



norden

Nordic Committee on
Bioethics

Summary of conference: Prenatal Diagnosis – Individuals and Society

In December 2010, The Nordic Committee on Bioethics (NCBio) and The Norwegian Biotechnology Advisory Board organised the conference Prenatal Diagnosis – Individuals and Society. The conference was held at Holmenkollen in Oslo, Norway, and there were 150 participants from a range of disciplines.

Prenatal diagnosis raises ethical questions both for the pregnant women/couples and the society. How much should the parents-to-be know about possible disease risk in the coming child, which conditions could be treated with foetal medicine, and which could be a reason for considering selective abortion? Is the public health system making a value statement when groups of pregnant women are offered prenatal diagnoses for free to look for Down's syndrome? The different Nordic countries have chosen different regulatory regimes for prenatal diagnosis and might benefit from each other's experience.

The subject of the conference was to discuss the ethical challenges of current prenatal diagnosis, and how the solutions of today might be challenged when new technology will make foetal genomic information available early in pregnancy.

What can be learned from the experience with various regulatory regimes? Will the development in genomic medicine challenge the way prenatal diagnosis is conducted? Is there a need to revisit the ethical dilemmas and prepare for new regulations?



Foto: Scandinavian Stockphoto.

The first day of the conference consisted of an overview both of the methods offered today, what they reveal and

of the regulatory differences in the Nordic countries. There were also reports on how prenatal screening is experienced by the women. Central to the debate at the first day of the conference, was the concept of choice and autonomy for the pregnant woman and the role of the state in risk assessment.

In Norway, screening for Down's syndrome is offered to selected groups only, like women older than 38 years. The Biotechnology Act is now being evaluated, and the age criterion is among the areas being debated. A steep fall in the number of babies born with Down's syndrome, as was observed in Denmark when risk assessment was made available to all, is viewed by many Norwegians as an unwanted "sorting society".

On the second day of the conference, the focus was on testing the foetal genome, which might soon be available as a screening early in pregnancy.

With the possibility of prenatal genomic testing, parents and doctors might be faced with the question of whether to examine and reveal information about genetic risks for future diseases in the coming child. If this information is revealed early in pregnancy, it might lead to termination of the pregnancy for less serious conditions than today. Should there be any limits to how much information the parents can get about the genetic constitution of their unborn child?

The Danish Council of Ethics has addressed these questions, and members of the council presented their report "Fremtidens fosterdiagnostik" at the conference. The council is of the opinion that prenatal genomic testing should be used only to reveal whether the foetus has a serious condition or disease that could be the reason for an abortion. No more genetic information should be generated than what the parents should have legal access to.

The consequences for individuals and the society of genomic prenatal testing early in pregnancy were addressed in the last session of the conference. How do we deal with uncertain information? Would parents be held responsible for their children's genes? Is there a need for new regulation?

What seemed clear, is that prenatal diagnosis and screening is likely to change considerably in the years to come, and make available a flow of genetic information about the foetus long before the pregnancy is visible. This will certainly warrant further attention and ethical consideration.

Speakers at the conference:

Klavs Birkholm, The Danish Council of Ethics, Denmark
Olav Bjørn Petersen, Aarhus University Hospital, Denmark
Grethe S. Foss, The Nordic Committee on Bioethics and The Norwegian Biotechnology Advisory Board
Sturla Eik-Nes, St. Olavs Hospital, Norway
Ilpo Helen, University of Helsinki, Finland
Janne Rothmar Herrman, The Nordic Committee on Bioethics
Thomas G. Jensen, chair, The Nordic Committee on Bioethics
Jón Jóhannes Jónsson, University of Iceland and University Hospital, Iceland
Hildur Krisjtánsdóttir, The Directorate of Health, Iceland
Rurik Löfmark, Karolinska Institutet, Sweden
Søren Pedersen, Aarhus University Hospital, Denmark
Sølvi Marie Risøy, Sogn og Fjordane University College, Norway
Annukka Ritvanen, National Institute for Health and Welfare, Finland
Ola Didrik Saugstad, Oslo University Hospital, Norway
Nete Schwennesen, University of Copenhagen, Denmark
Sirpa Soini, The Nordic Committee on Bioethics
Berge Solberg, Norwegian University of Science and Technology, Norway

Presentations from the conference can be seen at the homepage for the Nordic Committee on Bioethics:
www.ncbio.org

The Nordic Committee on Bioethics (NCBio) was founded in 1989 to promote Nordic cooperation and exchange of information between scientists, parliamentarians, opinion leaders and public officials in the area of bioethics. NCBio organise yearly public conferences and symposia. The Committee publishes reports and other publications to promote Nordic and international debate on bioethical issues.

