomy in health care, privacy and data protection in the field of health and conscientious objection in the health sector. The Chair receives support from the regional government’s Department of Economy and Knowledge to organize the international seminar.

3. Gender & Bioethics Research Project: Women’s Autonomy in Health Care

In late 2010, the OBD Chair began a research project entitled “Gender and Bioethics: Autonomy of Women in Health Care” which was funded by AECID with the aim of training legal agents in charge of allotting health resources and benefits focused on bioethics and gender. Furthermore the aim was to provide training for those in charge of making legal decisions to solve disputes and deal with complex situations which arise in their jobs. The main issue is women, and those attending the classes in the project are persons in charge of making decisions regarding health, civil servant, judges, practitioner, lawyers and teachers, among other. The project aims –through teaching and capacity building- to give women the power to make decisions regarding their health and the health of those who depend on them, such as children and the elderly, and who are often sick. To promote autonomy in health care by helping to establish the conditions so that autonomous decision-making can become a reality.

Several Latin American universities participated in the project led by the OBD-UNESCO Chair in Bioethics at UB together with various other agencies that carry out work in the health sector and medical insurance together with members of the judicature. This is not the first time the OBD-UNESCO Chair in Bioethics at UB has been in charge of a research project to train people in such skills by developing a style of networking using their own methodology, which is not
only applied throughout the period covered by the funding but is also sustainable in a longer term, since those attending are expected to gather and apply the skills learned by continuing to develop this methodology and expertise. The cost of the training is quite low since those attending the courses will use the training in their tasks once they finish the course and will hopefully apply what they have learned in their daily work.

The precedents of this project, specifically focused on studying the problems of gender and health as a main theme in bioethics, lie firstly in the aforementioned ALFA project carried out with the aid of the European Union to prepare syllabuses in the universities taking part that will include bioethics as a comprehensive subject. Later, the baton of the ALFA project, which has become a stable research and teaching network in bioethics, has been taken up by two research projects funded by the AECID: a joint postgraduate course in bioethics for judges, legal agents and members of ethics committees. The previous experience of collaboration among various groups specialized in bioethics can clearly be seen and these are, furthermore, led by women. The number of universities and schools taking part has increased with each project following applications received from those willing to take part in the network once the success of these courses to adapt to local needs was proven, and this is based on certain common ideas such as respect for internationally recognized human rights and how bioethical issues in the field of health are dealt with which necessarily require a focus on gender.

That the AECID should have funded a project of these characteristics led by the University of Barcelona through the OBD-UNESCO Chair in Bioethics at UB implies recognition of the work carried out by this Chair in the field of cooperation and transfer of knowledge among universities and society to promote the policies and priority lines of action in bioethics established by UNESCO from the moment it was set up. Hence the work of this Chair has been recognized as fostering social debate and educating and training in bioethics and it is committed to disseminate and put into practice principles contained in the 2005 Universal Declaration of Bioethics and Human Rights focused, in this particular project, on gender in bioethics. Social responsibility and health, respect for human vulnerability and personal integrity, equality, justice, fairness and non discrimination and stigmatization together with respect for cultural diversity and pluralism are all highlighted from the viewpoint of gender in bioethics and serve as the basis for developing the project to carry out a training strategy which includes developing specific methodologies and materials.

Another of the project’s cornerstones has been the United Nation’s Millennium Objectives of Development where equality between genders and improving the health of mothers and babies have become one of the fields which need to be explored from the perspective of bioethics and gender in health to detect problems locally and to draft proposals to teach and train and also foster the social debate to develop and change specific policies regarding gender and health.

From a practical viewpoint, as regards groups belonging to the project, the issue of dealing with gender in health care is seen as a priority and this is achieved through training and capacity building, setting up ethics committees in various fields which would include women, and which would deal with those issues that particularly affect women in health care, always with the aim, as mentioned earlier, of promoting the autonomy of women to make decisions in health care,
both decisions concerning themselves and those concerning the persons who depend on them. Setting up ethics committees is another of UNESCO’s priorities and the University of Barcelona’s UNESCO Chair in Bioethics also prioritizes and promotes these practices in its projects. Not only setting up ethics committees but also encouraging the establishment of networks of ethics committees where experiences can be shared, learning from one another’s mistakes and developing methodologies and work procedures to enable them to deal with the problems and detect loopholes.

One of the clearest outcomes in this sense has been the rise in the quality of health care and the fall in disputes and subsequent lawsuits. Consider for example the doctors working in primary health care or judges. The aim is to contribute to gender equality by defending human rights specifically related to the fair treatment of women in health care, promoting autonomy in health care and fostering the development of strategies to help women make decisions and respect for them become a reality while promoting respect for women’s decision-making among those involved in the project.

As regards the procedures used to achieve the objectives established and for these to be transformed into tangible results, in addition to periodical meetings to share experiences and create common work methods, the Chair offers an on-line area for work coordinated remotely where the parties can report and share information both during the project and once it has finished. These face-to-face meetings together with the permanent contact provided by the new information technologies are aimed at generating a specific body of knowledge and experience in bioethics and gender in health care, which includes the contributions made by each party and systemizes the work carried out by each group. At the time of writing this article, the book entitled *On Bioethics and Gender in Health* was being printed and this is the ideal platform in which to publish the results of the project.