IF Position Paper Prenatal Counselling
DRAFT
Introduction

In 1970 it was not possible to identify open neural tube defects (NTDs) in pregnancy; in 1980 it was. During this decade the science of prenatal screening was born. [Wald, Nicholas J. (2010) Prenatal screening for open neural tube defects and Down syndrome: three decades of progress (UK) – Historical Perspectives - Prenatal Diagnosis, Volume 30 Issue 7, Pages 619 - 621]

The question was raised, should ultrasound technology be used when a clinical problem was evident or suspected or should ultrasound be offered to the total pregnant population. The basic reason for the routine use was that a disorder/maldevelopment of the pregnancy, such as misinformation of the gestational age, placenta praevia, twins, anomalies, growth retardation, is not necessarily recognised by clinical means. In the following years, official health authorities in a number of countries decided to introduce routine ultrasound scanning as an offer. [Eik-Nes, Sturla H. (2010) The 18-week fetal examination and detection of anomalies – Review of current practice (Norway) - Prenatal Diagnosis, Volume 30 Issue 7, Pages 624 - 630]

Screening procedures in which healthcare providers approach a healthy population in order to detect deviations from normal are guided by recommendations aiming at ensuring that the benefits outweigh the potential risks. Patients need to be well informed about the aim of the procedure, the fact that it is an option to which they can say yes or no, and possible fetal risks. Studies of women’s expectations on routine ultrasound examination during pregnancy and how they interpret the information given suggest that informing women about the second-trimester scan is a great challenge. Pregnant women are not always aware that the examination is not compulsory. Also, they may have unrealistic expectations of the capabilities of the scan, patient expectations being focused primarily on getting reassurance that the baby is healthy. [Second-trimester routine ultrasound screening: expectations and experiences in a nationwide Swedish sample - Georgsson Ohman, S., Waldenström, U.; Ultrasound Obstet Gynecol 2008; 32: 15–22]

Improved resolution of ultrasound scans and greater expertise of operators have led to increased detection rates of fetal structural anomalies at earlier gestations. A variety of national policies or recommendations concerning prenatal screening and diagnostic testing for Down’s syndrome and ultrasound screening for structural anomalies have been developed in different countries and areas within countries. [Boyd P.A., de Vigan C., Khoshnood B., Loane M., Garne E., Dolk H. and the EUROCAT Working Group (2008), Survey of Prenatal Screening Policies in Europe for Structure Malformations and Chromosome Anomalies, and Their Impact on Detection and Termination Rates for Neural Tube Defects and Down’s Syndrome, BJOG, Vol 115, pp 689-696]

Many expecting parents agree to an ultrasound examination without realizing that the findings could put them in a situation of urgent decision-making. They appreciate the information about their unborn child that is gained through this diagnostic technique.

While the technical side of the examinations is judged to be trustworthy and serious, the communication between the expecting mother and the medical personnel leaves much to be desired. Institutes which care for women who are confronted with suspicious findings should develop guidelines for the correct means of caring for such extremely distressed people. It is also necessary to develop a concept for cooperation between doctors, nurses, chaplains, social services, and psychologists. [Centre for Technology Assessment at the Swiss Science and Technology Council (2001) Psychosocial Aspects of Ultrasound Examinations during Pregnancy; Baby Sighted]
Towards informed and unbiased decision-making

The discovery of a foetal abnormality in pregnancy is an extremely stressful experience for parents. In countries where abortion is an option, parents may need to decide whether to continue or terminate the pregnancy while they are still in a state of shock after receiving the adverse diagnosis.

It is important that health professionals do not influence the choices the parents need to make and they need to be aware that they may, inadvertently, influence parents by their words, body language and tone of voice. The parents’ decision must be in line with their personal beliefs and values, and only they can know what is right for them. They also need to understand that their decision will not affect the quality of the further care they receive.

All health professionals will need to be sensitive to the difficulties that detection and diagnosis of problems raise for some parents and help them overcome these.

When helping parents to make an informed decision you should bear in mind that it:

- is a partnership between the parents and the health professional
- involves exchanging information, communicating with and listening to each other
- may take time for the parents to make their decision
- involves presenting and considering more than one option
- takes into account evidence, risks and beliefs
- respects the parents’ autonomy.

NHS Screening Programmes Fetal Anomaly; 2.2.1 Helping women to make an informed choice

- Prenatal counselling for parents should be carried out by skilled professionals in a multidisciplinary team.
- Counselling should be supportive, focusing on all aspects of life with and for a child with impairments.
- The initial counselling should not be linked with termination or abortion.
- Parents deserve time to adapt to this new situation before being confronted with a proposal to terminate the pregnancy.
- After diagnosis, professionals should work with parent organisations to ensure that information is up-to-date, correct, and understandable for parents.

IF Resolution on Prenatal Diagnosis and the Right to be Different

- Spina Bifida and/or Hydrocephalus should never be an argument not to provide available life-saving and life-improving treatment.
- Parents should be informed about all recent scientific advances that have improved considerably the quality of life of people with Spina Bifida and/or Hydrocephalus, and about legislative initiatives, including non-discrimination and human rights legislation, which offer more legal protection to disabled people and their families.
- Parents should feel free to make fully informed decisions.
- Any explicit or implicit bias, practice or procedure in counselling that devalues the worth of the life of people with Spina Bifida and/or Hydrocephalus is a form of discrimination and is in breach of human rights principles and may be open to legal challenge.

IF Resolution on Active Termination of Life of Newborn Children with Spina Bifida and/or Hydrocephalus and the Right to Live
What kinds of support do parents need?

Parents may need different kinds of support at different stages during the screening process:

- They may need to make decisions based on concepts of risk – and will need information and support, and plenty of time to discuss complex information
- They may be given an uncertain result or a diagnosis they don’t understand – and will need clear and straightforward information and plenty of time to ask questions
- They may be given a distressing result – and will need respect, privacy, empathy, and information that they can absorb in a state of shock
- They may be given an antenatal diagnosis, have decided to continue with the pregnancy, and want to know more about how the condition will affect their child’s future – and will need to be given as much information as is available at the time of diagnosis about the birth, the predicted quality of life of the child, services available after the birth, and sources of detailed information, eg a local support group, or a national organisation
- They may be given an antenatal diagnosis and need to decide whether or not to terminate the pregnancy – and will need to be given time time to reflect and ask questions, information about the condition and national organisations, and to be treated with respect and empathy once they have made their decision
- They may be given a postnatal diagnosis – and will need respect, privacy and information about the condition, and time to consider the next stage and the treatment options available.

Depending on their situation and the arrangements in your service, this support may be given to parents by:

- Their GP
- The consultant
- The ultrasonographer
- A geneticist
- Their midwife
- Their health visitor
- A specialist screening midwife (local coordinator)
- A paediatrician (if continuing with the pregnancy)
- A counselor
- A bereavement counselor
- A chaplain or other religious representative
- A volunteer
- National organizations
- Local organizations
- Friends
- Family
- Information leaflets and booklets provided by your service
- Information provided by national and local organisations – leaflets, books and websites
- Books

or a combination of some or all of these.

Screening Choices: A resource for health professionals offering antenatal and newborn care. Unit: The parent perspective on screening, Revised November 2005
Literature

IF Documents
- IF Resolution Prenatal diagnosis and the right to be different – Toulouse, 2000
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Spina Bifida/neural tube defects

NHS Programmes
- NHS Fetal Anomaly Screening Programme
- NHS Antenatal and Newborn Screening Programmes

Screening policies in Europe

Informed consent/prescan and preconception counselling
- Nota Preconceptiezorg, Versie 1.0 – Nederlandse Vereniging voor Obstetric en Gynaecologie, 28-05-2008
Diagnosis of fetal abnormality

- Lalor, J. et al (2007) Unexpected diagnosis of fetal abnormality: Women’s encounters with caregivers (Ireland) - *Birth, Volume 34 Issue 1, Pages 80 - 88*
- Alkazaleh, F. et al (2004) What women want: women's preferences of caregiver behavior when prenatal sonography findings are abnormal (Canada) - *Ultrasound in Obstetrics and Gynecology, Volume 23 Issue 1, Pages 56 - 62*
- Centre for Technology Assessment at the Swiss Science and Technology Council (2001) *Psychosocial Aspects of Ultrasound Examinations during Pregnancy; Baby Sighted* (short version)

Prenatal screening

- Cameron, Martin and Moran, Paul (2009) Prenatal screening and diagnosis of neural tube defects (UK) - *Prenatal Diagnosis, Volume 29 Issue 4, Pages 402 - 411*

Termination of pregnancy

- Dommergues, Marc et al (2010) Termination of pregnancy following prenatal diagnosis in France: how severe are the foetal anomalies? (France) - *Prenatal Diagnosis, Volume 30 Issue 6, Pages 531 - 539*
- *Abortion Policies* – A Global Review (UN; 2002)

Examples of good practice

- *Toward Concurrence: Understanding Prenatal Screening and Diagnosis of Down Syndrome from the Health Professional and Advocacy Community Perspective* (US; 2009)
This publication is supported by the European Community Programme for Employment and Social Solidarity (2007-2013). This programme was established to financially support the implementation of the objectives of the European Union in the employment and social affairs area, as set out in the Social Agenda, and thereby contribute to the achievement of the Lisbon Strategy goals in these fields.

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