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# Healthy, happy, rational: reflections on genetic counselling in the GDR

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## ABSTRACT

The development of genetic counselling in the German Democratic Republic (GDR) was closely connected to a well-established system of prenatal care and a process that placed reproductive decisions in the hands of women. It was embedded in the pronatalist reproductive policy of the GDR and a narrative of medical and (socialist) humanistic progress. As in other countries at that time, it promoted the goal of avoiding the birth of children with disabilities and was hence based on ableist premises. In this paper, I focus on communicative aspects of genetic counselling, as it was established in the 1970s and 1980s in university and district clinics. Thus, on the one hand I explore the communication of genetic counselling to the public; and on the other, I study the communication processes in genetic counselling centres themselves. In contrast to the USA, where the 'genetic counsellor' became established as a professional identity in the 1970s, there was no distinct profession of 'genetic counsellor' in the GDR. Instead, counselling was practised by physicians or biologists with a special interest in human genetics. This resulted in a strong emphasis in these clinical encounters on diagnosis and technical solutions, as well as an educational impetus. I propose that an important goal of genetic counselling in the GDR was to generate a sense of 'rationality' in prospective parents. To achieve this, those advocating and giving counselling explicitly sought to distance this practice from the eugenic ideas of the past, and to dispel superstitious ideas of heredity and religious ideas of fate. In addition, they attempted to alleviate emotions such as fear and guilt. It was in that context that counselling physicians and biologists provided interpretations of genetic findings, risk figures and disease values. I show how different interests and experiences shaped these and how risk evaluations structured counsellor-counsee communication.

## INTRODUCTION

In 1977, the popular magazine *Neue Berliner Illustrierte* (NBI) titled its cover story 'Genes under Control? [Gene im Griff]' (Bergmann 1977).<sup>1</sup> Regine Witkowski, the main author of the principal book on genetic counselling in the German Democratic Republic (GDR), was featured in large print on the front page, dressed in a white coat, with a colourful shirt and scarf underneath.<sup>2</sup> Holding a roll of paper printed with chromosomes in her left hand, she is looking in a friendly manner into the camera. Her professional, yet not overly stiff, appearance radiates reliability, attentiveness and confidence. The published story 'Genes under Control?' included a one-page interview with Witkowski about genetic

counselling. Its subheading 'Do we have the genes under control?' was intended to catch the reader's eye by playing on their supposed fear of loss of control. However, this fear is immediately countered by a black box, positioned under the article title, which contains a more formal, professional photo of Witkowski, accompanied by her name and academic title, and the line: 'Hereditary diseases – Evil under control'. Thus, even a reader who does not read the whole interview gets the central message: do not worry! (Bergmann 1977, 16).

This published interview with Witkowski is a vivid example of the way that magazines and newspapers popularised and legitimised genetic counselling during its establishment at university and district clinics in the 1970s and 1980s. It illustrates how genetic counselling was portrayed as linked to health, happiness and scientific progress, and made to fit neatly into the pronatalist population policy of the GDR. Moreover, this particular interview and its illustrations provide insight into the various challenges and ethical issues that were faced by those practising genetic counselling in the GDR. The physicians and biologists who counselled families were careful to avoid associations of genetic counselling with the National Socialist sterilisation programme, although these associations might be readily made by linking reproduction with healthy offspring. In addition, they took delicate care when they evoked emotional engagement with genetic counselling—as the eugenic propaganda of the past had worked with fear-mongering images of an increasing number of so-called inferior people (eg, Helmut 1934).<sup>3</sup> Human geneticists in the GDR connected the National Socialist past not only to inhumanity and crime, but also to an 'abuse of science' (Freye 1973, 109; Bach 1983; Witkowski and Kulawik 1981, 1589) and the unscientific (Witkowski and Prokop 1974, 12; Bergmann 1977, 16). Witkowski and others never tired of opposing traditional ideas of heredity such as the division of humankind into genetically 'healthy' and genetically 'burdened' persons (Witkowski and Kulawik 1981). In doing this 'boundary work', human geneticists created an image of human genetics as a modern, fact-based science.<sup>4</sup> Thus, to legitimate genetic counselling, those practising and promoting it sought to counter any forms of 'irrationality'. The kinds of irrationality presumed among the recipients of counselling were quite diverse: they included eugenic ideas as well as 'genetic fatalism' (Herrmann and Rothe 1974, 454) or 'mystical ideas of the malformation process' (Wittwer 1973, 443).

Today, critiques and debates about prenatal testing and genetic counselling focus not so much



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on whether these practices are eugenic, but whether they are based on ableist premises—the notion that a life with a disability has less worth than one without.<sup>5</sup> Thus, to understand the development of genetic counselling in Germany today, it is helpful to look back not only to the older eugenic programmes, but also to the time when genetic counselling was first established.

While prior works on genetic counselling in the GDR depict the political, scientific and economic conditions for the establishment and practice of genetic counselling (Doetz 2017; Doetz 2021; Pittelkow 2017),<sup>6</sup> I examine here its communicative aspect. Therefore, I study the communication that took place in the context of popularising genetic counselling as well as the communication between experts and counselees in the counselling process. Moreover, I discuss the role of emotions in both topics. Historian Alexandra Minna Stern, in her trailblazing work on the history of genetic counselling in the USA, describes the transformation of genetic counselling in the late 1960s and 1970s by women, mostly white and middle class. They created the professional identity of the ‘genetic counsellor’, as it is known today in many countries. Stern characterises contemporary genetic counselling in the USA ‘as a feminised health care profession that combines scientific knowledge, empathic communication, and information delivery’ (Stern 2012, 5).<sup>7</sup> In contrast to the USA, a distinct profession called ‘genetic counsellor’ did not develop in the GDR. Instead, counselling was practised by physicians or biologists with a special interest in human genetics, who started genetic counselling on an ad hoc basis in some clinics in the 1960s. The institutionalisation of genetic counselling took place in the 1970s and 1980s after two pilot counselling centres in Jena and Magdeburg started operating in 1974. Moreover, in the 1970s, scientists of the Institute of Marxism-Leninism of the Medical Academy in Magdeburg and the Academy for Medical Training of the GDR in East Berlin analysed the philosophical and ethical aspects of genetic counselling.<sup>8</sup> I argue that the professional identities and interests of these groups influenced the discourse and, in the case of the physicians and biologists, the practice of genetic counselling in the GDR. This resulted in a strong emphasis on medical ethos, diagnostics and technical solutions.

I propose that an important goal of promoting genetic counselling and the counselling process itself was to generate a sense of ‘rationality’ in the public as well as in the individual counsellee. Human geneticists did not address ‘rationality’ directly, but they appealed to reason, medical education and science. In doing so, they called on concepts that were closely linked to ‘rationality’ in the GDR in those days.<sup>9</sup> In the context of the counselling process, a ‘rational decision’ would be expected to be avoiding the birth of a child with a disability and giving birth to children who were not expected to be at risk. Counsellors assumed that this approach met the needs of the counselees, as they perceived the lives of people with a disability to be connected to suffering. This assumed convergence of interests was also in line with the claim of Marxist-Leninist philosophy that socialism was able to realise the dialectic unity of the individual and society.<sup>10</sup> However, what were the practical implications of this presumed convergence for counsellor-counsellee communication? I argue that it led to the prioritisation of the delivery of medical information and instructions in the communication process, because the counsellors saw a lack of human genetics knowledge as the biggest problem. Furthermore, an ethical understanding that emphasised beneficence/welfare (which could be paternalistic to a greater or lesser degree) won out over recognition of the counsellee’s autonomy and the shift of responsibility to the counsellee that would have come along with it.<sup>11</sup> To generate ‘rationality’,

the concept of ‘risk’ played a major role. It became a central and dominating issue in counsellor-counsellee communication:<sup>12</sup> risk figures formed the endpoints of elaborate investigations; they were the desired results from pedigrees as well as an important basis for decisions. They delivered concrete numbers and human geneticists considered them to alleviate unfounded feelings of fear.<sup>13</sup> Nevertheless, counselees could interpret the same risk figures in different ways and appropriate the risk concept idiosyncratically. Thus, they could undermine the risk concept and the generation of ‘rationality’.

To make my point, I first give a short overview of the social and cultural context in which genetic counselling developed in the GDR. There, I also show how genetic counselling became interwoven with seemingly contradictory socialist ideology. Then, I will do a close reading of the previously mentioned interview with Regine Witkowski to give an example how ‘rationality’ was generated in the context of popularising genetic counselling. After this analysis of communication with the public, I will turn to communication between the counsellor and counsellee and explore the ‘talking side’ of the counselling process, especially before non-directive counselling became the ideal. Finally, I will show how the concept of ‘risk’ structured this communication and produced or also undermined notions of rationality. For my argumentation, I explored and analysed textbooks, doctoral theses, scientific and popular articles on genetic counselling, and archive files of the Ministry of Health and Society of Human Genetics in the GDR.

## THE DEVELOPMENT OF GENETIC COUNSELLING IN THE GDR

Genetic counselling was an important part of human genetics and clearly connected to questions of reproduction, as its aims were to avoid the birth of disabled or chronically ill children and to encourage procreation of people with unfounded fears of having disabled or chronically ill children. Therefore, I will show how the establishment of genetic counselling in the GDR was connected to: first, the development of human genetics; second, reproductive politics; third, the extension of prenatal care; and fourth, the position of people with a disability in society. In the aftermath of World War II, the science of human heredity had a difficult time in the GDR. Human heredity was understood to be connected to Nazi race politics; none of the former chairs or university institutes for racial hygiene or heredity and race biology continued their work; and the doctrine of Lysenko, which had been adopted from the Soviet Union, proclaimed the inheritance of acquired characteristics as a fact and denounced genetics as pseudoscience (Doetz 2017).<sup>14</sup> Nevertheless, East German scientists practised human genetic research in some niches, and the concept of hereditary diseases existed in spite of Lysenko.

Although the complete revocation in 1946 of the Nazi’s *Law for the Prevention of Hereditarily Diseased Offspring* (Gesetz zur Verhütung erbkranken Nachwuchses) in the Soviet Occupation Zone had marked a clear break with Nazi sterilisation politics, eugenic ideas did not completely disappear from the GDR. There were physicians and biologists who referred positively to the term ‘eugenics’ until the 1970s,<sup>15</sup> although the term was often used to refer to individual families and not to society at large (Doetz 2017).<sup>16</sup> The 1950 ‘Law Concerning the Protection of Mother and Child and the Rights of Women’ (Gesetz über den Mutter- und Kinderschutz und die Rechte der Frau) allowed abortion if one parent was ‘burdened with a severe hereditary disease’ (mit schwerer Erbkrankheit belastet).<sup>17</sup> In the 1960s, physicians and biologists interested in (human) genetics started networking

and lobbying. In addition, the first chromosome laboratories started operating in some clinics (Doetz 2017). At the end of the decade, a negotiation process began between biologists, doctors and the GDR Ministry of Health to create the 'human genetics research project' ('Forschungsprojekt Humangenetik'). This entailed that the ministry allocated dedicated (although limited) funding to clinical departments and laboratories engaged with genetic diseases, although these institutions also depended on the goodwill and resources of local health authorities.<sup>18</sup> Nevertheless, this research project was very important for building up a network for all physicians and biologists who worked in this field. There were regular meetings, lectures and—to a point—the possibility of international exchange. The 'Forschungsprojekt Humangenetik' took on the tasks of a professional society of human genetics. One of its main goals was the establishment of a nationwide genetic family counselling service. Considering the state's limited resources, this plan was more feasible than other ambitious missions, such as a proposed genetic population register (Weisemann 1997, 30–39; Doetz 2021).<sup>19</sup>

Counselling for pregnant women (Schwangerenberatung) had a long tradition in the GDR. Established in the 1950s, it comprised medical examinations, social care, hygienic education and mental prenatal programmes. Women were motivated to participate by means of material incentives. The effect was an impressive decline in infant and maternal death rates and the registration (and control) of most pregnant women.<sup>20</sup> Thus, the close surveillance of pregnancy was not a new development when amniocentesis and genetic counselling were established in the 1970s. With the introduction of amniocentesis, prenatal chromosome examinations became possible and, hence, the abortion of a fetus with a chromosomal aberration (Weise, Bernoth, and Quent 1976). The well-developed system of prenatal care was an important link as many referrals for genetic counselling came from gynaecologists and pregnancy counselling centres (Seidel 1984, 28; Janitzky 1990, 35; Marx 1990, 20). Women were already used to the surveillance of their pregnancies and likely considered these new tests and consultations yet another examination. Moreover, the term 'counselling' was already established in the field of reproduction and encompassed a whole cluster of different activities beyond communication, such as physical examinations and prenatal tests.

In 1974, two pilot genetic counselling centres in Jena and Magdeburg started operating. They were in strikingly different settings: the centre in Magdeburg was located at the paediatric clinic of the Medical Academy, while the centre in Jena was in the Institute for Anthropology of the Friedrich-Schiller University.<sup>21</sup> By 1981, the latter had become the leading institution for genetic counselling in the GDR, amid a nationwide network established in the 1970s and 1980s. By 1985, there were 20 genetic counselling services in the GDR, and each district of the country had at least one clinic. They were located at universities, medical academies or district hospitals and connected with laboratories (Doetz 2017). Most were part of clinical institutions—a fact understood to facilitate interdisciplinary exchange between cytogenetics, paediatrics, gynaecology and other medical disciplines which were relevant for the cases in question (Gedschold and Steinbicker 1984). The centralised organisation of GDR healthcare enabled task-sharing between the single counselling centres (eg, the counselling centre in Greifswald specialised in the examination of genetic metabolic disorders). However, despite centralised control, there were considerable differences in the level of care between the individual districts: in 1985, the districts of Gera, Berlin, Neubrandenburg, Leipzig and Rostock recorded one consultation per 1500–1800 inhabitants; while

the districts Schwerin, Dresden and Potsdam recorded one per 5600–12 000; and the Karl-Marx-Stadt one per 32 000. These differences were caused by variations in limited local resources, such as a lack of staff, space and equipment. Genetic counselling centres depended on district health authorities or university administrations and their priorities and possibilities (Doetz 2017; Doetz 2021, 406).

The new genetic counselling clinics aimed to engage all people who were considered to be at 'risk': that is, families with a disabled child, people who worried about a possible 'genetic burden' in their family, or people who knew about such a history and now wanted to get married. The target group also included older couples, people who were involuntarily childless, and relatives who wanted to marry each other.<sup>22</sup> Hence, the establishment of genetic counselling practices cannot be separated from the position of people with a disability in society, the development of reproductive rights and new diagnostic techniques.

Although the concept of 'socialist humanism' pronounced respect for the dignity of people with a disability and the development of their personality, in practice these people were often confronted with social exclusion (Löffelbein 2021).<sup>23</sup> The GDR had its roots in the German labour movement and defined itself as a 'Workers' and Peasants' State'. Consequently, it placed high significance on the ability to work. This shaped the way the state dealt with people with a disability.<sup>24</sup> Regardless of its cause, children understood to have a disability were categorised as 'eligible for education' or 'non-eligible for education'. While the former got special rehabilitation to integrate them into the work process, the latter were excluded from the school system and usually received no special support. In addition, there was a shortage of care facilities and placement options for those deemed not to be educatable. In the mid-1960s, this practice came under increasing criticism and resulted in a reform process at the end of the decade that stagnated in many cases. Moreover, children classified as 'non-eligible' still remained. They often had to live in special nursing homes or in psychiatric clinics. Given the often far-from-pleasant living conditions in those places, which suffered from a lack of resources, it is hardly surprising that many equated disability with suffering.<sup>25</sup> Thus, the situation of people with a disability in the GDR was characterised by structural problems, a lack of state interest, and an ideology oscillating between the exaggeration of the ability to work, equating disability with suffering, and 'socialist humanism'. This concept, in turn, allowed parents of children with a disability or chronic disease to advocate for their children's interests. Sometimes, parents were successful in this.<sup>26</sup>

How did the position of people with a disability in the GDR affect genetic counselling? First, there was a decisive concurrence of the reform process (though stagnating) and the introduction of prenatal testing and establishment of genetic counselling clinics. Although this concurrence was not explicitly referred to in the promotion of genetic counselling, cost-benefit calculations occasionally were. In 1973, for example, human geneticist (and head of the 'Forschungsprojekt Humangenetik') Bernhard Wittwer announced that for every 500 people, at least 1 was involved in the care of a person with a serious hereditary illness. This showed, he believed, 'what a significant medical, psychological, ethical and, not least, economic problem awaits a solution here' (Wittwer 1973, 436). However, ableist attitudes and insufficient state support did not automatically lead to an abortion or renunciation of a child, as I will show later.

In the 1970s and 1980s, genetic counselling was clearly connected to questions of reproduction, as its aims were to avoid the birth of disabled or chronically ill children and to encourage



people with unfounded fears of having disabled or chronically ill children to procreate. As Bernhard Wittwer, the first head of the previously mentioned research project ‘human genetics’ wrote:

On the one hand, genetic counselling can dissipate an unfounded fear of malformed children. On the other hand, a certain proportion of genetic disorders can be avoided by means of a well-founded decision not to have children (Wittwer 1973, 443).<sup>27</sup>

While Wittwer also argued in terms of population (‘a certain proportion of genetic disorders can be avoided’), the cytogeneticist Hannelore Körner and the paediatrician Ernst Ludwig Grauel stressed the individual character of genetic counselling:

The aim of our genetic counselling is to allay the fears of parents who are unprovokedly afraid of having malformed offspring, to prevent the conception and birth of genetically diseased children as far as possible, and to do everything in our power to help parents with genetic problems to have healthy offspring. It is a purely individual prophylaxis, which exclusively concerns the family (Körner and Grauel 1974, 269).

Consequently, genetic counselling brought together normative ideas of a healthy society and the pronatalist efforts of the socialist state. Attempting to draw a contrast to eugenic concepts of the first half of the twentieth century, human geneticists in the GDR emphasised its individual and voluntary character. Nevertheless, population-genetic objectives (ie, the notion that pre-pregnancy and prenatal testing and counselling might lower the incidence of genetic conditions) were still present, especially if state institutions were addressed or involved.<sup>28</sup> This notion was, for example, reinforced in a statement by several scientists of the ‘Forschungsprojekt Humangenetik’. Writing in one of the main medical journals of the GDR, *Das Deutsche Gesundheitswesen*, which was published by the Ministry of Health they explained:

Because a satisfying symptomatic therapy is possible only in a few cases, a reduction of genetically determined morbidity is only available by the means of prophylaxes—that means: timely genetic counselling. A key improvement of the genetically determined morbidity of our population can only be expected if genetically burdened persons arrange their family planning in a way that they avoid the procreation and birth of heavily genetically impaired children. This has to happen voluntarily, in their own interest and in the interest of society (Steinbicker *et al.* 1977, 179).

The understanding of genetic counselling as a preventive measure was not limited to the GDR; many other socialist countries did the same, as did the Federal Republic of Germany (FRG) (Bochkov 1975, 29; Seemanová 1975, 40; Wendt 1979, 11). Moreover, ‘prophylaxis’—the term used in the GDR instead of ‘prevention’—was a central issue in GDR healthcare. Thereby, Steinbicker *et al.* were following a general development in the East German preventive healthcare system: the shift from *structural* prevention (Verhältnisprävention), with the intention of changing social conditions, to *behavioural* prevention—promoting individual behaviour change. The latter emphasised each person’s responsibility for him or herself (Niehoff and Schrader 1991, 51–74).

We may understand this development against the backdrop of growing individualisation in the GDR in the 1970s and 1980s, which the historian Mary Fulbrook described in her sociohistorical study of the period (Fulbrook 2005). Although *individualism* was still a combative term that Marxist-Leninist philosophers connected to capitalist societies, this development

was not a contradiction for a socialist society. In such a society—so the argument went—the individual could evolve in dynamic interaction with the social conditions of life. Hence, the dialectic unity of the individual and society could be realised (Klaus and Buhr 1972, 513–14, 516). The textual preamble to the ‘Law on the Interruption of Pregnancy’ (1972) (Gesetz über die Unterbrechung der Schwangerschaft) serves as an example of this declared unity. It stipulated:

The equal rights of women in education and occupation, marriage and family life require that women can decide for themselves about a pregnancy and its termination. The realisation of this right is inseparably linked to the growing responsibility of the socialist state and all its citizens for the constant improvement of women’s health protection, for the promotion of the family and the love of children (Büro des Ministerrates der Deutschen Demokratischen Republik, ed 1972a, 89).<sup>29</sup>

This law granted women the right to first-trimester abortions on request regardless of the number of pregnancies they had had. In case of ‘serious medical reasons which [...] would significantly affect a woman’s state of health’,<sup>30</sup> the law granted the option to terminate the pregnancy beyond the first trimester, if approved by a medical panel (Büro des Ministerrates der Deutschen Demokratischen Republik, ed 1972a, 89). In practice, a positive diagnosis regarding a genetically determined disease within the fetus was considered such a ‘serious medical reason’. The liberalisation of abortion was part of a larger development that placed reproductive decisions in the hands of women and hence provided predictability. This trend went hand in hand with easy access to ‘the pill’, which was dubbed the ‘desired child pill’ (‘Wunschkindpille’). The latter was expected to improve the reconciliation of motherhood and work and was available for all women of reproductive age.<sup>31</sup> Preceding this development, in the 1960s, Karl-Heinz Mehlan, professor for social hygiene in Rostock and an activist for Planned Parenthood, had already combined the state’s interest in stable birth rates with the individual promise of happy and healthy families. In this process, he created the ideal of the Wunschkind, the ‘desired child’ (Mehlan 1966, 11). Only a few months after the ‘Law on the Interruption of Pregnancy’ came into effect, Witkowski and Steinbicker took up this issue in the health periodical *humanitas* and devised the following entitlement: ‘In a society, in which a woman can decide for herself whether to terminate or carry a pregnancy to term, she has the very special right to scientifically based counselling and to the birth of a normal, viable child’ (Witkowski and Steinbicker 1972, 4). An important prerequisite to fulfil these demands was the increasing technical possibilities of prenatal diagnosis.

## TALKING WITH THE PUBLIC

Human geneticists frequently complained about insufficient knowledge in the field of human genetics in the public but also among physicians. To remedy this, they held lectures, gave interviews or wrote articles not only in professional journals but also in popular magazines. In general, the ‘popularisation’ of scientific knowledge had high significance in the GDR, as science was highly valued. In addition, I follow the interpretation of the historian Thomas Schmidt-Lux in his study on the secularisation process in the GDR. He pointed out that by (Marxism-Leninism) exaggerating science to scientism it became a ‘scientific ideology’ (wissenschaftliche Weltanschauung) and even a substitute for religion by offering ‘meaningfulness, interpretations of the world, social norms, and directives which claim absolute

validity' (Schmidt-Lux 2008, 66).<sup>32</sup> The interview with biologist and cytogeneticist Regine Witkowski in the *NBI* illustrates how human genetics and genetic counselling were projected as being strictly connected to science.

The *NBI* was published weekly and attracted a broad audience. It included large-sized photos and a potpourri of topics such as political reports, information on distant countries, everyday-life features, news on cultural events, sports and fashion, serialised novels, DIY tips, health guidance, posters of athletes, riddles and a page for children. In 1974, it had an average circulation of 701 545—thus, it was one of the high-circulation magazines in the GDR and not a niche journal (Löffler 1999, 49; Kleinhardt 2016).<sup>33</sup>

The interview with Witkowski opens with the decision of the Ninth Party Congress of the Socialist Unity Party of Germany to foster the development of human genetics, and closes with an envisioned joint venture between socialist society and human geneticists—with particular emphasis on the recognition and promotion of individual qualities and talents. These starting and ending points frame the story and provide political legitimisation for the topic. Throughout the article, sometimes more and sometimes less explicitly, Witkowski mitigates and reigns in various fears: first, the fear of the deterioration of the human genome, second, the fear of being stigmatised as inferior because of hereditary dispositions, and third, the unfounded fear of having a child with a genetic disease, despite any scientific evidence. Instead, Witkowski presents genetic counselling as a preventive, predictable, strictly scientific method, based on the exclusion of risks. Moreover, it is portrayed as a voluntary endeavour that has nothing in common with eugenics, and especially not with 'Hitler's fascism'. According to Witkowski, genetic counselling will help to avoid severe human suffering, by which she means the birth of a child with a disability (Bergmann 1977, 16).

The dialogue structure highlights Witkowski's expertise. While her interviewer expresses concerns, Witkowski is able to dispel these by referring to scientific facts, and using neutral, factual language. By contrast, she uses emotive words when referring to the National Socialist past and talking about disability. In doing so, she refers to a medical model of disability that stresses physical and/or mental limitations.<sup>34</sup> At this point, it is notable that neither Witkowski nor her interviewer explicitly mention the following: that the way of avoiding this 'suffering' would be—in the case of a pregnancy—to have an abortion.

The dialogue structure is not limited to the interview itself, but continues in the communication between the text and two illustrations, which are embedded in the interview, and a single side photo at the other side. The illustrations, a diagram of an amniocentesis and a pedigree, are in a grey box in the middle column of the interview and are accompanied by an explanatory text. The amniocentesis shows a fetus in a uterus while a needle from outside enters. The explanatory text presents it as an examination that provides certainty over the presence of a hereditary disease. The pedigree chart shows a three-generation family with carriers of the recessive metabolic disease phenylketonuria (PKU) and two affected persons. The accompanying text points to the successful treatment of children with PKU in the GDR. It shows male and female carriers who have five children: two carriers, two affected children and one child without the trait. The text states, 'Pedigree of a family, in which two children are expected to have the hereditary disease phenylketonuria' (Bergmann 1977, 16).

Again, it is interesting what the explanations do not say: in case of the amniocentesis, the text does not mention the risk of a miscarriage and the possible failure to retrieve and cultivate

amnion cells. In case of the pedigree, it does not state that for each child the probability of having the disease is 25%. Thus, in a family with five children it is possible for all or none to have it. Instead, the pedigree functions to turn a probability into a fact. Its unambiguity and omniscience are striking. Each family member is either a carrier, a sick person or a person without the trait of the disease, implying perfect family knowledge<sup>35</sup> on the genetic constitution of each of them. There is no family member who we know nothing about. According to the pedigree, it is assumed that all family members live in stable, heterosexual partnerships. Against the backdrop of high divorce rates and the existence of single parent (mostly mothers) and stepfamilies in the GDR the pedigree is striking in its idealised and normative approach.<sup>36</sup> In addition, the article factored out any uncertainties.

The written interview is accompanied by a single side photo. The photo clearly shows a young, white family of four sitting on the beach. The woman and the man—both have a child on their lap—appear on equal footing. While this, and their short haircuts, which adhere to the unisex style of the 1970s, can be interpreted as embodying gender equality, it is still the man who plays a musical instrument (harmonica) and thus represents the active part. In the centre of the picture is a baby. All members relate to each other, no one looks at the camera, which conveys intimacy and safety. In addition, they all make a happy and content impression; no one seems ill or has an apparent disability. In the upper corner of the picture is a short text that says, 'Human genetics contributes to children being born healthy and growing up happily, which is consistent with the goals of our humanistic social order' (Bergmann 1977, 17). The background of the photo is a blurry grey—creating an effect that strengthens the dialogue between the grey amniocentesis on the left page and the healthy and happy baby on the right, linking genetic counselling and prenatal diagnosis to a bigger narrative of medical and humanistic progress with an individual happy end (Bergmann 1977, 16–17). Thus, the promise is family happiness and safety. It presents a striking contrast to the images Birgit Nemec presents in her article on genetic counselling in the FRG (in this volume): in the latter, fittingly for a market economy, the focus is on a couple's choice.

To sum up: by factoring out uncertainty and inappropriate emotions, the interview presented genetic counselling and prenatal diagnosis as safe, fact-based and reasonable methods. Moreover, it presented certain emotions—especially fear—as the opposite to rationality, something that disrupts true science. The simplified message of the interview was that the scientific progress of genetic counselling leads to healthy and happy children. Consequently, people with a disability did not really occur in this story.

## THE TALKING PRACTICES OF GENETIC COUNSELLING

Witkowski, who worked at the neurological clinic of the Charité university hospital in East Berlin, was the main author of the principal book on genetic counselling in the GDR (Witkowski and Prokop 1974). Its first edition was published in 1974, the second in 1976, and in 1983, the third, extended edition was published in West Germany. In English, the title reads 'Hereditary Syndromes and Malformations: A Dictionary for Family Counselling'. Although the matter of counselling is quite prominent in the title, there is no chapter on practical communication. Instead, the book served as a diagnostic manual (Witkowski and Prokop 1974; Witkowski and Prokop 1976; Witkowski and Prokop 1983). The focus on diagnostics was also implemented in the 'Complex 'Human Genetic Counselling Service' Transfer

Programme' of the Ministry of Health in 1977. According to it, the primary task of genetic counselling centres was the detection of genetic findings and their explanation to the counselees.<sup>37</sup> This was a strikingly different approach to that in the USA, where the psychologist Melinda Richter established the first genetic counselling training programme at the Sarah Lawrence women's college in Westchester (New York), at first against the resistance of medical geneticists. She created an independent job profile for (mostly white and middle class) women that was directed towards medical social workers. In the USA, sociopsychological communication was understood to be central to the counselling process, to the extent that Stern claimed that genetic counselling 'can be grouped broadly under the rubric of emotional labor' (Stern 2012, 122).

Although the GDR had a high percentage of women doctors and scientists (Schagen 1996, 328, 331–32), genetic counselling was not typically a woman's occupation. In addition, communication techniques and emotional management were neither a subject of the 'Guidelines for the Award of the Professional Title of Specialist Human Geneticist' (the qualification for scientists) nor of the education programme for medical specialists for human genetics (the qualification for physicians). Even though the latter stated that 'particular emphasis should be placed on the teaching of ethical and psychological principles', it did not specify what those entailed.<sup>38</sup> Neither did psychological topics appear in my studies of congress programmes and reports of the working group 'genetic counselling' of the Society of Human Genetics of the GDR.<sup>39</sup> This may be for several reasons: first, communication techniques were an important focus for psychologists, but they were not involved in the development of genetic counselling (in distinct contrast to the USA). Second, genetic counselling was regarded as a medical activity, and since doctor-patient communication was a responsibility of all doctors, it was probably considered unnecessary to train genetic counsellors in this field.<sup>40</sup> Third, in the USA, 'genetic counsellor' was a new professional identity and thus needed legitimacy, such as special abilities that other professions could not provide.<sup>41</sup> Physicians and biologists in the GDR, in contrast, already had their legitimacy.

While in the USA genetic counselling was formed by the client-centred approach of psychotherapist Carl Rogers (Stern 2012, 117, 126–28, 138–40), in the GDR, it was shaped by the educational, caring, therapeutic and scientific impetus of medical doctors and scientists. Physicians were used to treating patients, but they were not trained counsellors. Consequently, they regarded counselees not as 'clients' (a term often used in the USA) but as persons who needed guidance and who were looking for medical advice. Furthermore, the focus of genetic counselling in the GDR was on the diagnosis and interpretation of genetic findings, rather than on the process of reflecting on how to come to a decision. Moreover, philosophical and ethical aspects mattered. The Ministry of Health instructed the scientists of society ('Gesellschaftswissenschaftler')<sup>42</sup> Hans-Martin Dietl, Heinz Gahse and Hans-Georg Kranhold from the previously mentioned Institute of Marxism-Leninism of the Medical Academy in Magdeburg to explore the philosophical foundations of human genetic measures in socialist society with special consideration of ethical aspects.<sup>43</sup> Subsequently, they published several articles and a book on this topic and talked about it at several conferences.<sup>44</sup> They emphasised the moral commitment of the counselees and counsellors, not only to their conscience, but also to socialist society. In keeping with this, both society and counselees expected and needed healthy and happy offspring. Hence, the scientists concluded that it was not sufficient for

counsellors to solely inform the counselees based on facts. Even though in the end the counselees decide for themselves, counsellors should provide active support and instructions for the decision process. Via references to other scientists—including some in the Soviet Union and West Germany—and on the basis of their own empirical research, the scientists argued that this view was not only their individual opinion (Dietl, Gahse, and Kranhold 1977, 99–113).<sup>45</sup> Indeed, in 1973, Gahse and Kranhold had interviewed physicians, medical students, pedagogues, skilled workers, foremen,<sup>46</sup> and other staff from a local manufacturing company in Magdeburg, as well as staff in the food industry and in socialist commerce. Other than those professions, Gahse and Kranhold did not include any other categories. In total they surveyed 346 people, and reported that the majority of them expected not only a presentation of the facts and their consequences, but 'real advice', meaning a recommendation for the best possible conduct. This result was not very surprising as the question had been suggestive: Gahse and Kranhold had asked what counsellors should recommend, 'if in a specific case there is a high probability that severely hereditarily damaged offspring will result from a union (marriage)'.<sup>47</sup> Thus, they constructed an alarming ('high probability' and 'severely damaged') and unambiguous situation. Nine persons of the 346 answered that they did not want any interference (Gahse and Kranhold 1975, 267–72).

In keeping with the message from this survey, most physicians and biologists who practised genetic counselling considered and issued recommendations for prenatal diagnosis, birth control, abortion or adoption as part of their job. The terms 'to recommend' or 'to dissuade' are pervasive in the literature on genetic counselling published in the GDR, as well as in the archive files.<sup>48</sup> The genetic counselling centre in Jena, for example, developed a special form for the documentation of genetic counselling, which listed eight possible recommendations for a present pregnancy: (1) No objections to carrying the pregnancy; (2) Carrying with reasonable risk; (3) Prenatal diagnosis (absolute indication); (4) Prenatal diagnosis (relative indication); (5) Abortion; (6) Preventive or intrauterine therapy; (7) There is no present gravidity; (8) Others.<sup>49</sup> Analytical studies conducted at the time concluded that in most cases, the counsellors did not dissuade a couple from having their own children (Seidel 1984, 35–38, Janitzky 1990, 48). Moreover, counsellors and medical philosophers/ethicists stressed that even when a counsellee did not follow the recommendation, this had to be accepted (Bach 1974, 175; Körner and Körner 1981, 85).

In fact, there were cases in which counselees broke off the counselling process or did not follow the recommendations—they resisted elements of the counselling process. Evelyn Janitzky, who evaluated just over a thousand consultations in Jena between 1980 and 1985, reported that in 67 cases the counselees (and in 5 cases, the relatives of the counselees) did not cooperate—so that it was impossible for the doctor in the encounter to give a recommendation. Furthermore, she reported that two counselees refused a recommended abortion after prenatal diagnostic test, and another woman decided to have an abortion after taking medication during pregnancy, even though the counsellor had not recommended it (Janitzky 1990, 47, 51, 69). Nevertheless, most counselees accepted the recommendations given by the doctors counselling them. This is not very surprising as in most cases the recommendation might have met their needs. Since counsellors mostly did not dissuade women from having their own children, most of the counselees received confirmation that everything was fine. However, Janitzky's study also showed that in individual cases, counselees took the risk of



having a child with a disability or, on the contrary, did not trust the recommendation that they did not have to worry.

Janitzky's study also showed that in order for counselling to be successful, another factor was important: the relatives of counselees. As detailed genealogical exploration (the drawing of family pedigrees) was part of genetic counselling, this group could include the whole extended family. In those cases, communication did not only take place between the counsellor and the counsellee, but also involved other family members, such as siblings, uncles and aunts, even if they were not present for the encounter. In order to create a complete pedigree and come to a correct diagnosis, counsellors needed family support and participation. This could cause some problems when not all members of a family wanted to undergo medical examinations (Braun, Voigt, and Göhler 1977, 1436–40). Nevertheless, the director of the genetic counselling centre in Halle in the 1980s, Hermann Metzke, claimed that only few persons rejected the family examination. Together with specialist for medical law Hans Hinderer, he identified a possible conflict of duties: that of confidentiality towards the counsellee and that of informing a possible transmitter of a disease. According to them, the latter duty would exist in the case of a severe genetic disease, which would have a substantial impact on the person concerned. In such a case, they did not see a problem as long as the information stayed in the extended family, that is, the 'community based on kinship' (Metzke and Hinderer 1985, 42). In other words, they prioritised informing a possible transmitter over the confidentiality of the counsellee. This is remarkable in that the hospital regulations from 1979 explicitly required a patient's consent for a discussion with relatives (Mück 1982, 141). The deviation from this rule shows that Metzke and Hinderer took it for granted that a person concerned would want to know about their risk.

To sum up: those delivering genetic counselling in the GDR had to deal with a contradictory situation. On the one hand, genetic counselling should be strictly voluntary (parents and patients should decide whether to undergo prenatal diagnostics and/or an abortion); on the other hand, it had a clear target (the widespread understanding that the birth of a child with a disability should be avoided). The ideal counsellor would lead the counsellee to make the right, rational decision—but the ability of the counsellor to consciously lead this process was assumed, not taught or reflected in training programmes. The ideal counsellee, in turn, was cooperative, eager for knowledge and made rational decisions. Hence, how were they to arrive at their final judgement?

## RISK AND UNCERTAINTY

The counsellor's recommendation to prospective parents was based on a calculation of the risk of possible occurrence of a disease or disability, and its 'disease value'. According to Witkowski a risk of 1% was considered low, and a risk of more than 10%, high. The 'disease value' was a number designed to reflect the severity of a disease and its lack of treatability (Witkowski and Prokop 1974). Various methods were used: if the disease had monogenic inheritance (a disease inherited according to Mendel's rules), then statistical probabilities could be derived. In more complex, polygenic hereditary modes, however, empirical risk figures had to be used. These were based on the largest possible non-selective test series of the relatives of affected persons.

However, all these methods presented difficulties in themselves, because these were complex biological processes that could not easily be translated into numbers. Phenomena such as

reduced penetrance, variable expressivity or heterogeneity could lead to considerable deviations from statistically expected values (Witkowski and Prokop 1974, 14–33). Empirical risk figures were only an approximate guide, as the basic series of studies covered both high-risk and low-risk families. It could usually not be determined unambiguously to which of the two groups the counsellee belonged (Fuhrmann and Vogel 1968, 65–69). That means that even in the case of a clear diagnosis, a precise prediction was not always possible.

According to historian Theodore M Porter, American genetic counselling pioneer Sheldon Reed and Swedish human geneticist Jan Arvid Böök 'introduced the term 'empirical risk' in 1950 as a reframing of the older notion of 'empirical hereditary diagnosis' that meant 'a statistical prediction based on measurable or diagnosable traits' (Porter 2018, 283, 345).<sup>50</sup> By the 1960s, the term 'risk' had replaced not only the latter but also other older terms such as 'manifestation probability' in human genetics (Cottebrune 2015, 202–5). In the GDR, the term 'risk' in the context of genetic counselling was first mentioned in 1972 in the previously mentioned article on genetic counselling in the Soviet Union by Witkowski and Steinbicker (Witkowski and Steinbicker 1972, 4). Even though the words used to express risk changed, the principle did not: ultimately, the creation of risk figures was a matter of establishing probabilities. What changed was that probabilities were made more precise through new technical methods. However, additional laboratory diagnostics, the goal of which were to carry out testing more safely, could again produce uncertainty or even new risks (an amniocentesis could hurt a fetus or even cause a miscarriage). Even to get proper amniotic cells for an examination could be problematic: the sample gained from the amniocentesis might be too small; the amniotic cells might not grow; or the incubator might fail. Moreover, the enzyme activity of the amniotic cell in question might be in a threshold range or the interpretation of a karyogram might be ambiguous (Weise, Quent, and Hemke 1978, 769–78; Weise and Gabriel 1983, 2034–38). Consequently, the risks with respect to the probability of having a child with a disability had to be weighed against the risks and uncertainties of an amniocentesis.

In addition, another modification took place. The assessment of what was considered a 'high' or 'low' risk could change. To demonstrate this, I compare a passage of text on the inheritance of schizophrenia in a 1955 article by the psychiatrist Dietfried Müller-Hegemann, and a chapter on schizophrenia in a textbook by Witkowski and Prokop 1974. Müller-Hegemann wrote his contribution following a consultation with the Ministry of Health.<sup>51</sup> He, like Witkowski and Prokop, calculated the same probability (16.4%) for children with a schizophrenic parent to develop schizophrenia. While Müller-Hegemann saw no reason 'to kill germinating life, about 84% of which would manifest as healthy' (Müller-Hegemann 1977, 249), Witkowski and Prokop explained that they would dissuade a person from having their own biological children if one partner suffered from schizophrenia (Witkowski and Prokop 1974, 648). Thus, 19 years apart, the same risk could be evaluated in different ways. Considering the historical background, these different interpretations are not surprising. Müller-Hegemann, still reacting to the horrors of the National Socialist sterilisation programme, and also sympathising with Lysenko's ideas, emphasised the impact of environmental factors for the development of mental diseases. Witkowski and Prokop, by contrast, stressed the meaning of genetics for medicine over an impressive 1071 pages. So how were the estimated probabilities rated?

As already mentioned, Witkowski and Prokop considered a risk of 1% to be low, and that of more than 10% to be high. As

well as risk, the so-called 'disease value' was employed to help the counsellor to make a recommendation. It should be borne in mind that doctors were consulted in difficult situations and in the case of physical complications. They might even have experienced affected children dying prematurely. These experiences confronted them with the difficult aspects of a disability or chronic illness. It can be assumed that these experiences also shaped the disease value and thereby the recommendation. The disease value was based on the severity of the disease and rated the extent to which it could be treated. For example, in the case of haemophilia A—'a suffering that has lost much of its terror' (Witkowski and Prokop 1974, 310)—Witkowski and Prokop would not dissuade a person from planning to have a child. In case of Duchenne muscular dystrophy, a disease characterised by progressive muscle deterioration and without treatment options, they would do so (Witkowski and Prokop 1974, 512; Doetz 2021). In other words, feelings of helplessness as well as feelings of success were decisive factors in the way that these professionals were instructed to evaluate a disease, a disability or a variation.

Counsellors tried to modify the risk via the disease value in order to come to a recommendation, but how did counsellees handle this? Moreover, did they have the same perception of risk as the counsellors? Few sources provide insights; however, in her aforementioned thesis, Janitzky conducted retroactive examinations of 90 counsellees.<sup>52</sup> Her question was whether the counsellees had understood what the counsellors had recommended, and whether they had implemented those recommendations. With regard to risk assessment, Janitzky found that in 30 cases, the risk formerly given by the counsellors and the risks now given by the counsellees coincided exactly. However, in 16 cases, there was only relative consistency, in 10 cases, the counsellees did not answer the question, and in 34 cases, the value given had been clearly wrong. In general, there had been a tendency to estimate the risk to be rather too high than too low (Janitzky 1990, 63–67). This leads to the question as to what extent the risk assessment itself evoked, rather than reduced, new fears. Janitzky pointed out that the risk assessment was influenced by the way counsellees experienced the proceeding of a disease: in the case of a favourable course, a high risk could be underestimated; in the case of deterioration, a low risk could be overestimated (Janitzky 1990, 92).

Thus, counsellees may have had a different risk perception to genetic counsellors. That means that, besides the different interpretations of high and low risk, and the modifications of risks via the disease value, there was also the possibility that risk perception changed a risk figure itself. Consequently, risk figures were not only relative but could also become fluid. They were not only tools for a rational communication; counsellees could also use them to express fears and hope. One may interpret this as an idiosyncratic appropriation of the risk concept. But it also means that the interpretations of the genetic counsellors were not absolute.

Coming back to the communicative aspects of genetic counselling, I consider it important to state that the risk calculation was more than a tool for decision-making. Rather, I would describe it as a communication builder: first, counsellors had to collect information in order to arrive at a risk calculation. Then, they had to interpret the result of this calculation to the counsellee. Consequently, the risk evaluation structured the counsellor-counsellee conversation.

## CONCLUSION

The establishment of genetic counselling in the GDR was closely connected to a well-established system of prenatal care and a

development that placed reproductive decisions in the hands of women. Thereby, it was embedded in the pronatalist reproductive policy of the GDR and in a narrative of medical and (socialist) humanistic progress. At the same time, its promoters had to distance it from any association with the National Socialist sterilisation programme. While in the aftermath of World War II the term 'eugenics' was used ambiguously, it became a more and more problematic expression in the 1970s. In contrast to National Socialist eugenics, human geneticists stressed the individual and voluntary nature of genetic counselling. Even so, they at times mentioned population-genetic objectives. Moreover, the explicit goal of avoiding the birth of children with a disability was consistent with an ableist attitude that considered the lives of people with a disability to be mainly suffering and a burden for their families (and the state). It was within this context that a well-informed counsellee was supposed to take a rational decision.

Those delivering genetic counselling put strong emphasis on medical ethos, diagnostics and technical solutions. Counsellees were regarded as people who needed guidance, and who were looking for medical advice. The ideal counsellor would lead a counsellee to make the right, rational decision. The ideal counsellee, in turn, was cooperative, eager for knowledge and made rational decisions. These ideals were based on the philosophy that socialism was able to realise the dialectic unity of the individual and society.

Physicians and biologists delivering genetic counselling understood that they were to promote rational decision-making by obviating emotions of unfounded fear and guilt as well as superstitious ideas of heredity. Instead, they provided interpretation of genetic findings, risk figures and disease values. The latter were based on the treatability of a disease—again, a medical view. We know, however, that counsellees did not always follow the counsellors' recommendations. In addition, their risk perception could deviate from the risk figures given by the counsellor. This suggests an idiosyncratic appropriation of the risk concept on the part of some counsellees.

In contrast to the USA, where an independent profession of 'genetic counsellors' existed—understood by some as a kind of genetic social workers—in the GDR, physicians and biologists performed genetic counselling. This was quite similar to other European countries where mostly physicians performed genetic counselling in those days.<sup>53</sup> In other aspects, too, the development of genetic counselling in the GDR resembled that in other European countries: the general distancing from eugenics; the emphasis on voluntariness; and the close connection between the liberalisation of abortion and the introduction of prenatal diagnosis. The topos of 'choice' gained increasing importance in some Western countries such as Sweden, France or the FRG.<sup>54</sup> Despite this, the goal of making rational decisions, which meant avoiding the birth of people with a disability, was not limited to the GDR. However, in contrast to West Germany, where independent advocacy groups of people with a disability and some feminist groups questioned the strong medical view of disability and pregnant women's bodies,<sup>55</sup> those groups did not exist in the GDR. They were not allowed as they questioned the dialectic unity of the individual and society.

This changed after the reunification of Germany. Nevertheless, a strong medical influence on human genetic counselling has remained in Germany to this day: unlike in most European states and many other countries worldwide (Abacan *et al.* 2019), genetic counsellors are not yet recognised as an independent profession in Germany. Instead, only physicians are allowed to practise genetic counselling.

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## NOTES

1. I would like to thank Regine Witkowski for giving me a copy of the magazine.
2. The principal term used for 'genetic counselling' in the GDR and the FRG was 'humangenetische Beratung' (Beratung meaning 'counselling' or 'advice') and sometimes 'humangenetische Familienberatung' (human genetic family counselling).
3. On emotional control as a reaction to the National Socialist mobilisation of emotions see Biess 2010.
4. The sociologist Thomas Gieryn coined the term 'boundary work' in order to characterise scientists' efforts to construct a demarcation between science and non-science (Gieryn 1983). See also the articles on pseudoscience in Rupnow *et al.* 2008 and Edmund Ramsden's paper on stigma and 'boundary work' to distinguish genetics and demography from eugenics (Ramsden 2009).
5. For examples, see Parens and Asch 1999, 1–22; Achtelek 2015, 125–53.
6. Genetic counselling is partly also a topic in Pittelkow 2015, 88–102; Weisemann, Kröner, and Toellner 1997.
7. For the global distribution of genetic counselling, see Abacan *et al.* 2019, 183–97.
8. In the GDR, every student had to complete basic studies on Marxism-Leninism; physicians and scientists had to do further training in this field. Institutes for Marxism-Leninism were responsible for the implementation.
9. The popular GDR encyclopaedia *Meyers Lexikon* from 1980 defined rational as 'reasonable, in accordance with reason, logically justified; also scientific' (Lexikonredaktion 1980, 760). For a history of rationality in science, see Daston 2001. Daston's main argument is that 'rationality' is not a monolithic, universal category, but has a history. On the attribution of rationality/irrationality as an instrument of power, see also Schlichter 2010, 98–127.
10. Nevertheless, this assumed convergence of counsellor and counsellee has also been described for genetic counselling in West Germany. See Waldschmidt 1996; Thomaschke 2014.
11. This attitude must be considered against the background of a legal system in which counsellors could not be held liable for the birth of a child with a disability.
12. Volker Hess showed a similar effect for the entry of temperature measurement into doctor-patient conversations in the nineteenth century (Hess 1997).
13. In her study on the history of emotions of cancer in the twentieth century in Germany, the historian Barbara Hitzler points out that the evocation of feelings of fear and pessimism lost its legacy in the cancer prevention programmes of the GDR as it could call the optimistic narrative of the present and future of society into question (Hitzler 2020, 418). For the use of emotions in medicine in the GDR and the FRG, see also Thießen 2013. He shows two posters for polio vaccination—one from the GDR and one from the FRG. While the former appealed to reason and duty, the latter used emotions—especially fear—('oral vaccination is sweet, polio is cruel') to convince the observer.
14. For Lysenkoism in the GDR, see Diesener 2002; Hagemann 2002; Höxtermann 2000; Polianski 2016.
15. For examples, see Freye 1973, 109; Projektentwurf "Humangenetik", 21.10.1970, BArch (Bundesarchiv), DQ 1/3358. This is also true for the UK and the USA, see Ramsden 2009.
16. Nevertheless, most East German human geneticists in the 1970s and 1980s actively distanced themselves from first-half-of-the-century-eugenics and Nazi sterilisation politics (Witkowski and Prokop 1974, 12; Sommer 1978, 94–104; Bach 1983). Instead, they stressed the voluntary nature of genetic counselling (Bach 1975; Körner and Grauel 1974; Bergmann 1977).
17. Gesetz über den Mutter- und Kinderschutz und die Rechte der Frau 1953, 37.
18. Forschungsvertrag in BArch (Bundesarchiv), DQ 109/34. For dependency on local authorities see BArch, DQ 109/34; Universitätsarchiv Jena, 'S/II 219.
19. A genetic population register is the registration of genetic diseases of parts or the whole population.
20. For the development of prenatal care from a socialist paternalistic form in the 1950s to a 'liberal governance of pregnancy and childbirth' in the 1970s, see Harsch 2021, quotation: 409. For the counselling of pregnant women, see also Major 2003. Numbers for the decline of infant and maternal death rates are given by Obertreis 1986, 53–54.
21. Administratively, the latter belonged to the district of Gera.
22. Witkowski and Prokop 1974, 13; Steinbicker and Gedschold 1977, 236; Komplexes Überförungsprogramm 'Humangenetischer Beratungsdienst', 27.09.1977, BArch (Bundesarchiv), DQ 1/26482/2.
23. For the concept of 'socialist humanism', see Körner, Löther, and Thom 1981.
24. Mary Fulbrook has noted that the health politics in the GDR devoted most resources to those who held positions of power and those whose work or capacity for reproduction was of crucial importance to the economy (Fulbrook 2005, 95). For GDR categorisations relating to 'disability', see Wasem, Mill, and Wilhelm 2006; Fangerau *et al.* 2021.
25. For the position of people with a disability in the GDR, see Wasem, Mill, and Wilhelm 2006, 410–25; Wasem, Mill, and Wilhelm 2008, 391–409; Barsch 2013; Barsch 2016; Bersch 2020; Fangerau *et al.* 2021.
26. For examples, see Barsch 2013, 163–88; Doetz 2017
27. Witkowski and Prokop 1974, 13; Körner and Grauel 1974, 269; Gedschold and Steinbicker 1984
28. Projektentwurf 'Humangenetik', 21.10.1970, BArch (Bundesarchiv), DQ 1/3358. On the other hand, the biologist Hans-Albrecht Freye is an example for the adherence to eugenic ideas regardless of his audience (Freye 1972; Freye 1973).
29. I want to add that so-called foreign workers, especially from non-European countries, such as Vietnam and Mozambique, did not have this choice. If they got pregnant, they had either to undergo an abortion or return to their home countries (Jasper 1991, 178–79, 188–89, see also document 3 in that book, 204–5; Mende 2010, 69).
30. Durchführungsbestimmung zum Gesetz über die Unterbrechung der Schwangerschaft vom 9. März 1972, Büro des Ministerrates der Deutschen Demokratischen Republik, ed (1972b)
31. For the history of the 'Wunschkindpille', see Leo and König 2015. For the history of abortion in the GDR, see also Harsch 1997; Schwartz 2008.
32. The 'Medical Sunday' (Medizinischer Sonntag) in Magdeburg, an event at which medical topics were popularised, which was timed to coincide with Sunday services, might serve as a vivid example for the replacement of religion with science (Brinkschulte 2018). For the popularisation of scientific knowledge, see also Daum 2002; the articles in Wolfschmidt 2002.
33. See also Weißbahn, Guido. n.d. 'Comics in der 'NBI''. Accessed 5 November 2021. <http://www.ddr-comics.de/nbi.htm>.
34. In opposition to the medical model, the Anglo-American disability rights movement developed the social model of disability in the 1970s. This model distinguishes between physical, cognitive or psychic impairment and a disabling and discriminating society. Since the 1990s, contemporary disability historians have explored the cultural construction of the category 'disability'. They consider disability not as a natural fact but as a naturalised category of difference such as gender or race (Lingelbach and Waldschmidt 2016).
35. For the transformation of family knowledge in pedigree knowledge, see Palfner 2008, 32–35.
36. For family structures in the GDR, see Gysi and Meyer 1993, 139–51.
37. BArch (Bundesarchiv), DQ 1/26482/2. The programme was based on the recommendations of human geneticists, first and foremost Herbert Bach.
38. Institut für Ethik, Geschichte und Theorie der Medizin, Westfälische Wilhelms-Universität Münster (IEGTM), Bestand Humangenetik, Box 9.
39. Institut für Ethik, Geschichte und Theorie der Medizin, Westfälische Wilhelms-Universität Münster (IEGTM), Bestand Humangenetik, Box 11.
40. However, it is worth noting that some medical sociologists criticised physicians for not studying communication guidelines and techniques in their training, but instead relying on their intuition (Hüttner *et al.* 1982, 66–89). One example for 'how to talk' to the patients was given by the paediatrician Lothar Pelz and the biologist Wolfgang Mieler in the case of pregnancies where Down syndrome was suspected at birth.

They recommended avoiding discriminatory terms while talking about the future of these children. In addition, Pelz and Mieler stressed that the problem of chromosome distribution disorders should not be unilaterally shifted onto the mother, which, they believed, could lead to unfounded feelings of guilt (Pelz and Mieler 1972, 100–101).

41. On this topic, see also Stillwell 2015.

42. These were a kind of social scientist trained in Marxism-Leninism.

43. Forschungsprojekt Humangenetik, Pflichtenheft 1971, BArch (Bundesarchiv), DQ 109/34.

44. For examples, see Dietl and Gahse 1974; Gahse and Kranhold 1975; Dietl, Gahse, and Kranhold 1977; Institut für Ethik, Geschichte und Theorie der Medizin, Westfälische Wilhelms-Universität Münster (IEGTM), Bestand Humangenetik DDR, Box 7.

45. They referred, for example, to the West German human geneticists Walter Fuhrmann and Friedrich Vogel and to Soviet human geneticist Nikolai Pavlovich Bochkov.

46. In the GDR, nearly all professions were written in the male form.

47. 82% of all test persons answered that question.

48. Auswertung einer Stichprobe von 1075 Beratungsfällen aus dem Jahr 1985, BArch (Bundesarchiv), DQ 1/26482/2; Auswertung der Signierlisten des Dokumentationsblattes 'Humangenetische Beratung' vom Jahre 1987, BArch, DQ 1/26482/1; Pelz and Mieler 1972, 100–102; Wittwer 1973, 443; Witkowski and Prokop 1974; Körner and Grauel 1974, 270–71; Bach 1974, 175–78.

49. Dokumentationsblatt Humangenetische Beratung, Institut für Ethik, Geschichte und Theorie der Medizin, Westfälische Wilhelms-Universität Münster (IEGTM), Bestand Humangenetik DDR, Box 7.

50. For the development of the 'empirical hereditary diagnosis', see also Roelcke 2013.

51. BArch (Bundesarchiv), DP 1/7107, p. 198–200. The reason for this article was uncertainty about in which cases the hereditary indication in an abortion (according to the 'Law Concerning the Protection of Mother and Child and the Rights of Women') was justified. Physicians frequently demanded a guideline.

52. These were counselees who had undergone counselling between 1980 and 1984. Janitzky only chose counselees who had come to counselling on their own and not via referral from another doctor or a maternity or sexual counselling centre. She sent 146 questionnaires in 1987: 90 were answered, 2 came back without any answers, 43 did not answer and 11 were undeliverable.

53. An overview is given by Abacan *et al.* 2019.

54. For the UK, see Jenny Bangham and for the FRG, Birgit Nemec on this issue; for the FRG, see also Waldschmidt 1996, Thomaschke 2014 and Cottebrune 2019. Nevertheless, Schenk (2016) pointed out that there was no free choice for girls and women with intellectual disabilities. For Sweden, where the pronatalist argument was also quite important, see Björkman and Tunlid 2017; for France, see Gaudillière 2011. See also the contributions in the chapter on genetic counselling in Petermann, Harper, and Doetz 2017.

55. For examples, see Sierck and Radtke 1984; Bradish 1989. See also Nemec in this issue.

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