Origins and practices of genetic risk and responsibility

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2. Origins and Practices of Genetic Risk and Responsibility
Is it Irresponsible Not to Test?

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The beginning of life as a human being has historically been discussed and handled in very diverse ways. It was seldom an arbitrary thing to decide whom to admit and welcome as a fellow human being into a community, a collective or a society. One traditional way to become part of the community as a fellow human is through procreation and birth. Procreation has always fascinated people. There is also a fascination in using techniques and practices to improve one's own species, to guide society, i.e. to pursue population policy, to eliminate or even improve the "bad genetic material" for future generations – all these developments in biology, medicine and genetics clearly reveal an inherent entanglement of knowledge and values, of science and politics. The "sciences" aimed to improve heredity – race theory, eugenics and racial hygiene were particularly promoted in the 19th and 20th centuries. At its peak, this fascination turned into a cruel selection regime during the Nazi era. After the Second World War genocide of Jews and other ethnic groups, people with disabilities and political prisoners, the discourses in Israel and Germany about prenatal genetic testing and its associated responsibilities were still influenced by this historical event. In the first two decades of the 21st century, state-promoted eugenics as pursued under the Nazi regime, or other forms of systematically excising "unworthy life", has no official approval from health ministries, human rights advocates, politicians or ethicists.

Today, a strong concept of responsibility pushes the quest for individual and autonomous choice to the centre of the praxis of pregnancy. Under the "rhetoric of the 'right to know' and 'informed choice'" (Petersen 1998: 64), the pregnant woman bears the responsibility for her pregnancy and her child; depending on the context, she alone is considered to have this responsibility, per-

haps with her partner, with the aid of the medical staff, or in some Jewish religious contexts with support from a rabbi (Ivry/Teman 2019; see chapter 7 of this book). With the emergence of reproductive technologies and genetic testing, the concept of genetic risks became established, and a general responsibility of care during pregnancy essentially became *genetic* responsibility. This chapter therefore focuses on both terms, genetic risk and genetic responsibility, looking at their relationship and the different ways they have been conceptualised in the last two decades of prenatal care for mother and child.

The question is not how a pregnant woman might share or assume responsibility; I want instead to understand the motives and the object of being responsible and how these correlate with the perception of genetic risk. What is the aim of being responsibility in "responsible motherhood" or "irresponsible motherhood" (Ivry/Teman 2019: 861)? The general message seems to be finding what is best for the children (Ruckdeschel 2015). Is the main objective, for instance, the well-being of the child or the family, their health, avoiding unworthy life, or producing healthy offspring? In any case, it seems that the burden of responsibility can be heavy, and sometimes involve a decision about life and death; it certainly involves a decision about how much and what should be genetically tested and known about the foetus.

The increasing availability of genetic tests and the capacity to decide about the child's life in light of genetic findings corresponds with the genetic responsibility to test, to know and to act accordingly. Women who do not want to know about the genetic make-up of their offspring may face accusations of irresponsibility, as we found, for instance, in interviews conducted in Israel (cf. chapter 7 of this book). Reproaching a mother for irresponsibility about the future child is a strong attack on her moral integrity and affects her close family and social relationships. German interviewees mostly emphasised that genetic testing is a decision for the individual or couple. Even though the debate about NIPT is much more publicly driven in Germany, interviewees explicitly refrained from judging other decisions or opinions within the field of genetic testing. Yet it does not follow that parents who have a child with a disability always receive understanding and sufficient support.

The historical background of Nazi cruelty and atrocities still forms an underlying reference in both countries: the discourse in Germany cannot refrain from a restrictive approach towards genetic testing and research; the influence of guilt alternates between collective trauma that is perpetuated through generations (Bar-On 1989) and a "historic responsibility" (Zimmermann 2016) that

is also propagated by the state.[1] This leads to a balanced objection against prenatal practices that are implemented as a standardised routine that "selects" life. If prenatal genetic testing is *not* done on an individual and deliberate case-by-case basis, then at least in the German context, it may give the impression of a eugenic strategy (cf. Rubeis 2018; Braun 2021; Foth 2021).

Israel's culture still includes the memory of the Shoah in its discourse. As a consequence of this victimisation, it emphasises the survival of the Jewish people. This emphasis is supported by, as stressed by Weiss (2004), Jewish culture and the Zionist movement, both of which have an historical objective of producing strong and healthy Jewish bodies. Distinct from Protestant or Roman Catholic ethics, which emphasise the dignity of the foetus, Jewish religion does not have a concept of personhood or dignity of the foetus and is open to its physical improvement; hence, Israel's permissive genetic testing is supported by these historical, religious and cultural motives. Reproductive institutions – whether offering genetic testing, IVF or other reproductive technologies – provide the means for exercising one's responsibility towards the collective body of Israeli society (Prainsack 2006: 242). Germany hesitates to be permissive about prenatal genetic testing, and if anything, the discourse emphasises individual reproductive self-determination, with the focus especially on "the balance between the 'right to know' and 'not to know'" (Perrot/Horn 2021), and not on the *Volkskörper* ("body of the people") or the improvement of a race; these conceptualisations are not part of the discourse either semantically or structurally.

The complexity of the situation and questions at stake make it easy to categorise an action as irresponsible. For example, in Germany, aborting a foetus diagnosed with trisomy 21 for embryopathic reasons is sometimes condemned for "selecting life"; likewise, the parents of a child with Down syndrome may receive critical looks or comments that a child like that is not "necessary any more". On the other hand, several campaigns that fight for the rights of people with Down syndrome use the slogan "Don't screen us out!"[2] Consequently, in Germany, several religious and non-religious organisations and groups, such as the *Bundesvereinigung Lebenshilfe* (2015), that formulate a rather critical stance towards NIPT, arguing that these genetic tests discriminate against

1 https://www.germany.info/us-en/welcome/03-Jewish-Life-Germany, accessed 02 June 2022.

2 For instance, the British campaign "Against making chromosomes count" (https://makingchromosomescount.co.uk/dont-screen-us-out-2/ or https://dontscreenusout.org/ or rambazamba-theater.de), accessed 26 July 2022.

people with disabilities and the parents who have not prevented the birth of such children (Schidel 2020). At the same time, parents of a child with disabilities face discrimination, and pregnant women who learn that their foetus has a trisomy will include fear of such discrimination in their deliberations about genetic testing and abortion. At least in Germany, critical positions can be found for both the decision to genetically test or not to test, and parents are stuck between a duty towards health (meaning aborting foetuses with trisomy) and their reproductive autonomy (Primc 2018). Psychologists Philipp et al. (2000: 26f.) observe that "particularly the divided social attitude towards giving birth to a disabled child, but also towards terminating a pregnancy, puts couples under pressure and creates a sense of vulnerability and attackability."

In Israel, the question of genetic testing has largely been answered on the basis of a well-established prenatal care practice that includes a choice of invasive and non-invasive genetic tests. Where there is a positive finding of a genetic variation linked to disability, the reason for abortion is generally based on the possible "suffering" of a disabled child and whether her life would be "worth living" (Hashiloni-Dolev 2007; Remennick 2006). While the Israeli abortion law includes embryopathic reasoning, in Germany it is only the burden on the mother of having a child with disability that legally counts as reason to end a pregnancy. Thus, the Israeli and German discourse with regard to the main reasoning behind abortion shows very different groundings. Even more fundamentally, the difference between Israel's and Germany's practice and discourse on prenatal genetic diagnosis is based on different understandings of genetic responsibility and genetic risk. Working from this idea, I will introduce some historical background on the concepts of responsibility and risk. Both are rather recent concepts with histories predominantly in non-medical areas.

Responsibility and risk have distinct origins. After bringing out their diverging lines, I want to show how they merge with the establishment of genetic practice and how they are transformed into *genetic* risk and *genetic* responsibility. These historical and systematic observations will lay the ground for drawing a distinction between genetic responsibility and care responsibility in the contexts of pregnancy, the foetus, and the future of the child. Furthermore, I will introduce three types of moral conduct with reference to the genetic testing and care relationships: *responsibly, irresponsibility* and *non-responsibility*. The delineation of dissimilar thematic orientations of responsibility will support diverse paths of decision-making and acting in the realm of pregnancy care and genetic testing.

Era of responsibility

In the shadow of the Second World War and the atomic bombs dropped on Hiroshima and Nagasaki that killed more than 200.000 people – children, women, men – the concept of responsibility and care for the future and the human condition was brought to the fore by Hans Jonas, Emmanuel Levinas, Hannah Arendt and Günter Anders in the 1960s. Jonas, in his 1979 work *The Imperative of Responsibility*, presents a future-oriented responsibility concerned with the life of the next generation, the protection of humanity and nature, and a warning against large-scale technologies in general. One of his insights is that when we act, we cannot pretend not to know the meaning of this particular action, and we should be cautious if we do not know what the outcome of our action might be.

Hans Jonas' ethics of responsibility is an attempt to propose an ethics of global co-responsibility. Humans have the power to invent science and technology, and are therefore responsible for these inventions. Jonas primarily wrote about ecological ethics, calling for the protection of human life on earth. The context of this ethical need is the observation that technical and medical possibilities could endanger the lives of future generations because scientists *have the ability to* invent more than they are able to control. Since we, as humans of the 20th century, have the power to invent technologies whose effects are unforeseeable, far-reaching, and irreversible, and that might potentially endanger future generations, we must take responsibility. A "heuristic of fear" should guide decisions on which technology may be used and which we should refrain from using (Jonas 1984: 35). Thus, Jonas' concept of responsibility has a rather pessimistic overtone.

In this primary phase of the concept of future responsibility, warnings were issued against the new gene technologies and the possible biological hazards, in addition to other chemical industries and atomic technologies. This debate continued to be dominated by the growing awareness of limited resources, overpopulation and the looming ecological crisis, as discussed in the Club of Rome report (Meadows 1972; Leefmann/Schicktanz 2016). The recommendation was for society, and especially scientists and other experts, to adopt a political responsibility towards the next generation. An individualised concept of future responsibility that correlated with the concern about reproductive technologies very soon steered the discourse and practice of pregnancy and the beginning of life.

In the 1970s, pregnancy became increasingly medicalised; yet it was also criticised and the hope for a healthy child romanticised (Illich 1975; Conrad 2007), Later, in the 1980s, this attitude changed to a demand for comprehensive medical care during pregnancy. As a responsible person, and in consultation with her physician, the woman's concern had to be for her pregnancy and the foetus. Her responsibility was directed primarily toward good behaviour: eating healthily, avoiding drugs and alcohol. If a pregnant woman was not behaving "properly", she was considered irresponsible. Responsibility was primarily seen as a way of living and behaving according to particular social norms. Accordingly, Linda McClain (1996) critically discussed three paradigms of irresponsibility that were used to propagate social stigmatisation in the name of care: the single mother, the welfare mother, the teenage mother. This is the period in which the child (to be) became central to motherhood; the terms "responsible motherhood" and "responsible parenthood" appeared, and became a central part of the discussion and of the self-understanding of a mother (to be) (Haker 2001; Ruckdeschel 2015).

More specifically, since the 1970s and '80s a pregnant woman has been expected to pursue a particular medical and social practice of care and control, in which the foetus has become the strong focus of biomedical and social attention. Accurate genetic testing became the key to evaluating the "health" of the foetus from the point of view of the future parents. For the prenatal phase, the general responsibility for the health of the (expectant) mother was transformed into a *special responsibility* for the child to come: *genetic* responsibility. In the 21st century, *genetic responsibility* in pregnancy is central, focusing on genetic aspects of the foetus that may lead to physical or mental phenotypic variations.[3] These different options demand a set of *personal responsibilities* of the (expectant) parents, because as well as aspects of care, which may also be provided by family members, they demand a focused attitude towards consideration of the *genetic risk* associated with the genetic disposition of the foetus and the (biological) parents.

The term "genetic responsibility" became part of the discussion in genetic counselling contexts. The term "genetic responsibility" was used explicitly as

3 Currently, in addition to the wide range of reproductive services available, we can also observe a trend towards including non-medical practices of birth preparation and childbirth aimed at the health and well-being of mother and child (Matthew/Wexler 2000). And ultrasound provides images of the baby, located in the exciting ambivalence between "(bio)medicalisation" and "demedicalisation" (Ullrich 2012).

early as a 1972 symposium on "choosing our children's genes" (Lipkin/Rowley 1974). Here, genetic responsibility was seen in a collective perspective of acting "responsibly" towards the next generation. An ethics of responsibility was supposed to be one "which at once releases our hope and restrains our injustice," and avoids hereditary disease (Fletcher 1974: 94).

Ultrasound made the foetus visible and, hence, measurable; amniocentesis showed whether it is "genetically healthy". More and more tests are being introduced into prenatal diagnostics. The establishment of prenatal genetic tests signifies that responsibility is having a strong impact in bioethical and biopolitical discourse. This impact is particularly supported by neo-liberal tendencies of brash marketing in the form of "fertility fairs", which are actively accepted by inquiring consumers, and which increase individualisation and introduce a variety of genetic tests.[4] The conceptual linkage between genetic diagnosis, genetic knowledge and genetic responsibility is becoming a fixed parameter of *risk procedure* in the biomedical care of pregnancy and the beginning of life.

Silke Schicktanz states broadly: "*where there is risk there is responsibility*" (2018: 236), and describes how responsibility emerges in situations where a risk awareness is raised by the information about genetic risks (e.g. biological disposition of pregnant woman, genetic testing), is considered in decision-making, and is central to different practices.[5] She and Aviad Raz introduce the relationship between responsibility and risk as an "epistemic turn" (2016: 38f.) that takes place in the context of a socially implemented upheaval caused by the rising importance of paying attention to genetic risks.

With the epistemic and normative introduction of genetic risk into the practice of pregnancy and into the bioethics of prenatal genetic testing, the relationship between genetic responsibility and genetic risk is strong. However, responsibility and risk have different historical backgrounds. Having addressed the socio-historical horizon of responsibility, I now turn to the concepts of risk and security. Then I will consider the conjunction between genetic responsibility and genetic risk and observe some aspects of how it works in the respective socio-cultural contexts of Germany and Israel.

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4 "Fertility fears" have also become socially relevant in the contexts of egg-freezing and vaccines, e.g. COVID-19, or breast cancer treatment.

5 To refer to Hans Jonas in this matter is rather misleading because he does not, as I explain above, derive responsibility from risk but from human power. In addition, he is alluding not to risk but to the possible dangers of technology.

Risk, security and genetic responsibility

The modern concept of risk has its origin in the maritime insurance of the European Middle Ages and is therefore relatively young in terms of its linguistic history. From the Italian *rischio*, the term was introduced into German as *Risiko* and into English as "risk". [6] In the Romance languages, it is a Latin loanword from the Greek root *rico* (cliff), and probably originally referred to navigation round a cliff. In the merchant language of the Middle Ages, "risk" designated uncertain commercial transactions. In German-speaking countries, the term remained a technical economic one until the 19th century and only then found its way into other sciences and everyday life.

The German sociologist Ulrich Beck combines Jonas' observation that scientists have a power of knowledge that has potential for technological and industrial catastrophes with the thesis that, in the context of the 1980s, we live in a *risk society* which is organised in response to risks.[7] "Risk may be defined as a systematic way of dealing with hazards and insecurities induced and introduced by modernization itself" (Beck 1992: 21). Beck has global, environmental, industrial and gene technology risks in mind, and observes prenatal testing practices to be a "quality control of embryos" with reference to "a socially and ethically 'desirable', 'used' or 'healthy' genetic substance" (Bräutigam/Mettler 1985, quoted in Beck 1992: 206). Giddens emphasises that such a risk society is "increasingly preoccupied with the future (and also with

6 In Hebrew the word for risk is סיכון (sikun).

7 What is the difference between danger and risk? In referring to the atomic or chemical industry and gene technology we often speak about dangers and risks. Since the 1980s the triangle of danger, security and risk has become the focus of discussion. Although these terms have different meanings and objectives, they are often used interchangeably. Since our focus here is on genetic risk, I would like to distinguish it from danger. The perspective of system theory may help us to understand this distinction. Danger is a form of possible damage that is considered to be externally caused, i.e. attributed to the environment that lies outside one's own social system. If the cause of damage is attributed to one's own realm of decision-making then we speak of risk, and if it is outside our realm of decision-making then we speak of danger. This makes it possible to distinguish responsibilities from damage. In summary, the main difference between risk and danger is that in the case of a danger, the damage is caused externally and the system (or subject) does not know what decision it should or could make to avoid the damage (Luhmann 2003). This demarcation makes the decision into an immanent part of the risk. Thus, decisions and their consequences, i.e. risks and their consequences, are directly attributable to the decision-maker.

safety), which generates the notion of risk" (Giddens/Pierson 1998: 209; see also Giddens 1990), and answers to the problems of modernity insofar as it introduces a new concept of risk.[8] In a conversation with Pierson, Giddens goes on to explain that "[e]ssentially, 'risk' always has a negative connotation, since it refers to the chance of avoiding an unwanted outcome. But it can quite often be seen in a positive light, in terms of the taking of bold initiatives in the face of a problematic future. Successful risk-takers, whether in exploration, in business or in mountaineering, are widely admired" (1998: 209). As soon as dangers are transformed into risks, the range of possibilities for influence expands. Technology transformed dangers that were given by nature into risks, and perhaps in doing so has created new risks (Rosa et al. 2014: 103). In contrast, a genetic variation is given as a statistical calculation, and the concept of genetic risk is described not only in medical terms but also in terms of its social consequences and the difficulties it may bring for daily life. Genetic risks in pregnancy care are considered with regard to the foetus, and are described as being more or less severe according to particular criteria, such as the age or genetic heritage of the pregnant woman. Generally, within every pregnancy, there are genetic risks which call for technologies that make the genetic disposition of the foetus visible.

When it comes to "genetic risks", the prevention or avoidance of the consequences of certain genes that may result in particular conditions is seen as a heroic act, as exemplified by the tabloids' reporting about Angelina Jolie and her mastectomy. Thus, the concept of *genetic* risk as introduced into prenatal care implies a normative duty of the pregnant woman to be concerned about the foetus in terms of what behaviour is appropriate. It implies a responsibility to retrieve genetic information about the foetus and to decide on the basis of informed choice to minimise as far as possible the insecurity with respect to the risk. From a Foucauldian view of governmentality, the concept of risk has now become established in the field of prenatal genetic diagnostics and is part of society's concern and vocabulary, and leads to "genetic responsibilisation"

8 Beck and Giddens approach the concept of risk in the horizon of modernity and the traditional class structure of society. Contrary to Beck, Giddens defines risk more optimistically as also providing possibilities of empowerment and self-activity. He distinguishes two types of risks: external risks and manufactured risks. Manufactured risks depend on human agency and allow for both producing and mitigating risks. The Chernobyl disaster was one motive to think about risk. Genetic risks as we know them today were touched upon but not explored.

(Lemke 2000, 2004, 2006). Likewise, the notion of "genetic risk" is embedded politically in both modern liberal capitalism and the discourse on selection and eugenics that emerged in the 19th and 20th centuries. While the first is directly linked to the economic history of risk and the present social and economic order of society, the second is connected to the medical discourse on risk factors that developed during the early 20th century with regard to social hygiene, and in the late 20th century as a reaction to an increase in diseases typical of Western civilisation (e.g. heart attack, particular forms of cancer). Furthermore, genetic risk can be traced back to the 19th and 20th centuries' history of genetics, eugenics and racial hygiene.[9] Certainly, the late 19th and early 20th century was a period of vivid discussions about different understandings of the biological foundations and mechanisms of heredity. For instance, in researching the basis of heredity, the zoologist August Weismann was able to show that the biologisation of social contexts has no hereditary equivalent. Nevertheless, a fear of the danger of social degeneration, as it was perceived, stirred by the unholy alliance of Darwin's and Lamarck's theories, developed further in the 20th century and became a major source of the eugenic movement before and during the National Socialist regime (Weingart et al. 1992).

In 1909, the physician Archibald Garrod set a milestone in the history of genetics. He noticed that there were diseases with a family history whose characteristic, for example, could be found in both father and son at the same time. Further, he noticed that the disease is inherited as a Mendelian autosomal recessive trait. His work made him into a founder of medical biochemical and molecular genetics and established the study of genetic disease (Perlman/Govindaraju 2016). By 1909 the Danish botanist Wilhelm Johannsen, who first used the word "gene" as an empirical working concept, was well aware of the vagueness of the collective term. In the early 20th century, the notion of "gene" nevertheless increasingly became – first in the natural sciences and then in public perception – a central concept for denoting questions of the biology of heredity (Paul 2006: 343; Keller 2002). Later, heredity, which is related to medical human genetics, focused on cancer research and tumour development in somatic mutations. However, the international upsurge of eugenics and, later on, National Socialist race politics (*Rassenpolitik*) overshadowed the results of

9 The term "racial hygiene" (in German: *Rassenhygiene*) denotes a special and dehumanising interpretation of eugenics in the German-speaking countries (for further reference, see Schües 2021a). It is important to mention this background in this context because it still overshadows the discussion of prenatal genetics (see Foth 2021).

molecular genetic research into the functions of the hereditary substance. The intertwining of medical, genetic and social concerns is described in, for instance, the *Reichsgesetzblatt* of 3 July 1934, which speaks of looming "dangers" for the health of the *Volkskörper* (body of the people) (Fangerau/Noack 2006; Fuchs 2008: 195, 197).[10]

The population and racial policies of the Nazi regime meant that after the Second World War the field of genetics was challenged to position itself in a new way. Eugenics had come under general suspicion after the recent inhumane and horrific selection procedures. Scientific genetics found it difficult to free itself from this suspicion. While "eugenics" became taboo in Germany (Foth 2021), the improvement of the "gene pool" of the population nevertheless continued to be propagated under the heading of "reform eugenics", especially in the USA (Paul 2006: 346) and also in Israel. In the USA, improving the genetic basis of human existence was also supposed to lead to an improvement in human living conditions. In Israel, eugenics was much discussed between 1930 and 1955. "Psychiatrist [Arie] Kochinsky, for one, argued in 1938 in the journal *Harefuah*[11] that the findings of a census of the mentally ill in Palestine should serve primarily as 'a basis for methods to improve the [Jewish] race'", as the journalist Yotam Feldman reported in the newspaper *Haaretz* (Feldman 2009). Later, in 1942, with the aim of strengthening the Jewish race by means of controlling births, Kochinsky focused on "population policy and psychopathology" at the second conference of the Neuro-Psychiatric Society. In August 1952, a decision was passed by the World Congress of Jewish Physicians to establish a scientific institute dedicated to issues of eugenics in Israel (ibid.). The institute was never established.[12]

Jewish physicians and psychiatrists who escaped from Germany to Israel stirred the debates about population policy, racial hygiene, and eugenics. The basic question was, as Yosef Meir, the head of a health fund, wrote in 1934

10 In the horizon of this research and in the year 1949, Linus Pauling, for example, described sickle cell anaemia as a "truly molecular disease with its origin in the change of gene structure and function" (cf. Paul 2006: 345).

11 The journal Harefuah is the medical-scientific periodical of the Israeli Medical Association. It was founded in 1920 (https://www.ima.org.il/eng/ViewContent.aspx?CategoryId=11081), accessed 26 July 2022.

12 In 2009 the daily newspaper Haaretz also reported on a 1958 letter by Golda Meir, then foreign minister of Israel, to the Israeli ambassador to Poland. Golda Meir raised the possibility of preventing handicapped and sick Polish Jews from immigrating to Israel (Galili 2009).

in *Ha'em Vehayeled* ("Mother and Child"): "Who is entitled to bear children?" (quoted in Feldman 2009). The focus of this question particularly concerned the psychiatric community, whose members were often immigrants from Germany; they included Kurt Löwenstein (Levinstein), originally a German psychiatrist and neurologist and president of the neuropsychiatric society in Israel, who promoted eugenics at a 1944 medical conference in Tel Aviv (Feldman 2009). In his lecture, he argued against allowing those with mental disorders to bear children. He was not alone in this view, yet it was important to him that he be understood as distancing himself from Nazi ideology. He certainly knew about eugenic ideology's political connotation and close connections to the Nazi regime and its systematic atrocities against Jews and other groups. I presume these thoughts should be seen in the historical context and as an attempt to understand mental disorder and to find a social-moral order to alleviate human suffering. The historian Rakefet Zalashik (2012) wrote about the history of psychiatry in Palestine during the Mandate and following the founding of the State of Israel. She explains that eugenic social engineering was not only part of the ideology of Israeli/German psychiatrists, but was also central to the Zionist vision of Israel and to the idea of a Jewish body which should be born under the "condition" of being healthy (cf. Weiss 1994). Thus, the question: Who is entitled to be born?

In 1962, the CIBA Foundation organised the symposium "The Biological Future of Man" in London. Not only was so-called "reform eugenics" discussed at this meeting, but also the view, spurred on by the discovery of the double helix in 1953, that genes were essentially building blocks of biological information. Genetics became an information-based science. The idea that "genetic information" was present in the chromosomes as a biological "code" was born[13] (cf. Kay 2000). This scientific activity inspired the expansion of genetics and acceleration towards the human genome project.

Research into human genetics has not only advanced into knowledge of the structural instability of a gene and even the decoding of the human genome, but has also provided the basis for a radical expansion of the concepts of health and disease. Once genetic prognoses, or at least statistical probabilities, are

13 Terms like "information", "message" or "code" did not appear in the language of biologists until the 1950s. This way of thinking basically goes back to the scientists of the Cold War, e.g. John von Neumann's game theory, because during that period many physicists, mathematicians and cyberneticists who had previously been involved in war-related activities moved into biology. They brought this metaphor with them.

possible, methods of prenatal genetic testing can be used to diagnose diseases or disabilities (such as trisomies, Huntington's disease, cystic fibrosis) before they become symptomatic. Biomedicine now includes the search for genetic dispositions and risks for disease or disability. This not only expands the concept of disease and makes new legal, economic or insurance policy issues relevant, but also shifts the responsibility to those who are confronted with genetic testing of their foetus (or of their own genetic disposition).[14]

By 1978 the maternity guidelines (*Mutterschaftsrichtlinien*) in Germany mentioned "genetic risk", which at that point referred primarily to the recommendation that the doctor should offer counselling (Fuchs 2008: 306). In addition, the guidelines spoke of a "genetic age risk", which is why "high-risk pregnant women" should "make use of prenatal diagnostics" (Fuchs 2008: 299). The paradigm of genetic risk was born. Today, pregnancy care is understood, experienced and guided by the concept of genetic risk. It is thus assumed that the pregnant woman has a genetic responsibility towards the foetus, the family or society according to the perceived genetic risk, i.e. whether this risk is socially or culturally perceived as being low or high. She has a responsibility to determine the genetic risks and to take steps to control them with the help of her gynaecologist. These steps include taking genetic tests and subsequent action should a test be positive.

NIPT, genetic risk and genetic responsibility

Prenatal genetic testing has been under discussion for several decades, and NIPT has been offered since 2012 as a prenatal genetic test in Germany and as a screening test in Israel.[15] If NIPT is positive, it has to be confirmed through

14 *Prediction* is both a medical and an everyday concept, even a utopian ideal, aimed at reducing health risks and preventing disease. It is firmly anchored in the individual consciousness as well as at the societal level. The prediction of individual health risks that ideally corresponds with prevention and a therapeutic intervention is of great interest to the individual patients and to the social perception of health and disease.

15 Principally, diagnostic testing is used when there is cause for concern, i.e. a risk; screening tests are performed in order to find out whether there are reasons to be concerned, i.e. whether there is a genetic risk to be followed up. (https://www.healthknowledge.org.uk/public-health-textbook/disease-causation-diagnostic/2c-diagnosis-screening/screening-diagnostic-case-finding), accessed 02

amniocentesis, a genetic test. Strictly speaking, the positive result of a chromosome variation found by amniocentesis, such as trisomy 13, 18 or 21, is not a risk but a medical diagnosis which, however, does not say all about the severity of the symptoms in real life. Thus, the notion of risk is firstly formulated on the side of the pregnant woman who may transmit a genetic risk based on predefined criteria, for instance being aged over 35 years, which means that statistically she has a higher risk of having a foetus with a chromosomal variation. Secondly, risk is considered on the side of the foetus before any test or diagnosis is done and, furthermore, a risk is perceived as the result of a positive outcome of a genetic test. Such risk includes the question of how the genetic variation will become symptomatic as a phenotype. For example, some children with trisomy 21 develop heart problems or malformations of the gastrointestinal tract (Guedj/Bianchi/Delabar 2014), while others do not.

Most disabilities or health problems associated with chromosomal variations cannot be treated. Some families, as reported by interviewees in Germany, say they took the test result as a chance to prepare themselves better for a child with disability, socially, psychologically and practically (Philipp et al. 2020: 27f.; cf. chapter 8). However, most parents respond to a positive finding by ending the pregnancy. It is worth mentioning that some of these pregnancies are terminated without confirmation of a test result. This should probably be understood as an expression of the enormous psychological stress under which the pregnant woman finds herself in the case of an "abnormal finding" (Kagan/Hoopmann 2020: 22).

The recommendation to verify a positive NIPT with amniocentesis indicates the risk of false positive results. The clinical geneticist Christian Netzer (2022) has investigated the test security of NIPT. Companies advertise NIPT as having a sensitivity (false positive) of 99 per cent and a specificity (false negative) of 99.9 per cent with regard to trisomy 21. However, these numbers depend upon the frequency of trisomy in the investigated group. In 20-year-old pregnant women, trisomy is less likely to be found in the foetus, which is why accuracy is reduced to 48 per cent (sensitivity), compared to 93 per cent in 40-year-olds. NIPT is considered a quantum leap compared to first-trimester screening, with a false positive rate of only 3 per cent in 20-year-old pregnant women. If a test result is positive, what can women do? Usually, they feel a strong insecurity. Now they *must* decide: once the positive result is known, the "risk" is

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June 2022. In our interviews, some women perceived NIPT as a diagnostic test because the first-trimester nuchal fold scan revealed a risk of trisomy.

no longer on the side of the pregnant women (e.g. her age), but on the side of the biomaterial of the foetus. The risk can no longer be suppressed. This situation leads to further diagnostics, possibly to an abortion or to a constant uncertainty about whether the child, once it is born, might have something that has turned out to be a false diagnosis. In this context women feel that they are caught in a testing "spiral" (Schöne-Seifert/Junker 2021: 962). Society, politics and the market push the genetic responsibility onto the woman. She knows the risk and has to deal with it, yet she may not be fully aware of the complexity of the personal and social issues at stake. Even though she may not be fully aware of it, the ethical discourse defines her as a person with reproductive autonomy, which does not release her from genetic responsibility – especially not when NIPT strongly indicates a genetic risk. In view of these various genetic options, pregnancy care increasingly focuses on risk aspects and the possible termination of the pregnancy (Steger et al. 2018: 15).

Overall, prenatal genetic tests are well established in Germany, Israel, and throughout the countries of the Western world. Genetic knowledge obtained by prenatal testing conveys either the possible statistical distribution of genetic differences in the population, or the assurance of a genetic variation that leaves it more or less open how severe this variation, e.g. trisomy 21, will turn out. The idea of "genetic responsibility", which may be ascribed to the (future) parents/pregnant mothers, shows that the content and goal of medical and genetic consultation may include the entire family as well as any future offspring (Remennick 2006). For Israel in particular it has become a social norm to "equate 'good mothering' in pregnancy with taking 'genetic responsibility' for future offspring and the entire family" (Hashiloni-Dolev 2018: 126).

The results of testing always affect the individual, the family and perhaps others who are close, and they reflect different debates in public health (Ravitsky 2017). In the context of human genetics and genetic testing, the separation of individual and public health issues is increasingly blurred.

The genetic risk status within a pregnancy may be low or high depending, among other aspects, on the age of the woman and the family history. Risk determination as part of genetics is not just about an individual, but about biological connections that become socially relevant. The geneticisation of life, and of foetal life, supports the social development of genetic responsibility and risk management practices that normalise and institutionalise prenatal genetic testing practices, such as NIPT, amniocentesis or chorionic villus sampling (CVS). These practices are being implemented in both Israel and Ger-

many, with different meanings, patterns and regulation (Raz et al. 2022; see chapter 3 of this book).

Paid for privately as in Israel or, since spring 2022, in individual cases by insurance companies as in Germany, the availability of genetic tests and the associated promotional information has strengthened the perception of genetic risk and pushed the way in which people respond to it. If a woman is pregnant she will have to respond to the practice of prenatal genetic testing and its availability – but how she responds to it will show whether she is acting with genetic responsibility. With regard to general risks, it is first of all important to state the obvious: whereas amniocentesis includes the small risk of miscarriage, any description of NIPT mentions that there is no risk of this kind, since it is performed on a blood sample from the pregnant woman (Holloway et al. 2022). NIPT is provided by private companies that publish advertising information about the tests, their use and aims.[16] Such advertising information sets an epistemic and emotional context for the meaning of genetic responsibility and its connection to the perception of genetic risk. Looking at different websites can also illuminate some differences between Germany and Israel.

An overview of company websites in Germany shows that the advertising and information leaflets about NIPT focus on the *security* of the test, the *feelings* of the woman, and her overall *responsibility*. For instance, information about the Harmony® Test promises: "Gain certainty", "Be unburdened", "Be reassured" ("*Gewissheit erlangen*", "*Entlastet sein*", "*Beruhigt sein*"),[17] "Three steps to clear answers" ("*Drei Schritte zu klaren Antworten*"). The pages convey the sense that the test provides quick and easy assurance and soothes the anxiety. This is accompanied by pictures showing a happy mother with her big belly. Clearly, a private company is advertising its product. The focus on safety and security prevails: "safe method, secure result" – this is the promise of the Harmony® Test.[18] The counter-notions are "risk" and "insecurity". Women with a so-called risk pregnancy are particularly targeted. When they search for information, they quickly find *genetic* information and the picture of a young woman with trisomy

16 Representatives of genetic prenatal diagnostics argue that the close link between reproductive medicine and selective abortion prematurely conflates the two and ignores the possibility that parents may wish to prepare for a child with special needs (Löwy 2018: 147, with reference to the CEO of the company *Natera*). The fact that over 95 per cent of foetuses tested with a genetic defect are aborted is concealed by this company.

17 https://lifecodexx.com/fuer-schwangere, accessed 02 June 2022.

18 http://www.cenata.de/der-harmony-test/, accessed 02 June 2022.

21. Her picture is more reminiscent of police mugshots than of pregnancy websites. All in all, the site seems to play on the worries of the parents-to-be and emotionally suggests avoiding the "result" shown on the picture.[19] The *Gemeinsamer Bundesausschuss* (G-BA) in Germany first published its patient information as recently as 2021.

In Israel, the information about prenatal genetic testing is provided by the health ministry, clinics and companies. The tenor is informative. NIPT is described as a screening test, alongside ultrasound, and as something done prior to amniocentesis. The concept of risk with regard to bearing a "Down syndrome baby" is part of this information; it is explained statistically: "In Israel, the risk of Down syndrome is considered high if it is greater than 1:380 (0.26 per cent). Women with this risk level (or higher), are recommended to undergo an amniotic fluid test. This risk level of bearing a child with Down syndrome is equivalent to that of women in the general population who were aged 35 at the time of becoming pregnant. When the risk is lower than 1:380, it is considered low."[20] The message is clear: the risk level lies on the side of the woman and the object of the risk is a Down syndrome baby. Thus, the reader understands that the only responsible thing to do is have the test in order to avoid such a "result".

Another Israeli website informs its readers about replacing amniocentesis, and lists the common tests, such as MaterniT21, the Harmony® Test, and NIFTY, states which company is marketing and manufacturing them, and provides information about their advantages and shortcomings, e.g. they do not endanger the pregnancy, but on the other hand they are expensive and the accuracy of the test is unclear.[21] Mostly, NIPT is presented as one test option among others as part of prenatal care. When it comes to company advertising, accuracy is the major selling point: "Harmony is the most precise test of its kind, whose accuracy has been proven in dozens of scientific studies," promises Fugene Genetics.[22]

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19 http://www.downsyndromenipt.info/genetik/?lang=de, accessed 02 June 2022.

20 https://www.health.gov.il/English/Topics/Genetics/checks/during_pregnancy/Pages/screening_tests.aspx, accessed 02 June 2022.

21 https://www.genes.co.il/%D7%91%D7%93%D7%99%D7%A7%D7%94-nipt/. An example from the information site of a clinic: https://hospitals.clalit.co.il/soroka/he/med-units/ob-gyn-division/pages/prenatal-diagnosis.aspx; https://iw.lifehealthdoctor.com/prenatal-screening-tests-25423, accessed 02 June 2022.

22 הרמוני בדיקת | Harmony תסמונות לגילוי דם בדיקת הרמוני – Fugene Genetics, accessed 02 June 2022.

It seems that the information provided for future parents varies widely in style. General information is basically always given, but the framing of responsibility seems a bit different: safety and security in Germany, normal procedure in prenatal care in Israel. Looking at this advertising information suggests that genetic testing does not just concern medical practices but is embedded in a social setting that varies in policy regulation, normative consideration, and emotional understanding.

Furthermore, the concern of genetic testing – illness or disability – despite its genetic factors, is a complex multifactorial event involving the interplay of genome, environment and behaviour, and is also a social phenomenon from the perspective of the (future) parents. This fact seems rather underemphasised in the bioethical debate on genetic information. It seems that the "genetic risk" is largely absent from the discourse on social risk and, accordingly, from strategies of coping with risk which may develop in connection with the parents' social circumstances and individual environment. Put practically, the life of a family with a child (or an adult) with Down syndrome may be very different according to how this genetic disposition is realised. In addition, such realisation is developed according to social support, institutional structures, and emotional acceptance, among other things. Thus, the feeling that there is a social risk in having a child with a disability depends upon the concrete social context. However, accepting a child regardless of whether she has a disability is often something the parent(s) have to do even beyond any feeling of taking a "risk". If the intertwinement of the genetic and social context is disregarded, the individual – whether the pregnant woman or the affected person with health risks – is left alone with her decision. In practice, genetic risks and the question of how to deal with them are individualised by transforming the rational category of risk probability into a non-social category of a biological risk-body, which is determined in disregard of its ascribed social complexities. But it conveys as biological fact a specific social calculation that functions in the logic of prevention and mitigation.[23]

The idea that a pregnant woman should have genetic testing in order to retrieve genetic knowledge about the physical material of the foetus and to en-

23 Since about the early 1990s, insurance companies have also included the logic of prevention and mitigation, especially in the health sector, in their calculations. This form of logic does not work in the old way of insurance companies trying to predict the statistical possibility of events in order to calculate sums of capitalisation and compensation.

sure that there is no genetic risk of a trisomy (or other genetic variation) implies that she is supposed to take genetic responsibility. Even more so if a pregnant woman fulfils certain criteria, such as being older than 35 or already having a genetic condition, she should take particular genetic responsibility. The stronger the perception of genetic risk, the more important genetic responsibility becomes. Is taking *genetic* responsibility the only way to be responsible as a (future) mother?

Assuming genetic responsibility correlates with perceiving genetic risk

Generally speaking, responsibility is a relational and temporal concept which is interpreted within a concrete situation, and which includes several poles and aspects. A *prospective relational intergenerational concept of responsibility* is most suitable for questions posed in the context of pregnancy and birth, children and family. This concept of responsibility is oriented towards the future, is based on a relationship context, and is directed towards both the well-being of individuals and the success of relationships. These relationships are intergenerational, i.e. between parents and children or grandparents and grandchildren, or they exist within one generation, i.e. between a couple, siblings and others. These familial and social relationships may of course be very different, such as relationships of care, neglect, attention, disregard; they can be broken or close. Very concretely, during pregnancy (future) mothers especially are asked to assume genetic responsibility. But perhaps care responsibility, irrespective of any genetic check-ups, is equally appropriate? Care responsibility has a much broader focus than genetic responsibility; it extends beyond individual ethics because it is not only attentive and responsive towards the general well-being of the foetus, but also towards the familial context and social relationships, which can be more or less supportive and caring. Focusing on care responsibility acknowledges that the vulnerability and well-being of someone (also) depends upon the kind of care relationships in which that person lives. This table depicts the different structural elements of genetic responsibility and care responsibility.

Responsibility	Genetic responsibility	Care responsibility
subject	pregnant woman + partner	pregnant woman + partner
object, content	bio-material of foetus; testing?	(future) child, family, relationship
addressee	future child, family, or society	future child, family, or society
legitimating instance	society, family, authorities, religion, conscience, medical perspective	society, family, authorities, religion, conscience, feelings of humanity
value, norm	humanity, dignity, health, sanctity of life, benefit	humanity, dignity, health, sanctity of life, well-being
motive	standard procedure, specific risk awareness, fear, or concern	general concern and care for the individuals and the relationships
intention and aim	prevention, mitigation of risk, knowledge for decisions, care, family planning	care, good relationships, well-being, family planning
consequences of the action	personal life, avoidance of discrimination, benefit of family	general well-being of individuals and family (provided the care succeeds)

Elements of prenatal genetic responsibility and care responsibility.
Inspired by Lenk/Maring 1993: 229; Schicktanz/Schweda 2012: 142.

Prenatal genetic responsibility and care responsibility are forms of prospective responsibility and related to prenatal care. They are similar with regard to the question of who the subject and the addressee of the responsibility are. For each type of responsibility, it is mostly the (future) parents or the family who are part of the decision-making process; but it seems that in the end it is still the pregnant woman who takes responsibility for the foetus/child. For both forms of responsibility, the legitimating social instances are similar, but in addition, genetic responsibility is strongly supported by a medical perspective. In Israel and Germany, the obstetricians or gynaecologists are legally requested to mention prenatal genetic testing, and they often even

recommend it as part of parental responsibility (Ravitsky 2021: 320; Schmid et al. 2015: 508).

Although both types of responsibility generally focus on pregnancy and the (future) child, each form has a specific thematic content and a specific motive. However, I argue that in contrast to genetic responsibility, (future) mothers can assume a *responsibility of care* that does not include a responsibility for the genetic disposition of the foetus. The motive of genetic responsibility is based on risk perception, whereas care generally focuses on the well-being of a person regardless of particular concerns about needs, illness, special vulnerabilities or general problems – or genetic risks. I will first describe how genetic responsibility relates to genetic risk perception and then turn to the question of whether not to test would be irresponsible. By arguing that (future) mothers/parents may have "good reasons" not to have genetic testing, I will introduce the concept of non-responsibility as well as the notion of care responsibility, which is broader than genetic responsibility.

Genetic responsibility in pregnancy is directed toward detecting genetic variations of the body material of the foetus on the basis of perceiving genetic risks, or even just fearing them. It focuses on getting to know the genetic dispositions of the foetus. The motive to test is thus mostly wondering or fearing that there may be something "wrong" with the "child" (Remennick 2006: 21; Schicktanz 2018). Genetic prenatal testing provides genetic information that is intended to give pregnant women knowledge so that they can reduce "risk", and to help them to exercise their "reproductive autonomy". However, it is not always clear what exactly women perceive and understand when they are informed about the genetic disposition of their foetus. In bioethical discussions, some authors understand genetic information as empowering (Beauchamp/Childress 2008; Schicktanz 2018: 237), while others see the women's insecurities and uncertainties, since it is sometimes difficult for them to really understand the outcome of prenatal genetic tests because there is no prognosis about how, for instance, trisomy 21 will be realised in life and in the family.

The object of genetic responsibility is the foetus under genetic consideration. The genetic testing concerns the body material and the biological substance: genetic tests, statistical probabilities, and genetic prognosis. Genetic testing needs a strong focus on the biological substrate, the carrier of its genetic information. The foetus is subjected to biomaterial technology, whether in testing or subsequent selection. Prenatal genetics does not address the individual as a whole, but is a practice that targets the genotype of the species.

Biopolitically speaking, in the age of "making life" (Foucault 2008) genetic tests are not about someone. They omit the person (cf. Gehring 2006: 175). The focus on the "biological substrate" leaves the person outside the consideration and leads to a "biologisation of everyday life"; and prenatal genetics become an "everyday biology" (Gehring 2006: 182). This description can even be extended further: the biological substrate, the material, is understood as being inherent to the human being. It certainly does not simply determine behaviour or characteristics in their entirety; to assume this would be to adopt an unfounded naturalisation of persons. Nevertheless, this biological substrate, decoded as genetic determination and biological disposition, is like a promise implanted in the body and radiating into the future. It is a transmitter of coded information containing species characteristics that can be separately judged as "inconspicuous" or "conspicuous", "desirable" or "undesirable" (Schües 2016a: 287).

From the perspective of genetic responsibility, the child will be born (or not born) precisely under the conditions of the biological substrate. As Löwy (2018: 1, 147) argues, prenatal genetic diagnosis allows us "to see *what* is about to be born" (my emphasis). The reference to "*what* will be born" implies, on the one hand, a vision of "what" will happen – "life" with a disability or without – and on the other hand, technical insight into a biological substrate whose characteristics may reveal a particular vision to be interpreted beyond medical statistics. Because it is bound to the biomedical perspective, the test result cannot mean a person in her social entirety; but later, after birth, it will be possible to tell the person in retrospect that her genetic disposition has been tested. The "what" is understood differently depending on the temporal perspective and personal attitude. The biomedical discourse itself does not simply mean a human being or biological substrates. But once a person is born, the genetic check has been carried out; from the point of view of biomedical laboratory practice, only the biological material of a foetus is examined. But from the everyday point of view, the issue is understood differently: if genetic prenatal tests had produced the desired outcome, i.e. a "negative" result, then a genetically non-disabled – "healthy" as most parents would say – child is born.

In contrast to genetic responsibility, care responsibility may include concern about genetic risk but is primarily attentive to a wider range of themes, such as care and support. Care responsibility is understood as an ethics of relationship (*Beziehungsethik*) that considers the well-being of all persons involved and their relational practice of care, attentiveness, support and responsiveness (Schües 2016b; see also Tronto 1993: 127 ff.). Responsibility of care and concern can be grounded on very different facts, such as empathy, needing or wanting

to help, but perhaps also risks. In other words – and this is the main difference – the observation of risk is only *one* possible motive for being concerned and of responding with care, but care responsibility is not just guided by a risk paradigm. It may therefore include genetic responsibility, but it can still be valuably exercised without it. Not acting according to genetic responsibility presupposes a different set of motives, intentions and aims, as mentioned in the table.

How not testing may yet be considered as a form of responsibility will be discussed in the next section.

Genetic irresponsibility, non-responsibility, and care responsibility

When we look at the practice of NIPT, in society as well as in our interview study, some people judge a woman or future parents *as being irresponsible* if they do not follow up a perceived genetic risk in pregnancy, and if they do not want to know the genetic disposition of their child (cf. chapter 11). It seems these reproaches assume that if she had known about a trisomy she would surely have aborted the foetus. At this point I do not want to discuss the question of whether a woman would or should terminate a pregnancy if a diagnosis is positive. I ask whether a woman who does not test is necessarily irresponsible.

Most generally, a (future) mother is considered morally irresponsible if she is capable of reflecting, deliberating and thinking ahead, yet makes insufficient effort to do so,[24] and she is unconcerned about the future of her child (or her family) and the consequences of her decisions. We might furthermore refer to a violation of norms and values as well as the observation that she is acting in a field of knowledge that she should have considered.

Andre et al. (2000) argue that acting wrongly and acting irresponsibly should be distinguished morally and philosophically, and that this distinction should be applied to the question of what it means to reject prenatal testing. They argue that responsible care for a child does not necessarily mean having genetic testing. Parents may have reasons not to question the future

24 The condition of sufficiency is context-sensitive and depends on medical practice and cultural and social norms. Generally speaking, children or people with intellectual disability, i.e. people who do not think ahead or reflect sufficiently because they lack the capacity to do so, can be considered non-responsible but not irresponsible.

existence of this one child they have conceived. If they reflect on their reasons and "if they make a conscientious decision not to control genetic outcomes they are *exercising* their responsibility, not evading it" (Andre et al. 2000: 145). This argument takes the presence of moral reflection and a conscientious decision as testimony against the accusation of irresponsibility. By showing that irresponsible action can be taken without the action itself necessarily being judged as wrong, it separates a person's attitude from the decision or action, which can come out good or bad. Thus, in this approach, the concept of irresponsibility is aimed at the attitude of the persons acting and not at their actual choice. Andre et al. define irresponsibility as an attitude that leads to imprudent decisions or actions. I agree with their argument that responsible care in pregnancy does not necessarily involve genetic testing but I disagree that responsibility is *just* a matter of the attitude of the person in question. Surely, irresponsibility describes an attitude of a person but in light of the relational concept of responsibility laid out above, and the fact that irresponsibility structurally involves the same elements as responsibility, the evaluation of a person's decision-making or action does not depend just on the attitude of the person whose responsibility is under scrutiny. An ethics of responsibility is not *just* bound to the attitude of the actor, nor *just* to the morality of the action. Rather, in light of the different elements that structure responsibility and irresponsibility, we have to consider elements in addition to the pregnant woman's attitude, such as the addressee, the motive, the intention, and the thematic realm.

In order to explain my approach, I would like to emphasise the following: the criteria for responsibility concern both the future child and the future of the child. While the former idea denotes the characteristics of the child (i.e. genetic dispositions) in relation to seeing *what* is about to be born, the latter concerns the future of whoever is born in the context of care, relationships and the environment. If a test is positive, the biological material of the foetus is associated with a possibly disabled future body; and a future is often imagined depending on possible health problems, suffering, or special need for care. The mother's possible life is also considered in terms of whether she is willing or able to care for a child with a disability. After such a test result, the question of abortion is raised. *Genetic* irresponsibility means that even though the pregnant woman, her partner, obstetrician or gynaecologist, or society's accepted medical discourse perceive a genetic risk for the foetus, the woman does not want to know its genetic disposition and denies any considerations to act accordingly.

Is not wanting to have genetic testing necessarily irresponsible? Is the charge of "genetic irresponsibility" necessarily applicable to all non-users?[25] Or can we find the preference of not-knowing irresponsible within a discourse of biologisation but socially still consider it a responsible option? To address these questions, I introduce three different forms of morality of how to deal with the scope of genetic knowledge and care in pregnancy and for a child: genetic responsibility, irresponsibility, and non-responsibility. I would like to advocate that the conscious and justified rejection of genetic responsibility can also be acknowledged and respected as a form of genetic *non*-responsibility looking at the future of the child and not only at the "future child". Those who choose not to know and not to be concerned about genetic dispositions can still – for better or for worse – be responsible for the care of the child (and the family) in the future. Prenatal genetic diagnostics gives them the option to decide which foetus to select on the basis of a genetic disposition. This option is based on a genetic risk discourse and comes with genetic responsibility. However, this option and the idea of being guided by the paradigm of genetic risk can be rejected without therefore being considered irresponsible.

Generally defined, the term "non-responsibility" refers to a situation or action in which responsibility is rejected with "good reasons"; for example, in cases where we cannot do anything, in fields we do not know anything about, for which, clearly, someone else is responsible (Heidbrink 2017). The practice of pregnancy is very much governed by a genetic risk discourse and (future) mothers are more or less expected to assume this perception of risk and the associated genetic responsibility. But if a woman decides against testing, with "good reason", I call this *responsible genetic non-responsibility*. It is a decision that involves declaring oneself not responsible for the area of genetic decision-making, but nevertheless assuming responsibility of care for a child with whatever genetic disposition.

The thesis of responsible genetic non-responsibility can be understood in terms of two different positions: one, opting out of testing, and the other, opting in. The first would argue that typically and according to standard procedure (unless there are "good reasons"), care responsibility includes genetic responsibility. The burden of proof, i.e. having "good reasons" not to do genetic testing,

25 One reason for not-testing, as Jackie Leach Scully has mentioned (personal communication, 2022), could be that the parents themselves have the disability and consider life with that disability to be normal. From that perspective discourse of testing and abnormality is irrelevant.

lies with the pregnant woman. The other position, opting in, reverses the burden of proof: this position of responsible genetic non-responsibility is found when genetic testing is not standard practice. It argues that women who want to have the foetus genetically tested need to express "good reasons" to do so. Thus, the burden of proof lies on the side of the women (and the gynaecologist) and their view that genetic testing is necessary. Whereas the former reasoning practice regards genetic testing as normal and standard, and, hence, asks the women not willing to test to give reasons for opting out, the latter considers the individual cases and finds reasons to opt into the practice of genetic testing.

Having considered the different status of the positions of opting out and opting in, we now need to consider the difficult question "What are good reasons?" They are "good" if they are convincing. But whether they are convincing depends quite strongly on social and cultural norms and values that differ according to context and country. For example, "good reasons" may be religious reasons, respect for the genetic privacy of the future child, or the refusal to connect social care to the perception and calculation of risk. Certainly, responsibility for the genetic testing of the biological substrate and responsibility for the future life of a child are by no means the same thing; however, they are often implicitly equated. Even though it is not possible for one person to find "good reasons" that are convincing for all, I nevertheless want to argue that not wanting to know the genetic dispositions and not wanting to think and decide on the basis of risk-considerations might not necessarily be regarded as irresponsible. If the parents confirm that for them any genetic test result would be irrelevant to the continuation of the pregnancy and the future care of the child, then the issue of irresponsibility is questionable in relation to their intention. However, social normative orders might not be on their side.

If a genetic practice is socially and culturally normalised, self-evident and firmly established, as in Israel, and refusing a genetic test, opting out, would be only conceivable for religious reasons or perhaps for some "alternative lifestyles", then ultimately a woman who does not have her foetus genetically tested and who does not regard genetic risks as a basis for responsibility cannot find socially convincing reasons to reject *genetic* responsibility. A concept of genetic non-responsibility seems unacceptable even if parents decide to give full care to a child unconditionally, i.e. regardless of any illnesses or disabilities.

Germany has an ambivalent norm-oriented social context for genetic responsibility (cf. chapter 5). It seems that both positions, finding "good reasons" for opting in and opting out, must be brought to the consideration. The dis-

course on genetic testing still tries to maintain a balancing act between a normative critique of routinisation and case-by-case decision-making, and a normalising practice that is increasingly becoming established. If a woman finds "good reasons" and an accepted norm for not wanting to know the genetic disposition of her foetus and if she openly states that she cares unconditionally for the child, this attitude may be accepted under the acknowledged concept of individual decision-making. However, this does not mean that children with disability are necessarily welcomed in society. To phrase this ambivalence more optimistically, the German paradox is between social rejection and support: "It has never been so easy to identify a foetus with trisomy 21 in a society that approves of this chromosomal defect as a legitimate reason for abortion. And it has never been so easy to raise a child with Down syndrome in a society that is rightly proud of its efforts towards inclusion" (Schulz 2017: 198; TAB 2019: 157). Yet this optimistic view may not be shared by many women or families confronted with a positive test result. Although Schulz observes that the situation for people with disability has improved during the last decade, this does not mean that society – in Germany as well as Israel – is sufficiently supportive of people with disabilities and their families.

Theoretically, the difference between genetic irresponsibility and genetic non-responsibility comes down to the question of whether or not a woman has "good reasons", i.e. acceptable or convincing reasons, to reject genetic responsibility. Nonetheless, the distinction between genetic irresponsibility and genetic non-responsibility may not make sense in countries where genetic practice is seen as routine and is an integral part of prenatal care, i.e. it is considered prenatal risk management; there would be no "good reasons" not to test. All possible explanations would bounce off a firmly established reproductive medical practice that is taken for granted and perceived as normal.

Depending on the country's regulations, genetic practices and their social contexts, we may see inconsistencies, contradictions, dilatory compromises and dissents in interpretation, but we also see different tendencies in discourses in terms of what counts as good reasons or criteria for decisions or risk perception, and different understandings of responsibility and irresponsibility, security or insecurity. It appears that the constellation of responsibility and irresponsibility and the option of finding "good reasons" to refrain from genetic responsibility presupposes a concrete kind of care perception (that is not guided by genetic risk) and a particular normative order.

When it comes to the genetic disposition of the foetus, the narrower concept of genetic responsibility seems decisive; but when looking much more

generally at the future of the child, a broader concept of responsibility would be in play, one that includes various health and societal aspects, the child's general welfare, and the life of the family. Today's transformation of the concept of responsibility in the social discussions of reproductive medicine practice appears in the fact that it is not just the question of what belongs to responsible parenthood that is relevant, but the question of *how responsible decisions* can be made in order to avoid irresponsible actions. Pregnancy and the beginning of life has become a morally challenging "project" that demands many decisions from the parents-to-be, and each decision has to be made with careful deliberation and moral reflection.

Ascribing genetic responsibility to expectant parents appears an attempt to translate a normative order of care into a specific cause-effect relationship. The irrationality of this translation consists in the assumption that, by analogy with contexts of social interaction, we can equally assume responsibility for our decisions in the context of genetic predispositions and the resulting consequences for the condition of the life in the future (Schües 2021b). If the broad notion of care responsibility is guided by reframing pregnancy into risk management and by reducing responsibility to genetic responsibility, the aspect of care may be lost in translation. Care responsibility extends more broadly over all structural elements and is mainly motivated by care for the other, the family, and social relationships.

Does responsibility of care, a responsibility that concerns the care of a child who is *entrusted* to someone, necessarily need genetic information as a prerequisite? How this question is answered is strongly correlated with the perception of genetic risk and whether prenatal genetic testing is perceived as a "standard procedure". If the general perception acknowledges genetic risks and perceives genetic testing as *standard*, this will influence how we evaluate what it means to be a responsible mother/parent. How the options of a responsible genetic non-responsibility are perceived and exercised might bring out central differences between prenatal care practices in Israel and Germany.

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