

Social implications of Prenatal Diagnosis (PND) and Preimplantation Genetic Diagnosis (PGD). A sociological trial

Introduction and Background

In Germany, prenatal diagnosis (PND) has been used to detect possible gene deviations in fetus since the late 1980s.¹ While the aim of standard prenatal care is to monitor pregnancy and identify health risks for mother and child, PND, beyond that, includes tests that specifically look for genetic malformations in the fetus. PND allows to predict a limited number of hereditary diseases, hereditary functional limitations or pathological dispositions for diseases. In practice, the distinction between standard care and further PND is often unclear, as standards in prenatal care change and pathways lead from standard to additional diagnostic tests, when there is an abnormal result in the former. In addition to that, PND is often also used as a self-pay service. PND can be divided into invasive and non-invasive procedures. Non-invasive procedures are ultrasound examinations and genetic blood tests of maternal blood. They pose no risk to mother and child and in most cases predict only a relative probability of genetic deviation. Invasive procedures are used to confirm the findings of non-invasive tests. They include examination by punctuation of placenta and fetal cavity. This carries a risk of miscarriage of 0.5–1%. Regarding the punctuation of the umbilical cord complications occur in 1–3%.² In many cases, PND has only little significance with regard to the severity of the diagnosed genetic deviation or outbreak of disease. Therefore, the diagnostic finding is rather a statistical risk calculation than a reliable clinical fact. The consequences of PND can be prenatal therapies, which are only possible to a very limited extent. It can be useful for appropriate

1 Stengel-Rutkowski: Vom Defekt zur Vielfalt. Ein Beitrag der Humangenetik zu gesellschaftlichen Wandlungsprozessen, in: Zeitschrift für Heilpädagogik 53 (2002), No. 2, p. 46.

2 Bundeszentrale für gesundheitliche Aufklärung: Pränataldiagnostik-Beratung, Methoden und Hilfen. <https://shop.bzga.de/pranataldiagnostik-beratung-methoden-und-hilfen-c-394/> (15.04.2024), pp. 22–24.

preparations, e.g. to choose a clinic with a perinatal center as place of birth. Apart from that, PND often results in a decision to be made for or against an abortion. To which purpose PND is applied is therefore a crucial question, often not well considered in advance. These ›selective abortions‹ are only a small fraction of all abortions and can be defined as those cases in which a particular fetus is perceived as having not desired characteristics.

Historically, the development of a series of procedures for prenatal diagnostics started in the 1930s. A starting point was Amniocentesis, the examination of the amniotic fluid by means of a puncture of the amniotic sac, which was first performed in 1881/1882. Initially, the procedure was used to treat the abnormally increased volume of amniotic fluid (hydramnios). From the 1950s onwards, the procedure continued to develop into a diagnostic method with increasingly controllable risks for mother and child. It was used for the detection of rhesus incompatibilities between mother and child, as well as a possibility of early sex determination and later for analyzing the chromosome set.³ It still is one of the most common invasive procedures.

From the beginning, the introduction of PND was accompanied by a discourse on its ethical implications. Beck-Gernsheim discussed the growing demand for PND in Germany as early as in 1996.⁴ The rough lines of the discourse span between self-determination of woman and medical feasibility/disease avoidance on the one hand and protection of ›inappropriate life‹ and the ideal of an inclusive society on the other. Thereby, the general focus of this discourse seems to have changed. The bio-political problem of modernity, the social question of ›what should we do with people who do not fit into society or whose performance value makes them industrially useless?‹,⁵ has been solved without any explicit rating of humans, e.g. a racist ideology.⁶ In Germany, abortion of life that does not fit into society has currently been normalized and privatized due to

3 Paul, Norbert: Pränatale Diagnostik, in: Gerabek, Werner E. (ed.): Enzyklopädie Medizingeschichte. Berlin et al. 2011, pp. 1178–1180.

4 Beck-Gernsheim, Elisabeth: Die soziale Konstruktion des Risikos — das Beispiel Pränataldiagnostik, in: Soziale Welt, 47 (1996), No. 3, pp. 284–296.

5 Dörner, Klaus: Tödliches Mitleid. Zur Frage der Unerträglichkeit des Lebens oder: die Soziale Frage: Entstehung – Medizinisierung – NS-Endlösung – heute – morgen. Mit einem Beitrag von Fredi Saal. Gütersloh 1989.

6 Rösner, Hans-Uwe: Behindert sein – behindert werden. Texte zu einer dekonstruktiven Ethik der Anerkennung behinderter Menschen, Bielefeld 2014, p.129.

the primacy of self-determination. Consequently, giving birth to a child with genetic deviations appears as a matter of individual choice. What was once understood in 1970s as a right to defend against state interference is now increasingly asserting itself as a right to claim a healthy child, with recourse to all medical options⁷. This is also what the providers aim for when they establish and expand new processes. Each decision is always about individual cases and problems, which is a valuable achievement in itself. But socio-ethical considerations, social contexts and effects are being left out.⁸ A critical perspective is occupied by mostly conservative and religious voices of Pro-Life-Movements, which have been politically successful e.g. in USA, Poland and other Eastern European countries recently. Any interference with natural or divine destinies at the beginning and end of life is rejected by them and protection of ›inappropriate life‹ is prior to the choice or even health of the pregnant woman.

This chapter examines the social impact of PND, but also of PGD (Preimplantation Genetic Diagnosis) from a sociological perspective in Germany. We want to highlight the social risks and side effects or down-sides and ambivalences of a preventive examination method that is often euphemistically presented by medical staff in everyday routine and which, from the authors' point of view, play only a subordinate role in social discourse. To this end, we attempt to synthesize the prevention literature and various sociological approaches.

PND and PGD as treatments of prevention

PND can be described as part of the broader societal phenomenon of prevention, which is by some authors pointed out as a general *modus operandi* in modern time.⁹ The term ›prevention‹ is derived from the latin word ›praevenire‹, which means ›to come before‹. Preventive action there-

7 Achteplik, Kirsten (2018): *Selbstbestimmte Norm. Feminismus, Pränataldiagnostik, Abtreibung*, 2nd ed., Berlin.

8 Baureithel, Ulrike: Das ist keine rein private Frage. Pränataldiagnostik: Soll der Test auf das Down Syndrom Kassenleistung werden? Nächste Woche debattiert der Bundestag, in: *der Freitag*, No. 14, 04.04.2019.

9 Bröckling, Ulrich: Vorbeugen ist besser... Zur Soziologie der Prävention, in: *Behemoth. A Journal on Civilisation* 2008, No. 1, pp. 38–48, id.: *Gute Hirten führen sanft. Über Menschenregierungskünste*. Berlin 2017.

fore refers to ›pre-empting‹ an anticipated undesirable development,¹⁰ but also to preventing certain events or conditions altogether.

While the concept of prevention could be clearly assigned to the legal sciences with regard to crime prevention towards the end of the nineteenth century, the conceptual attribution has been increasingly shifted to the area of health risk prevention from the twentieth century onwards.¹¹ Before industrialization, health and especially the prevention of illness of the population was not a major political issue. In the course of industrialization due to the increasing demand for labor, rapid population growth in the cities and associated risks of illness, health became increasingly important as a capital factor in the economic system.¹²

Already in 1779, Johann Peter Frank's ›System einer vollständigen Medicinischen Polizey‹ provided a basis for legitimizing governmental regulation of people's lives according to medical rules that went far beyond medical expertise, but remained a paper claim for the time being. At the same time as these socially disciplinary measures of late absolutist police science, concern for health in bourgeois society became the most important element of an enlightened and rational lifestyle, with which the politically powerless educated bourgeoisie set itself apart from the nobility and at the same time integrated other social classes into bourgeois society.¹³ This also can be associated with the fact that scientific knowledge has always been and usually still is regarded as value-neutral.

In the course of modernity, the authority to interpret inexplicable phenomena relating to illnesses and functional limitations was passed from the hands of theologians to those of doctors, who, after turning to natural science, were able to achieve ever greater success in healing. It should be

10 Brockhaus: Enzyklopädie in 30 Bänden, 21., völlig neu bearbeitete Auflage, Band 22, POT-RENZS, Leipzig 2006, p. 54f.; Papenkort, Ulrich: Prävention: Wort, Felder und Begriff, in id. (ed.): Prävention. Fachübergreifende Einführung in eine besondere Intervention. St. Ottilien 2008, p. 9.

11 Labisch, Alfons: Gesundheitskonzepte und Medizin im Prozeß der Zivilisation, in: Labisch, Alfons/Spree, Reinhard (eds.): Medizinische Deutungsmacht im sozialen Wandel. Bonn 1989, pp. 15–36

12 Mutz, Gerhard: Sozialpolitik als soziale Kontrolle am Beispiel der psychosozialen Versorgung, München 1983, p. 204ff.; Stöckel, Sigrid / Walter, Ulla (eds.): Prävention im 20. Jahrhundert–Historische Grundlagen und aktuelle Entwicklungen in Deutschland. Weinheim & München 2002, p. 11.

13 Welsh, Caroline: Brauchen wir ein Recht auf Krankheit? Historische und theoretische Überlegungen im Anschluss an Juli Zehs Roman *Corpus Delicti*, in: Frewer, Andreas/Bielefeldt, Heiner (eds.): Das Menschenrecht auf Gesundheit. Normative Grundlagen und aktuelle Diskurse, Bielefeld 2016, p. 224.

noted here that they had already received this power of interpretation a long time ago through their proximity to the middle class, through moral arguments and justifications.¹⁴ »It was only when natural science became the reference science of medicine that the subject and morality were repressed and the health theory of the previous epoch was relegated to the realm of speculation: the objective method of natural science became the truth par excellence, health/illness as a manifestation of life became statistical and physical-chemical norms and laws in ›measure, number and weight‹ «.¹⁵

In the course of the nineteenth century, citizens were given a right to health, but also had a duty to society to maintain their health in the sense of maintaining an appropriate lifestyle.¹⁶ According to Labisch, this represented the birth of *Homo Hygienicus*, who regarded health as the primary goal of life and subjected his lifestyle entirely to health principles derived from medicine¹⁷—admittedly not yet with the same preventative view as today. This was the beginning of medicalization of life.

With a view to today's lifestyle, preventive measures and fitness trackers, the path of internalization of the former social constraints into self-constraints can be outlined in terms of civilization theory.¹⁸ Nowadays, very few people doubt the value of a medically recommended lifestyle, whereas at the end of the nineteenth century there were still so-called sick visitors who checked on behalf of the large local health insurance funds whether the doctor's instructions were being followed and, for example, whether the prescribed medication was actually being taken.¹⁹

Today, people monitor their own health with the help of fitness trackers, for example, and take advantage of a wide range of preventive services

14 Roelcke, Volker: Vom Menschen in der Medizin. Für eine kulturwissenschaftlich kompetente Heilkunde, Gießen 2017, p. 155.

15 Labisch, Alfons: Medizin und soziale Kontrolle. Zum Verhältnis von Sozialgeschichte und Soziologie der Medizin am Beispiel neuerer Literatur aus der Bundesrepublik Deutschland mit einem Exkurs: Neuere Forschungen zur Medizin im Nationalsozialismus, in: Dynamis. Acta Hispanica ad Medicinam Scientiarumque Historiam Illustrandam 1987-1988, No. 7–8, pp. 437.

16 Roelcke, Volker: Vom Menschen in der Medizin, p. 154.

17 Labisch, Alfons: Homo hygienicus: soziale Konstruktion von Gesundheit, in: Wagner, Franz (ed.), Medizin. Momente der Veränderung, Berlin et al. 1989, p. 116.

18 Elias, Norbert: Über den Prozeß der Zivilisation. Soziogenetische und psychogenetische Untersuchungen. Band II. Wandlungen der Gesellschaft. Entwurf zu einer Theorie der Zivilisation. 2nd ed., Frankfurt a. M. 1977.

19 Labisch, Alfons: Homo hygienicus, p. 126.

to prevent potential illnesses in good time. All these actions are carried out also in the interest of the state, but without real government pressure (surely with some exceptions like mandatory vaccinations). In the second half of the twentieth century, responsibility for health has shifted from the state to the individual, flanked by the healthcare market.²⁰ Overall, prevention is perceived as rational, positive and socially desirable. No doubt, the utilized preventive services have improved health in all ages and are a factor for increasing life expectancy. Nevertheless it is important to consider side effects of prevention, especially potential negative aspects that seem to be consequently underexposed in individual perception, public discourse and often also in science. Side effects may concern the unreflected norm-building power of facts, as discussed in this chapter. Also, over treatment and stirring up fear can be an effect of preventive rationality.

The statistical understanding and mathematical development made it possible to anticipate future dangers and calculate risks. In this context, evidence-based medicine aims to reach the best possible results for a person's future by taking into account what we know from the past of other individuals. Since evidence-based medicine and therapy in a neoliberal society saves costs in the healthcare system and at the same time gets people back to work more quickly, there is a corresponding demand for it. Naturally, in other cultures or societies the social system has a different orientation. The inherent logics thereby differ between that of intervention in curative medicine and the logics of prevention. While curative intervention always refers to a *diagnosis*, that is to say a (more or less) secured and present health issue, prevention aims to eliminate or minimize a risk, a vague future health issue that might occur and is not yet *diagnosed* but *prognosed*. In other words, prevention strives to replace a calculated version of the future by a not defined other. In both cases, curative intervention as well as prevention, it is only the declined situation that is defined and guiding the action. In medicine, the focus is on diseases that are diagnosed and treated as deviations from a desired norm. Therefore, prevention in this sense also has an exclusively negative perspective: deviations should

20 Martschukat, Jürgen: Das Zeitalter der Fitness. Wie der Körper zum Zeichen für Erfolg und Leistung wurde. Frankfurt am Main 2019.

be recognized and corrected. A more lifeworld-centered perspective also opens up positive scenarios for dealing with deviations.²¹

Prevention approaches differ in terms of the time perspective in the course of the disease according to primary prevention (before the onset of the disease, for example vaccination), secondary prevention (in the early stages of a disease, for example early detection measures) and tertiary prevention (when a disease manifests itself, for example patient training).²² Gordon criticized the division into primary, secondary, tertiary prevention because it overstretches the concept of »prevention«. As an alternative, he developed a categorization that distinguishes between universal, selective and indicated prevention approaches, using a narrower concept of prevention. Universal prevention starts before a specific problem occurs in target groups that do not exhibit any abnormalities or an increased risk. In contrast, targeted prevention measures take effect when risk factors are already recognizable (selective prevention) or when the first signs of a problem appear (indicated prevention). Prevention is therefore only considered if something can still be prevented, namely the full manifestation of the undesirable phenomenon.²³

From a sociological perspective, PND can be described as a social selective prevention, as in the case of positive findings (e.g. trisomy 21), the »prevention« of »inappropriate life« is usually carried out as a measure (selective abortion). On the other hand, a positive result can also be used to prepare for this life and, if necessary, to prevent or alleviate the potential disease and/or impairment through prenatal surgery. Fetal surgery is currently still at an experimental stage, but may offer (in the future) the possibility of prenatal treatment and thus the desired reduction in later impairment.²⁴ How high the risks of these surgical interventions are for mother and child can only be estimated at present. However, from this point of view PND can also be seen as behavioral prevention, which focuses on the individual behavior. In contrast, social responsibility, which could reflect aspects of environmental prevention, is barely recognizable in public discourse.

21 Schütz, Alfred/Luckmann, Thomas: *Strukturen der Lebenswelt*. Konstanz & Stuttgart 2003.

22 Caplan, Gerald: *Principles of Preventive Psychiatry*, 5th ed., New York, NY 1964.

23 Gordon, Robert S.: An operational classification of disease prevention. *Public Health Reports*, 83 (1983), No. 98 (3), pp. 107–109.

24 Tchirikov, Michael: Intrauterine fetale Chirurgie, in: *Deutsche Hebammenzeitschrift* 14 (2017), No. 1, pp. 32–46.

Historically, dealing with impairments was a matter for the individual or the domestic community. It only became a »social problem« with the changes in the world of work during industrialization. The value of a person was increasingly based on his or her ability to work, to be fit for military services and perform, so that anyone who did not meet these requirements was devalued.²⁵

Viewing disability as a participation problem was a milestone caused by the disability movement—similar to the 1968 motto »the private is public«. PND shifts the »problem« back into the private sphere and, from this perspective, can be seen as a push back of the achievements of the disability movement.²⁶

State control over whether individuals meet the ideal and whether they are productive, as envisioned by the eugenicists of the nineteenth and twentieth century and implemented in practice in the Third Reich, has become obsolete. Wherever control is possible, it is demanded by society and regarded as normal.²⁷ In most cases, the result is an abortion, although the extent of the impairment is often unforeseeable. It should also be borne in mind that with some measurement procedures, such as nuchal translucency measurements, an abnormal finding does not necessarily lead to a real impairment of the child. The diagnostic methods usually work with probabilities. In order to better confirm the positive result, the pregnant woman ends up in a »diagnostic spiral«. Forecasts and probabilities do not provide absolute security. The uncertainty of the pregnant woman is in this case a significant side effect of PND. The measurement results can be viewed in some cases sociologically as a kind of pseudo-control. This is because only around 25% of congenital impairments can be detected prenatally and 96% of impairments are experienced by people in the course of their lives.²⁸

The responsibility to decide for and to deal with the results of PND lies with the mother, who—if she decides against an abortion—acts irre-

25 Egen, Christoph: Was ist Behinderung? Abwertung und Ausgrenzung von Menschen mit Funktionseinschränkungen vom Mittelalter bis zur Postmoderne. Bielefeld 2020.

26 Hartwig, Susanne (ed.): Behinderung, Kulturwissenschaftliches Handbuch. Berlin 2020.

27 Egen: Was ist Behinderung?, p. 194ff.

28 Nicklas-Faust, Jeanne: Behinderung als soziale Konstruktion und Pränataldiagnostik, in: Duttge, G. (ed.): »Behinderung« im Dialog zwischen Recht und Humangenetik. Göttinger Schriften zum Medizinrecht 17, Göttingen 2014, pp. 59–70.

sponsibly« according to survey results.²⁹ In addition to the (consciously) taken risk, the parents/mother now bears the burden of justification for rejected prevention offers. The implementation of PND corresponds to a ›voluntary compulsion«. ³⁰ Prevention is always viewed euphemistically, but selective prevention in the context of PND means prevention not only of an impairment or disease but of human life and should be clearly named as such. Here, prevention reveals its normative character. With the introduction of PND, control over life is possible with the consequence that decisions now have to be made where previously fate decided.³¹ The possibility of averting disaster also gives rise to the duty of prevention.³² The future price of rejecting PND may be partial exclusion from solidarity communities. Politically, these procedures are merely declared to be an extension of choice; however, the decision and responsibility are individualized. But individual decision-making autonomy always takes place in social space, which is structured and limited by institutional rules and constraints and by the interpretation and relevance systems of medical experts.³³

Preimplantation Genetic Diagnosis (PGD) is an even more far-reaching biomedical measure that examines embryos created in vitro and only inserts embryos with ›healthy« genetic material into the uterus. The worrying trend that is becoming apparent here leads to the point that it may no longer seem reasonable to give birth to a child with an increased risk of disease, but that babies with desired characteristics, so-called ›designer babies«, will become the norm. The avoidance of ›undesirable« genetic dispositions possibly leads to the production of a type of human with a ›desired« genetic make-up. PGD shifts the boundary from avoiding a hereditary child (PND) to producing a child with desirable characteristics.

-
- 29 Beck-Gernsheim, Elisabeth: Genetische Beratung im Spannungsfeld zwischen Klientenwünschen und gesellschaftlichem Erwartungsdruck, in: id. (ed.): *Welche Gesundheit wollen wir? Dilemmata des medizinischen Fortschritts*. Frankfurt a. M. 1995, pp. 111–138.
 - 30 Beck-Gernsheim, Elisabeth: Gesundheit und Verantwortung im Zeitalter der Gentechnologie, in: Beck, Ulrich / Beck-Gernsheim, Elisabeth (ed.): *Risikante Freiheiten. Individualisierung in modernen Gesellschaften*. Frankfurt a. M. 1994, pp. 316–335.
 - 31 Lemke, Thomas: *Veranlagung und Verantwortung. Genetische Diagnostik zwischen Selbstbestimmung und Schicksal*. Bielefeld 2004.
 - 32 Leanza, Matthias: *Die Zeit der Prävention. Eine Genealogie*. Weilerswist 2017
 - 33 Bogner, Alexander: *Grenzpolitik der Experten. Vom Umgang mit Ungewissheit und Nichtwissen in pränataler Diagnostik und Beratung*. Weilerswist 2005.

Habermas warns against ›liberal eugenics‹ with regard to the increasing availability and use of biomedically intervening procedures.³⁴ Other authors speak of ›eugenics from below‹, which, in contrast to ›eugenics from above‹, no longer requires state planning or encouragement.

Both representatives of the disability movement and bioethics therefore understandably regard the possibility of PGD, but also of PND, as humiliation for people with disabilities and perceive it as a questioning of their existence and a signal of not being welcome and not belonging.³⁵ There are also fears that the willingness to assume the costs of therapy and care costs, as well as the necessary investment in medical research projects, could decline.³⁶

The concern that PGD has already opened a door to eugenics that needs to be defended is not entirely unjustified from the perspective of people with functional limitations. On the contrary, all existing studies indicate that even after (or despite) the introduction of PND and PGD, the situation of people with functional limitations tends to improve, to the extent that once they are born, their dignity is fully respected legally and socially and they are not regarded as objects of possible selection. In this context van den Daele speaks of a ›moral watershed‹ in the consciousness of the population. Acceptance of prenatal selection does not automatically and causally lead to acceptance of postnatal selection. Prenatal selection and discrimination against living people with functional impairments must therefore be regarded as two completely independent phenomena.³⁷

Conclusion

One can identify two partly contradictory currents of social reaction to people with functional impairments in the postmodern era: legal equality combined with an increasing public presence of people with functional

34 Habermas, Jürgen: Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik? Frankfurt a. M. 2001.

35 Deutscher Ethikrat: Präimplantationsdiagnostik. Stellungnahme, <https://www.ethikrat.org/fileadmin/Publikationen/Stellungnahmen/deutsch/stellungnahme-praeimplantationsdiagnostik.pdf> (15.03.2024), p. 64f.

36 Lemke, Thomas/Rüppel, Jonas: Reproduktion und Selektion. Gesellschaftliche Implikationen der Präimplantationsdiagnostik. Wiesbaden 2017, p. 71.

37 Daele, Wolfgang van den: Vorgeburtliche Selektion: Ist die Pränataldiagnostik behindertenfeindlich?, in: id. (ed.), Leviathan Sonderheft Biopolitik 2005, No. 23, p. 106f.

impairments and simultaneous efforts to avert the lives of these people through prenatal biomedical interventions.³⁸ The ›ambivalences of modernity‹³⁹ (e.g. optimism of healing through science with the simultaneous existence of incurable diseases or a homogeneous view of humanity with the simultaneous existence of diversity/heterogeneity) have not been resolved in postmodernity. What has changed, however, is the processing, which has shifted from the state to the individual, where it often causes orientation problems and feelings of being overwhelmed and therefore repeatedly triggers counter-movements (xenophobia, unscrupulousness of the sciences, etc.). This can ultimately be seen as a reaction to the inability to come to terms with the ambivalences.

However, there is a risk that biologically defined health will develop into a central social value, which will have an impact on the image of humanity. It should be borne in mind that only 4% of severe disabilities in Germany are present from birth; all others are acquired in the course of life. Sooner or later, we will all have to deal with impairments directly or indirectly—anything else would be a very utopian and unrealistic view. Disability studies therefore describe non-impaired people as ›temporarily abled‹. Nonetheless, prenatal health conditions attract outstanding attention regarding the dealing with disability in society. While there is – at least theoretically – great consensus about equal opportunities and support for people with impairments, the situation is regarded differently at the very beginning of life (and also the end of life, as the discussion about euthanasia shows). As Graumann points out, birth marks the dividing line for the constitution of a social person.⁴⁰ Birth or a legally defined age of pregnancy also marks the line between whether health might be prioritized over life. To emphasize the sociogenesis and psychogenesis of this liminality of life is important to recognize the achievement of individual degrees of freedom as well as its potential for unwanted social control.

38 Köbsell, Swantje: Behinderte Menschen und Bioethik. Schlaglichter aus Deutschland, Großbritannien und den USA, in: Hermes, Gisela/Rohrmann, Eckhard (eds.): Nichts über uns – ohne uns! Disability Studies als ein neuer Ansatz emanzipatorischer und interdisziplinärer Forschung über Behinderung, Neu-Ulm 2006, pp. 59–79.

39 Bauman, Zygmunt: Moderne und Ambivalenz. Das Ende der Eindeutigkeit, Neuausgabe 2005, 2nd ed., Lemförde 1992.

40 Graumann, Sigrid: Die Geburt als Grenze zur Konstitution sozialer Personen: Ein soziologisch-theoretischer Beitrag zur bioethischen Diskussion über Spätabbrüche und die Behandlung von Frühchen, in: Joerden, Jan/Hilgendorf, Eric/Petrillo, Natalia/Thiele, Felix (eds.): Menschenwürde in der Medizin: Quo vadis? Baden-Baden 2012, pp. 13–32.

Life always means risk, not everything in the course of a life will ever be controllable.⁴¹ Learning to live with the resulting feelings of powerlessness is the only thing that helps here, German history shows how much worse their counterparts—the fantasies of omnipotence—can be.

Elias' statement remains: the social existence of people is not least dependent on the image that people have of each other, on the meaning and value that they ascribe to each other.⁴² As long as our thinking about human coexistence increasingly corresponds to a cost-benefit analysis, the image of humanity will certainly not change for the better. However, it would definitely be helpful to extend the many efforts to establish and maintain biological health also to promote social coexistence or health.

References

- Achtelik, Kirsten: *Selbstbestimmte Norm. Feminismus, Pränataldiagnostik, Abtreibung*. 2nd ed., Berlin 2018.
- Bauman, Zygmunt: *Moderne und Ambivalenz. Das Ende der Eindeutigkeit*, Neuausgabe 2005, 2nd ed., Lemförde 1992.
- Baureithel, Ulrike: Das ist keine rein private Frage. Pränataldiagnostik: Soll der Test auf das Down Syndrom Kassenleistung werden? Nächste Woche debattiert der Bundestag, in: der Freitag, 04.04.2019.
- Beck-Gernsheim, Elisabeth: *Gesundheit und Verantwortung im Zeitalter der Gentechnologie*, in: Beck, Ulrich / Beck-Gernsheim, Elisabeth (ed.): *Risikante Freiheiten. Individualisierung in modernen Gesellschaften*, Frankfurt a. M. 1994, pp. 316–335.
- Beck-Gernsheim, Elisabeth: *Genetische Beratung im Spannungsfeld zwischen Klientenwünschen und gesellschaftlichem Erwartungsdruck*, in: id. (ed.): *Welche Gesundheit wollen wir? Dilemmata des medizinischen Fortschritts*, Frankfurt a. M. 1995, pp. 111–138.
- Beck-Gernsheim, Elisabeth: *Die soziale Konstruktion des Risikos — das Beispiel Pränataldiagnostik*, in: *Soziale Welt* 47 (1996), No. 3, pp. 284–296.
- Bogner, Alexander: *Grenzpolitik der Experten. Vom Umgang mit Ungewissheit und Nichtwissen in pränataler Diagnostik und Beratung*, Weilerswist 2005.
- Brockhaus: *Enzyklopädie in 30 Bänden, Band 22, POT-RENNZS*, 21st ed., Leipzig 2006.

41 Castel, Robert: *Die Stärkung des Sozialen. Leben im neuen Wohlfahrtsstaat*. Hamburg 2005, p. 128.

42 Elias, Norbert: *Sozialer Kanon, soziale Existenz und das Problem der Sinngebung. Ein soziologischer Essay*. Wiesbaden 2022, p. 79.

- Bröckling, Ulrich: Vorbeugen ist besser... Zur Soziologie der Prävention, in: *Behe-moth. A Journal on Civilisation* 2008, No. 1, pp. 38–48.
- Bröckling, Ulrich: *Gute Hirten führen sanft. Über Menschenregierungskünste*, Berlin 2017.
- Bundeszentrale für gesundheitliche Aufklärung: *Advice, Methods and Assistance. Prenatal Diagnosis*, 2023, <https://shop.bzga.de/pranaetaldiaagnostik-beratung-meth-oden-und-hilfen-c-394/> (15.04.2024).
- Castel, Robert: *Die Stärkung des Sozialen. Leben im neuen Wohlfahrtsstaat*, Ham-burg 2005.
- Caplan, Gerald: *Principles of Preventive Psychiatry*, 5th ed., New York, NY 1964.
- Daele, Wolfgang van den: Vorgeburtliche Selektion: Ist die Pränataldiagnostik be-hindertenfeindlich?, in: id. (ed.): *Leviathan Sonderheft Biopolitik* 2005, No. 23, pp. 97–122.
- Deutscher Ethikrat: *Präimplantationsdiagnostik. Stellungnahme*, 2011, <https://www.ethikrat.org/fileadmin/Publikationen/Stellungnahmen/deutsch/stellungnahme-praeimplantationsdiagnostik.pdf> (15.03.2024).
- Dörner, Klaus: *Tödliches Mitleid. Zur Frage der Unerträglichkeit des Lebens oder: die Soziale Frage: Entstehung – Medizinisierung – NS-Endlösung – heute – mor-gen. Mit einem Beitrag von Fredi Saal, Gütersloh* 1989.
- Elias, Norbert: *Über den Prozeß der Zivilisation. Soziogenetische und psycho-genetische Untersuchungen. Band II. Wandlungen der Gesellschaft. Entwurf zu einer Theorie der Zivilisation*, 2nd ed., Frankfurt a. M. 1977.
- Elias, Norbert: *Sozialer Kanon, soziale Existenz und das Problem der Sinngebung. Ein soziologischer Essay*, Wiesbaden 2022.
- Egen, Christoph: *Was ist Behinderung? Abwertung und Ausgrenzung von Menschen mit Funktionseinschränkungen vom Mittelalter bis zur Postmoderne*, Bielefeld 2020.
- Graumann, Sigrid: *Die Geburt als Grenze zur Konstitution sozialer Personen: Ein soziologisch-theoretischer Beitrag zur bioethischen Diskussion über Spätabbrüche und die Behandlung von Frühchen*, in: Joerden, Jan/Hilgendorf, Eric/Petrillo, Natalia/Thiele, Felix (eds.): *Menschenwürde in der Medizin: Quo vadis?*, Baden-Baden 2012, pp. 13–32.
- Gordon, Robert S.: *An operational classification of disease prevention*. *Public Health Reports*, 83 (1983), No. 98 (3), pp. 107–109.
- Habermas, Jürgen: *Die Zukunft der menschlichen Natur. Auf dem Weg zu einer liberalen Eugenik?*, Frankfurt a. M. 2001.
- Hartwig, Susanne (ed.): *Behinderung. Kulturwissenschaftliches Handbuch*, Berlin 2020.
- Köbsell, Swantje: *Behinderte Menschen und Bioethik. Schlaglichter aus Deutsch-land, Großbritannien und den USA*, in: Hermes, Gisela/Rohrmann, Eckhard (eds.): *Nichts über uns – ohne uns! Disability Studies als ein neuer Ansatz emanzipatorischer und interdisziplinärer Forschung über Behinderung*, Neu-Ulm 2006, pp. 59–79.

- Labisch, Alfons: Medizin und soziale Kontrolle. Zum Verhältnis von Sozialgeschichte und Soziologie der Medizin am Beispiel neuerer Literatur aus der Bundesrepublik Deutschland mit einem Exkurs: Neuere Forschungen zur Medizin im Nationalsozialismus, in: *Dynamis. Acta Hispanica ad Medicinæ Scientiarumque Historiam Illustrandam* 1987-1988, No. 7-8, pp. 427–459.
- Labisch, Alfons: Gesundheitskonzepte und Medizin im Prozeß der Zivilisation, in: Labisch, Alfons/Spree, Reinhard (eds.): *Medizinische Deutungsmacht im sozialen Wandel*, Bonn 1989, pp. 15–36.
- Labisch, Alfons: Homo hygienicus: soziale Konstruktion von Gesundheit, in: Wagnier, Franz (ed.): *Medizin. Momente der Veränderung*, Berlin et al. 1989, pp. 115–138.
- Leanza, Matthias: *Die Zeit der Prävention. Eine Genealogie*, Weilerswist 2017.
- Lemke, Thomas: *Veranlagung und Verantwortung. Genetische Diagnostik zwischen Selbstbestimmung und Schicksal*, Bielefeld 2004.
- Lemke, Thomas/Rüppel, Jonas: *Reproduktion und Selektion. Gesellschaftliche Implikationen der Präimplantationsdiagnostik*, Wiesbaden 2017.
- Martschukat, Jürgen: *Das Zeitalter der Fitness. Wie der Körper zum Zeichen für Erfolg und Leistung wurde*, Frankfurt am Main 2019.
- Mutz, Gerhard: *Sozialpolitik als soziale Kontrolle am Beispiel der psychosozialen Versorgung*, München 1983.
- Nicklas-Faust, Jeanne: Behinderung als soziale Konstruktion und Pränataldiagnostik, in: Duttge, G. (ed.): »Behinderung« im Dialog zwischen Recht und Humangenetik (Göttinger Schriften zum Medizinrecht 17), Göttingen 2014, pp. 59–70.
- Paul, Norbert: Pränatale Diagnostik, in: Gerabek, Werner E. (ed.): *Enzyklopädie Medizingeschichte*, Berlin et al. 2011, pp. 1178–1180.
- Papenkort, Ulrich: Prävention: Wort, Felder und Begriff, in: id. (ed.): *Prävention. Fachübergreifende Einführung in eine besondere Intervention*, St. Ottilien 2008, pp. 9–39.
- Roelcke, Volker: *Vom Menschen in der Medizin. Für eine kulturwissenschaftlich kompetente Heilkunde*, Gießen 2017.
- Rösner, Hans-Uwe: *Behindert sein – behindert werden. Texte zu einer dekonstruktiven Ethik der Anerkennung behinderter Menschen*, Bielefeld 2014.
- Schütz, Alfred / Luckmann, Thomas: *Strukturen der Lebenswelt*, Konstanz/Stuttgart 2003.
- Stengel-Rutkowski, Sabine: Vom Defekt zur Vielfalt. Ein Beitrag der Humangenetik zu gesellschaftlichen Wandlungsprozessen, in: *Zeitschrift für Heilpädagogik* 53 (2002), No. 2, pp. 46–55.
- Stöckel, Sigrid / Walter, Ulla (eds.): *Prävention im 20. Jahrhundert – Historische Grundlagen und aktuelle Entwicklungen in Deutschland*, Weinheim München 2002.
- Tchirikov, Michael: Intrauterine fetale Chirurgie, in: *Deutsche Hebammenzeitschrift* 14 (2017), No. 1, pp. 32–46.

Welsh, Caroline: Brauchen wir ein Recht auf Krankheit? Historische und theoretische Überlegungen im Anschluss an Juli Zehs Roman *Corpus Delicti*, in: Frewer, Andreas/Bielefeldt, Heiner (eds.): *Das Menschenrecht auf Gesundheit. Normative Grundlagen und aktuelle Diskurse*, Bielefeld 2016, pp. 215–238.

