

## **Introduction - How prenatal diagnosis is entangled in historical and social contexts**

Schües, Christina

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# Introduction – How Prenatal Diagnosis is Entangled in Historical and Social Contexts

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Christina Schües

When reproductive medicine introduced prenatal testing and when genetics began to transform diagnosis and general prognoses into predictive genetics, genetic responsibility was introduced into bioethics and became the concern of (future) parents and affected persons. A country's biopolitics included these biomedical practices and became concerned with how states can evaluate and regulate genetic testing, and related questions of risk management. In order to better understand social and technological changes in the field of prenatal genetic diagnosis, their implications for the individual and society, and their cultural, philosophical and ethical meanings, a research project was funded by the Deutsche Forschungsgemeinschaft (DFG). Entitled *Meanings and Practices of Prenatal Genetics in Germany and Israel (PreGGI)*:<sup>1</sup> *A comparative empirical and prospective study of the views and ethical concerns of users, non-users and providers of prenatal genetic services in their social and cultural contexts*, the project was conducted in 2017–2021 and led by Aviad Raz, Christoph Rehmann-Sutter and Christina Schües. The researchers thought that the emerging biomedical and social practices could best be studied through a comparative study of Israel and Germany. Such a cross-cultural approach is suited for giving insight into prac-

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1 From 2017–2021, the PreGGI project was funded by the Deutsche Forschungsgemeinschaft (DFG, RE2951/3-1 and Schu2846/2-1). As one of the principal investigators of the project, as the editor of this book, and on behalf of the members (Aviad Raz, Christoph Rehmann-Sutter, Yael Hashiloni-Dolev, Hannes Foth, Tamar Nov-Klaiman, Anika König, Stefan Reinsch) of the research project, I would like to thank the DFG for their financial support of this research and publication. Furthermore, I am very grateful to Monica Buckland and Jackie Leach Scully for their careful language editing and helpful comments. Lena Steimle deserves my thanks for her great assistance in handling the manuscript.

tices of prenatal genetic testing as well as differences and similarities in how they are implemented and understood.

This book about genetic responsibility grew out of that research project, using its results as the basis for further reflection to gain a deeper insight into the complex issue of prenatal genetics and how it is understood and implemented differently in Israel and Germany. The issues discussed include how innovations in prenatal diagnosis affect social relationships, and how prenatal genetic tests address moral questions and touch upon themes of eugenics and selection. Thus, the book assembles observations, interpretations and conversations from interdisciplinary angles across the social sciences, bioethics and philosophy, and with a comparative view of Israel and Germany.

## **The rise of new concepts and conditions**

In modern medicine of the 20th and 21st centuries life, and elements of the beginning of life, are subject to a discourse of risk and security, as well as decision-making about who would be welcomed or who, prospectively, might be too burdensome for the parents, the family, or society, or considered to suffer too much. Since the notion of risk, and especially genetic risk, is at the centre of prenatal care, the guiding thread of this book is how issues of genetic responsibility are discussed in Germany and Israel. Considering these questions means opening up bioethics or biopolitics beyond the focus of prenatal genetic testing, to the ontology of the life sciences, the historical and cultural horizon of social norms and general values, and the perceptual practice and epistemic understanding that are equally, yet often only implicitly, involved in considerations and discussions.

Within the history of philosophy, responsibility is a rather young concept that has become more common from the 19th century. The growing complexities of the interrelation between humans, society and technology make responsibility an interesting and important notion because of its temporal, relational and multidimensional structure, which involves at a minimum the responsible person who performs an action or task with regard to another person, the addressee, according to prescriptive, normative criteria, within a particular realm of responsibilities and a certain time frame.

In the context of this book responsibility is taken mainly as a futural concept, yet it includes questions about retrospective responsibility, that is a responsibility directed toward the past and present. It is a question of how we

care about the past, and so also about the future; how we care about other people, our offspring, and so also about society. The question of responsibility is traditionally directed at the shaping of interpersonal relationships and social conditions, at questions of the past, such as guilt, or questions of the future.

In the 1970s and '80s, prenatal genetic testing was established as part of pregnancy care, and with it the idea of genetic responsibility. Generally, responsibility as well as the more specific form of genetic responsibility concerns three areas: the legal area, which is the most strictly regulated and the narrowest, since it concerns the different laws and regulations. The political area of responsibility is the broadest, as besides policy making it also addresses the biopolitical discourses that are usually rather vigorous in Germany, for instance considering the question of whether non-invasive genetic testing should be financed by health insurance, and much calmer in Israel. The third area is ethics, probably the most difficult to understand. In addition to the very complex ethical concept of the responsibility to care for someone or something, the notion of genetic responsibility is already established in bioethical discourses of genetics and predictive genetic testing.

Relationships and the family are embedded in political, social and cultural practices, and norms of responsibility. Responsible acting is thus an ethical and political practice that is not simply there, but is characterised by a normative order and its dynamic transformation within a social and historical context. As well as the normative order of society, biomedical reproductive practices concern the social-ontological dimension of relationality, and the existential and temporal dimensions of plurality. These three dimensions are underpinned by the conviction that children are conceived within a particular normative, relational context, and that pregnancy and birth are not just a biomedical procedure but are shaped by a particular social, cultural, scientific and economic situation. Thus natality, the fact that humans are conceived and born by someone else, a woman, is central to the practices of reproduction and responsibility. Furthermore, natality is shaped according to the specific situations, relationships and society in which reproductive decisions take place. These dimensions inhere in all decisions concerning the foetus that may develop towards being born or being aborted during pregnancy.

Today's reproductive technologies and genetics show "what is about to be born" in advance (Löwy 2018: 1). The genetic disposition of the foetus can be tested and, according to genetic responsibility, *should* be tested. In prenatal diagnosis, invasive and non-invasive testing is differentiated. Invasive examinations involve intervening in the woman's body to take samples of the pla-

centa (chorionic villus sampling), amniotic fluid (amniocentesis), or embryonic blood (cordocentesis). These samples are then examined for chromosomal defects or serious hereditary diseases. Invasive prenatal diagnostics are associated with risks to the pregnant woman or the foetus.

In contrast, with non-invasive prenatal diagnostics the risk to the pregnant woman or the foetus is much lower. Non-invasive prenatal diagnostics include ultrasound examinations, nuchal fold transparency measurement, and molecular genetic blood tests known as non-invasive prenatal tests (NIPT). This development in prenatal genetic testing – in particular the introduction and societal implementation of NIPT for chromosomal variations such as trisomies 13, 18 and 21 – change a morally and culturally complex practice of prenatal diagnosis in a variety of ways. These changes touch on fundamental ethical and philosophical questions about intergenerational relationships, pregnancy, and who should be born and why. With the introduction of NIPT in the Western world, medical testing of foetuses became even easier and more morally defensible for the (future) parents. Most of all, there is no risk to the foetus during the procedure.

In the course of NIPT, 10 ml of blood is drawn from the pregnant woman, containing the genetic information of the foetus in the form of cell-free DNA chromosome fragments as well as the DNA of the mother in her own cells. Subsequently, foetal and maternal blood components are detected, and the foetal components are isolated and analysed for trisomies 13, 18 and 21. It is also possible to determine the sex of the foetus. Further development of NIPT aims, for example, to detect microdeletion syndromes, i.e. the absence of small pieces of chromosomes. This condition can lead to heart defects and developmental delays. In 2012, the PraenaTest®, one of the first non-invasive molecular genetic blood tests, was introduced in Germany. NIPT has also been available in Israel from June 2013. Many other tests from different companies followed. In the meantime, the tests have become firmly established in Europe and the USA. The aim of all these examinations is to obtain the most accurate knowledge possible about diseases, such as heart defects, genetic predispositions to disability such as trisomies 13, 18 or 21, and other genetic mutations, such as Klinefelter syndrome. The examinations also reveal the sex of the foetus.

In view of these various test options, pregnancy care increasingly focuses on risk aspects and the possible termination of wanted pregnancies (Steger/Orzechowski/Schochow 2018: 15). Since NIPT requires confirmation by amniocentesis, it is considered a “test” in Germany; in Israel it is included in the

standard medical practice during pregnancy and can be chosen as part of the prenatal screening programme.

In Germany, prenatal diagnosis is differentiated into standard and additional examinations, some of which are not covered by health insurance and are considered something that should be a private expense. Standard examinations include three ultrasound examinations at the 10th, 20th and 30th weeks of pregnancy, as well as an examination of the abdomen and a blood sample to determine the normal course of the pregnancy (TAB 2019).<sup>2</sup> Additional tests include first-trimester screening with nuchal translucency measurement, NIPT, and the confirmatory and invasive procedures of chorionic villus sampling and amniocentesis, which can result in miscarriage in approximately 4 out of every 1000 tests. In Germany, it is estimated that more than 85 per cent of pregnant women with a positive test for trisomy 21 decide to have an abortion (TAB 2019: 12; Schidel 2020).

Shortly after the introduction of the first molecular genetic blood tests in Germany, the German Ethics Council gave its evaluation of the future of genetic diagnostics and its clinical application (Deutscher Ethikrat 2013; Steger et al. 2018). This evaluation states that the scope of genetic diagnostics is expected to expand in the future, and that the associated rapid increase in genetic information of each human being born will continue. The rapid and cost-effective availability of NIPT means that these tests are increasingly being considered as part of standard prenatal diagnostics. It is interesting to see that in Israel, NIPT is only one option within standard pregnancy care, yet it is not covered by health insurance. In general, critics warn about the medicalisation of pregnancy, which may lead to an increasing focus on the risk aspects of prenatal care and the termination of wanted pregnancies (TAB 2019: 168f.; Remennick 2006). Despite all the criticism, the use of NIPT in fact represents no risk for the pregnant woman, and prenatal detection of trisomies 13, 18 and 21 is improved. This leads to a reduction in invasive testing and, consequently, of miscarriages.

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2 Bundesministerium für Gesundheit. Bekanntmachung eines Beschlusses des Gemeinsamen Bundesausschusses über eine Änderung der Mutterschafts-Richtlinien: Aufnahme einer Versicherteninformation zur Durchführung der Nicht-invasiven Pränataldiagnostik zur Bestimmung des Risikos autosomaler Trisomien 13, 18 und 21 mittels eines molekulargenetischen Tests (NIPT-Trisomie 13,18, 21) für die Anwendung bei Schwangerschaften mit besonderen Risiken vom: 19.08.2021, (<https://www.bundesanzeiger.de/pub/de/amtliche-veroeffentlichung>), accessed 10 July 2022.

Therefore, NIPT may be seen as a game changer in the field of prenatal genetic testing.

The social implementation of NIPT<sup>3</sup> as a technology that allows the testing of foetal DNA by testing the blood of the pregnant woman as early as 9 weeks after conception raises a series of different and difficult questions. With accuracy and scope of the tests improving, and costs decreasing, the German and Israeli healthcare systems are both currently implementing it in certain defined situations and for some conditions, yet they differ in how NIPT is implemented and also in the framework of reasoning used to justify it.

## The focus on Germany and Israel

In recent decades, practices of and debates about prenatal genetic testing have resulted in heated controversies, an awareness of new routines and of aspects of producing a child that are now taken for granted. These controversies and normalities can best be brought out in a comparative study. When differences and similarities are brought to light, their conditions and implications, understandings and norms can be studied and evaluated. Israel and Germany are interesting countries for such studies because they take opposite directions in terms of what is permissible, how reproductive medicine and tests during pregnancy are experienced and viewed, and how practices are established and evaluated. The comparative setting of these two nations has already been established by Yael Hashiloni-Dolev (2010), Aviad Raz and Silke Schicktanz (2009, 2016). The two countries differ not only in moral and political terms but also in their geographical and historical situations. The juxtaposition of their painfully entangled histories and their different – almost opposite – regulations and politics on biomedicine at the beginning of life presents unique opportunities and challenges for sociological, bioethical and philosophical research in the 20th and 21st centuries.

The lessons learned from history are still an implicit or explicit part of bioethical and biopolitical discussions. In the German discourse, references to the historical dimension dominate – often implicitly – in public deliberation, in the form of a need to establish a distance from the inhuman practices of the National Socialist period and to avoid any resemblance to “selection” or

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3 Now also referred to as Non-Invasive Prenatal Screening (NIPS) or cell-free DNA testing (cfDNA).

“eugenics”, while emphasising the individual role of the pregnant woman and her right to an informed choice (Foth 2021). Meanwhile, in Israel’s practice the different prenatal tests are well established, and are understood as empowering woman’s choices, securing the life of the family, and enhancing the “health” of the Jewish collective body.

Israel and Germany are both countries with cutting-edge technology and very advanced healthcare systems; yet, to foreshadow a general thesis, Germany follows a *discourse of norms* that takes the notion of dignity as central. Different, and disputed, understandings of dignity and its role in different areas also provide the ethical legitimization of constitutional state democracy, including ideas of participation and freedom. Thus, ethical controversies and biopolitical questions about genetic tests are based on ongoing political and bioethical dispute about norms and their implementation in the practices of prenatal genetic testing. Israel, on the other hand, implements a *practice of normalisation* and holds the conviction that genetic diagnostic techniques may help to balance the responsibilities of human life and society’s goods and qualities. The distinction between Jewish ethical positions, which are partially based on the hermeneutic of Jewish religious texts, and state regulations, is not perceived as being controversial. Here we see a genetic practice that is well established and normalised; therefore, there does not seem to be a reasonable basis for controversy.

It can be argued that both inclinations – the discourse of norms for Germany and the discourse of normalisation for Israel – follow a lesson learned from the 20th century’s history and the atrocities of the Shoah: Never Again! The German Jewish political theorist Hannah Arendt tried to understand the Holocaust and, in 1961, reported on the trial of Adolf Eichmann in Jerusalem. This trial is generally seen as a significant moment in the public perception of the Holocaust. The eight-month trial, which ended with Eichmann’s death sentence, was part of growing attention being paid to German crimes during National Socialism and, in particular, to the intention to exterminate European Jews. For the first time, a worldwide public was confronted with Jewish victims and witnesses of the Holocaust and their traumatic experiences. The focus of the trial in Jerusalem was not primarily the person of Eichmann and his deeds, but the history of the Jews under National Socialist rule itself. Both Israel and Germany adopted the conviction that this history must not be forgotten. “Politically speaking, the death factories did constitute a ‘crime against humanity’ committed on the bodies of the Jewish people” (Arendt 1946; see also Arendt 1965: 267f.). Arendt’s report led to highly emotional disputes with Jewish intel-



lectuals and was discussed beyond the Jewish community. In Arendt's understanding, the Holocaust could be interpreted in two ways: it was either a crime against the Jewish people, or a crime against humanity committed on the body of Jewish people. The second interpretation is the more universal one and includes the first one, but not the other way around. The distinction is important because the meaning of the famous dictum "Never Again!" changes depending on the interpretation. A "'Never again' crimes against the Jewish people" is different from "Never again crimes against humanity".

The concrete interpretations of "Never Again" are contrasting. Germany's concern is never again to be a perpetrator (*Täter*), which in the context of prenatal diagnosis means never-again-doing anything close to eugenics. The avoidance of biopolitical regulations or practices that could be connected to eugenics as pursued by the Nazi state still draws Germany's policy-making and bioethical discourses into normatively ambivalent regulations that avoid any reasoning on the basis of the foetus' wellbeing. In Israel however, "Never Again" usually means never again being a victim. Never being a victim again drives the urge to have power over one's own reproductive possibilities and, hence, a rather affirmative handling of reproductive technologies. Even though Israel is considered a secular state, biomedical ethics and bioethics are mainly considered within Jewish religion and traditions: more than half the population belong to Judaism, and one third describe themselves as religious. Overall, there is a pro-natal attitude anchored in religion (as in the book of Genesis: "be fruitful and multiply") as well as in the historical background of *society*: the intended extermination of the Jewish people during the time of Shoah, as well as the ongoing Arab-Israeli conflict, has produced the aspiration to secure the nation and promote a child-friendly policy. Having a large family compensates for the search for the Jewish homeland and for feelings of being uprooted. Family creates belonging and children mean life. Children are "the attempt to build a bridge to a better future," as psychologist Tali Gogol-Ostrowsky explains.<sup>4</sup> Thus, a birth rate of 3.1 among Israeli women, which is more than twice as high as in Germany, is not surprising. It is very common for Israeli women to use prenatal diagnostics when pregnant, not least because it is easily accessible and seen as part of "normal" prenatal care (Ravitsky et al. 2021; Zlotogora 2014).

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4 Münch, Peter (2017) "Warum in Israel so viele Kinder geboren werden." For a different view about reproductive technological practices in Israel, see also Boas et al. (2018); Granek et al. (2017).

In one way or another, some chapters of this volume implicitly or explicitly refer to the observation that technological advances are approved of by the Jewish religion and by Israel's society because they are a means to an end: the preservation of Jewish values and family. Science may be used to overcome resistance from nature, in this case the occurrence of foetal diseases or of infertility. Biotechnological procedures such as prenatal diagnostics and IVF are also acceptable because of the ontological belief that a foetus only acquires the status of a human being after birth. According to the Talmud, before the 40th day of gestation the foetus is no more than "clear water".<sup>5</sup> As Larissa Remennick (2006: 46) points out, the central place of reproduction in the public agenda makes Israel an ideal "laboratory" for studying the social implications of reproductive and genetic technologies. Yet Germany could likewise also be described as a "laboratory" because of its anxieties and responsibilities for the past and its concerns about reproductive practices and options. Its regulations and bioethical concerns are distinctly different from those of other European countries. In Germany, some feminist and disability activists, conservatives and Roman Catholics are concerned that the use of technology leads to a blasphemous attempt to "play God", going against nature, discriminating against people with disabilities, or using eugenic methods that resemble the Nazi past. Thus, the individual decision, based on values and norms such as the value of life, dignity or free will, is the focus of bioethical discourses.

## About the book and its four parts

Taking the countries' distinct differences and similarities as a point of departure, this book analyses the philosophical horizon, socio-cultural contexts, religious backgrounds, ethical and political key issues, and implications of the reproductive practices of both countries. Compiled as an interdisciplinary study, it presents a comparison between Israel and Germany from an empirical bioethical perspective and offering a transnational philosophical reconsideration of the historical, social and biomedical contexts. Combining comparative empirical bioethics with systematic philosophical reflection, this book introduces an interdisciplinary and transnational *conversation* to the field of biomedical ethical research. Looking at two very different cultural settings, biopolitical practices and social imaginaries, we find the distance needed to

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5 For an empirical study see Rimon-Zarfaty et al. (2011).

understand both the other and ourselves, the unfamiliar and our own practice. Taking the specific topic of NIPT as our focus allows us to start a conversation between the experiences and observations, disciplines and backgrounds of these countries. Using conversation as a method enables the researchers to do comparative empirical work but also share their observations and self-reflections with each other, and to communicate and reflect across disciplinary and national boundaries. Conversation has thus created a third space within which ideas, experiences or arguments are addressed from different personal, philosophical, cultural or social perspectives.

The book is organised into four dimensions, presenting different methodological themes and approaches, and allowing for different ways of having conversations and different levels of abstraction. The first, rather theoretical dimension addresses historical and philosophical perspectives in terms of the entanglement between forms of the *biomedical rationalisations of “life”, reproduction and responsibility*. In his chapter *Biological reproduction, offspring, and radical otherness*, Burkhard Liebsch explores the shaping of “life” by the biomedical approach of the life sciences, and considers the claims of responsibility within their epistemic horizons. The practice of genetic testing of the foetus focuses sharply on the biological substrate, the carrier of the genetic information. The biologisation of the foetus, human reproduction, and human generativity, as current reproductive technology presupposes, has particular prerequisites, such the focus on humans as organisms, that we all come from living cells, and also that questions of reproduction and risk are thought in terms of the recombination of cells. But then, how can we understand the “future”? As an irreversible future of mother and child, or a “radical future”? Or a future of “Never Again” (as Natan Sznaider thematises in his commentary)? Considering the future and reproduction in modern medicine leads to Christina Schües’s chapter on the *Origins and practices of genetic risk and responsibility*. This concerns the historical and social entanglement of genetic risk and genetic responsibility, and re-evaluates the political and ethical understanding of responsibility, non-responsibility and irresponsibility in light of the biopolitical regime and perceptual practices in Israel and Germany.

The second, more concrete dimension of *Governance and biopolitics* compares Israel and Germany in a straightforward way in terms of their policies, regulations and norms. In both countries, as Tamar Nov-Klaiman, Hannes Foth and Yael Hashiloni-Dolev show in their policy analysis, key decisions related to NIPT were made only recently. In 2019, NIPT was submitted to the Israeli “health basket” committee to be considered for public funding, where

it competed against other technologies and drugs in the context of a limited budget. Following evaluation of all submitted items, funding for NIPT was rejected. Consequently, NIPT has not been adopted by the statutory health insurance and is not publicly funded. Since 2019, all invasive tests in Israel have been coupled with chromosomal microarray analysis, which enables a high-throughput analysis of genotyping and gene expression, and has a higher detection rate than standard karyotyping that provides only a genome-wide snapshot of an individual's chromosomes. In 2021, the German Federal Joint Committee (*Gemeinsamer Bundesausschuss GB-A*) developed new regulations for the coverage of NIPT in health insurance, and the officially recommended procedures in prenatal care (*Mutterschaftsrichtlinie*). The result is that from spring 2022 NIPT has been covered by health insurance (although only on a case-by-case basis, taking into account the situation of the pregnant woman and not of the foetus); yet its implementation has been accompanied by concerns and criticism.

The authors of the next two chapters present the individual positions of the two countries, before meeting for a conversation about their respective insights. In *Health services and uptake in cultural context* in Israel, *Aviad Raz* discusses the different health services that are available and how they are embedded in the cultural and historically influenced horizon. *Moral concerns and consumer choice* in Germany is the theme of the chapter by *Kathrin Braun* and *Sabine Könninger*. They discuss the ambivalence of German discourse between public concern about preproductive practices that involve selective decisions about which children should be born, on the one hand, and the increasing routinisation of genetic testing, on the other. Both the details of *Policymaking in Germany and Israel* they describe and the jointly written comment by *Braun, Könninger* and *Raz* on the different concerns show that in many respects, the regulation of and cultural attitudes towards genetic and reproductive medicine in Israel and Germany are contrary to one another. The general idea of presenting the chapters in this specific order and inviting the authors to comment on each other led to conversations between the authors, and should also inspire implicit conversations with the readers.

The third section focuses on themes from the angle of comparative empirical bioethics. Each chapter of this section discusses one particular thematic area and presents a particular methodological approach to comparing the social context of Israel and Germany. The comparative empirical study conducted a total of 42 semi-structured interviews in Germany and 52 in Israel. Interviewees included health professionals specialising in obstetrics and gynaecology

and/or genetics, disability activists, women without unusual medical family history, and parents or other close family members of children with Down syndrome. The interviews were conducted in Hebrew and in German. They were transcribed, and key parts were translated into English, so they could be interpreted and discussed by the Israeli-German team.

For the cross-cultural comparative work, it was important to focus empirically on a set of more narrowly defined questions. Working from the Israeli and German interviews, *Tamar Nov-Klaiman*, *Marina Frisman*, *Aviad E. Raz* and *Christoph Rehmann-Sutter* brought out the different views and concerns of families with Down syndrome, their understanding of discrimination, and the attitudes of parents of children with Down syndrome towards NIPT. One commentator from Israel and one from Germany was invited to discuss, from their specific social context, the meaning of prenatal diagnosis for people with disabilities. The perspective of disability studies, contributed by *Swantje Köbsell* from Germany, is very hesitant about genetic testing, while the Israeli disability activist *Rachel Lishansky* tells her personal story of having a child with Down syndrome. These approaches stand as examples of the different social and cultural contexts that need to be taken into account when considering prenatal diagnosis and disability.

The Israeli and German researchers *Christoph Rehmann-Sutter*, *Tamar Nov-Klaiman*, *Anika König*, *Stefan Reinsch*, *Yael Hashiloni-Dolev* and *Aviad Raz* ask: what does prenatal testing mean for women who used the test? This question involved extensive discussion in the team about the interviews and how they can be understood from the different cultural and social angles of the research. The aim of this chapter is to bring out the different ways of making sense of genetic testing, and to show how the women who had used it interpreted their own choice. For example, one German woman said that she had NIPT/PND in order to be prepared for the birth of a child with special needs, while an Israeli woman wanted to do everything right and according to her physician's suggestions.

These concrete empirical insights show that pregnancy and the beginning of life has become a morally challenging project that demands many decisions from the parents-to-be, each of which must be made with careful deliberation and moral reflection. The distinct national laws and cultural contexts therefore demand a specific type of "genetic responsibility", as well as care responsibility from expectant parents and pregnant women. Israel and Germany are seen as two political entities, as cultures and as constellations of practices, and each is a melting pot of secular or religious, national or international ethical discourses.

Although Israel is considered to be a Jewish state, both Israel and Germany can also be considered non-religious states. Yet religion still plays an important role in policy-making, public opinion, and the personal decision-making of (future) parents, although the roles are different with respect to pregnancy, family, and matters of life and death. All this results dynamically in concrete, yet very different, cultural settings, medical practices and social understandings of what constitutes responsible prenatal care.

Regardless of whether a pregnant woman tests or not, she always has her social context. This context, as well as the overall discussion about prenatal genetic testing, is framed by religious traditions, beliefs and authorities. In order to find out more about the different religious horizons, *Anne Weber* and *Christina Schües* initiated a conversation between the German Catholic theologian and philosopher *Hille Haker* and the Israeli ethnographer and anthropologist *Tsipy Ivry*, whose research focuses on the interrelation between Jewish religion and new reproductive technologies. They share their insights into different socio-cultural and religious views in Israel and Germany, and the social and religious practices and reasonings, concerning the use of reproductive or re-progenetic technology, taking into account the different histories, political circumstances and religious beliefs about the family, relationships and children. The question of who is or is not allowed into the human community highlights the importance of the Christian church and the rabbis. The following chapter turns the conversation to another setting. In a review of two films, the Israeli film *Week 23* (שבוע 23) and the German film *24 Wochen*, *Christoph Rehmann-Sutter* and *Christina Schües* discuss the familial and social contexts of prenatal genetic testing and, most importantly, female intuition and ambivalence towards medical knowledge.

Conversations about sense-making, about different beliefs, religious, social or cultural settings, and the comparison of the two films show that it is necessary to examine the *intertwining of knowledge practice, epistemology and ethics*. Thus, the fourth dimension of the book reconsiders particular historical and philosophical horizons of prenatal genetic testing in Israel and Germany and shows how the empirical sciences work together, thematically and methodologically. An overall aim of several chapters of the book is to understand how diverging meanings of medical practices of prenatal genetic testing are entrenched in familial and social settings, the human condition, and understandings of responsibility. If, traditionally, when children are born, their physical traits are accepted unconditionally, and if it was – at least implicitly – assumed that the parent-child relationship is characterised by unconditional

bonding, then the question arises of whether such “unconditionality” will be transformed by prenatal genetic diagnosis. This is discussed by *Hannes Foth* through concrete prenatal genetic practices in Israel and Germany. He shows how philosophical scrutiny may interact with concrete observations in a way that can lay the ground for future questions. There are urgent questions to address about whether human life, value or dignity should depend on biological disposition or social performance. More and more children are born on condition that prenatal genetic tests are negative and that other people, at least the parents – of course without having obtained the child’s consent – already know their genetic disposition, at least partially. Meanwhile, scientists are discussing the expansion of NIPT to NIPW – whole-genome sequencing. This seems possible technically, although not yet economically feasible, and philosophically it opens up a new shift in the paradigm of genetic testing.

There are women who do not want to know and who do not want to test. This observation prompts us to reconsider the concept of not-knowing, a concept that, philosophically and scientifically, has a bad reputation. Yet for prenatal genetic practices, it is not only interesting but also philosophically stimulating to sort out the “other side” of choice, of normality, or of routine. *Christina Schües, Stefan Reinsch, Aviad Raz and Christoph Rehmann-Sutter* discuss conceptually and empirically the phenomenon of not wanting to know, and whether it is irresponsible not to know genetic risks in advance (which one Israeli woman clearly suggested in her interview). Not-knowing is not simply the opposite of knowing, but has its own rational structure and ontological, epistemic and social status. As several conversations seem to suggest, in Israel prenatal testing is normal and standard, and may even be considered a social requirement, whereas in Germany such assurance and “normality” of NIPT seems less common. Thus, the meaning of not-knowing oscillates culturally and socially, changing with the communicative and social context.

Towards the end of the “PreGGI” project, some members of the research team felt a strong urge to write about what they had actually done. The last chapter is therefore devoted to questions of the methodological approaches, interdisciplinary and transnational conversations, and what it means to think through different differences. Readers of this book may find our paths of doing so an enrichment for their own future studies or observations.

This book about responsibility contributes to an ongoing philosophical, sociological and ethical discussion about the prenatal genetic diagnostics and intergenerational responsibility.

Thus, it will enrich and inspire a range of debates in bioethics, social philosophy, sociology of biomedicine, and medical anthropology. It shows that concepts of ethics and epistemics are not absolute, but dynamic, socially contextualised, historically inspired, and formed by technically produced paradigms of perception. Ultimately, it may well be that it is not the application of a particular technology that reveals differences between practices, cultures or countries, but how they are justified and what is considered good reasons for their use.

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