

## Prenatal medicine

A responsible use of prenatal diagnostics opportunities has to be clarified. Consulting for expectant parents is necessary. This consulting must be comprehensive but should not influence any eventual decisions.

The measures of prenatal medicine require the consent of those concerned. Also the right to not be informed must be declared and respected.

The future parents, to whom the birth of a disabled child was diagnosed, must be informed about all details concerning the alternatives to a possible interruption to the pregnancy. At the right moment, they also need to be given the opportunity to contact associations of parents who have dealt with a similar situation.

Obligatory screenings aimed at attributing selective roles and states are to be avoided and prevented.

The fact that the disability of a child is diagnosed before the birth must not be retained as a valid reason to then not have the right to health and social services.

Prenatal medicine may not be used for selection objectives.

## Abortion

A discovered disability itself may not be considered as a sufficient reason to justify abortion. Nevertheless, a legally recognized automatic procedure between the prenatal prognosis of a disability and the interruption of a pregnancy cannot be accepted. Similar social behaviors need to be opposed.

## Euthanasia

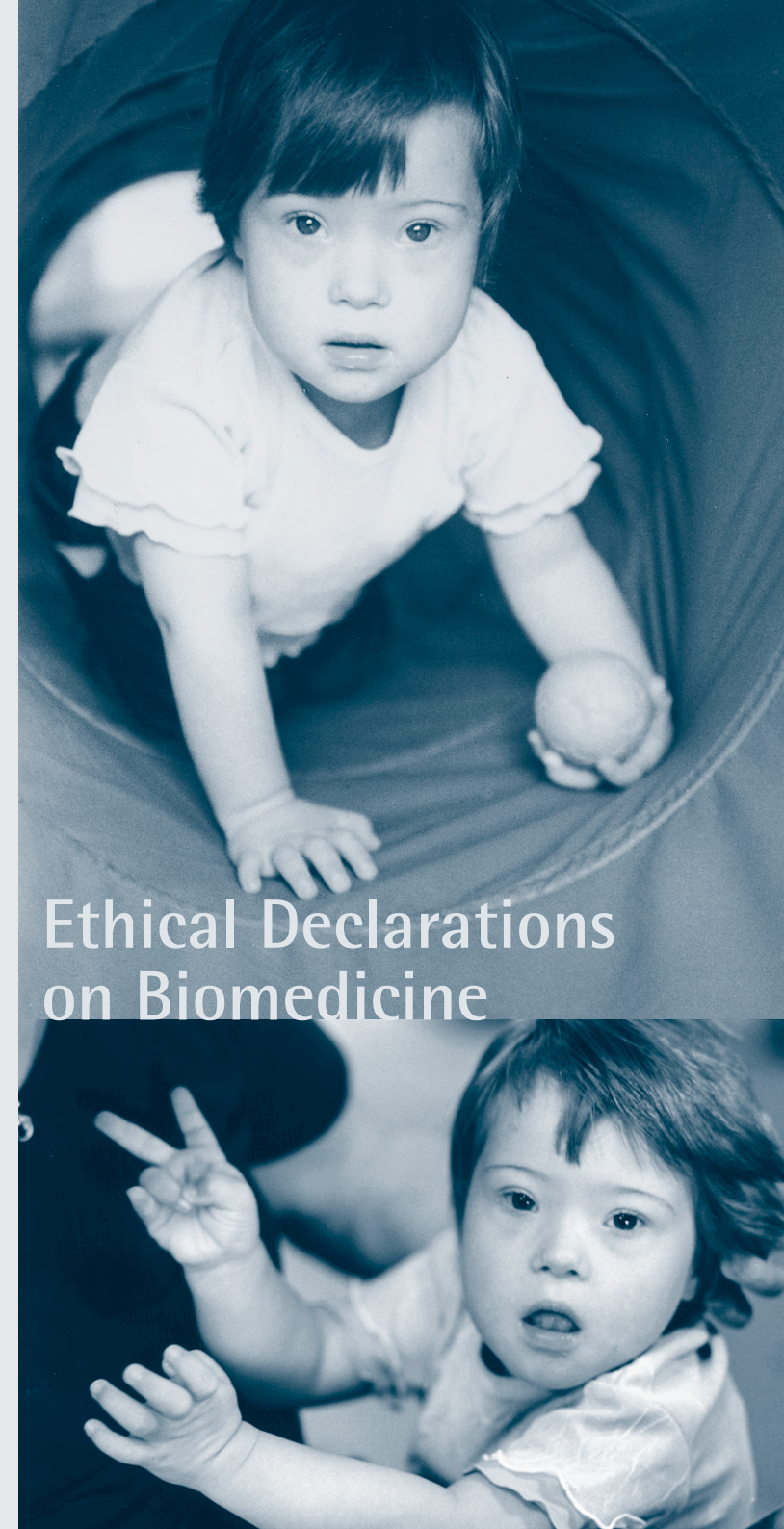
Any legalization of active euthanasia towards persons with intellectual disabilities is not acceptable. An authorization to use euthanasia is in definite contrast with the right of an intellectually disabled person to live and could also make a distinction between a life that is worth living and one that is not. Illness or disability does not influence the level of human dignity.

*insieme Swiss Community of the Associations of Parents with children with intellectual disabilities, Federal Association Lebenshilfe for persons with intellectual disabilities (Germany), Association Lebenshilfe Austria, Federal Association for persons with intellectual disabilities, Regional Association Lebenshilfe for persons with disabilities (South Tyrol),*

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# Ethical Declarations on Biomedicine



lebenshilfe

**Joint document on basic principles of the Federal Association Lebenshilfe Germany, the Association Lebenshilfe Austria, insieme Switzerland and Lebenshilfe South Tyrol.**

The discussion about basic principles and boundaries of modern biomedical science, which involves human life in a radical and wide-ranging manner, has reached a global scale. New issues regarding relations among the human race continuously arise, especially when the research subject is man himself. The picture of humanity, based on the Declaration of Rights of the United Nations which is founded on the fundamental principles of human dignity, autonomy, equal rights and solidarity, can seriously be put into question.

In biomedical debates the demand for international and European regulations has been steadily increasing, since there are considerable differences between some national regulations. This requirement originates from the necessity to consider, based on a legally recognized standard, the need for research at a European level and to guarantee the competitiveness of the genetic and biomedical industry. There is a great danger that important reflections and ethical questions are set aside.

Because of this reason the research of ethical limits and general standards of human genetics must surpass national borders as well. For all the people and organizations who are responsible for persons with intellectual disabilities it is required to conform to a common Charta and to look out for an international guideline in order to declare, apart from national directives and regulations, a society with human values.

The signatory associations are dedicated to fulfill this objective. With their «Ethical Declarations» the German, Austrian, Swiss and South Tyrolean associ-

ations want to establish joint worked out positions and submit them to international public opinion.

These declarations exclusively deal with issues relative to biomedical science that directly concern persons with intellectual disabilities and their relatives. They do not claim the right to want to define the foundations and limits of modern biomedical science for all social groups.

### Foundations

The signatory associations are dedicated to defend the rights of persons with intellectual disabilities and their relatives. Their objective is to support the right of self-determination and the integration of persons with intellectual disabilities in a society based on the fundamental principles of human dignity, autonomy, equal rights and solidarity.

Every human being always has the right that his/her dignity and rights are respected:

- Persons with intellectual disabilities have the same basic rights as all other human beings. Persons with intellectual disabilities have the same right for freedom and safety and to be an integral part of society.
- Every human being has unlimited dignity and is unique and irreplaceable. The phase of personality development cannot be considered as valid criterion to define a human being.

These convictions must be the basis of every policy that regards persons with intellectual disabilities. In fact, the relations with persons with intellectual disabilities are what shape the picture of a society based on human values.

### Principles of biomedicine

Based on one's ethical convictions, the signatory associations assert the following positions on the fundamental principles and boundaries of modern (bio)medical science.

### Biomedical research

The research of medical and biological science opens opportunities of action that are often unpredictable. On one hand, the scientific achievements and acknowledgements offer the hope of obtaining the best opportunities of treatment for illnesses. Nevertheless, on the other hand, the same scientific progress presents the danger of human being exploitation. This reference to the multiplicity of the progress of medicine is contrary to the complete and uncontrollable amplification of genetic engineering.

The new methods used for the recognition and alteration of the genetic layout of a human being must be able to provide precise answers to the questions linked to the consequences and legitimacy of such research. What is possible and feasible is not necessarily justifiable. It is necessary to set well-defined limits in order to protect dignity and human rights. The freedom of research must be aware of ethical principles and cannot define the boundaries of acceptability considering only their own interests.

- All of the activities in biomedical science must be based on the awareness that the persons with disabilities can lead a rich and happy life. Disability is only one of many possible forms of existence of a human being. Disability alone does not determine the essence of a man. Disability is not an illness.

- The power of biomedical science requires a high level of responsibility, ethical awareness and respect of human rights, especially for those that are not part of a social picture of healthy and efficient people.
- Human dignity must be respected in every phase of biomedical science research and in all its fields of application.
- Those who are not able to make decisions must be protected and must not be placed under care with intentions only for scientific research. Biomedical science must strive to improve the opportunities and quality of life of every man. This science must never support eugenic purposes. Changing the human race according to determined characteristics cannot be the objective of biomedical science. The achievements and acknowledgments of this science must never favor the systematic selection of human life according to determined criterion or characteristics.
- Research can be carried out with the personal consensus of the person with intellectual disability only.

### Preimplantation genetic diagnosis (PGD)

PGD, as legitimating a selective method of research, goes against the historical concept of human dignity.

PGD creates a great danger of stigmatizing persons with intellectual disabilities while it favors the myth that a child can be customized.