

Do people have to be perfect?

**On the practical meaning of ethical issues
for the concept of community living**

Talk

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Dear Ms. President,

Dear Ladies and Gentlemen, dear Friends,

In the program of this world convention, current medical and biotechnical procedures have been cited as conceivable dangers for handicapped people. I would like to address this topic by posing what I consider to be the central question; that is:

Do people have to be perfect?

The national chairman of the German *Lebenshilfe*, Robert Antretter, who by the way sends his greetings, has presented a definition of ethics in a speech titled “Ethics and Persons with serious handicaps”: “The basis of all ethical endeavours are the lessons in people’s moral will and actions in various life situations; in short, ethics is the theory of proper behaviour.” This has a very practical implication, as I will show you!

When we look at handicapped people and their families, bioethics comes into focus. What I am referring to is the controversy over rules of behaviour in situations that demand a decision and that have emerged with modern medicine and genetic engineering. Questions that arise are, for example:

Relevant Medical/Biotechnical Issues

- Prenatal diagnostics; that is, from the beginning of life
- Selective procedures, for example, pre-implantation diagnostics
- Genetic diagnostics
- Research on individuals unable to give consent
- Active euthanasia; that is, all the way to the end of life

To elaborate their current implications, I would like to point out a few social phenomena that are relevant to our subject:

- We are living in an era of global economization. We are witnessing the prevalence of profit-oriented mentality. Those responsible in politics and economics too often think in short terms (shareholder value) and too seldom in terms of overall responsibility toward society. With respect to our topic this means: Modern medicine and technology offer vast opportunities for economic success. There the danger lies that more profound ethical aspects are lost or even resisted along the way.
- The “cost-benefit mentality” is omnipresent, at least below the surface, and directed toward handicapped individuals as well. This mentality took on its most radical form in Germany under the National Socialist regime: Over 200.000 handicapped people were eliminated as “ballast existences”. This may be one reason why especially we in Germany and Austria are particularly sensitive to handicapped people’s right to life.
- Rapid developments in medicine and the natural sciences (especially biotechnology) allow more and more insight into illnesses and disabilities. This only magnifies the belief that affliction, disease and disability can be eliminated. The assumption that it is generally possible to avoid affliction and disability discriminates all those who have not been “avoided”.

- On top of this notion lie the “feasibility-mania” and the desire for perfection. Today’s ideal image is to be dynamic and enterprising, able to bear with pressure and stress, and always in a “good mood”. Keyword: “designer-baby!”

It is important in this context to differentiate between individual ethics and collective ethics. At the beginning of the last century collective ethics were predominant. Example: “Ballast existences are a burden to society.” Today, the ethics of individuality, with the goal of avoiding personal hardship, is prevalent. However this often threatens to slip back to the former collective ethic that sees, for example, a handicapped person as an unproductive cost factor - with all the disastrous consequences that reached their culmination under Hitler. It is difficult to share some researchers’ optimism that our descendents will be more ethically judicial and responsible than our ancestors were.

In contradiction to that is a statement from Adorno “that what was possible once is possible forever.”

From all of these points I draw my thesis that:

The belief that hardship can generally be avoided, that one can demand flawlessness and raise perfection to the norm, is perilous. It discriminates all persons who do not fulfil this norm. The threat of being discriminated against will increase with the degree of a person’s handicap.

Why do people with disabilities feel frightened and threatened? Why are they simply skeptical?

The Fears of disabled persons

- Fear for recognition of the right to life
- Loss of social solidarity
- Fear of growing demand in society for mass screening

“You didn’t have to have this child.” This sentence is one that parents of a handicapped child have to hear repeatedly. Alleged preventability gives society the pretence to isolate handicapped people and their families.

This endangers tolerance and acceptance of the disabled. Why should handicapped people live in my neighbourhood? Why should some of my taxes go to those people who don’t even need to be alive? Why should I donate to associations that exist only because handicapped people exist?

You see: The discussion of human rights and dignity of handicapped people has highly pragmatic and highly practicable implications.

In order to protect the right to life we need straightforward, unequivocal positions and principles – ethical principles:

- All human beings are of equal value. The same safeguards apply for disabled as for non-disabled lives.
- The level of person’s development cannot be implemented as a measure of humanness.
- There must be no differentiation made between life worthy and unworthy of living.
- Research and scientific interests must not divert from legal standards.

- Human life – including prenatal life – must not be sacrificed.
- Each and every form of selection is to be rejected.

How does all this apply specifically to current tendencies in the fields of modern medicine and biotechnology?

With respect to prenatal diagnostics, I do not assume to pass judgment on those women and men who do take advantage of this option during pregnancy. However, I do reject every form of moral pressure to implement it. Parents must retain the right to refuse prenatal diagnostics.

Mothers and fathers who decide against terminating a pregnancy despite a diagnosed handicap earn our greatest respect; it is the duty of each and every one of us to ensure that they are not left alone with their handicapped child.

It is therefore not the question of prenatal diagnostics in the interest of the mother's and child's health. Instead, the problem arises when PND becomes a sweeping, indiscriminately utilized instrument.

I therefore support counselling sessions before prenatal screenings. Here future parents could discuss how they would react to a prenatal diagnosis of "defect".

I would like to see a decisive renouncement of pre-implantation diagnostics: "The PID is a method in which the genetic makeup of an embryo can be tested for undesirable genes. This method requires in vitro fertilization. The embryo's right to survival is contingent on the

absence of a defect. This is a conscious selection of handicapped life.”

(R. Antretter)

The Dilemma

Without a doubt, modern medical and biotechnical methods allow for immense opportunities in the areas of diagnosis and therapy. Those who express caution are therefore quickly cast off as skeptics.

Is it feasible to allow progress and at the same time to preserve the ethical values mentioned before?

We have now reached the question of where to draw the line. Are we risking a breach if we try to define when a life is worthy of life and when it is not? Isn't it possible to shift any boundary? Of course there will be individual cases in which severe impairments raise doubt about whether such a life can be endured. Should we be allowed to argue with such singular examples? Isn't it more humane to hold on to basic values allowing for the moral right of each individual to “be dependent on” the doctor, the parent?

What can we do?

Basically this is all about human rights – their existence and their application in everyday living.

Which rights do we have to protect?

- Rights at a national level
 - constitutional rights

- basic legal regulations (*i.e.*, anti-discrimination laws)

- Rights at an international level
 - international standards
 - international agreements (UN Convention!)

- “Moral” rights
 - the right to imperfection
 - the right not to be in the know
 - acceptance of dependency

From a legal point of view we would like to see the given positions secured in the judicial systems of our nations. Prerequisite is that our respective constitutions guarantee the right to life and dignity to all, including disabled persons.

The Constitution of the Federal Republic of Germany provides these two basic rights; that is, the “right to life” (Article 2, paragraph 2, clause 1GG) and die inviolable right to human dignity (article 1, paragraph 1, clause 1GG). Furthermore, the German federal constitution comprises the statement “No person may be discriminated on the grounds of disability.” (article 3, paragraph 3, clause 2GG) – the cornerstone of the German anti-discrimination law.

What is also noteworthy is the preamble of the Swiss Constitution: “The strength of a peoples can be measured by the welfare of its weak.”

Although handicapped individuals are not usually so very weak as many non-disabled people may believe, I do very much appreciate this statement in the Swiss constitution: The criterion for the strength of a nation is not the gross national product nor the export quota nor even

the degree of perfection of its citizens, but the welfare of those whose fate it is to be disadvantaged.

The perspective must extend beyond the boundaries of national judiciary systems. What is becoming more and more important, particularly concerning ethical issues, are internationally negotiated and recognized standards, agreements between nations that confirm the protection and rights of individuals with disabilities. Among these is the new UN Convention for the protection of the rights of individuals with disabilities. Founded upon a comprehensive anti-discrimination approach, it emphasizes the legal position “right to life” (article 10), the freedom from [...] humiliating treatment (article 15).

Ladies and Gentlemen, the “classical” ethical themes I have spoken of so far played only a subordinate role at the early stages of the convention. Nevertheless, from my point of view the convention has created an ethical compass that could guide the direction of bioethical debate in an international context.

Within my own list of preferences are not only the “enforceable” but also the moral rights.

Such as the right to imperfection:

To advocate this would be a worthy cause for each one of us. For, who among us is flawless? Which one of us, at least as we get older, is insured against becoming dependent upon others to treat us with tolerance and consideration? The realistic image of the (im-)perfect being must become acceptable. How much is nearly everyone doomed

to perfection – at work, in sports, in love! What a show people must put on to appear flawless! How human it is to be imperfect.

Or the right to a lack of knowledge:

Should this right tumble, the knowledge of some probability of a disease occurring would dangle over us like the sword of Damocles at the expense of many of life's pleasures. This may cause considerable psychological strain – not to mention the costs that would come with it.

I continue to actively support the ethics of “acceptance of dependency” (Häberlin). As children we were all dependents, and we will all return to that state some day through illness or old age. Each of us should understand that accepting dependency is part of a good life.

I have two more examples before I reach the end of my talk. One of them refers to political lobbying, and the other to blatant publicity.

- The member organisations of Inclusion International in the German-speaking region of Austria, Switzerland, South Tyrolia and Germany have composed ethical guidelines to biomedical issues. I have brought along the leaflet in English and French and I would be pleased with your interest.
- In Germany, organisations involved with supporting the disabled have combined efforts with a television station to launch a campaign called “1,000 Questions to Hasty Answers.” Our goal is to initiate a broad public discourse. To reach it we have chosen the path of asking questions, and have posed them in television spots, posters and advertisements. Some of the questions are:

- Does prenatal diagnostics make life easier or more difficult?
- Will genetic testing some day replace the job placement test?
- Cancer risk 60:40...
- Will I have to be afraid to have children in a world in which perfection is the only thing that counts?

I have now come to the closing remarks. When we concern ourselves with ethical issues from the perspective of handicapped people, we experience an old, well-known phenomenon: Not only do the positive effects of our efforts benefit the handicapped. What is good for the disabled is always good for the whole of society. Thus we are all making a contribution not to Aldous Huxley's Brave New World, but to a much better world for all people, with and without disabilities. The UN Convention provides the compass; the path we must seek and travel ourselves!

Thank you very much!