



INTERNATIONAL FEDERATION
FOR SPINA BIFIDA AND HYDROCEPHALUS

Consultative status special category with Economic and Social Council of the United Nations
Participatory status, Council of Europe

IF POLICY STATEMENT ON PRENATAL DIAGNOSIS AND THE RIGHT TO BE DIFFERENT

**Adopted by the IF Annual General Meeting
on 28 June 2005 in Minneapolis**

The existence of spina bifida in a foetus is not a sufficient reason for termination. Parents must feel free to make a choice, after receiving counselling from trained professionals on the full range of issues relating to spina bifida and hydrocephalus.

IF calls for action to recognise:

1. the need for counselling from trained professionals and peers familiar with spina bifida and hydrocephalus.
2. that the counselling should provide access to the full range of issues relating to spina bifida and hydrocephalus.
3. that counselling by its very nature should be non-judgmental
4. that parents deserve time to adapt to this new situation before being confronted with a proposal to terminate the pregnancy. Parents must feel free to make a choice.

Background

At the 12th International Conference for Spina Bifida and Hydrocephalus in Toulouse, which focused on "The Right to be Different", 270 people – including parents and adults with these impairments - from 22 different countries came together to consider all elements involved in this theme.

In recent years new methods of early diagnosis such as ultra sound, have given parents the opportunity to know about their baby's condition before birth. In Western countries more than 90% of parents opt for abortion or termination of pregnancy when the child has spina bifida. Prenatal diagnosis cannot yet state exactly the severity of the impairment. Despite this, in an increasing number of states abortion is legally and socially accepted. Further, in many countries there is no time limit for legal abortion where the foetus has severe impairments.

The motivation for termination is the prognosis that the outcome for the unborn child could be very poor, which can be taken to mean that life with spina bifida is not worth living. This information is often given by people who have insufficient knowledge about the lives of people with spina bifida and hydrocephalus.

Planned Parenthood and Primary Prevention - taking folic acid before and during the first part of the pregnancy - has been shown to considerably decrease the numbers of births with spina bifida. Primary Prevention requires national educative programmes to ensure that the message reaches the whole population.

All this has an impact on the lives of people with spina bifida and all future parents.

Agreed Statements

1. People with spina bifida and hydrocephalus can live a full life with equal value to that of any other citizen and they should not be seen as a medical condition. Their views should be sought and heard by governments and health professionals, who should acknowledge the right of people with spina bifida and hydrocephalus to speak for themselves.
2. People with disabilities have the right to aim for lives as rewarding as those of their peers who have what is regarded as a normal life. Supportive systems must be in place when they are needed.
3. Experience over the past 30 years has improved considerably the medical outcome and the quality of life of people with spina bifida and hydrocephalus.
4. Most adults with spina bifida underline that their quality of life is not automatically - and should not be given as - a reason for abortion.
5. Prenatal counselling for parents should be delivered by skilled professionals. Such counselling should provide access to the full range of issues relating to spina bifida and hydrocephalus. Counselling by its very nature should be non-judgmental. Parents deserve time to adapt to their new situation before being confronted with a proposal to terminate the pregnancy. Parents must feel free to make their own choice.
6. After diagnosis, professionals should work with parent organisations to ensure that information is up-to-date, correct, and understandable for parents.
7. Terminology such as therapeutic abortion and secondary prevention can be misleading.
8. The International Federation is keen to ensure that terminology used is not misleading.
9. Primary prevention should be the focus for the prevention of disability.
10. More research is needed to ascertain all the causes of neural tube defects and in particular the role that folate plays.
11. Primary prevention campaigns must not be seen as carrying hidden messages. All campaigns must safeguard the dignity of disabled people.
12. Discrimination, for example issues relating to insurance, should not impact upon the decisions that parents are asked to make.
13. Prevention and prenatal diagnosis is an ongoing complex moral and ethical matter which needs a great deal of deliberation and it will be an ongoing debate. Organisations of and for people with spina bifida and hydrocephalus should be full partners in this debate.

To achieve this IF - through its members - will:

1. Create and promote an International Knowledge Centre to provide access to the full range of issues relating to spina bifida and hydrocephalus.
2. Promote Research into the causes of neural tube defects and, in particular, the role that folate plays.
3. Monitor the message promoted in prevention campaigns to safeguard the dignity of people with a disability.
4. Promote awareness of the effects of discriminatory practices both in the language used by professionals and the practice of administering medical insurance.
5. Provide awareness raising activities so that more people are aware of spina bifida and hydrocephalus.